Dealing with AIDS in Canada: The Unmet Challenge

A Brief to the House of Commons Standing Committee on Finance regarding Fiscal Priorities for the Future

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Executive Summary

1. The Canadian Strategy on HIV/AIDS (CSHA) has slowed rates of HIV infection and contributed to a marked decline in AIDS cases and deaths.

- Compared to those of many other nations, the Canadian strategy has been successful in protecting vulnerable populations through a range of measures from basic research to population-based community development.
- Since 1993, only 25,000 new HIV cases have been reported, a significant reduction from the 30,000 cases reported in the epidemic's first decade.
- The number of reported new AIDS cases dropped from 1,481 in 1995 to 158 in 2001.

2. However, the challenge now is enormous, given HIV's move into new and often more difficult-to-reach populations.

- HIV infects about 4,200 Canadians every year, and the number of reported new cases, after a period of decline from 1995 to 2000, began rising again in 2001 and has risen since.
- The virus continues to infect growing numbers of heterosexual women, Aboriginals and young gay men, among other new populations.
- There is no vaccine for HIV and no cure; so, for most people, a diagnosis of HIV still foretells an inevitable progression to AIDS and death.

3. We must build on the successes of the Strategy if terrible additional costs are not to be incurred.

- With 4,200 new infections each year, HIV is costing Canada annually $600 million in direct future medical costs.
- If the current Canadian rate of infection were reduced to 1,700 new cases, an estimate $1.4 billion would be saved in the next five years.

4. To be effective, and save money, the budget of the CSHA should be increased to $125 million per year.

- There has been no increase in the annual appropriation for the Strategy since the maximum figure of $42.2 million was established in 1993.
- During this time, HIV prevalence in Canada has increased from 35,000 to 55,000, up about 60 percent; and, inflation has eroded the CSHA budget by at least 25%.
- There is ample evidence that the epidemic is once again growing and diversifying in Canada; failure to meet these new challenges by building on the real successes enjoyed to date will be ultimately to lose the entire effort.
- Given the complexities of the epidemic, it is essential that the Canadian Strategy be funded in an amount commensurate with the challenges faced; BCPWA submits an investment of $125 million annually would enable the scale of response necessary to beat HIV/AIDS in Canada.

BCPWA is Western Canada's largest AIDS organization with a membership of more than 4,000 HIV+ full voting members. The Society's services are also available to and regularly accessed by many of the 12,000 to 15,000 HIV+ individuals in BC. Unique among major HIV/AIDS agencies in Canada, BCPWA's Board of Directors is composed entirely of HIV+ members, and all of its programs are operated by committees led by HIV+ persons.

Introduction

The Persons With AIDS Society of British Columbia (hereafter, BCPWA) wishes to extend its sincere thanks to the members of the Standing Committee on Finance for soliciting and considering its views. We very much appreciate the opportunity to meet with the Committee for the purpose of presenting the following.

Founded in 1986, BCPWA is a registered charitable society run by and for persons living with HIV disease and AIDS. In the words of its mission statement, BCPWA "exists to enable persons living with Acquired Immune Deficiency Syndrome and Human Immunodeficiency Virus to empower themselves through mutual support and collective action. *From our personal struggles and challenges come our courage and strength."*

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The purpose of this brief is to argue that an important spending measure which should be taken to ensure progress in caring for all members of Canadian Society is a dramatic increase in the appropriation for the Canadian Strategy on HIV/AIDS (hereafter, CSHA) as administered within the Department of Health. It is argued that, in the face of an estimated 4,000 new cases of HIV every year in Canada, the appropriation should increase from its current level of roughly $42.2 million per year, to $125 million. As well, the addendum to this brief will argue that the federal government should use its leadership role – and its residual spending power, if necessary – to foster the creation of a national pharmaceuticals purchasing pool which, by combining the purchasing power of the various individual provinces' Pharmacare formularies, will permit both economies of scale and, more importantly, vigorous price and supply bargaining with the various pharmaceuticals manufacturers on the basis of which substantial cost savings may be realized.

