
Getting Ahead of the Epidemic: The Federal Government Role in the Canadian Strategy on HIV/AIDS 1998-2008

Prepared for
Health Canada and the
Five-Year Review Advisory Committee
by
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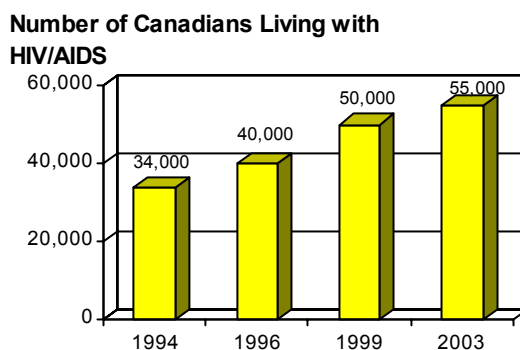
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Executive Summary

Introduction

HIV/AIDS may well be the most devastating infectious disease since the bubonic plague decimated Europe in the 14th century. Worldwide, it has been responsible for the death of over 20 million people. In some countries, HIV/AIDS has turned back the development clock by several decades while in Canada it has cut a swath through vulnerable communities, leaving 13,000 deceased and 55,000 coping daily with its effects and impact.

The Government of Canada bears a very significant responsibility for addressing the HIV/AIDS epidemic. This responsibility flows, in part, from the epidemic being virtually unique among major illnesses given its association with discrimination and stigma. This responsibility flows also from the profound nature of the epidemic's threat and impact, and from it being 100% preventable but still inevitably fatal.



This Five-Year Review of the Canadian Strategy on HIV/AIDS (CSHA) was designed to help the government get ahead of the epidemic. The Review defines what is:

- the most appropriate federal government role within the broader CSHA; and
- the most appropriate level and allocation of federal funding for the CSHA, 2004-2008.

The Canadian Experience

Since the 1980s, Canada has enjoyed many successes in its effort to address the HIV/AIDS epidemic:

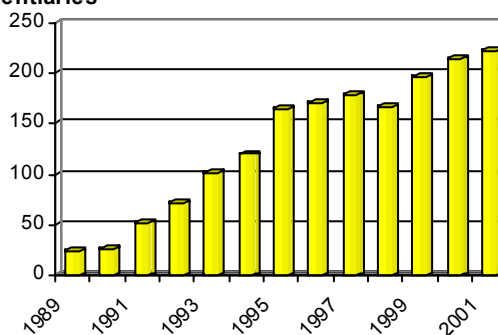
- many people are now much better informed about HIV/AIDS, about preventing HIV infection, and about the relationship between HIV vulnerability and the social determinants of health;

- there is now a host of national and community organizations addressing the epidemic and a new maturity characterizing their relationship with Health Canada; and
- Canadian researchers are contributing in a very significant way to the national and international knowledge pool that alone can defeat the epidemic.

These efforts have contributed to Canada having incidence and prevalence rates comparable to those in other developed countries. They also served to provide many lessons about responding effectively to the epidemic. One such lesson concerns the importance of addressing the marginalization that makes people vulnerable to HIV infection. Another is the importance of focusing prevention efforts not only on the general population but also on those who are living with HIV/AIDS. Another still is that governments cannot become complacent since both the virus and the epidemic are constantly changing and posing new threats. Prevention and other efforts, therefore, must be continuous and, in the coming years, will have to adapt to a number of emerging trends, for example:

- the number of people living with HIV/AIDS will increase significantly given the treatment, care and support now available and given the annual number of new infections. The infected and affected population will become increasingly diverse.
- the epidemic's impact on First Nations, Inuit and Métis communities could become even more devastating. The epidemic could spread rapidly among other vulnerable populations, for example injection drug users who share needles, women from countries in which HIV/AIDS is endemic and those incarcerated in correctional institutions.
- Although gay men will remain the largest group of people living with HIV/AIDS, women will make up an ever larger share of the HIV-positive population. Women now account for almost 45% of HIV infections diagnosed in people aged 15 to 29 years.

Reported Cases of HIV+ Inmates in Federal Penitentiaries



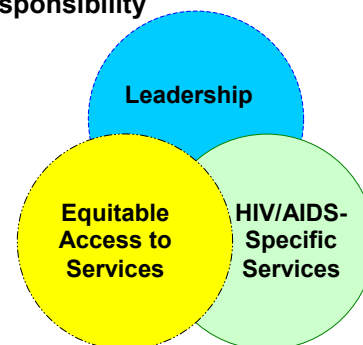
The Government of Canada Role, 2004-2008

The Government of Canada role, 2004-2008, will have a single goal, namely to organize, align and direct Canadian efforts and resources so as to most effectively prevent the epidemic's spread, reduce the vulnerability of at-risk populations, enhance the capacity of individuals, groups and organizations to address the epidemic, ensure that appropriate treatment, care and support are equitably available to all Canadians, and minimize the adverse personal, social and economic impact of HIV/AIDS. An important aspect of that goal is to anticipate the epidemic's course, and to get out in front of it.

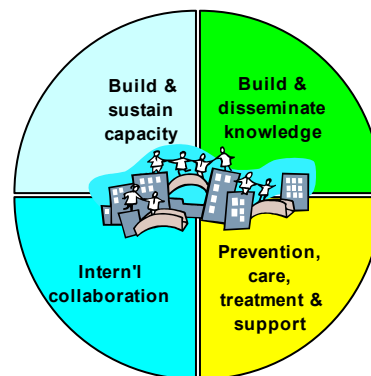
In working toward this goal, the government will organize its activities within three interconnected *realms of responsibility*. It will:

- provide **leadership** by assuming direct responsibility for certain activities, by enabling others to assume responsibility where appropriate, and by coordinating and giving direction to intergovernmental and community efforts.
- ensure that those infected with or affected by HIV/AIDS have **equitable access** to its many programs and services, and that its departments and agencies are working cooperatively with Health Canada, with each other and with their provincial or territorial counterparts.
- provide certain **HIV/AIDS-specific supports and services** within the context of the CSHA. This responsibility lies primarily within Health Canada and will include efforts related to knowledge, prevention, care, treatment and support, international collaboration and capacity.

Proposed Realms of Federal Responsibility



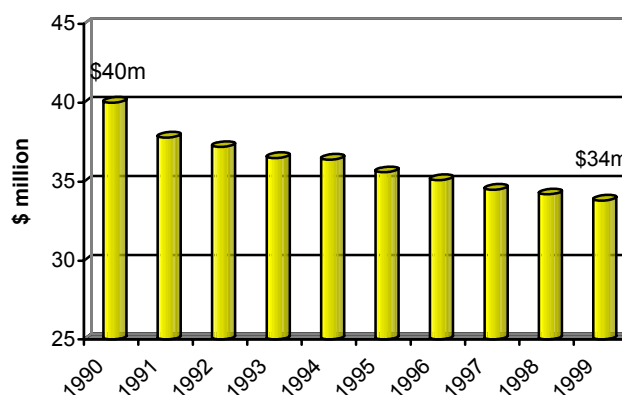
HIV/AIDS-Specific Supports and Services



The Canadian Investment

Between 1994/95 and 2002/03, the Government of Canada invested \$42.2 million annually in the CSHA. Inflation has reduced this investment's real value to less than \$34 million, an amount that is inconsistent with the increasing number of people living with HIV/AIDS and with the epidemic's proliferation into more diverse and harder to reach populations. It is inconsistent also with the government's improved fiscal situation and with the spending patterns in other jurisdictions, for example Ontario, British Columbia and the United States.

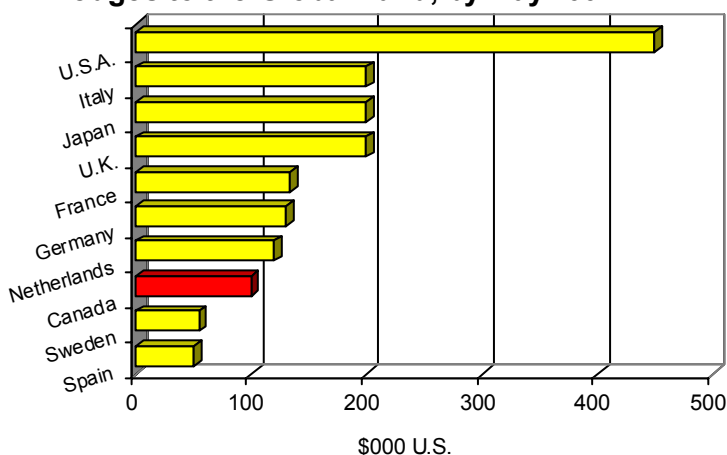
Impact of Inflation on Strategy Funding



The static Canadian investment has also compromised both the country's role in addressing the global pandemic and its reputation as a caring and committed nation.

The Ministerial Council on HIV/AIDS, the Parliamentary Standing Committee on Health, a variety of experts and a host of community organizations have all suggested that this \$42 million investment is both inadequate and inappropriate. Important prevention efforts have not been sustained and new prevention programs initiated; new policy has not been developed and important research not conducted; community organizations have been weakened and have had to compete rather than cooperate. The government should invest more because:

Pledges to the Global Fund, by May 2002



- Canadians want it to do so and want Canada to meet its social and health responsibilities, in Canada and internationally;
- doing so would generate very significant savings in the health care sector and throughout the economy, in both the short and the long term;

- doing so would produce new knowledge and skills that could strengthen the country's ability to address both other outbreaks – such as SARS – when they appear and other health conditions such as tuberculosis and hepatitis-C;
- there are no private or philanthropic alternatives to government funding; and
- current expenditures are being used responsibly and are producing important benefits.

Investment Options

A status quo investment of **\$42.2 million** will result in Canada losing the fight against HIV/AIDS and not having the capacity to address new epidemics as they arise. This level of investment will send a clear but disappointing message to those addressing HIV/AIDS in Canada and to those concerned with public health and well being. A larger investment – of **\$85 million** annually – will significantly strengthen the country's response to HIV/AIDS although it represents only the equivalent of what was invested in 1990 adjusted for inflation and prevalence. It represents a commitment only to managing and living with the epidemic.

A greater investment – of **\$106 million** – represents a clear and strong commitment to fighting HIV/AIDS and other epidemics, in Canada and around the world. This amount will allow Canada to get ahead of the epidemic and, very possibly and very soon, prevent its further spread. It will enable the Government of Canada to be a leader and to attack the very roots of HIV vulnerability. It will support an intergovernmental and multi-sectoral approach that signals to all Canadians that preventing infectious diseases is a national priority. Conceivably, this level of investment could be reduced over time as Canada gets ahead of the epidemic and brings it fully under control, and as the impact of its proactive measures is felt.

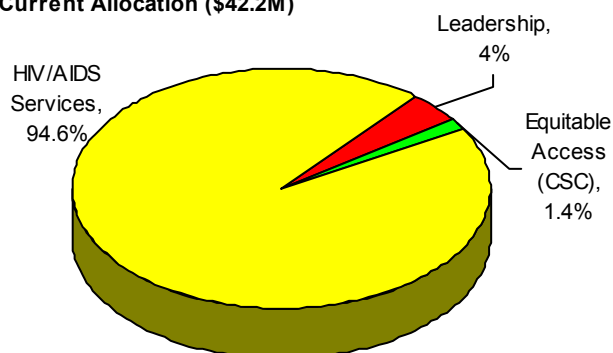
Enhancing the public investment in this way, and to this level, is also an eminently practical option given the country's fiscal situation, budget surpluses, spending in other sectors, social conscience and commitment to public health and well being. It is eminently practical given the financial costs that will be avoided in the future.

Allocating the Federal Investment

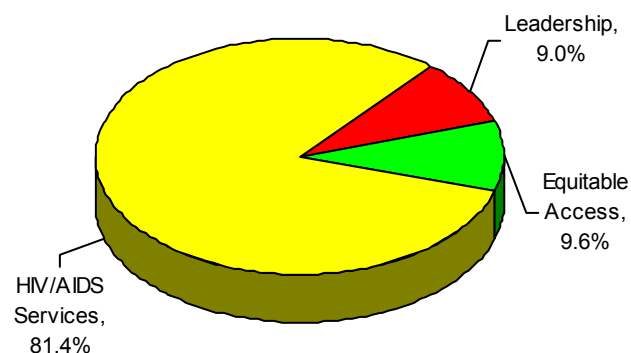
The federal investment will have to be allocated among the government's three realms of responsibility with the largest portion – over 80% – being directed toward HIV/AIDS-related supports and services. The remaining 20% would support the government's leadership and ensuring access responsibilities. This allocation is illustrated below as is the suggested allocation among the four activity areas encompassed within the HIV/AIDS-specific supports and services realm of responsibility.

Allocation among the Three Realms of Responsibility

Current Allocation (\$42.2M)

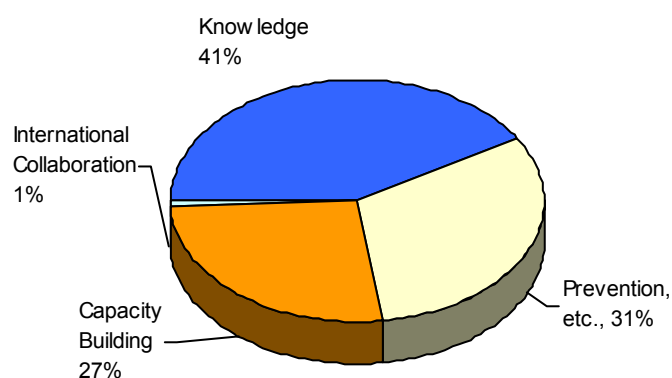


Proposed Allocation, 2004-2008

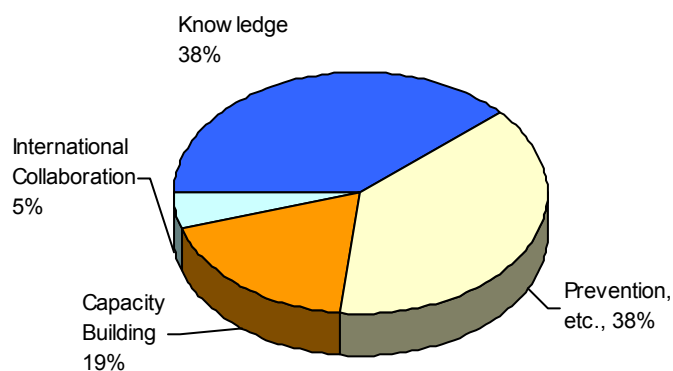


Allocation among HIV/AIDS-Specific Areas of Activity

Current Allocation by Activity Area



Proposed Allocation by Activity Area



Over the past two decades, the Government of Canada has responded to the HIV/AIDS epidemic in a consistent manner by endeavouring to build commitment, partnerships, knowledge, awareness and capacity. These efforts have paid important dividends. However Canada's success is neither adequate nor secure. HIV/AIDS remains a deadly disease for which there is no vaccine and no cure. The virus' ability to mutate, to re-emerge and to race ahead means there is no place for complacency. The status quo – simply maintaining the past or continuing with the present – is not an adequate response for the future.

The federal government's response to HIV/AIDS, therefore, must continue to evolve and its investment, for the first time in more than a decade, enhanced.

