

British Columbia's "seek and treat" strategy: a cautionary tale on privacy rights and informed consent for HIV testing

The British Columbia Centre for Excellence in HIV/AIDS (BC-CfE) is credited with pioneering the "treatment as prevention" strategy. While Dr. Julio Montaner, the Director of the Centre, has expressed frustration over the government of Canada's "lack of support for the program,"¹ it is clear that the government of British Columbia strongly supports the "seek and treat" approach. Currently, a large-scale seek-and-treat pilot project — the STOP HIV/AIDS Project — is underway in B.C.

The provincial government has pledged CAN\$48 million for the four-year initiative, said to be the first of its kind in the world.² The pharmaceutical company Merck has reportedly committed CAN\$1.5 million to help evaluate it.³ Pilot programs operate in the cities of Vancouver and Prince George, and include a focus on Aboriginal populations. The project has extensive partnerships with regional health authorities, health care facilities and non-governmental organizations.⁴

The STOP HIV/AIDS Project includes education campaigns aimed at patients and health care providers that expressly juxtapose an old, purportedly out-of-date approach to HIV with a new, supposedly optimal approach. Hence, the main social marketing slogan is "It's different now."⁵ However, this new scenario, as it is being introduced in B.C., is decidedly contrapuntal: as the treatments are advancing, the approaches to patient rights and provider ethics are regressing. In particular, legal and ethical concerns are arising with respect to informed consent for testing and privacy rights.

The push for "routine," opt-out testing

The success of the STOP HIV/AIDS Project is highly dependent on greatly increased levels of HIV testing. While the literature of the BC-CfE cites "voluntary, confidential testing for HIV" to identify people needing treatment through a program to "normalize HIV testing,"⁶ documents from Vancouver Coastal Health (VCH), a project collaborator, spell out what "normalization" means in this context. The medical health officers of the health authority have called on physicians to implement "routine," annual, opt-out testing of all sexually active patients.⁷ In the view of VCH, this routine testing does not require detailed pre-test counselling, but merely a handout as needed and answering questions if they arise.⁸

STOP HIV/AIDS partners and proponents often express the view that pre-testing counselling is a barrier to testing and a simplified approach is claimed to be beneficial to patients.⁹ This is mirrored in terms of the new post-test practices, which move away from the norm of only

giving HIV test results in person and instead endorse giving HIV negative test results over the phone.¹⁰ That this is tantamount to giving all test results over the phone — for, if one cannot get his or her results on the phone, by process of elimination the person will know that the result is positive — has either not been considered or is considered acceptable.

Notably, none of the handouts that are meant to serve in lieu of pre-test counselling appear to mention the criminal jeopardy of people living with HIV (PHAs) who are accused of not disclosing to sexual partners.

VCH has also decided to actively discourage non-nominal testing.¹¹ It takes the position that nominal testing is "standard" and, while noting that patients should be informed of the option to test non-nominally, it suggests that health care providers discourage non-nominal testing and inform patients that non-nominal testing "offers little additional privacy and can make any follow-up care you might need more complicated."¹² There is no anonymous HIV testing available in B.C., so the best privacy protection available is through a non-nominal test. This option, however,

will presumably become more difficult to access in an environment where it is actively discouraged by providers.

In addition, routine testing is not limited to family practice: VCH has committed to implementing routine testing in primary and acute care. The STOP HIV/AIDS Project is piloting routine testing in three Vancouver hospitals.¹³ Posters have been printed to be placed in these hospitals. The text of the posters reads: "You will be asked to have an HIV test." The hospital setting further heightens the informed consent concerns of a shift to routine testing. It is likely that a significant portion of patients will simply fail to understand or appreciate that they can decline a blood test that appears to be folded into the "blood work" that is needed for their care in the hospital.

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Not long after the pilot for routine testing in hospitals was launched, there were anecdotal reports of patients who said they had been tested without their knowledge. The STOP HIV/AIDS Project has also partnered with at least one women's health clinic that provides abortion services. Abortion services are

clearly a context in which shifts to minimal pre-test counselling and "routine" HIV testing should be resisted on the grounds of safeguarding informed consent.

Failure to provide proper information about medical privacy

PHAs in B.C. are among Canada's most active and effective grassroots advocates for patient privacy rights in the context of electronic health records, and their efforts helped to secure a provision in the province's e-health legislation that allows for a limited ability for patients to mask records in the provincial system. Since the start of the STOP HIV/AIDS Project, the only component of the provincial e-health system that has been operational is the Patient Laboratory Information System (PLIS), the data repository for laboratory tests.¹⁴ As a consequence, almost all HIV tests since the project began are held and distributed within this new system.