AIDS In Canada

Acquired Immuno-Deficiency Syndrome – AIDS – (and the Human Immunodeficiency Virus – HIV – which causes the syndrome) has been a fact of life and death in Canada for more than two decades.

According to the Centre for Infectious Disease Prevention and Control, between January 1, 1979 and June 30, 2002, there were 12,674 deaths of persons officially reported as "AIDS cases". This out of a total of 19,213 AIDS cases reported during that period. And it is important to remember that, as the Centre itself puts it, "The number of reported deaths among reported AIDS cases … is an underestimate …". This is so for many reasons, some having to do with complicated problems of epidemiological tracking and some with simple AIDS stigma.

And the number of potential new AIDS cases in Canada is enormous. Since the mid-1980's, when a reliable test for HIV became widely available, more than 52,000 Canadians have tested positive for the virus. Although the advent of anti-retroviral therapies in the mid-1990's had a wonderful impact on the progression from HIV to full-blown AIDS in most people – such that new AIDS cases per year, after rising steadily for a decade and a half, dropped from 1,481 in 1995 to 1,046 in 1996 to 448 in 1997 to 158 in 2001 – that progression remains inevitable for most people diagnosed as having contracted HIV (hereafter, HIV+ people). It is only a matter of time.

What is even more alarming in the long run is that, after declining steadily from 2,985 per year in 1995 to 2,120 in 2000 – a drop of almost 30 percent – the number of Canadians testing positive for HIV began climbing again, to 2,182 in 2001 and then to 2,473 in 2002. That's a 16.6 percent increase in two years. (It should be noted that more than half of the increase in 2002 may be attributable to some degree to a new testing policy at Citizenship and Immigration Canada – still, the trend is clear.)

Further, it is widely accepted that roughly one-third of HIV infections in Canada are undiagnosed and so unreported.

The prognosis is not good. There is evidence that the disease is showing up with new strength and frequency in what may be called "non-traditional" populations (in addition to gay men and injection drug users) – especially heterosexual women contracting the disease through sexual intercourse and young gay men contracting it through both intercourse and injection drug use.

The Costs

Earlier this year, the House of Commons Standing Committee on Health conducted a study on the Canadian response to HIV/AIDS. In its June 2003 report of its findings ("Strengthening the Canadian Strategy on HIV/AIDS"), that Committee validated both the estimate of 4,000 new cases of HIV annually in Canada – reported and unreported. That Committee also accepted the widely credenced (but now half-decade old) estimate of $150,000 in lifetime direct costs of each new HIV case.

A recent draft analysis of HIV/AIDS in BC produced within that provincial government's Ministries of Health Planning and Health Services ("Priorities for Action in Managing the Epidemics – HIV/AIDS in BC: 2003-2007", draft, March 2003) estimated the current lifetime cost of each new HIV case to be between $180,000 and $225,000.

This figure will only rise – possibly dramatically – as new pharmaceuticals are brought onto the market at prices considerably higher than those for pharmaceuticals presently available. (Why not stick with the pharmaceuticals we've got? Because their effectiveness erodes with use. The rates of such cumulative inefficacy vary with the pharmaceutical and the patient, but the need for new pharmaceuticals able to attack different aspects of the virus is inescapable for most HIV+ people.)

Given the regime of federal transfer payments to the provinces for healthcare, it is probably impossible and certainly pointless to attempt to determine the relative share of the costs of HIV/AIDS borne by the federal and provincial governments.

What is certain is that only an effective and concerted HIV strategy – incorporating both prevention initiatives and the care, treatment and support for HIV+ people that enables them actively and effectively to devise and participate in such initiatives – will allow the public purse in its various Canadian guises to avoid significant additional cumulative expenditures on HIV/AIDS. It has been estimated that by driving down the current rate of new infections from 4,000 cases per year to 1,700, $1.4 billion would be saved in the next five years.

The implications are obvious and stark.