"The fact is that we know what to do about care and we know what to do on prevention, and we know what to do on treatment, and we could turn this pandemic around in a few years if we were able to summon the energy and mobilize the resources and the response....it is partly a matter of human resources, partly a matter of infrastructure, but it is overwhelmingly a matter of financial resources. (Stephen Lewis, United Nations Special Envoy for HIV/AIDS in Africa, Presentation to the Standing Committee on Foreign Affairs and International Trade, April 2003)

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1. Introduction

The Government of Canada has a responsibility to address the HIV/AIDS epidemic in Canada and internationally. This responsibility flows from the epidemic being virtually unique among major illnesses.

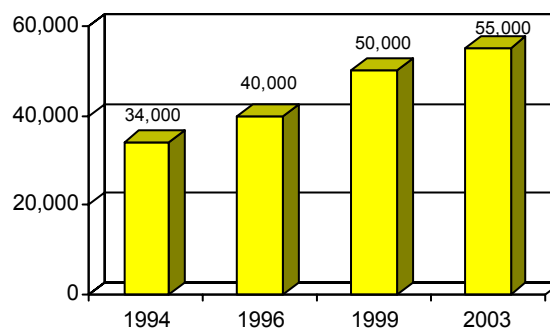
First, the epidemic's roots lie in the discrimination too often associated with sexual orientation, race, addictions or poverty, and in the social and economic conditions that influence health. Second, those living with HIV/AIDS are very often stigmatized and marginalized because of the profound ignorance that characterizes the epidemic. Third, HIV/AIDS does not receive the level of private and philanthropic support that is available to other health conditions such as breast cancer or diabetes. Fourth, both the virus and the epidemic are ever changing and posing new prevention and treatment challenges. And, importantly, HIV is unique in that it is 100% preventable although AIDS remains inevitably fatal.

The government's responsibility derives also from its fiduciary relationship for the health of Aboriginal people¹ in Canada and from its obligations to those serving in the military and RCMP, or incarcerated in federal prisons. It derives as well from the threat and impact of HIV/AIDS being so very profound:

- over 13,000 Canadians have already died as a result of HIV/AIDS along with 20 million others around the world; and
- 55,000 Canadians are today living with HIV/AIDS and each day, another eleven Canadians become infected with HIV, adding to the 5 million people internationally who were newly infected through the past year.

The federal government's responsibility extends beyond the borders of Canada itself because the epidemic's impact on many countries has been so very "corrosive and catastrophic."² The magnitude of this impact is:

Fig. 1, Number of Canadians Living with HIV/AIDS



¹ This report uses the term "Aboriginal people" in its constitutional context, i.e. including First Nations (living on and off reserve) people, Metis people and the Inuit.

² OECD, 2002:4.

... almost unimaginable. The figures (e.g., 20 million deaths) are statistical abstractions, of course, but behind them lies a community and family disaster In many countries in southern Africa, the millennium development goals are in reverse. Infant mortality rates are going up. Maternal mortality rates are going up. Life expectancy is going down so dramatically that it takes your breath away. There are numbers of countries whose life expectancy should be 60 [but where] ... it has dropped, literally, to 39 or 40 in the period of one decade.³

Evidence from Canada and elsewhere indicates that a vigorous, coherent, sustained and adequately-funded response is required to address the epidemic in an effective manner.

1.1 Purpose

In the 1980s and for much of the 1990s, HIV/AIDS was poorly understood. Governments, in Canada and elsewhere, were responding to a crisis and to a new and unprecedented emergency. The urgency of the epidemic's threat did not provide the time required to articulate a clear federal role within the context of a national, pan-Canadian strategy.

The Government of Canada is now engaging in a more deliberate and considered process. First, Health Canada is participating with stakeholders in a national strategic planning process to identify what is needed from whom if Canada is to respond effectively to the epidemic. Second, Health Canada is endeavouring to articulate, through this Five-Year Review of the federal role in the Canadian Strategy on HIV/AIDS (CSHA), what is:

- the most appropriate role for the federal government within the broader Canadian strategy; and
- the most appropriate level of federal funding for the CSHA, 2004-2008, and how to allocate these funds among its different responsibilities and priorities.

³ Canada, Parliamentary Standing Committee on Foreign Affairs and International Trade, April 11, 2003. (Steven Lewis)

Figure 2 presents the relationship between these two processes.

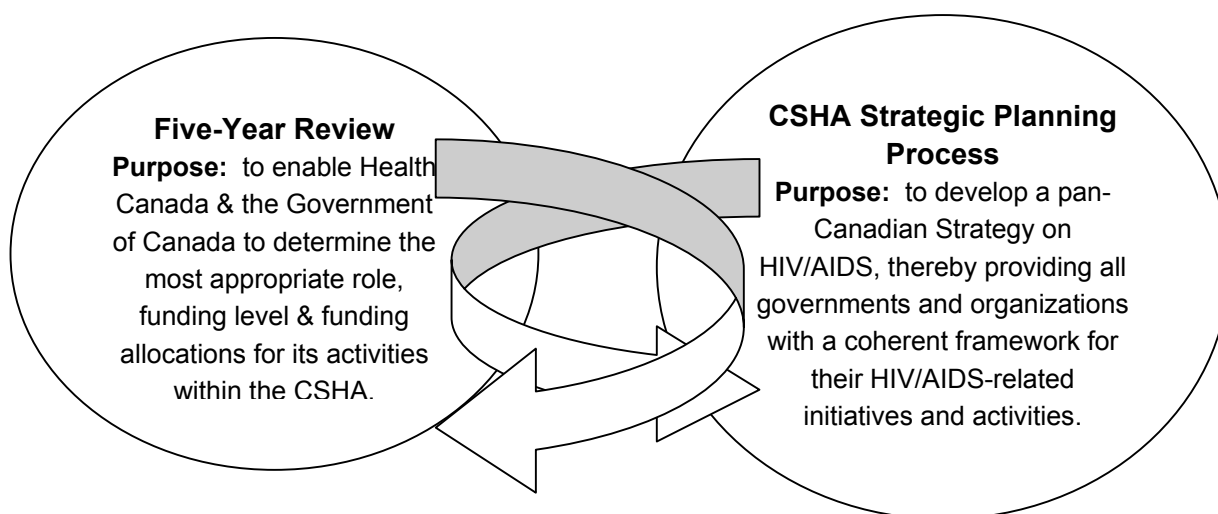


Fig. 2, Relationship Between the Five Year CSHA and the CSHA Strategic Planning Process

1.2 Methodology

The *Getting Ahead* project methodology included:

- reviewing the extensive literature on the Canadian and international efforts to address the HIV/AIDS epidemic;
- incorporating the diverse experiences and perspectives provided by the project's Advisory Committee, focus group participants (see **Appendix A**), members of both the Federal/Provincial/Territorial Advisory Committee on HIV/AIDS and the Ministerial Council on HIV/AIDS, and other key informants who responded to various questionnaire, email or telephone enquiries; and
- preparing a series of Working and Discussion Papers (see **Appendix B**) for consideration by the Advisory Committee, Health Canada and other government staff, and key informants associated with a host of national and community HIV/AIDS-related organizations.

The project's flow is represented in charts included in **Appendix C**.

1.3 Organization

Following this introduction, Part A focuses on the federal role while Part B focuses on funding issues. Sections 2 and 3, in Part A, offer “considerations” on the federal role within the Canadian Strategy on HIV/AIDS, first in the period 1998 to the present and, second, in the period 2004–2008. Section 4 takes these considerations into account as it conceptualizes a new federal government role in the CSHA. Section 5 defines that role in more detail.

In Part B, Section 6 outlines federal expenditures to date while Section 7 identifies some of the challenges inherent in building an evidence-based foundation for funding decisions. Sections 8 to 11 address a series of questions around funding issues, i.e. is the current budget adequate, why should Canada invest more, what outcomes will flow from a new investment, and how much more should Canada invest. Subsequently, Section 12 and Section 13 consider allocating that new investment among the federal government's different responsibilities and priorities, and present an overview of what each investment level would support.

Finally, Part C – *Getting Ahead* – and Section 14 offer conclusions.

A. Defining the Federal Role in the CSHA

2. Considerations – Focus on the Past, 1998-2003

2.1 The Canadian Strategy on HIV/AIDS

The federal efforts to address the epidemic began in the mid-1980s but were more fully coordinated after 1990 with the first National AIDS Strategy and its focus on learning about HIV/AIDS. The second National AIDS Strategy, 1993-1997, emphasized building an infrastructure capable of addressing the epidemic.

In 1997 the Government of Canada engaged non-governmental AIDS organizations in a comprehensive consultation process to develop a new Canadian Strategy on HIV/AIDS. Health Canada provided its Stakeholder Group with 58 briefs while 225 people participated in five multi-sectoral meetings and 50 people participated in the different focus groups. The feedback

may have been disappointing. For example, of the 4500 workbooks distributed to stakeholders – including 280 to individuals in the hard-to-reach groups – only six were returned.⁴

The Stakeholder Group had some concerns about the time allowed for the process, about receiving information in a timely fashion and in both official languages, and about the government commitment to partnership.⁵ Nevertheless it reached a consensus on how to allocate the Strategy's \$42 million budget although some objected to different sectors having to compete for a share of what they perceived as an inadequate budget.

The CSHA built on the previous National AIDS Strategies and was intended to be pan-Canadian in nature, providing a coherent, national framework for the different orders of government and for the many community organizations endeavouring to address the epidemic. For a variety of reasons, however, the CSHA has not yet achieved that national breadth and status and is generally perceived as defining the federal government's own role.

Nevertheless, the CSHA period, 1998-2003, witnessed important accomplishments:

- Many people are now much better informed about HIV/AIDS, about preventing HIV infection, and about the relationship between HIV vulnerability, discrimination, stigma and the social determinants of health.
- There is now a host of national and community organizations addressing the epidemic and a new maturity characterizing their relationship with Health Canada.
- Canadian researchers are participating in important clinical trials and are contributing in a very significant way to the national and international effort to address the epidemic.
- The federal government has encouraged innovative practices and now needle exchange programs, for example, are in place in many communities across Canada.

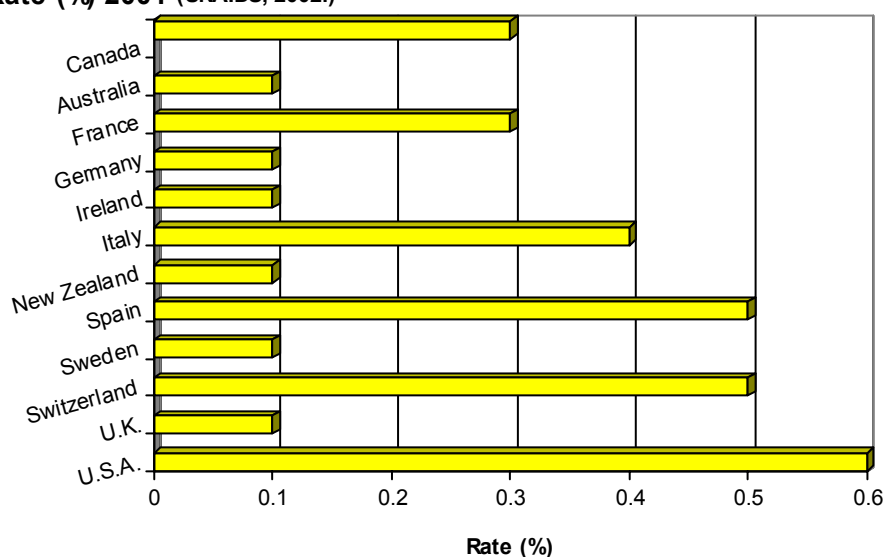
As illustrated in Figure 3, these efforts have contributed to Canada having incidence and prevalence rates comparable to those in other developed countries.⁶

⁴ Health Canada, Recommendations for Phase III of the NAS, 1997.

⁵ *Ibid.*

⁶ UNAIDS, 2002:189-202.

**Fig. 3, Adults, 15-49 Years, Living with HIV/AIDS,
Rate (%) 2001 (UNAIDS, 2002.)**



2.2 Effective Practices

Two decades of experience with HIV/AIDS have provided many lessons on how to address every aspect of the epidemic, for example the following.

- a) A major cause of HIV vulnerability is the discrimination directed at certain groups of people and their exclusion from the country's social and economic mainstream. Discrimination, marginalization and the other health determinants influence not only vulnerability but also the speed with which HIV infection will progress to AIDS and a person's ability to manage their condition.

Addressing these health determinants – through human rights, family and income equity policies – is the key to reducing vulnerability and preventing the epidemic's spread. However, it is a long-term strategy that requires committed leadership, an informed public and sustained effort.⁷

- b) Prevention priorities have to include not only the general public but also those who are already living with HIV/AIDS and those who are not aware of their being HIV-positive and who, possibly, are spreading the virus to their partners. In this regard, it is

⁷ See Spigelman, HIV/AIDS and the Health Determinants, 2002.

estimated that nearly one-third of the 55,000 people currently living with HIV/AIDS in Canada may be unaware of their HIV-positive status. Prevention, care, support and treatment are mutually reinforcing and constitute a continuum in the effort to address the epidemic.

- c) Many prevention initiatives and strategies – for example, distributing condoms, outreach nursing and care, needle exchanges, safe injection sites and particular prison-based programs – have proven their effectiveness either in Canada or elsewhere. However, these programs must be adapted to the specific needs and cultures of the target populations. Importantly these programs should be complemented by appropriate health and social services and should be based upon sound evidence rather than on stigma or perception.
- d) Early, accurate diagnosis and reporting is essential for preventing outbreaks and for containing the epidemic. Better information, from community organizations and from epidemiological surveillance, will enable agencies to anticipate where the epidemic is going rather than simply respond to where it has been.

Strong sentinel surveillance systems enhance jurisdictions' ability to address the epidemic. To be effective, such systems have to monitor and analyze newly reported cases of HIV infection as well as the behaviours that place people at risk of infection and the progress being made on addressing the social determinants of health.

Understanding the epidemic's course and responding effectively are also enhanced by efforts:

- to link epidemiological and laboratory data relating to a host of conditions, for example HIV/AIDS, hepatitis-C, sexually transmitted infections and tuberculosis; and
 - to build a bridge between surveillance and practice so as to transfer knowledge and design programs on the basis of this knowledge.
- e) A variety of factors contribute to a government's success in managing the epidemic including having support from across the political spectrum, committed and sustained leadership, partnerships with community-based organizations, the involvement of infected and affected communities, and a willingness to adopt harm reduction strategies.⁸

⁸ Spiegelman, 2001.

- f) Communities and governments cannot become complacent since both the virus and the epidemic are ever changing. Experience in Canada and elsewhere has shown how quickly the epidemic can spread from one population to another and how quickly it can re-appear in a population just when it appears to be under control. Prevention efforts must be continuous.

The challenge confronting the Government of Canada is to transform these lessons into practice as part of its redefined role in the CSHA.

2.3 Federal Accomplishments and Shortcomings

Both accomplishments and shortcomings characterize the federal government's involvement in the Canadian Strategy on HIV/AIDS. In some cases, however, the same characteristic is perceived by some as a strength and by others as a shortcoming. For example, the government's commitment to inclusiveness and consensus is said both to enhance the quality of its decisions and to compromise its ability to act decisively and in a timely fashion.