While point-of-care (rapid) HIV test results are not processed through a laboratory, confirmatory blood tests are done by the British Columbia Centre of Disease Control laboratories, which now use PLIS. In fact, an amendment to the privacy provisions of the Health Act Communicable Disease Regulation was quietly passed in order to ensure that reportable diseases like HIV could flow in the provincial repositories without patient consent.¹⁵

It is also notable that, as for patients tested "routinely" in the pilot hospitals, the data system used in those facilities has recently been heavily criticized by the provincial Office of the Information and Privacy Commissioner for providing vastly

over-broad access to patients' personal health information and failure to provide patients with a mechanism for limiting disclosure.¹⁶ This created a perfect storm of privacy concerns in relation to HIV testing: more people being tested through "routine" testing and special testing initiatives, as well as less privacy protection for those test results, because of newly instituted data-sharing systems providing broad access to personal health information along with legal reforms that allow for that broad access.

Under the provincial e-health legislation, patients may implement a "disclosure directive" that locks down their health record to most system users, while allowing access to providers to whom the patient gives their personal identification number. This is the only control that a patient can exercise in relation to his or her personal health information held in the B.C. e-health system — and it is no protection at all if patients do not know about it.

Community-based AIDS organizations were key advocates in the campaign to secure some patient controls over access to personal health information held in the e-health system. However, a subsequent campaign to convince the Ministry of Health to inform patients of their option to protect their health information has been unsuccessful to date. While the STOP HIV/AIDS Project did not create the medical privacy problems of the e-health system, the e-health backdrop presents a pointed ethical challenge for the initiative.

The newly revised privacy policy of the Canadian Medical Association states that physicians have an obligation to inform patients that, when the patient's information flows into an electronic health record, the physi-

cian cannot control access or guarantee confidentiality.¹⁷ While the CMA admitting that e-health undermines medical confidentiality is highly significant, it is merely a statement of the obvious: without an ability to control access, there can be no ability to guarantee confidentiality.

Many in the B.C. AIDS community feel that the STOP HIV/AIDS Project is therefore misleading patients with the language of "confidential testing" and "confidential computer systems," and that the project and its partners should instead be proactively explaining to all patients the changes that have occurred in medical privacy in B.C., and actively assisting in the process of securing disclosure directives for patients who wish to limit access to their records. The advocates have managed, in some places, to get mention of disclosure directives into some of the written materials on HIV testing. At best, however, messages are mixed and there appears to be a general reluctance on the part of STOP HIV/AIDS Project proponents to provide explicit information for fear of scaring people away from HIV testing.

Incentivizing HIV testing

Another troubling aspect of the STOP approach is incentivized testing. The Downtown Eastside (DTES) of Vancouver is a particular focus of the STOP HIV/AIDS Project. That part of the city has extremely high rates of HIV infection, is often cited as "the poorest postal code in Canada"¹⁸ and is home to Vancouver's supervised injection facility, Insite. The STOP HIV/AIDS Project, in collaboration with partners in the DTES, has been holding HIV testing fairs, which are essentially large street parties, with streets closed to vehicular traffic and which include day-long music and

entertainment as well as incentivized HIV testing.

The poster¹⁹ for the testing fairs held on 9 and 10 July 2010 at Victory Square in the DTES announced that those getting an HIV test at the fair "get a \$5 Gift Card to Army & Navy and a free meal." The testing fairs have been well attended and popular enough that notices were posted advising that the campaign limits HIV testing to once every three months, although those who had already tested within the previous three months were welcome to attend at the event.

The STOP HIV/AIDS Project misleads patients with the language of "confidential testing."

DTES community partners who help sponsor the HIV testing fairs have said that they participate because increased "access" to testing is urgently needed. However, it is entirely unclear why HIV testing needs to be incentivized for people who purportedly have an urgent need for access. The notion that there is limited access to HIV testing in the DTES is extremely odd, given that there are well-used and -respected health care facilities right in the DTES that provide ready access to HIV testing, such as the Vancouver Native Health Clinic and Downtown

Community Health Centre. Rather than an urgent need for access to HIV testing, a more likely explanation for the popularity of the HIV testing fairs is that people have an urgent need for gift certificates and free food.

Incentivizing is a difficult arena in medical research ethics, but it does not appear that the testing fairs are considered part of research and have not been subject to ethics review. This is another confounding aspect of the STOP HIV/AIDS Project, because it is clearly research (which Merck is helping to evaluate), and yet it is entwined with the local health authorities and their new "policies" in such a way that it becomes extremely difficult to sort out the research components from the program components, as well as when the patient is simply a patient and when the patient is (also) a research subject.