A Canadian Response – the National/Canadian AIDS Strategies

By 1990 it had become obvious to federal health authorities that HIV/AIDS was something that had to be addressed at a national level as well as provincially. That year, a provisional national response to HIV/AIDS was constructed and launched, effecting a three year commitment of $112 million in federal government funding, $37.3 million annually.

This was succeeded in 1993 by the first five-year National AIDS Strategy, which carried with it a funding commitment of a maximum of $42.2 million per year – exactly the same commitment as in 2003.

As one example of the good work it enabled, the National AIDS Strategy, through its AIDS Community Action Program (hereafter, ACAP), took a lead role in fostering the development of community-based AIDS service organizations that quickly became the front line troops in the battle against further spread of the disease and in assisting and advocating for "those infected or affected" by HIV/AIDS. This was especially so in those provinces, or areas of provinces, where provincial government funding was meager. Although the horrors of AIDS played a decisive role in driving the prevention message home in the late 1980's and early 1990's, it was the ACAP-funded community-based organizations that translated this generalized climate of receptivity into actual effective prevention (and care, treatment and support) initiatives on the ground. It is not unreasonable to afford a considerable amount of the credit for the reductions in new HIV cases in Canada between 1995 and 2000 to the ACAP-funded work of these generally small, shoestring operations. Other elements of the Strategy had similarly beneficial effects.

A further five-year renewal of the federal government's HIV/AIDS program was formalized under the rubric of the Canadian Strategy on HIV/AIDS (hereafter, CSHA) in 1998. However, there was, in effect, no new money attached, and the annual appropriation remained static at $42.2 million.

It wasn't enough. The virus had continued to seek new vectors of transmission, to work its way into new populations of relatively disadvantaged, disempowered and just plain despised people. And the overall population of people living with HIV and AIDS continued to grow, requiring ever more of the strictly limited resources available to provide them with some semblance of a reasonable life and a bit of hope.

Which brings us to 2003, and the mounting evidence that the failure effectively to address the epidemic in the period 1998 to 2001 has created the conditions – rising rates of infection and substantial penetration into new populations – with which we must now contend.

Priorities for the Future

Start with two understandings.

The first was stated baldly by Dr. Martin Schechter, Director of the Epidemiological Unit in the BC Centre for Excellence in HIV/AIDS. In his testimony before the Standing Committee on Health on March 17, 2003, Dr. Schechter said: "… unlike any other prevention/causation issue in health, we have a situation where we have a virus that is 100 percent correlated to the outcome of AIDS. That means every person who gets HIV infection will eventually get immune deficiency and become ill. And no one who does not get HIV infection will ever get AIDS."

The second is a truism, but is nonetheless real and important for that: HIV infection is 100 percent preventable. Indeed, it is almost remarkably easy to prevent. It is not stretching matters overly to contend that in each instance at least two people must actively collude for HIV transmission to occur.

What is required to stop the Canadian HIV epidemic in its tracks, then, are interventions aimed at breaking those instances of collusion.

These interventions must be undertaken across a wide range of activities. Basic and applied research, community-based research (aimed at better understanding those instances of collusion and so how most effectively to intervene), general and targeted information campaigns, care, treatment and support measures for HIV+ people, appropriate support for the United Nations Global Fund, work with key target populations such as aboriginal persons and inmates in federal corrections Institutions – all these, and more, are components of an effective response.

And all are, at present, woefully under-funded.

Remember: in 1993, there were only roughly 30,000 cumulative HIV cases in Canada, and there are now more than 55,000, an increase of over 80 percent (and this speaks nothing of the evermore complex nature of the epidemic); in 1993, the federal government spent $42.2 million on its national HIV/AIDS program, and in 2003 will spend $42.2 million, an increase of nothing – in constant dollars (factoring in the impact of percent inflation over the decade), its actually a decline of more than 20 percent!

In the Health Standing Committee report previously referenced, the members of that Standing Committee are blunt. The very first section of their very first recommendation calls for the federal government to "… increase the total funding for the renewed federal Canadian Strategy on HIV/AIDS to $100 million annually".