The literature, key informants and the project's Advisory Committee suggest the following as the most significant strengths evident within the federal role to date:

- a) its pursuit of inclusive, multi-sectoral partnerships that emphasize cooperation and consensus, and the maturity of its relationship with non-governmental organizations;
- b) its ongoing financial support for national HIV/AIDS-related organizations engaged in the full range of public policy, research, prevention, treatment and care activities;
- c) its flexibility and willingness to provide enhanced support to particularly vulnerable populations and to particular regions in a manner consistent with the epidemic being a national emergency; and
- d) its efforts to address difficult issues and to raise the tenor of public discussion through publicly-funded organizations such as the Canadian HIV/AIDS Legal Network and the Ministerial Council on HIV/AIDS, and its willingness to provide leadership on certain prevention and harm reduction strategies.

Similarly, the research suggests the following as the most significant shortcomings evident within the federal role to date:

- a) its efforts are insufficiently strategic and timely in terms of both what it seeks to accomplish and how it works with other jurisdictions and agencies;
- b) its inability, as of yet, to overcome the jurisdictional, planning and other factors that limit the development of a comprehensive pan-Canadian response to the epidemic, or to create effective, seamless linkages among the different federal departments involved in some aspect of the HIV/AIDS epidemic;
- c) its inability to increase the CSHA budget in a manner that reflects increasing need and the epidemic's changing character; and
- d) its periodic reluctance to pursue bold, evidence-based but controversial harm reduction initiatives such as needle exchange programs in its correctional institutions.

The most common criticism of the federal effort to date, however, is very simply that it is not doing more. There is a perception that its leadership role makes it responsible for meeting every need and filling every gap including those left by other jurisdictions.

The federal government will have to face a number of key challenges in the coming years. One will be to reconcile the need to be more *strategic* with its commitment to an inclusive, cooperative approach based upon consensus. Another challenge will be to provide the leadership necessary for building public support for controversial prevention or harm reduction programs. A third will be identifying and allocating funds adequate to the many tasks associated with addressing the epidemic. A fourth will be to effectively address the emerging epidemic among certain particularly vulnerable groups, for example Aboriginal people, women and those using injection drugs and sharing needles.

3. Considerations – Focus on the Future, 2004-2008

3.1 Areas for Enhanced Effort

The research has suggested that the areas presented below will require greater effort if Canada is to effectively address the HIV/AIDS epidemic and, indeed, if it is to get ahead of the epidemic. A challenge will be to define the limit, if any, of federal involvement given the jurisdictional, policy and fiscal parameters within which it must operate.

- a) Currently the federal government provides funding to ten CSHA priority areas (see **Appendix D**). In reality, these can hardly be described as “priorities” since they include almost every conceivable activity, from community-based social research to prison-based prevention programs. Similarly the CSHA goals are very general – for example, “to find a cure” – and are not accompanied by quantitative objectives that permit some measuring of progress.

The government may need to clarify its priorities in the coming years and to adopt a more strategic approach. Similarly it will be important to monitor and measure progress on an on-going basis.

- b) The federal role and responsibilities need to be placed within the context of a broader intergovernmental strategy on HIV/AIDS. The federal government has provided invaluable support to the Federal/Provincial/Territorial (F/P/T) Advisory Committee on AIDS and the F/P/T Heads of Corrections Working Group on Infectious Diseases, and it has worked closely with Aboriginal governments. Beyond this, however, there is much that could be done to better coordinate efforts across governments, for example in the country’s correctional institutions or for Aboriginal people moving between reserve and urban communities.

Other governments – provincial, territorial and municipal – also have an important role to play in addressing the epidemic. The responsibility for working cooperatively cannot lie with the Government of Canada alone.

- c) There is a need to coordinate efforts more fully with other federal or intergovernmental initiatives that have some implications for the HIV/AIDS epidemic, for example the National Drug Strategy, the Healthy Living Initiative and the Voluntary Sector Initiative.

Better bridges are needed to link efforts directed at HIV/AIDS with those directed at hepatitis-C, sexually transmitted infections and tuberculosis.

It will also be important for Health Canada to partner with other government departments and with non-governmental agencies so as to address the social determinants that are the epidemic's root. Income, family and housing policy, for example, will influence the epidemic's course and the country's ability to respond to HIV/AIDS.

- d) Governments in Canada do not have all the information and data needed if they are to plan for where the epidemic is going rather than to respond to where it has been. Some jurisdictions, for example, do not identify the ethnic or Aboriginal background of those newly reported as HIV-positive. Similarly, prevalence data by region and community are not readily available in spite of their importance for planning and programming purposes.

Efforts to augment, improve and standardize surveillance data bases linked to laboratory data, data collection methods and data dissemination would fill an important gap and help build a comprehensive sentinel surveillance system meeting the needs of all jurisdictions. These efforts would be further strengthened by better linking the formal surveillance system with the informal one provided by organizations, working at the community level, who often recognize emerging trends before they are captured from the case data. A strategic approach to surveillance might also include partnerships with other jurisdictions, ways to impact on policy and programs, and efforts to ensure policy and programs impact on surveillance priorities.

3.2 Future Trends

The epidemiological data, such as those in the following Figures, illustrate some very encouraging trends in the Canadian experience with HIV/AIDS. The number of newly reported infections and of AIDS-related deaths, for example, has declined very considerably since the mid-1990s.⁹

The data, however, can be misleading in that they often lag behind the street-level reality. They reflect *what has been* rather than *what is*, and say little about *what will be*. Both the Canadian and the international experience highlight the speed with which HIV/AIDS can mutate and either

⁹ Health Canada, Surveillance Report to June 30, 2002.

spread to new groups or re-emerge in certain populations. The encouraging patterns, in other words, should not be allowed to foster complacency. Indeed the number of positive HIV test reports increased by 2.9% between 2000 and 2001 (from 2119 to 2180) and by 9.7% during the first six months of 2002 relative to the same period in 2001.¹⁰

Fig. 4, Number of HIV+ Test Reports, by Year

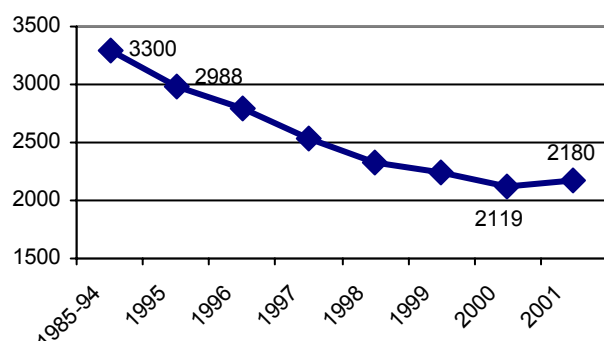
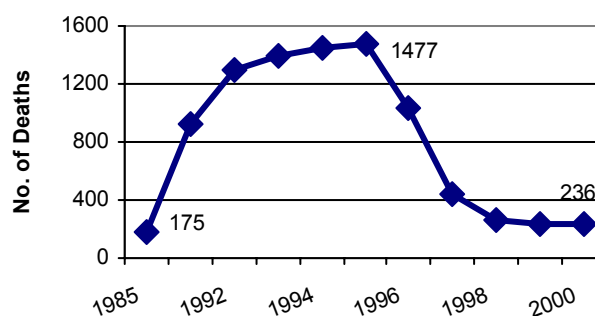


Fig. 5, AIDS-Related Deaths, Canada by Year



In considering its future role, the federal government can anticipate having to respond to the following trends.

- a) The number of people living with HIV/AIDS will increase significantly through the coming years given the treatment, care and support now available and given the annual number of new infections. The diversity of the infected and affected populations will necessitate responses that incorporate a range of culturally and site-specific efforts.
- b) Discrimination, marginalization and stigma will continue to be a major factor in the epidemic's spread among vulnerable populations. Efforts will be required to address these forces and to respond in a manner that incorporates a population health philosophy.
- c) Gay men will remain the largest group of people living with HIV/AIDS in Canada. In 2000 – for the first time in many years – there was an increase in the number of newly

¹⁰ Health Canada, Surveillance Report to June 30, 2002.

reported HIV cases among men who have sex with men. Unsafe sexual practices continue to place this group at high risk of HIV infection.¹¹

- d) Women will make up an ever larger share of the HIV-positive population given the increasing proportion of reported infections attributed to heterosexual activity, the incidence of violence against girls and women, and the economic vulnerability of many women.¹²

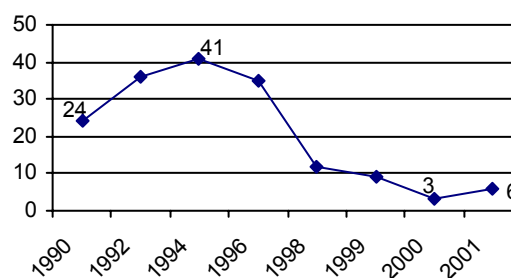
Women now account for almost 45% of HIV infections diagnosed in people aged 15 to 29 years, an increase from 41% in 2000 and from 15.6% for the entire period 1985-1996.¹³ The proportion of women among all newly-reported HIV-positive cases increased from 10.7% in the period from 1985-1995, to 21.8% in 1998 and to 24.9% in 2001.¹⁴

- e) Incidence among women who are originally from countries in which HIV is endemic will continue to be an issue that requires a concerted and culturally-sensitive response. Prevention efforts will have to acknowledge that most are contracting the virus while in Canada. The efforts will also have to include a focus on infant cases since most of the infants born with HIV between 1984 and 2000 have mothers from these countries.

- f) The number of HIV-positive infants will likely remain very small given the increasingly common practice of testing pregnant women for HIV and the success associated with using antiretroviral drugs.¹⁵

At the same time, testing practices raise certain legal and ethical issues that require consideration and discussion.¹⁶

Fig. 6, Number of HIV-Positive Infants, by Year



¹¹ Health Canada, HIV/AIDS Epi Update, 2002:39-44.

¹² Spigelman, 2002.

¹³ Health Canada, 2002, Record of Proceedings:16; 95; Health Canada, Surveillance Report to June 30, 2002:2.

¹⁴ Health Canada, Surveillance Report to December 31, 2001:2.

¹⁵ Health Canada, Surveillance Report to December 31, 2001, 2002:23.

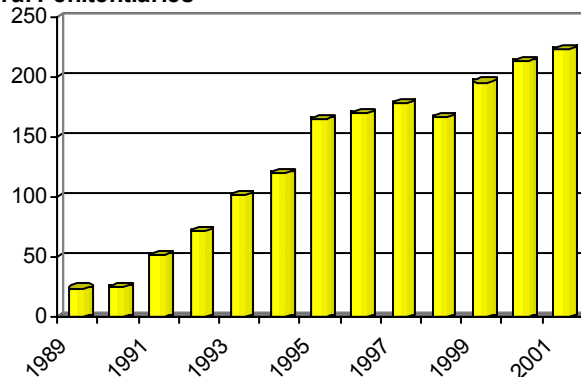
¹⁶ See Canadian HIV/AIDS Legal Network, HIV Testing and Pregnancy, 1999.

- g) The number of new infections among injection drug users and sex trade workers may continue to decrease if harm reduction programs become a larger part of the Canadian response to HIV/AIDS. This pattern could change very quickly, however. Similarly, these groups' limited ability to access appropriate treatment, care and support could result in an increase in the AIDS-related mortality rate. Co-infection with hepatitis-C in particular will become an important issue given the estimate that 90% of HIV-positive injection drug users are also infected with hepatitis-C.
- h) The epidemic's impact on First Nations, Inuit and Metis communities could grow much worse in the coming years given the discrimination confronting them, their socio-economic situation and the relative youthfulness of their populations. Between 1990 and 1999, the proportion of Aboriginal AIDS cases rose from 1% to 10% of the total number of newly reported cases.¹⁷ Aboriginal people now account for about 9% of new HIV infections even though they constitute less than 3% of the country's population.¹⁸

Addressing co-infection issues – with other sexually transmitted infections, hepatitis-C and tuberculosis – will have to be a vital part of the Aboriginal Strategy on HIV/AIDS in Canada.

- i) Greater attention and resources will have to be committed to those Canadians incarcerated in federal and provincial correctional institutions. Information from Correctional Service Canada suggests that a high proportion of inmates engage in behaviours – either before being incarcerated or while incarcerated – that place them at high risk of contracting HIV. Indeed the number of known HIV/AIDS cases in federal prisons rose from 14 in 1989 to 159 in 1996 and 217 in 2000. It is estimated that the prevalence rate in the provincial prison systems is equally high.¹⁹

Fig. 7, Reported Cases of HIV+ Inmates in Federal Penitentiaries



¹⁷ Ministerial Council on HIV/AIDS, 2001:iv. See also Health Canada, 2002, HIV/AIDS Epi Updates, "Ethnicity Reporting for AIDS and HIV in Canada."

¹⁸ Health Canada, 2002, Record of Proceedings:16.

¹⁹ Jurgens, 1996:2. See also Canada, Correctional Service Canada, 2003:2.

- j) The ever increasing complexity of the virus and the epidemic will make interdisciplinary approaches very important. Greater cooperation among specialists, agencies and jurisdictions, and among researchers, clinicians and service providers will be vital for effectively addressing the epidemic.
- k) It has been suggested that governments, everywhere in the developed world, will have to ensure that the epidemic does not fade from public consciousness. Reduced public awareness could result if the epidemic is perceived as affecting only certain countries or particular populations, for example injection drug users. Conversely, Canadians may become more concerned as HIV continues to spread through heterosexual activity, as the total number of people living with HIV/AIDS continues to increase, and as entire countries in the developing world are devastated by its impact.

3.3 Jurisdiction and Effectiveness

Canada has a federal system of government that divides responsibility between orders of government. The CSHA would benefit from efforts to clarify which order of government is responsible for what and to highlight the role of Aboriginal governments.

- a) The HIV/AIDS epidemic is clearly a matter of national significance and yet many of the tools required to address the epidemic lie within provincial jurisdiction. The provinces and territories, for example, have primary responsibility for education, health services, housing and the child welfare and child protection issues that influence vulnerability to HIV infection. At the same time, however, the Government of Canada traditionally has been willing to use its significant financial resources to define national priorities and to influence provincial or territorial policies.
- b) The federal government can act in different ways in different parts of the country given the principle that Canadians should enjoy roughly equal services regardless of where they live. In terms of the HIV/AIDS epidemic, therefore, the federal government has played a more active role in those jurisdictions – the Atlantic provinces primarily – that have fewer available resources. Similarly the government has chosen to fund a variety of local agencies through its AIDS Community Action Program (ACAP). In some cases, in Alberta for example, it has partnered with the provincial government to ensure projects are consistent with local priorities and hence sustainable through the long term.

- c) The efforts and strategies of the federal and provincial/territorial governments are not well coordinated. Addressing the vulnerability of inmates in both federal and provincial correctional institutions is one example where greater coordination would be useful. Improved intergovernmental cooperation is also needed with regard to epidemiological data collection and dissemination, population-specific and population health initiatives, and efforts to address the hepatitis-C epidemic.
- d) Addressing the needs of certain geographic areas and certain populations may be beyond the capability and capacity of any single jurisdiction. Vancouver's downtown eastside is one such example. Similarly the mobility of certain populations – immigrants from countries in which HIV is endemic or First Nations people moving between reserve and urban communities – may require efforts that transcend geographic or jurisdictional boundaries.