On the subject of access to testing, there is an apparent irony that, as the STOP HIV/AIDS Project proceeds, B.C. is simultaneously closing five sexual health clinics, leaving huge areas of the province without any sexual health services.²⁰ It remains to be seen if this is, in fact, indicative of how a treatment-as-prevention approach, as it is evolving under the STOP HIV/AIDS Project with routine HIV testing imported into primary and acute care, is going to be seen — that is to say, not as an enhancement, but as an alternative to comprehensive, specialized sexual health services.

Certainly the question of the allocation of resources, particularly the perceived funnelling of resources away from community-based services, is a contentious aspect of the STOP HIV/AIDS Project. It has provided funding to a number of community-based partners and, while

that is obviously welcome in terms of making resources available to community-based groups, it also means that there has been reticence among community partners and members to bring forward concerns about the project.

Its advertising campaigns and the media portrayals paint a picture of a seemingly unassailable win-win scenario: people become healthier and transmission rates decline. Nevertheless, this is a very partial vantage point. Obviously, everyone is in favour of increased access to testing and treatment. The questions posed by the B.C. experience of treatment as prevention go far deeper, and those questions have to do with where human rights will be situated in health care.

The question of rights

As noted, there are various patient-rights concerns that have arisen with respect to the STOP HIV/AIDS Project. These concerns are focused on the issue of informed consent and the shifts in norms that are eroding patient autonomy by minimizing the amount of information provided to people who are considering whether or not to have an HIV test (little or no pre-test counselling; pre-test counselling perceived as "barrier" to testing); mischaracterizations and failure-to-disclose risks ("confidential tests" and failing to mention criminal law

regarding non-disclosure); limiting the ability of patients to protect privacy and confidentiality (dissuading patients from non-nominal testing); capitalizing on the inherent vulnerability of patients (opt-out, "routine" testing); and incentivizing testing.

None of these shifts in approach is required to improve access to HIV testing and treatment. Rather, they suggest that the true aim of the program is solely one of increasing testing and treatment, and in which patient rights, like pre-test counselling, are perceived as a "barrier." Stated broadly, the concern is that the justification of the purported "greater good" of the new paradigm is very quickly eroding the foundation of the human rights approach to health care that has informed the approach to HIV testing and treatment.

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¹ K. Wong, "Locally made HIV strategy brings new hope," *Metro News*, 12 January 2012.

² British Columbia Centre for Excellence in HIV/AIDS, "Forecast: Journal of the BC Centre for Excellence in HIV/AIDS," February 2010. On-line: www.cfenet.ubc.ca/news/forecast.

³ Ibid.

⁴ Ibid.

⁵ See www.itsdifferentnow.org/.

⁶ British Columbia Centre for Excellence in HIV/AIDS, "Forecast: Journal of the BC Centre for Excellence in HIV/AIDS," December 2011.

⁷ R. Gustafson, "Memorandum to Vancouver Coastal Health Affiliated Physicians, Nurse Practitioners and Registered Nurses," 30 June 2011.

⁸ Ibid.

⁹ Vancouver Coastal Health, "Routine HIV Testing in Primary Care Frequently Asked Questions." Internal document made available to and on file with the author.

¹⁰ Vancouver Coastal Health, Vancouver HIV Screening Standards of Care, 8 July 2011. Internal document made available to and on file with the author.

¹¹ Vancouver Coastal Health, *supra*, note 9.

¹² R. Gustafson, *supra*, note 7.

¹³ Vancouver Coastal Health, "BC hospitals begin routine testing for HIV to help curb global epidemic," news release, Vancouver, 23 September 2011.

¹⁴ Province of British Columbia, Order of the Minister of Health Services, Ministerial Order No. M011, 11 January 2011.

¹⁵ Province of British Columbia, Order of the Lieutenant Governor in Council, Order No. 726, 18 November 2010.

¹⁶ Office of the Information and Privacy Commissioner for British Columbia, *Review of the Electronic Health Information System at Vancouver Coastal Health Authority Known as The Primary Access Regional Information System ("Paris")*. On-line: www.oipc.bc.ca/orders/investigation_reports/InvestigationReportF10-02.pdf.

¹⁷ Canadian Medical Association, "Principles for the Protection of Patients' Personal Health Information," 2011 CMA Policy.

¹⁸ R. Matas and I. Peritz, "Canada's poorest postal code in for an Olympic clean-up?" *The Globe and Mail*, 15 August 2008.

¹⁹ On-line: <http://ahamedia.ca/2011/07/09/hiv-status-testing-event-at-victory-square-in-vancouver-downtown-eastside-on-sat-july-9-sun-july-10-2011/>.

²⁰ C. Takeuchi, "Closure of B.C. Interior sexual health clinics concerns nurses," *The Georgia Straight*, 19 December 2011.