We are also aware of a review internal to Health Canada of the CSHA's workings between 1998 and 2003, and are hopeful that it will be recommending a figure higher than that recommended by the Standing Committee on Health.

In the interests of ensuring progress in caring for all members of Canadian society, we strongly urge you to support such increased spending measures when their advancement comes before the various bodies within the Canadian parliament and federal government with which you are associated – indeed, where it is within your competence to do so, we strongly urge you to recommend them.

Will these spending measures ensure the end of the HIV/AIDS epidemic in Canada? We cannot know. Will the absence of these measures ensure the worsening of the epidemic, and the consequent arrival in the not too distant future of the truly monstrous choice between the expenditure of billions of dollars in additional health care costs on the one hand, or the consignment of scores of thousands of Canadians to AIDS fates of the sort not widely seen in our country since the mid-1990's on the other? Yes.

Conclusion

HIV transmission is preventable and AIDS is thus avoidable. This is good, if for no other reason than the ongoing costs of dealing with HIV/AIDS are substantial and growing.

Clearly the steps taken in the past to combat HIV/AIDS in Canada are no longer adequately funded. In the absence of concerted new measures, swiftly implemented, the plague of HIV/AIDS in Canada will burst forth with renewed vigor, stunting and prematurely terminating the lives of countless thousands of Canadians. As well, it will simultaneously cost the public purse in its various federal and provincial guises additional billions of dollars.

What is required of Canada's federal government now is a substantial additional commitment to the battle against the HIV/AIDS epidemic. The Canadian Strategy has enjoyed numerous successes, and has contributed substantially to mitigating the advance of the epidemic in this country. But it has come to be starved of the funds it needs if it is to enjoy decisive success.

It is recommended that investment in the renewed Canadian Strategy on HIV/AIDS be pegged at $125 million per year for the next five years.

Addendum: Pharmaceuticals

As is generally known now, the single fastest growing portion of Canada's overall health care bill is that part devoted to the purchase of pharmaceuticals. This is so for a variety of reasons, including:

(1) perhaps most importantly, it has generally been found to be cheaper to treat a large variety of illnesses and traumas with pharmaceuticals rather than with hospitalization (the simple corollary of this should be kept in mind: even limited restriction of current access to pharmaceuticals can reasonably be projected to result in increased utilization of acute and chronic care facilities and systems, and thus even higher costs arising from such increased utilization);

(2) the combination of increased patent protection for new drugs (further raised by the federal government from 17 to 20 years in 2001) and an ineffective federal drug prices review system has resulted in a regime of pricing for new drugs that guarantees huge and ever-rising drug prices (prices now sufficient to make the pharmaceutical industry generally the most profitable legitimate endeavor in the world); and,

(3) there are strong indications that, for a variety of reasons ranging from consumer "demand" through physician enthusiasm (both arguably the product of growing advertising efforts by major pharmaceutical companies), over-prescribing or inappropriate prescribing of pharmaceuticals is a problem.

All provincial Pharmacare programs are struggling with the task of providing the pharmaceuticals their prescribing physicians and the patients they serve demand without doing serious damage to their respective treasuries. Solutions vary from province to province, but almost all involve some regime of access restriction or other, ranging from failing to list newly available pharmaceuticals and/or "delisting" of previously covered pharmaceuticals, to imposing special prescription rules on some, to increasing the share of the cost borne by individual purchasers of pharmaceuticals – with all steps in between.

The implications for the federal government are clear: an ever greater proportion of the funds transferred to the provinces for health care purposes are going to the purchase of pharmaceuticals. This tendency can only deepen. Either that, or Canadians' health and well-being generally will suffer possibly substantial deterioration

Current trends are unsustainable. But what can be done?

Current Pricing/Purchasing Practices

Once Health Canada, through its Therapeutic products Directorate, has approved a pharmaceutical for marketing, prescribing and consumption in Canada, the question of what that pharmaceutical ought to cost is referred to the Patent Medicines Price Review Board (hereafter, PMPRB).