4. A Framework for the Government of Canada Role

During the first phase of the CSHA, 1998-2003, the federal government's many activities derived from a variety of responsibilities. It undertook certain activities because of:

- its constitutional or legal obligations, for example to provide health services for the Aboriginal people for whom it has a fiduciary responsibility and to ensure the safety of the country's blood supply;
- its responsibility as a national government to undertake certain activities, for example establishing national standards, developing policy and promoting public awareness;
- its CSHA goals, for example national prevention campaigns, coordinating planning and certain strategic initiatives; and
- its responsibility to ensure the quality of HIV diagnostic and prognostic testing was equivalent across jurisdictions.

Furthermore, the federal government undertook certain other activities because doing so made sense given the epidemic's context, for example building capacity among national and local HIV/AIDS-related organizations, undertaking research and disseminating knowledge.

Given the seriousness of the HIV/AIDS epidemic, it is very easy to suggest that the federal government's role could encompass a limitless range of activities. However it is important to identify what the federal government *should* do rather than what it *could* do. Ideally, the government's activities should have national significance, should reflect national priorities and should fit within a coherent national framework. Its activities should also reflect the financial, policy and bureaucratic constraints that shape federal activities, and should acknowledge that other governments and agencies may be more appropriately placed to undertake certain activities.

The following is proposed as a framework for the federal role within the CSHA, 2004-2008.

4.1 Vision

A vision presents a picture of what the situation will be in the future.

In 2008, the Government of Canada is partnering with other governments and with non-governmental agencies to address the HIV/AIDS epidemic at the community, regional, national and international levels. By organizing and directing its human and fiscal resources in an efficient manner, the federal government is working strategically to address national priorities, to meet current needs and to anticipate future trends. Its efforts are shaped by a clear commitment to human rights and social justice, and by the best evidence available about effective means for addressing the epidemic in all its diversity.

4.2 Goal

Goals identify, in a general way, what is to be achieved through a certain period of time.

The Government of Canada goal for the period 2004-2008 is to organize, align and direct its efforts and resources, in partnership with other stakeholders, so as to most effectively:

- prevent the epidemic's spread in Canada and around the world;
- reduce the vulnerability of populations at high risk of HIV infection;
- enhance the capacity of individuals, groups and organizations to address the HIV/AIDS epidemic;
- ensure that appropriate treatment, care and support are equitably available to all Canadians; and
- minimize the adverse personal, social and economic impact of HIV/AIDS on individuals, groups and communities.

A further goal is to anticipate the epidemic's course – and to get out in front of it – rather than simply react to its manifestations.

4.3 Principles and Policy Directions – a Road Map

Principles express the values and beliefs that shape an organization's activities while policy directions respond to these principles and describe the manner in which it will work. The following are proposed as a road map for the federal government's effort, 2004-2008.

Principles	Policy Directions
The Government of Canada believes that heightened vulnerability to HIV infection results from the exclusion of people from the social and economic mainstream of Canadian society.	Pursue a social justice approach: The Government of Canada will address the HIV/AIDS epidemic by confronting the discrimination and prejudice that marginalize certain populations and make them vulnerable to HIV infection. The federal role will be based upon a fundamental respect for the human rights of those vulnerable to HIV infection and those living with HIV/AIDS, and will incorporate and promote social justice, equity and human rights.
The Government of Canada believes that it has an obligation to serve all Canadians in an equitable manner, including those vulnerable to HIV infection or living with HIV/AIDS.	Fulfill its particular responsibilities: Every federal department and agency has a role in meeting this obligation. The Government of Canada has an additional obligation to promote prevention and to provide treatment, care and support to those for whom it has a fiduciary responsibility and to those for whom it has a particular duty, namely people incarcerated in federal prisons or serving in the military and RCMP.

Principles	Policy Directions
The Government of Canada believes that cooperation, coordination and mutual respect are vitally important if governments and organizations are to achieve their common goals and if their efforts are to address the epidemic's diversity.	Build and sustain a cooperative, pan-Canadian approach: The federal government will engage the full range of federal, provincial, territorial and community organizations involved in addressing the epidemic as well as those individuals and communities who are infected with or affected by HIV/AIDS. The federal government will endeavour to build practical and effective partnerships across departments, jurisdictions and sectors.
The Government of Canada believes that Canada has a clear responsibility, as a caring and affluent nation, to contribute its knowledge and resources to the international effort to fight HIV/AIDS. It also believes that international experiences will enhance its own effort to address the epidemic in Canada.	Strengthen Canada's role in the global fight against HIV/AIDS: The federal government will be actively involved in the global response to HIV/AIDS. It will acknowledge and respect its international obligations and commitments, and will contribute to and be an active participant in international efforts to address the HIV/AIDS epidemic.
The Government of Canada believes that its role must be based upon the best available evidence, science and data.	Pursue an action strategy founded upon the best available evidence: The federal government will not allow prejudice, stigma or ill-founded perception to shape its response to the HIV/AIDS epidemic. Rather, it will endeavour to raise the tenor of public discussion concerning the epidemic by basing its role on this evidence. In partnership with other sectors, it will endeavour to inform, shape and lead public opinion.
The Government of Canada believes that its efforts to address the epidemic must be transparent and that it is accountable both to those most directly affected by HIV/AIDS and to all Canadians.	Use monitoring and evaluation to inform and strengthen action: The federal government will ensure there is a careful accounting of outcomes and expenditures for all federally-funded activities. The federal role will be continually assessed and evaluated for effectiveness on the basis of clear and measurable objectives, and the findings will be used to further inform and shape federal efforts.

Road Map for the Government of Canada

Cooperation, coordination and mutual respect
important

Vulnerability to HIV results from the
exclusion of people from the social and
economic mainstream of Canadian society.

Respect for
human rights

Elimination
of
judicial



Pursue a social justice approach

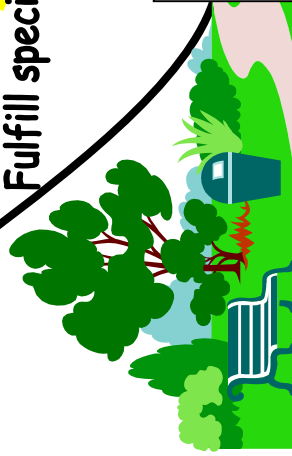
Additional obligation for
Aboriginal people, & for
those in the military, RCMP
or federal prisons

Role for every
federal dept.
ncy



Fulfill special responsibilities

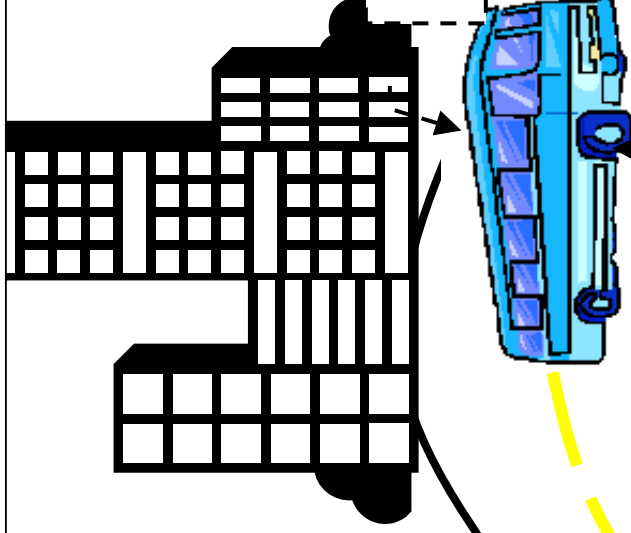
on to
manner, including those
vulnerable to, or living with HIV/AIDS.

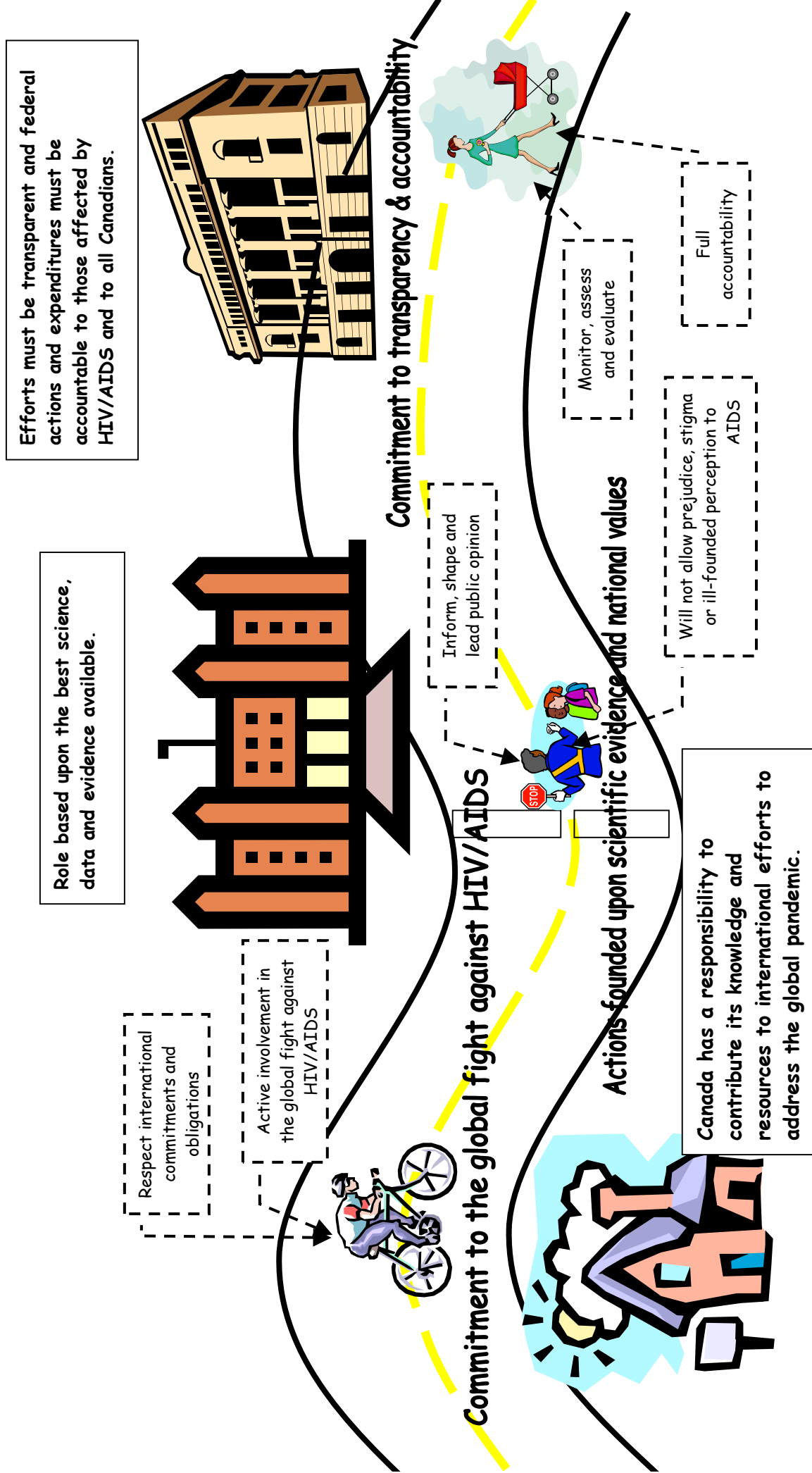


Build and sustain a cooperative, pan-Canadian approach

Enga
atio
commu

Build
effective
partnerships





5. Defining the Federal Role, 2004-2008

The road map provides a direction for the federal government as it anticipates where the epidemic will be through the period 2004-2008. The following addresses the responsibilities it will assume and the activities in which it will engage while travelling this route. These responsibilities and activities are being redefined so as to enable Canada to respond effectively to the epidemic during this period and to achieve the goal identified above.

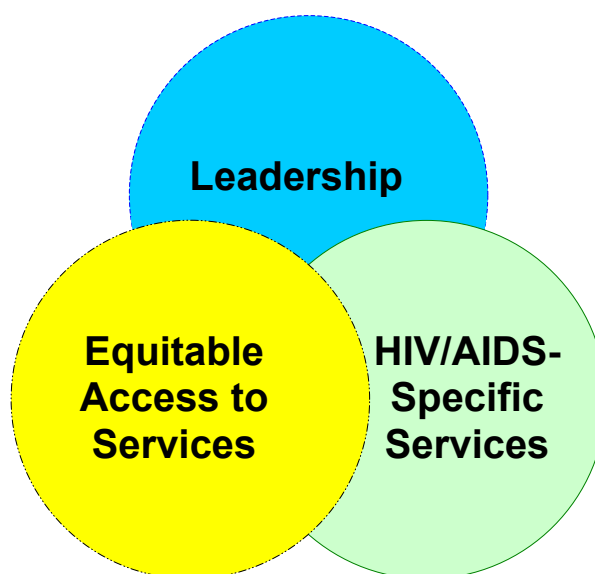
5.1 Proposed Realms of Federal Responsibility, 2004-2008

The Government of Canada activities for the period 2004-2008 will be encompassed within three *realms of responsibility*, namely:

- to provide leadership to the Canadian effort to address the epidemic;
- to ensure that those infected with or affected by HIV/AIDS have equitable access to its programs and services; and
- to provide certain HIV/AIDS-specific supports and services.

Figure 8 presents these realms and emphasizes their interconnectedness. Over time, the government will identify specific and measurable objectives for each realm of responsibility, and will ensure they are consistent with those articulated for the broader CSHA.

Fig. 8, Proposed Realms of Federal Responsibility, 2004-2008



5.2 Realm of Responsibility: Leadership

The federal government's first and foremost responsibility is to provide leadership for the Canadian effort to address the HIV/AIDS epidemic at the national and international levels. Importantly, leadership involves both:



- assuming direct responsibility for certain activities; and
- mobilizing or enabling others to assume responsibility for certain activities where this approach is considered to be most appropriate or most effective.

Providing leadership has many dimensions. One is to demonstrate and model a commitment to national goals and objectives particularly with regard to equity and social justice issues.

Another dimension involves acting decisively in order:

- to anticipate and respond to shifts in the epidemic and to emerging threats;
- to mobilize the full range of federal resources to address particular issues and to undertake research and other efforts having national significance;
- to build public and political awareness, and a national commitment to addressing the HIV/AIDS epidemic; and
- to break new ground with efforts to remove the systemic barriers that continue to feed the epidemic.

Another dimension of leadership is to act in those areas in which only a national government can act effectively, for example:

- in controversial policy and program areas. Federal leadership could involve efforts to encourage innovation and experimentation, and to ensure that all Canadians – including those in government and community organizations – appreciate the efficacy of the evidence-based prevention strategies.

-
- in creating, organizing, analyzing and disseminating epidemiological and other knowledge. The federal government is uniquely well placed to blend information and experiences from many different jurisdictions, and to promote efforts to embed this knowledge in practice. It is also uniquely situated to maintain a national laboratory to provide quality assurance and reference service testing for HIV and perhaps other infectious diseases.
 - in linking its HIV/AIDS strategy to those for hepatitis-C and other infectious diseases, and in this way to serve as a model for all jurisdictions while addressing the roots of the HIV/AIDS epidemic.

Another dimension of leadership involves coordinating and giving direction and coherence to federal, provincial, territorial and community efforts. This dimension is vital given the country's federal structure wherein responsibility for health policy is shared but responsibility for health services lies with the provinces and territories. It is also vital given the benefits associated with engaging community-level knowledge and experience. Leadership here will require vigorous efforts to build partnerships that can define national priorities, enhance national awareness, forge a national consensus and develop national action plans for different priorities.

There are other dimensions to leadership as well. One is to bring experts and stakeholders together to develop national standards, guidelines and policy frameworks. Another is to maintain strong but flexible regulatory frameworks for treatments, biotechnologies and diagnostics including blood safety. A final but important dimension of federal leadership involves speaking for Canada and acting on its behalf in various international fora. That will mean efforts to fulfill the country's international obligations and commitments, for example under the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) or to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Providing leadership in all these realms will require:

- a commitment to build and sustain capacity in Health Canada and its national non-governmental partners;
- on-going efforts, involving the full range of organizations and governments, to encourage and facilitate joint planning and direction setting, and to foster cooperative or coordinated endeavours;

- efforts to broaden responsibility for the Canadian Strategy on HIV/AIDS by strengthening intergovernmental structures such as the Federal/Provincial/Territorial Advisory Committee on AIDS and the F/P/T Heads of Corrections Working Group on Infectious Diseases;
- vigorous efforts to dispel the stigma and prejudice so commonly associated with the epidemic as well as the discrimination that leaves some groups particularly vulnerable to HIV infection; and
- sustained initiatives that promote the concept of population health as an effective long-term prevention strategy.

5.3 Realm of Responsibility: Equitable Access to Services

The Government of Canada provides a broad range of services and supports to all Canadians. Many of these are particularly important for people living with or affected by HIV/AIDS, and for Aboriginal and other communities endeavouring to address the epidemic in their midst. The second realm of responsibility for the Government of Canada, therefore, is to ensure that:



- its departments and agencies are working cooperatively, with Health Canada and each other:
- to understand the HIV/AIDS epidemic and the potential impact of their services and supports on the epidemic and on those living with or affected by HIV/AIDS; and
- to respond to the epidemic's needs within their mandated areas and ensure that their services and supports are equally accessible to people living with HIV/AIDS as to other Canadians.

In essence, the Government of Canada has a responsibility to ensure that all of its departments and agencies recognize that HIV/AIDS is not simply a health issue and that addressing the epidemic is not solely the responsibility of Health Canada. Correctional Service Canada (CSC) and the CIHR provide a model for what is needed from all departments and agencies. They are not only active partners in the Canadian Strategy on HIV/AIDS but have made the epidemic one of their areas of ongoing concern.

In contrast the Department of Indian and Northern Affairs Canada (INAC) is not a CSHA partner even though Aboriginal people are particularly vulnerable to HIV infection and even though INAC policies – for example, with regard to housing – have a significant influence on the social conditions that contribute to HIV vulnerability. This department's involvement in the CSHA is particularly important given that First Nations people frequently move back and forth between reserve and urban communities.

It is also vital that the Canadian International Development Agency be an integral partner in the CSHA given its concern for HIV/AIDS internationally, its responsibility for international development issues and its large budget. Similarly the departments of National Defence and of the Solicitor General, beyond the CSC, should be engaged in the CSHA given their responsibility for the health of those in the military and the RCMP. Many other departments need to be CSHA partners as well, for example:

- Human Resources Development Canada given its responsibility for the Canada Pension Plan (Disability), for Employment Insurance and for re-employment programming;
- the Canada Mortgage and Housing Corporation given the importance of housing as a social determinant and for those endeavouring to manage their HIV/AIDS;
- the Voluntary Sector Initiative given the need to build and sustain capacity in both national and community-based HIV/AIDS-related organizations; and
- regulatory agencies within Health Canada given the need to remove any undue legal or regulatory barriers confounding certain harm reduction initiatives and given also the importance of new drugs and the timely approval of new drugs in managing HIV/AIDS.

This second realm of responsibility for the federal government, therefore, is to make the HIV/AIDS epidemic part of the operational mainstream in all of its many departments and agencies, and to ensure that these departments and agencies are working cooperatively with Health Canada, with each other, with community-based HIV/AIDS-related organizations and with other jurisdictions. The following Figure illustrates that interdepartmental links will have to be constructed if the Government of Canada is to achieve its goals and reach its vision within this second realm of responsibility.

Fig. 9a, Current Federal Structure for Addressing HIV/AIDS

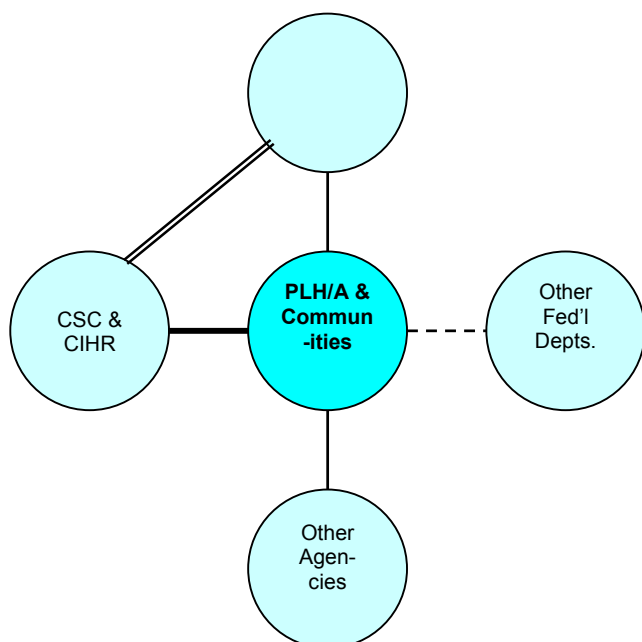
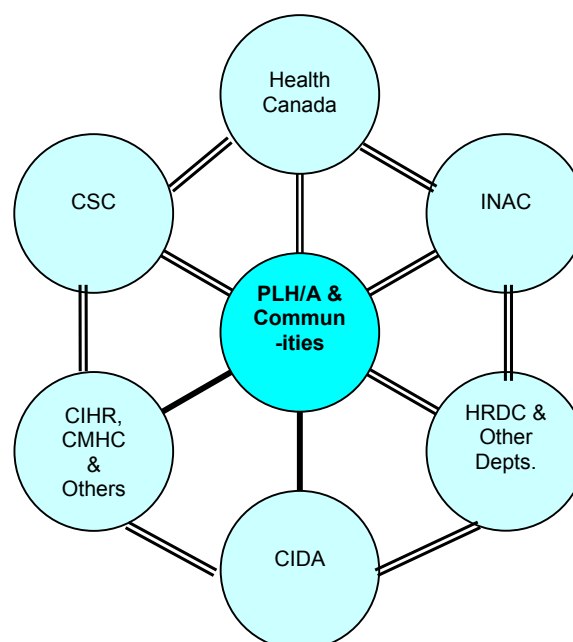


Fig. 9b, Proposed Federal Structure for Addressing HIV/AIDS



5.4 Realm of Responsibility: To Provide HIV/AIDS-Specific Supports and Services

The federal government's third realm of responsibility is to provide HIV/AIDS-specific supports and services within the context of the CSHA. This responsibility lies primarily within Health Canada and would incorporate the ten funding priorities and the different activities currently associated with the CSHA, namely:

HIV/AIDS-Specific Services

- research, largely through the CIHR
- community development & support to national NGOs
- care, treatment and support
- surveillance
- legal, ethical and human rights
- prevention
- Aboriginal communities
- consultation, evaluation, monitoring and reporting
- Correctional Service Canada
- international collaboration

In the past, the federal government engaged in or supported many activities including the organization of national direction-setting meetings, building capacity among non-governmental organizations at both the national and local levels, funding pilot projects, epidemiological surveillance and reporting on trends, laboratory quality assurance and HIV reference services, and funding important research. This proposed third realm of federal responsibility – providing HIV/AIDS-specific supports and services – will maintain and enhance activities in all of these areas given their vital importance for addressing every aspect of the epidemic, from prevention to on-going care and support. Figure 10 conceptualizes this third realm of responsibility while Table 1 identifies the specific activities encompassed within each realm.

Fig.10, HIV/AIDS-Specific Supports and Services

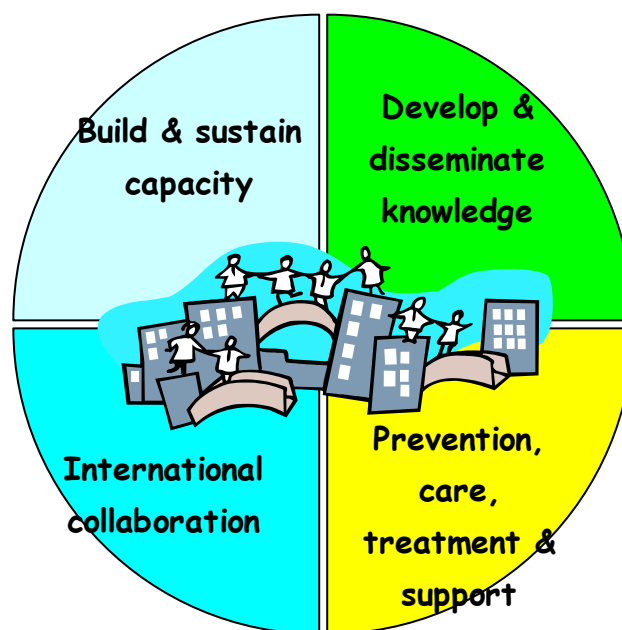
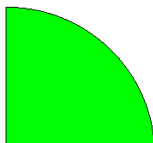
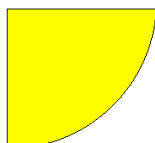
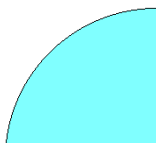


Table 1, HIV/AIDS-Specific Supports and Services

Nature of Activity	Examples
<p>Develop, analyze and disseminate knowledge</p> 	<ul style="list-style-type: none"> ▪ collect, synthesize, analyze and disseminate epidemiological and surveillance data for federal, provincial, territorial and community planning purposes. ▪ HIV reference and testing services in support of surveillance provided by the National HIV laboratory. ▪ monitor HIV and AIDS among vulnerable populations. ▪ fund research examining health services and systems as well as the social, cultural, legal and environmental factors that influence HIV vulnerability. ▪ fund bio-medical and clinical research including vaccine & microbicide development, cohort studies and community-based research and evaluation. ▪ develop, analyze and disseminate knowledge concerning effective practices related to all aspects of addressing the epidemic. ▪ develop national standards and guidelines as appropriate. ▪ monitor, evaluate and report on work and activities funded under the CSHA.
<p>Prevention, care, treatment and support in areas (i) of federal jurisdiction or (ii) having national significance</p> 	<ul style="list-style-type: none"> ▪ prevention, care, treatment and support initiatives consistent with the federal government's fiduciary responsibility for the health of Aboriginal people. ▪ prevention, care, treatment and support initiatives for those incarcerated in federal correctional institutions, and for those in the military and RCMP. ▪ initiatives for populations or communities in crisis whose needs exceed the capabilities of other jurisdictions. ▪ efforts to fill service or resource gaps in particular regions and communities in order to address particularly complex situations and/or particularly high vulnerability. ▪ programs and pilot projects having national significance. ▪ national education and prevention efforts targeted either to vulnerable groups or to the general population. ▪ National HIV laboratory quality assurance and reference service programs in support of prevention and care programs.
<p>Build and sustain capacity as part of a broad, integrated and effective response to the epidemic</p> 	<ul style="list-style-type: none"> ▪ support an infrastructure of HIV/AIDS-related organizations for the purpose of developing policy, ensuring a vigorous response to the epidemic and encouraging public discussion. ▪ strengthen the participation of vulnerable populations and of infected and affected individuals in the Canadian response to HIV/AIDS. ▪ enhance the knowledge and skills of professionals and non-professionals working in HIV/AIDS-related areas. ▪ promote or support initiatives for populations and communities in crisis, for example through the Non-Reserve First Nations, Inuit and Metis Fund. ▪ promote or support efforts to fill service or resource gaps in particular regions and communities.

Nature of Ac	Examples
International collaboration 	<ul style="list-style-type: none"> ▪ represent Canada at the international level and fulfill its international obligations and commitments. ▪ facilitate knowledge transfers between Canada and other countries. ▪ contribute to the international effort to develop a vaccine and to ensure that appropriate treatments are available and affordable. ▪ support agencies promoting or facilitating international understanding and collaboration. ▪ undertake bilateral and multilateral efforts to manage the epidemic internationally.

Some of these activities may duplicate some provincial, territorial or municipal government undertakings. However there is a strong consensus among CSHA stakeholders that these supports and services are vitally important for addressing the epidemic and that duplication can be minimized and sustainability enhanced if federal, provincial and territorial governments were working cooperatively within the context of the emerging CSHA.

B. Funding the Federal Role in the CSHA

Between 1998/99 and 2002/03, the Government of Canada invested \$42.2 million annually in the CSHA. Although a significant amount compared to the federal investment in other health conditions, most groups – including the Parliamentary Standing Committee on Health – consider it to be very inadequate given the challenges posed by the epidemic. Thus, at the same time as reconsidering its role in the CSHA, the federal government must determine whether to increase its investment and, if so:

- by what amount given its realms of responsibility within the CSHA; and
- how to allocate this funding both among its different realms of responsibility and within each realm.

This section of the *Getting Ahead* report provides options both for the most appropriate level of federal funding, 2004-2008, and for the allocation of that funding.

6. HIV/AIDS-Related Expenditures to Date

Table 2 presents an overview of federal funding and allocations since 1990 and indicates that:

- the annual budget increased by 13.4% from 1990 to 1994 but subsequently remained constant;
- the 1998 allocation for “care, treatment and support” was 12% less than in 1994 even though the number of people living with HIV/AIDS had increased by 43%;
- funding for prevention declined by 37% from 1994 to 1998 in spite of the epidemic’s spread into more diverse, marginalized and difficult to reach populations;
- funding for local initiatives, community development and national non-governmental organizations increased by 63% from 1990/93 to 1994/98 but then increased by only 2% for the period 1998-2003;
- funding for research purposes increased by 62% from 1990/93 to 1994/98 but then declined by 26% for the period 1998-2003;and
- funding allocated to Health Canada for administration, coordination, collaboration, consultation, monitoring and evaluation increased by 27% – but only to \$1.9 million – from 1994/98 to 1998/2003. That amount is 37% lower than in 1990/93.

During this time, both over and under expenditures characterized the Strategy’s different components although it is not clear whether these reflected need and demand, community capacity or an administrative inability to approve expenditures in a timely fashion.²⁰

²⁰ Spigelman, Taking Stock, 2001:9-10.