Weighing a variety of factors (none of which, oddly, has directly to do with the given pharmaceutical's therapeutic value), the PMPRB devises a price for the pharmaceutical under review. That then becomes the price at which the pharmaceutical is sold across Canada – and, so, is the price that the various provincial Pharmacare plans have to pay to greater or lesser degrees. In an age in which the marketplace is heralded as the proper arbiter of all questions of supply and demand, this is surely an anomaly. Nonetheless, this system has unquestionably resulted in a regime of pharmaceuticals prices often considerably below those obtaining in the United States of America.

Still, the costs of pharmaceuticals, especially new pharmaceuticals just now making their way onto the market, continue to rise. Coupled with the rising volume of pharmaceuticals being prescribed generally, this places an all but intolerable burden on provincial treasuries attempting in to sustain Pharmacare programs.

The provincial response to this challenge has been the creation of the so-called Common Drug Review (hereafter, CDR). The CDR was created by an agreement among the various participating provinces' (all except Quebec) ministers of health; their various deputies now administer it.

The CDR's workings are, on the surface, simplicity itself. Once the PMPRB has determined a "fair" price for a given pharmaceutical, and Health Canada has approved it for consumption in Canada, the CDR, on behalf of its member provinces, assesses that pharmaceutical's merits and determines whether or not to recommend it for inclusion on the various provincial formularies. In the event of a negative assessment, the matter goes no further, and the pharmaceutical reviewed does not make it onto any participating provincial formulary. In the event of a positive review, the pharmaceutical reviewed is then further reviewed by each provincial formulary using whatever mechanisms and criteria it chooses.

There are problems. The most obvious is the duplication of effort inherent in individual provinces' substantially repeating the review already done by the CDR. This is neither efficient nor timely. Equally importantly, the principal mandate of the CDR is the determination of the "cost effectiveness" of the pharmaceuticals under review, rather than ensuring that consumers have the most timely access to safe and effective medicines. Precisely what constitutes "cost effectiveness" for the purposes of the CDR has never been made public, nor have any of the other criteria – if any – which the CDR may employ in its reviews. Indeed, there is a problem generally with an almost complete lack of transparency surrounding the CDR's operations. This is further evidenced in the complete absence of any kind of consumer input into the CDR's deliberations.

Finally, each province is ultimately left falling back on its own devices when it comes to the actual purchase of the pharmaceuticals approved. As noted above, this division of the Canadian market into ten-plus constituent elements, each doing little more than accepting the PMPRB-determined price, amounts to an unconscionable waste of the bargaining strength implicit in one coherent national market.

A National Purchasing Pool

As has been argued elsewhere (notably in BCPWA's submission of September 2003, to the House of Commons Standing Committee on Health) – and as can be inferred in the proposal for a national drug agency and attendant national drug formulary regime advanced in the Report of the Royal Commission on the Future of Health Care in Canada in November 2002 – the pooling of the purchasing power of the various Canadian provincial Pharmacare formularies into one national purchasing and distribution scheme could not help but result in significant savings on pharmaceuticals purchasing generally.

This is so for two reasons: (1) at two percent of the world's total, the buyer's market represented could not be ignored by any pharmaceutical manufacturer, all of which would be in a position of having to bargain, and (2) the possibilities for innovative deal-making – for example, agreeing to a somewhat higher price on one pharmaceutical for the purpose of achieving a somewhat lower price on another by the same manufacturer (thereby achieving a lower overall cost for the two), seeking combination deals with two or more manufacturers, and so on – are limited only by the creativity of the persons hired to administer the pool.

Further, it may prove quite possible for a Canadian national pharmaceuticals purchasing pool, once it is established, to enter into joint buying arrangements covering selected pharmaceuticals with similar bodies in other countries – a sort of reverse OPEC for pharmaceuticals-consuming nations.

The time has come for a national solution to the problem of rising pharmaceuticals costs. In the current international economic and political climate, it is best that that solution be substantially "market-based". A national pool of various provincial Pharmacare formularies' purchasing power can create the market "clout" necessary to ensure Canadians get best value for their pharmaceuticals dollars.