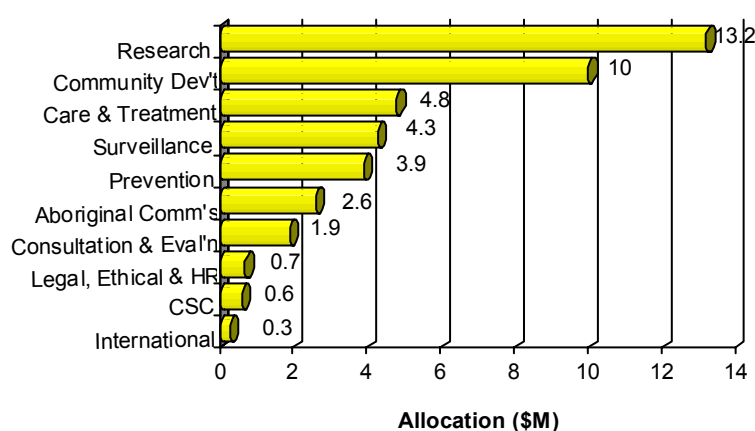
Table 2, Financial Allocations by Strategy Component, 1990-2003²¹

N		II, 1994-98		CSHA, 1998-2003	
A	\$M	Area	\$M	Area	\$M
Public education	14.0	Education & prevention	6.2	Prevention	3.9
Support to provincial & local initiatives	6.0	Community development & support to national NGOs	9.8	Community dev't & support to national NGOs	10.0
Health & social support	2.0	Care, treatment & support	5.4	Care, treatment & support	4.75
Research including epidemiologic studies	11.0	Research & epidemiologic monitoring	17.8	Research	13.15
International activities				International collaboration	0.3
Program administration	3	Coordination & collaboration	1.5	Consultation, evaluation monitoring & reporting	1.9
Total	\$37.2	Ministerial discretion to address emerging issues	1.5	Surveillance systems	4.3
		Total	\$42.2**	Legal, ethical & human rights	0.7
				Aboriginal communities	2.6
				Correctional Service Canada	0.6
				Total	\$42.2

** NAS II was characterized by small annual under-expenditures. Actual program expenditures totaled \$40.7 million annually.

Other expenditure highlights include the following.

- a) The federal government's budget for the CSHA is allocated among the ten priorities identified in 1997/98. This allocation remains unchanged.

Fig. 11, CSHA Funding Priorities (\$M)

²¹ Health Canada/CPRN overview, 1998/99. The comparisons are somewhat tentative given (i) organizational changes within Health Canada, (ii) definitional changes within the Strategy, and (iii) new funding routes, for example through CIDA in the international sector. See also Spigelman, Taking Stock, 2001:9-10.

Research received the highest priority for funding purposes with Community Development activities being the second priority.

- b) Other federal departments and agencies have committed additional funds to addressing the epidemic,²² for example:
- \$4.0M through Correctional Service Canada;²³
 - \$4.8M through the Canadian Institutes of Health Research in 2002-03;²⁴
 - \$2.5M through the Health Canada First Nations and Inuit Health Branch; and
 - \$62M in 2002/03 through the Canadian International Development Agency (with a planned increase to \$80M in 2004/05)²⁵ and a commitment of \$100 million over four years to the Global Fund to Fight AIDS, Tuberculosis and Malaria.
- c) Health Canada itself distributes almost 65% of the CSHA budget through Grants and Contributions for community-based research, the national HIV/AIDS-related agencies and community-based programs. Grants and contributions are also provided for the purpose of:
- generating knowledge on best practices, for example through the Best Practices Fund and the National Demonstration Fund; and
 - developing tools and sponsoring workshops and conferences, for example through the National HIV/AIDS Capacity Building Fund.

Health Canada also assumes responsibility for costs associated with evaluation and coordination, for example the Year Three CSHA Evaluation (\$100,000), the Ministerial Council on HIV/AIDS (\$175,000), the 2000 CSHA Direction-Setting Meeting in Gray Rocks (\$300,000) and the 2002 Follow Up Meeting in Montreal (\$600,000).

- d) The AIDS Community Action Program (ACAP) has a budget of \$8 million for community-based organizations and community development initiatives. That amount has remained constant since 1998. ACAP grants range in amounts from a few thousand dollars to over \$70,000. Efforts are currently underway to evaluate ACAP.

²² Canada, 2003, Report to the Secretary General.

²³ The CSC also commits \$5.3 million for a National Methadone Maintenance program and \$0.23 million in infectious disease surveillance activities.

²⁴ The CIHR contributed an additional \$1.0 million to HIV/AIDS research.

²⁵ This is part of a five-year \$270 million target commitment with annual incremental increases to \$80 million in 2004-2005.

- e) The Canadian Institutes of Health Research (CIHR) manages approximately \$10.2 million of the \$13.2 million CSHA allocation for research. The remaining amount largely supports community-based research. Approximately \$3.2 million is committed to the Clinical Trials Network (CTN). In 2002, Canada also committed \$45 million over three years to the International AIDS Vaccine Initiative (IAVI) as well as \$5 million to the African AIDS Vaccine Programme for research being undertaken outside of the country.

In 2002-03, the CIHR awarded 95% (\$10.9 million) of its research funds to investigator-initiated projects and only 5% for strategic or directed research projects. Efforts are underway to establish a HIV/AIDS Research Advisory Committee that can help set research priorities and direct research funding to specific purposes and priorities.

- f) CSHA funds flow to each of the Health Canada regions on the basis of a complex formula. As illustrated in Figures 12 and 13, the Atlantic provinces received the smallest proportion of total funding (14%) in 2001/02 – a reflection of the small number of HIV+ tests reported there – while Ontario received the largest (26%).

Fig. 12, Health Canada G&C Expenditures by Region, 2001/02

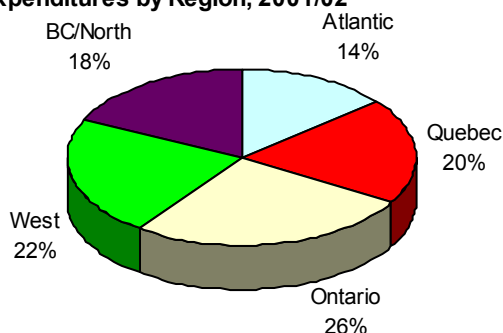
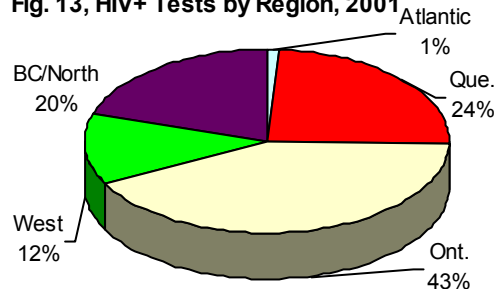


Fig. 13, HIV+ Tests by Region, 2001



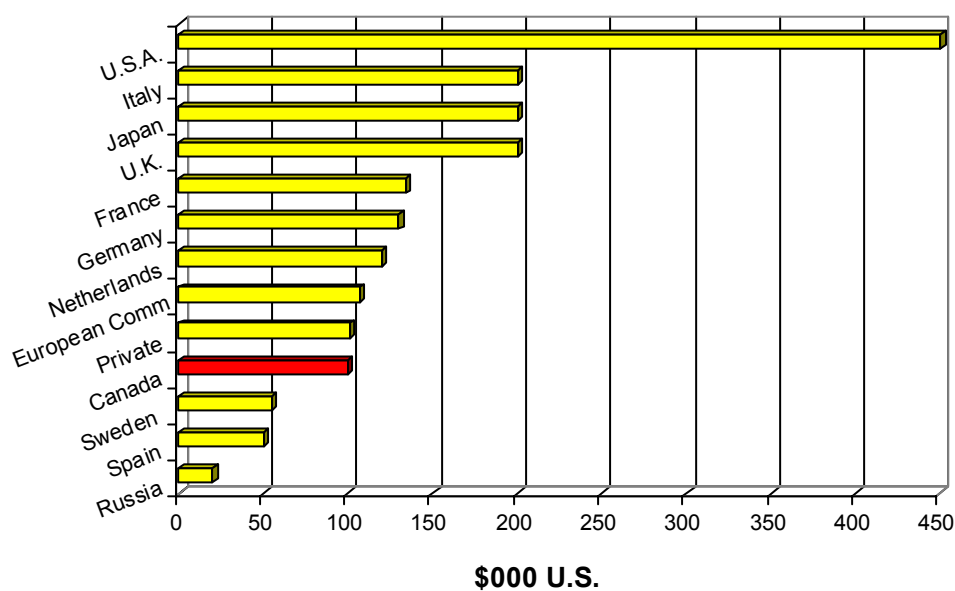
- g) Canada has also contributed to the international effort to address the HIV/AIDS pandemic. The following and Table and Figure compare this contribution to that of other developed countries.

Table 3, Total Pledges to The Global Fund to Fight AIDS, Tuberculosis and Malaria as of mid-May, 2002 (\$US)²⁶

Donor	Pledge (\$000 USD)
United States	450,000
Italy	200,000
Japan	200,000
United Kingdom	200,000
France	133,600
Germany	132,500
Netherlands	120,300
European Commission	106,900
Private Sector	101,200**
Canada	100,000
Sweden	55,000
Spain	50,000
Russia	20,000
Belgium	16,000
Nigeria	10,000
Switzerland	10,000

**Bill and Melinda Gates Foundation, \$100m; Winterthur Insurance (Credit Suisse), \$1m; International Olympic Committee, \$100,000; others \$53,000.

Pledges to the Global Fund, by May 2002 (\$US)



²⁶ International Council of AIDS Service Organizations, 2002:10.

7. Challenges and Considerations

Some formidable challenges and important considerations influence the effort to address the CSHA funding issues. The first challenge is that the current Strategy does not have quantifiable objectives and thus Health Canada's ability to assess its impact on the basis of outcomes rather than outputs is severely compromised. The absence of these objectives also compromises the government's ability to build a budget from the bottom up, i.e. by identifying what specifically has to be done to address the epidemic and then identifying the dollar amount for each activity.

The second challenge is that neither the Canadian nor the international literature – on HIV/AIDS specifically and public health more generally – was particularly helpful for addressing funding issues. There is considerable literature, for example, considering the cost-benefit of various prevention and public health initiatives, best practices and spending both wisely and effectively. There is virtually none that considers funding adequacy for strategies that are long-term, broad, multi-sectoral and comprehensive in scope.²⁷ And there is no discussion of practical and transparent means for allocating funds within such strategies.

The other challenges and considerations confronting this project are described below.

Alternate Funding Models

The process for allocating resources in the health sector is based largely on existing service patterns rather than upon a full and complete assessment of current or future need. It is also often based upon incidence rates and as such may well reward failure, i.e. if past efforts to prevent infection have failed, the incidence rate may increase and trigger new money for treatment.²⁸

Some basis for sharing resources among different needs and priorities is required. Clearly there is a “*serious need for a rational, practical, process-based approach*” for making decisions about funding levels and allocations.²⁹ Yet the literature and the experience of other jurisdictions provide no appropriate models or lessons in this regard. There is a full body of literature on developing programs and strategies, and on the strategies

²⁷ Spigelman, Taking Stock, 2001:4.

²⁸ Birch, 1993.

²⁹ Mitton, 2002:3/29.

themselves. Almost never, however, are there discussions on defining resource needs, establishing priorities or reconciling competing priorities.

The Legacy Discussion Paper prepared for Health Canada, for example, poses questions about addressing capacity issues but does not deal directly with funding or allocation issues.³⁰ This also characterized both the HIV Prevention Strategic Plan prepared by the Centers for Disease Control in the United States and the various national strategies prepared in Australia.

Establishing Funding Levels

In the past, funding levels for HIV/AIDS strategies – in Canada and other countries – have not been based upon an assessment of need but rather on two foundations: historical funding levels and political or public will. In one Canadian jurisdiction, for example, the Auditor General spoke directly to the issue of its health authorities *“allocating resources across the health care system without the benefit of essential cost and performance information. Instead, the ministry allocates resources based on historical spending levels.”*³¹ Similarly the C.D. Howe Institute has noted that *“recent reports from provincial auditors general and surveys of the management of regional health authorities reveal a lack of formal processes for setting priorities and allocating resources, with history being the most important driver of allocations, and little consideration [given] to issues of transparency and explicitness.”*

The C. D. Howe Institute suggests building a consistent framework with which to compare the costs and benefits of health administrators' choices.³²

Shared Responsibility

Addressing funding issues is further confounded by the reality that addressing the epidemic is not the responsibility of Health Canada alone. The Health Canada CSHA funds are supplemented by those of the CSC and CIHR and dwarfed by those of the Canadian International Development Agency. Furthermore, the Government of Canada is only one of numerous jurisdictions addressing the epidemic. Government of British Columbia expenditures on pharmaceuticals alone for those living with HIV/AIDS (\$35

³⁰ Young, 2000.

³¹ British Columbia, Office of the Auditor General, 2002.

³² Mitton, 2002:2/29.

million) is close to the total federal allocation for the CSHA. Similarly the Province of Ontario spends more than does Canada in response to the epidemic.

Currently, and in spite of the work of the Federal/Provincial/Territorial Advisory Committee on AIDS, there is no study documenting total federal, provincial and municipal government spending on HIV/AIDS in Canada.

Funding Relative to Other Strategies

The issue invariably arises as to how the federal investment in HIV/AIDS compares to its investment in other public health efforts. The following provides an overview of a variety of Canadian public health and other strategies.

Table 4, Federal Spending on Health Strategies

Strategy	Funding
Canadian Strategy on HIV/AIDS	\$211 million through 5 years (\$42.2m annually) for 10 priority areas including research, community development and prevention.
Aboriginal Early Childhood Development Strategy	\$320 million through 5 years (\$64m annually) for Aboriginal Head Start, child care, FAS/FAE initiatives and research.
Hepatitis-C Prevention, Support and Research Program	\$50 million over 5 years (\$10m annually), for prevention (10%), care and treatment (17%), community-based support (36%), research and epidemiological data gathering (28%) and program management and delivery (9%).
Canada's Drug Strategy	\$245 million over 5 years (\$49m annually) for education, prevention, health promotion and enhanced enforcement measures.
Canadian Diabetes Strategy	\$115 million through 5 years (\$23m annually) with approximately 50% for the Aboriginal Diabetes Initiative.
National Crime Prevention Strategy	\$265 million over four years (\$66.3m annually).
Youth Employment Strategy	\$315 million over 3 years (\$105m annually) to provide youth with employment and training opportunities, in addition to very significant amounts committed by other federal departments and agencies.

In the United States, the level of HIV/AIDS-related funding is often criticized as being out of proportion to its impact. The Kaiser Foundation, for example, reports on the media coverage of the \$1.8 billion that HIV/AIDS receives from the National Institutes of Health (NIH).

The number one killer, heart disease, last year got half a billion dollars less. Per patient the disparities are even greater. Last year, AIDS got \$2,400 per patient from the NIH; breast cancer \$230; heart disease, just \$108; Parkinson's, \$78; and diabetes, which last year killed more people than AIDS and breast cancer combined, just \$28.... If you have a politically correct disease, the prospects of getting federal funding to help find a cure are a hundred times greater than if you have some other disease, even though it may be a much more common disease... Sixteen million people suffer from diabetes in America, five times more than AIDS and breast cancer combined.³³

The more rigorous literature also addresses this issue. The Johns Hopkins Magazine, for example, described the disability adjusted life-years (DALY) concept that identifies the costs associated with a broad range of diseases. It found that actual funding levels for research from the NIH approximated the DALY for most diseases. A few diseases, however, “were significantly overfunded: AIDS received \$1.4 billion compared to a DALY-based prediction of \$104 million; breast cancer, with a DALY of \$110 million, received \$382 million.”³⁴

In reality, however, few of these other diseases approximate HIV/AIDS in their virulence, their threat to the community and their impact on people in their prime of life.³⁵

Capacity to Spend

The CSHA experience illustrates the need to build capacity in order to utilize the available financial resources and avoid under-expenditures in the midst of significant need. Clearly the concept of “need” depends not only on the epidemic’s character but also “upon the zeal and outreach capability of community service providers and local governmental

³³ Kaiser Foundation, 1999.

³⁴ Johns Hopkins Magazine, 1999.

³⁵ For a discussion of the uniqueness of HIV/AIDS, see Spigelman, Five-Year Review, 2003.

administrators.” This problem speaks to the need also for consistency and on-going funding since “case-loads are rarely flexible in both directions: once built up, they are not amenable to shrinkage without hardship and loss of confidence.”³⁶ The National Institute of Medicine in the United States further cautions that “failures in implementation related to inadequate training or lack of operational capacity, detract from the desired outcome.”³⁷

At the same time, UNAIDS warns that “lack of capacity to absorb increased resources allocated for HIV/AIDS, while posing challenges, is no reason to delay the boosting of responses....”³⁸

8. Is the Current CSHA Budget Adequate?

8.1 How to measure adequacy?

Defining “adequacy” is a significant challenge since there can never be an “adequate” amount of money to do all that could be done or even all that should be done. In 1997, for example, Aaron Wildavsky in the United States formulated his *Law of Medical Money* whereby “costs will increase to the level of available funds.”³⁹ Indeed it is suggested that “scarcity is a normal condition in publicly funded health care.”⁴⁰

Furthermore, it is not clear that society should want to invest ever greater amounts in health services since, at some stage, the expected benefit from further investments may be so small that what has to be given up is of more value. Indeed further investments may draw money away from the other programming – in the housing sector for example – that can contribute to population health and well being.

The *Taking Stock* report prepared in 2001 for the Ministerial Council on HIV/AIDS is perhaps the only thorough examination of whether the federal government’s CSHA budget is “adequate.” The report cautions that there is no clear definition of “adequacy,” in Canada or elsewhere, and no practical means for assessing adequacy since the CSHA did not have concrete objectives. If

³⁶ Jeffreys, 1991:2/8.

³⁷ National Institute of Medicine, 2000:2.

³⁸ UNAIDS, Report on the global HIV/AIDS epidemic, 2002:16-17.

³⁹ CPHA, 2000:7.

⁴⁰ Mitton 2002:1/29.

such were in place, it could be possible to determine what investment is needed to achieve each particular objective.

The *Taking Stock* report also indicates that few stakeholders have thought about how to measure adequacy.

[This] characterized key informants both in Canada and in other countries. And it characterized people in government, community agencies and research institutions alike. People more commonly focus on all that needs to be done and all they would like to do. They focus on how to obtain more funding and on ensuring that the funds they have are being used in the most appropriate and effective manner.⁴¹

Furthermore few people are very familiar with the full range of activities encompassed within the CSHA. The clinical researcher, therefore, may know how much is needed for clinical trials but likely knows little about how much is needed for outreach by community-based AIDS Service Organizations. Conversely, community workers may know little about the costs associated with managing a national surveillance system.

8.2 Is the current investment adequate?

There is a clear consensus that the current CSHA investment is inadequate. Indeed the \$42 million allocation was considered inadequate even in 1998 as the new Strategy was being introduced. The stakeholder group responsible for allocating those funds noted that *"All of the recommendations in this document are limited by the fact that the proposed allocation ... is seriously inadequate to meet the needs of the evolving, expanding HIV/AIDS epidemic in Canada."*⁴²

Some years later, the Year Three CSHA Evaluation concluded that the impact of inflation has reduced the real value of the CSHA investment to a level *"less than the original start-up funding for the Strategy."*⁴³

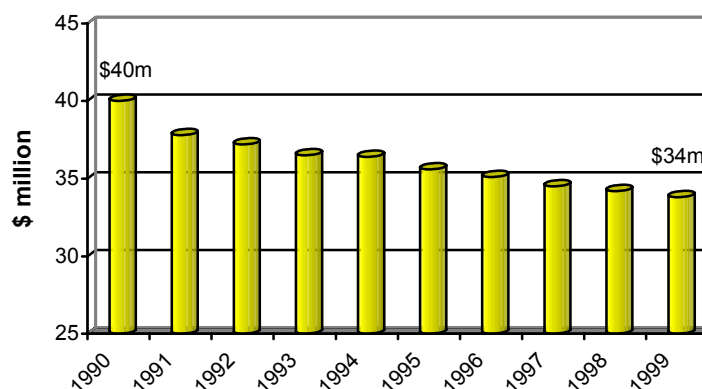
⁴¹ Spigelman, *Taking Stock*, 2001:3.

⁴² Canada, Health Canada, 1997:4.

⁴³ SPR Associates, 2002a:56.

The Ministerial Council *Taking Stock* report also noted the real value of the Strategy's funding has been significantly reduced as a result of inflation. Figure 15 uses constant 1991 dollars and indicates that a \$40 million commitment in 1991⁴⁴ was worth about \$33.8 million in 1999. In reality the purchasing power of this amount may be even less given that inflation affects different sectors of the economy in different ways.

Fig. 15, Impact of Inflation on Strategy Funding, 1990-99



Adjusting for inflation alone, the report concludes that the Strategy's 1990 base of \$37.2 million would, in 2001, require a budget of at least \$43.8 million in order to have equal purchasing power. Similarly the 1994 base of \$42.2 million would require a budget of \$45.4 million in order to have equal purchasing power. More recent Statistics Canada data indicate that \$40 million in 1991 would require over \$51 million in 2003 to compensate for the impact of inflation.⁴⁵

The Ministerial Council's report also concluded that if \$42.2 million was *appropriate* in 1994 – as opposed to *adequate* – it now has to be regarded as inappropriate given not only inflation but also:

- the increasing number of people living with HIV/AIDS and their ability to live longer in spite of the disease. In 1994, there were approximately 35,000 people living with HIV/AIDS. In 2001, there were 50,000.
- the epidemic's proliferation into more diverse, harder to reach and more marginalized populations. This magnifies the challenge of delivering effective services that are culturally or socially appropriate.

⁴⁴ For the sake of clarity, the \$40 million figure represents an average of the 1990/93 and 1994/98 allocations.

⁴⁵ Statistics Canada, 2003.

- the potential for positive outcomes to emerge from the biomedical and social research currently underway in Canada and elsewhere.
- the devastation which the pandemic is causing in the developing world.⁴⁶

The federal government's static investment stands in sharp contrast to some Canadian jurisdictions that are closer to the impact of HIV/AIDS on people. *"British Columbia, for example, provided \$750,000 to community-based AIDS Service Organizations in 1992. It increased this allocation to \$1.5 million in 1994/95 and to \$5.5 million in 1995/96. Today the province provides these organizations with over \$11 million."*⁴⁷ Additionally, as noted earlier, it provides the BC Centre for Excellence in HIV/AIDS with \$32 million annually for HIV/AIDS-related drugs alone.

8.3 What is the impact of inadequate funding?

The Parliamentary Standing Committee on Health heard that funding inadequacy has made this *"a decade of decay."*⁴⁸ Assuming that the level of funding is inadequate, key informants and the literature suggest that the consequence has been to compromise the Canadian effort to address the epidemic at the community, national and international level. Key informants and the literature identified the following as some of the ways in which inadequate funding has affected the effort to address the epidemic.

Prevention

- Insufficient resources hinder the successful implementation of prevention efforts.⁴⁹ Inadequate resources may have contributed to the recent increase in the number of new infections among gay men. Prevention measures could not be sustained because of inadequate funding and because of the need to divert some funding to new priorities.

⁴⁶ Spigelman, Taking Stock, 2001:i.

⁴⁷ Spigelman, Taking Stock, 2001:32-33.

⁴⁸ Canada, Parliament of Canada Standing Committee on Health, March 24, 2003. (Dr. Kenneth Rosenthal, President of the Canadian Association for HIV Research and Professor of Pathology and Molecular Medicine at McMaster University)

⁴⁹ National Institute of Medicine, 2000.

- Vigorous new measures to address the stigma and discrimination associated with HIV/AIDS have not been undertaken. Similarly agencies have not been able to undertake new housing or other initiatives that address those health and social determinants that leave people vulnerable to HIV infection and allow those living with HIV/AIDS to manage their condition more effectively.⁵⁰
- The level of work being undertaken in Aboriginal communities across Canada is inadequate to the need and to the urgency of the threat. The same is true for initiatives targeted specifically at other groups who are at high risk of HIV infection, for example homeless youth or injection drug users who share needles.⁵¹ Clearly, inadequate resources compromise Canadian efforts to address the epidemic among vulnerable populations, for example the increasing number of those in federal penitentiaries who are HIV-positive.⁵²

Research

- Funding inadequacies have meant that important policy is not being developed relative to issues such as provincial formularies, inequities in the ability to access treatment, testing technologies, informed consent and routine testing of pregnant women for HIV. One consequence is the current court case involving a woman who was not offered such testing and whose infant was born being HIV-positive.
- Inadequate resources have meant that only 50% of research projects deemed “worthwhile” have been funded by the CIHR.⁵³ Important cohort studies that would help prevent HIV infection are not being done because of their cost.
- The BC Centre for Excellence in HIV/AIDS is truly a world class research institute that has contributed immeasurably to the Canadian and international effort to address the epidemic. Yet it is constrained in what it can do and what it can contribute because it has no infrastructure support from the Government of Canada.

⁵⁰ See Spigelman, HIV and the Health Determinants, 2002.

⁵¹ Canada, Parliament of Canada Standing Committee on Health, March 24, 2003 (Art Zoccole, Canadian Aboriginal AIDS Network)

⁵² Canada, Correctional Service Canada, 2003:2.

⁵³ Parliament of Canada Standing Committee on Health, March 24, 2003. (Louise Binder, Canadian Treatment Action Council) This assertion was supported by others in the research sector who served as key informants for the project.

- Canadian scientists and researchers have not had the opportunity to contribute fully to the international effort to develop a vaccine for HIV. Doing so is a costly process. However it is also a process in which Canadians are and can be world leaders. Their efforts remain under-funded even though the Government of Canada contributed \$50 million to the International AIDS Vaccine Initiative to support such work in other countries.
- There is not the money needed to attract talented minds into HIV/AIDS-related research. There is not the money to attract a younger generation of researchers and scientists “*who are state of the art, who know what they're doing, who want to be trained in Canadian labs.*” Canada is losing some of its “*best and brightest to the United States and other countries.*”⁵⁴

Cooperation and Coordination

- Inadequate funding is creating an unhealthy competition among organizations instead of the partnerships that are vital to CSHA success. The Year Three CSHA Evaluation, for example, concluded that “*competition for the limited CSHA dollars is itself a barrier to the cooperation that is one of the strategy's goals.*”⁵⁵
- Inadequate funds have constrained Health Canada efforts to draw other federal departments into the CSHA and to enlist their cooperation. There have not been the dollars needed to ensure that HIV/AIDS can compete with these departments' other priorities.
- Inadequate funds have compromised the federal government's effort to engage all the provinces and territories in the CSHA. Resources and contributions – “seed money” in some cases – are needed in order to influence provincial and territorial priorities.

Community Capacity

- People working and volunteering with community-based organizations are approaching exhaustion as they struggle without adequate resources and with ever

⁵⁴ Canada, Parliament of Canada Standing Committee on Health, March 2003. (Dr. Mark Wainberg)

⁵⁵ SPR Associates, 2002:57.

greater needs and demands. Their ability to contribute to the Canadian effort is being sorely compromised.

- Salaries in the community sector are well below the norm and are based on an assumption that staff zeal and commitment are sufficient to maintain their engagement. Community-based organizations often are unable to attract professionals who can ensure program effectiveness and develop new policy. Some community agencies have been obliged to shift funds to administration from policy development and evaluation because of inadequate funding and because of the ever more rigorous Health Canada accountability requirements. Key informants suggest that Health Canada needs and demands “more” but is not paying for more.

9. Why Should Canada Invest More?

9.1 Is more money needed?

Efforts to discuss adequacy are complicated by the apparent clash among growing need, competing priorities and limited resources. No matter how wealthy a nation, *“there are demands and desires that will go unsatisfied.”*⁵⁶ No matter what resources are allocated, *“they are never likely to be sufficient to keep pace with growing needs and demands. Resources are finite ... whereas needs, and certainly demands and wants, are infinite.”*⁵⁷

Although the previous section suggests that the current CSHA funding level is “inadequate and inappropriate,” there remains the question of why Canada should invest more.

Some suggest there are not good reasons for investing more and that the emphasis should *“be not on more money for health but on more health for money.”*⁵⁸ Others suggest that, given *“the ever-expanding and innovation-driven nature of modern health care,”* the Canadian system has *“a powerful engine and no brake”* that will consume an ever increasing share of Canadian wealth.⁵⁹

⁵⁶ Hoffmeyer, 1994:137.

⁵⁷ Hunter, 1997:6; Spigelman, Taking Stock, 2001:25-26.

⁵⁸ Murray, 2001:1698.

⁵⁹ Forget, 2002:3.

Others still suggest countries could achieve greater success in their effort to address HIV/AIDS by ensuring that money is spent more wisely.⁶⁰ The National Institute of Medicine in the United States, for example, argues that reallocating funds – for example, to needle exchange programs and comprehensive sex education for youth – could reduce the number of new HIV infections by 30%. It also notes that prevention funding currently is allocated on the basis of the reported number of AIDS cases. This approach “rewards people for counting cases of AIDS instead of preventing HIV infections.”⁶¹ Researchers at the University of California Center for AIDS Prevention Studies have also recommended a shift from the current focus on HIV case-based reporting which gives a “window on the past” to an emphasis on sentinel surveillance systems that provide a much needed window on the future.⁶²

In spite of these concerns and suggestions, there is a broad and vigorous consensus that Canada should be spending more on the CSHA. Most recently, for example, the Parliamentary Standing Committee on Health recently recommended increasing CSHA by over 100%. It joins a chorus of voices in this regard including:

- the Ministerial Council on HIV/AIDS, in its Taking Stock report, and the Year Three CSHA Evaluation.
- the Canadian Coalition of Organizations Responding to AIDS (CCORA) representing some 36 community-based AIDS Service Organizations, other non-governmental organizations and professional associations.
- participants at the 2002 Direction-Setting Meeting in Montreal, sponsored by Health Canada, who are argued that “*There is a need for significantly more funding at all levels – federal, provincial/territorial, municipal – for efforts to stop the HIV/AIDS epidemic.*”⁶³
- UNAIDS which asserts that “*To turn back the epidemic and reduce its impact, funding from all sources needs to increase substantially....*”⁶⁴

⁶⁰ Hanssens, 2001.

⁶¹ Yale Medicine, 2001.

⁶² Catania, 2000:717.

⁶³ Canada, Health Canada, Record of Proceedings, 2002:47.

⁶⁴ UNAIDS, Special Session, 2001.

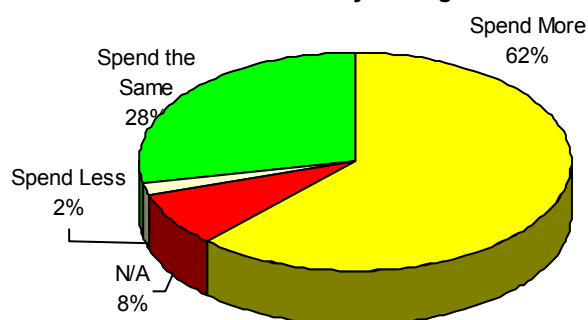
9.2 Why should Canada invest more?

There are a host of compelling reasons for Canada to invest more in the effort to address the HIV/AIDS epidemic, in addition to the impact of inadequate funding and the consensus for more funding described above,

Canada should invest more because Canadians want to do so.

As illustrated in Figure 16, a recent survey indicated that Canadians clearly want their governments to spend more on HIV/AIDS.⁶⁵ Perhaps intuitively, Canadians understand that amounts adequate in 1990 or 1994 are not adequate today.

Fig. 16, Should the Gov't spend more, less or the same on HIV/AIDS as 10 years ago?



Canada should invest more because it has a social responsibility to do so.

Additional funds, invested wisely, will reduce the destructive impact of HIV/AIDS. Additional investments “*will save children from orphanhood, keep households and businesses intact, maintain social cohesion, enhance the return on social investments, ... boost economic growth, enhance national security and help prevent the exacerbation of poverty.*”⁶⁶ Additional investments are required because the epidemic can devastate communities:

*... in some parts of Canada we have explosive epidemics. In the downtown east side of Vancouver ... we have found infection rates of HIV as high as 40% in some populations. Forty percent! That's the kind of rate you don't see anywhere in the world but in places like Botswana and South Africa and Zambia and central and sub-Saharan Africa.*⁶⁷

Canada has a social obligation to invest more in addressing the HIV/AIDS epidemic, both in Canada and internationally. And, perhaps importantly, it is in its own self-interest to do so.

⁶⁵ Ekos, 2003. (n=2400)

⁶⁶ UNAIDS, HIV/AIDS Prevention and Care, 2002.

⁶⁷ Canada, Parliament of Canada Standing Committee on Health, March 2003. (Dr. Martin Schechter, BC Centre for Excellence in HIV/AIDS)

... it is a crime against humanity, in my judgment, that we as a world sit back and do precious little while watching millions of people die each year, year in and year out, of a disease that is 100% preventable [By investing more] Not only are we going to help the people who are today living with HIV disease, we are also going to help the societies in which they live by lowering rates of HIV transmission to people who are yet uninfected, and by so doing, provide long-term benefit to those societies and ultimately to ourselves as Canadians as well.

There is nothing that can compete with HIV for demanding top step on the totem pole. We have to bring HIV down off of that totem pole. We have to crush it. We have to cripple it. We have to win this battle because if we as a world don't, when dealing with a virus that doesn't stop at any borders, then believe me, we as Canadians are ultimately going to have to pay a terrible toll, a much more exacting price than we have had to pay thus far.

*We've been lucky so far. We won't be lucky forever. But by helping the world, we can help ourselves.*⁶⁸

Canada should invest more because it has an economic interest in doing so.

Investing more now will save very significant sums down the road. The literature provides almost overwhelming evidence as to the cost/benefit of investing in efforts to prevent the spread of HIV/AIDS.

On one side of the equation are the tremendous costs of not investing enough. A report to the Ministerial Council on HIV/AIDS, for example, spoke of the “*almost incalculable costs of the human suffering associated with the disease, for people living with HIV or AIDS, for their families and for their communities.*”⁶⁹ Globally a blue ribbon panel of scientists concluded the cost of doing nothing is considerably higher than the \$27 billion price tag they placed on the cost of preventing AIDS. The panel suggested that 29 million of the 45 million infections expected to occur between 2002 and 2010 could be prevented with an investment of \$27 billion, or less than \$1,000 for each case of HIV/AIDS avoided.⁷⁰

⁶⁸ Canada, Parliament of Canada Standing Committee on Health, March 2003. (Dr. Mark Wainberg)

⁶⁹ Spigelman, Taking Stock, 2001:1.

⁷⁰ Picard, 2002:A3.

On the other side of the equation, the literature speaks to financial costs and savings.

- In Canada, the lifetime care and treatment costs are estimated to be \$150,000 - \$160,000 per person while the indirect cost of their lost productivity and premature death may be as much as \$600,000 per person. Use of the new anti-retroviral therapies may add \$60 million annually to health care costs in Canada.
- The annual number of new infections among gay men in 1984 was nearly 3,600, generating long-term costs to the economy of \$2.16 billion. By 1991, the annual number of new infections in this population dropped to 1,200, saving \$1.4 billion in long-term costs (2,400 infections averted x \$600,000).
- The current investment of \$42 million annually need prevent only 70 new infections per year in order to avoid the equivalent amount in long-term costs associated with medical care and lost productivity (\$600,000 x 70). Seventy infections represents only 3% of the newly reported infections occurring every year in Canada.
- Some have suggested there may be as many as 4,000 new HIV infections each year in Canada. They have suggested that reducing this number by 50%, to 2,000, *"would save 10,000 lives ... over a five-year period. A conservative estimate of the cost of one new infection is \$150,000. So a conservative estimate would be that the savings would be of \$1.5 billion over a five-year period of time."*⁷¹
- The Parliamentary Standing Committee on Health heard that *"If you calculate the average cost of providing drugs to HIV-infected people at roughly \$15,000 per year now, and if we could prevent 2,000 new cases each year, that translates to \$30 million in saving, just in drug costs, never mind all the rest – the cost of physician salaries and nurses, and the various tests that need to be performed. Over 20 years, as a conservative estimate in terms of treatment, that translates to \$600 million in savings, just in drug costs alone. We will save money."*⁷²

Given this, the real issue is:

⁷¹ Canada, Parliament of Canada Standing Committee on Health, 2003. (Ralf Jurgens, Canadian HIV/AIDS Legal Network)

⁷² Canada, Parliament of Canada Standing Committee on Health, 2003. (Dr. Mark Wainberg)

... not how much you have this year to spend on an issue, but how much you're willing to spend next year or the year after.... do you want to spend another \$42 million this year to get the [CSHA] budget to \$85 million, or do you want to spend \$600 million every year later on? It's like the oil filter commercial: you can pay me now or you can pay me later.

*Why do the provinces keep coming back to the federal government [for health care dollars]? Because the health-care-system burden is breaking them and the answer is it's the infections we **didn't** prevent 10 years ago that we're now having to treat with \$30,000-a-year drugs. So, let's prevent now so that the provinces don't come to you in 10 years asking to treat another 50,000 people with HIV infection.⁷³*

In other words, by investing only inadequately in HIV/AIDS now, Canada is inviting costs of billions of dollars annually for treatment, care and support down the road. Furthermore the evidence is clear concerning the importance of health to economic development.

Healthy societies are more likely to become wealthy societies ... Healthier people make more productive workers; they have greater incentives to invest in their education and in that of their children; they are likely to save more in expectation of a long retirement Healthy populations can also be a powerful magnet attracting direct foreign investment, new technology, and jobs.⁷⁴

This pattern is evident internationally and in developing countries as well. UNAIDS has calculated that the rate of return on Thailand's investments in HIV/AIDS prevention, 1990-2000, are "in the order of 12–33% If averted income losses are added (as additional benefits that stem from the reduced numbers of AIDS deaths), the rate of return rises to 37–55%."⁷⁵

Similarly, Brazil has provided clear evidence of the savings that will accrue from early investments. Its political commitment and financial investment have cut the transmission rate by 50%, stabilized the epidemic, prevented hundreds of thousands of new hospitalizations – each AIDS patient is now only 25% as likely as before to be hospitalized – and improved the overall state of public health.⁷⁶

⁷³ Canada, Parliament of Canada Standing Committee on Health, March 2003. (Dr. Martin Schechter)

⁷⁴ Bloom, 2002:1.

⁷⁵ UNAIDS, Report on the global HIV/AIDS epidemic, 2002:50.

⁷⁶ Rosenberg, 2001.

Adding to this cost/benefit equation is the leveraging effect of the government's investment. The early federal investment of \$2.9 million in the Canadian HIV Trials Network generated \$5.7 million in additional provincial and private sector expenditures in 1992-93, growing to an additional \$15.6 million in 1995-96.

Similarly, federal "seed money" generated approximately 400,000 volunteer hours in one year in some 62 community groups. At \$10 hour, this translates into \$4 million in leveraged labour costs. The BCPWA Society, as just one of many examples, documented almost 41,550 volunteer hours in 2000/01 and, using a different counting system, is expecting close to 32,000 hours in 2002/03. This is the equivalent of 17.5 full-time staff and almost equal to its entire paid employee complement. *"Valued at even the wretchedly low rate of the minimum wage of \$8/hour, that's a value to the Society of some quarter million dollars last fiscal year ... and more than 10% of our entire annual cash flow."*⁷⁷

Canada should invest more because more is needed to address the epidemic's increasing complexity.

A greater investment will enable Canada to respond to the virus' increasing complexity as it mutates and continues to spread.

*... the epidemic has become much more complicated and much more of a challenge. The people who are becoming infected are the harder to reach people in Canada, under serviced people and marginalized people who need a great deal of targeted prevention and harder work. I'm talking about youth, women in poverty, aboriginal people, inner city people, street youth, the homeless, people in prison and so on.*⁷⁸

What was once one epidemic, affecting primarily gay men, is now several very different epidemics, each affecting a different community of people and each requiring a different public health response. Increasingly:

- the virus is being spread through heterosexual contact and injection drug use;
- the virus is infecting women, youth and those who are poor, homeless, the targets of violence and discrimination, or struggling with mental health problems;

⁷⁷ Personal correspondence with the BCPWA, May 2003.

⁷⁸ Canada, Parliament of Canada Standing Committee on Health, March 2003. (Dr. Martin Schechter)

- the epidemic is taking root in the Aboriginal community where discrimination, poverty, homelessness and violence too often combine to make people vulnerable to HIV infection; and
- the epidemic is being spread by people – perhaps one-third of all those currently living with HIV/AIDS – who are not aware they are HIV-positive.

Furthermore, changes in the epidemic and in the virus itself have left researchers and clinicians racing simply to keep up with the disease. They are so engaged in where the epidemic has been that they cannot plan for where it will be.

The current CSHA budget does not have the capacity to redirect money to these emerging needs and challenges. And reducing expenditures in one area, in order to meet these needs and challenges, can quickly lead to the epidemic's resurgence, for example among gay men. The evidence clearly shows that *"Prevention is not a one-time thing. You have to keep getting the message out to that original population, and now, of course, to all the other populations where there are epidemics."*⁷⁹

Canada should invest more because it can afford to do so and because other jurisdictions are doing so.

The federal government should invest more because the \$42.2 million level established in 1994 and maintained in 1998 reflected the country's fiscal situation at those times. Deficits and debt were then the country's fiscal priorities. This is no longer the case as Canada leads OECD countries in managing its debt and amassing budgetary surpluses, and was the only G7 country to record a surplus in 2002 and 2003. The Canadian government's fiscal situation, in other words, has improved very dramatically from 1997/98 to the present, i.e.:

- its budgetary surplus increased from \$3.8 billion to over \$18 billion. In the four fiscal years 1999/2000 to 2002/03, its total surplus amounted to almost \$30 billion.
- its total revenues increased from \$154 billion to \$173 billion and are projected to increase to \$193 billion by 2004/05.

⁷⁹ Canada, Parliament of Canada Standing Committee on Health, March 2003. (Louise Binder)

- its program spending increased from \$45 billion to \$47 billion although, as a percent of GDP, this represented a decrease from 12.3% to 11.6%.
- its debt charges declined from \$41 billion to \$38 billion, representing 6% and 4% of GDP respectively. Its public debt charges are projected to decline further to 3.0% in 2004/05.
- its financial requirements declined from \$13 billion to \$5 billion.⁸⁰

Even with the tax cuts and new spending initiatives announced by the federal government in the past few years, the federal surplus is likely to grow considerably over the next decade.⁸¹ Additionally the February 2003 budget indicated that the government's accumulated deficit has been reduced by \$47.6 billion.

The Government of Canada should also be investing more in order to keep up with other jurisdictions. Since 1998, for example, the Government of Ontario *"has provided almost \$13 million more each year in funding for HIV services ... \$8 million to support the Ontario HIV Treatment Network (OHTN), \$1 million for IDU outreach program, \$1 million for community-linked evaluation of AIDS programs/services, \$1 million to increase the base operating funding for AIDS service organizations, \$.789 million for the HIV prenatal screening program and \$50,000 for the infant formula program."* Importantly, this \$13 million enhancement does not include increasing costs related to physician care, drug programs, or inpatient hospital, home care and palliative care services.⁸²

The United States also provides a model for investing more in response to the epidemic's threat. Beginning with a few hundred thousand dollars in 1981, federal investments in HIV/AIDS-related activities increased to \$8 million only one year later and then nearly doubled every year from 1982 to 1989. In 2002, federal spending on HIV/AIDS in the U.S. was \$14.7 billion, almost 350 times the amount committed by the federal government in Canada. The President's 2003 budget request included an estimated \$15.8 billion for HIV/AIDS programs, representing a 7% increase from the previous year.⁸³

⁸⁰ Canada, Department of Finance, 2003. See also <http://www.fin.gc.ca/budget03/PDF/bp2003e.pdf>, http://www.fin.gc.ca/toce/2002/afr_e.html and www.statcan.ca/english/freepub/68-213-SIE/surplus.htm.

⁸¹ St. Hilaire, 2002:2-3.

⁸² Ontario Advisory Committee, 2002:3, 53.

⁸³ Kaiser Family Foundation, 2002:1.

Furthermore, in the United States, the investment in research grew by 86% between 1995 and 2002 while the investment in prevention grew by 48%, the smallest percentage increase of all spending categories. Additionally, the U.S. investment in global HIV/AIDS programs has increased more than six-fold since 1995, rising faster than any other spending category even though it still represents a relatively small share of total HIV/AIDS spending, i.e. 2% in 1995 and 6% in 2002.⁸⁴

Canada should invest more because of the intellectual benefits that will accrue.

Investing in HIV/AIDS now – in virology, in research, in scientific and community capacity, in public health and in awareness and prevention – will help to prepare Canada for the next Severe Acute Respiratory Syndrome (SARS) outbreak, for West Nile and for the inevitable flu pandemic that will rival 1918/19. The spill over is clear: addressing the HIV/AIDS epidemic in all its manifestations will help Canada fight other viruses and diseases not *if* they occur but *when* they occur.

This preparation is vital as the Ontario experience with SARS so clearly indicates. There will be new epidemics in the future given that at least 30 previously unknown disease agents, for which there are no cures, have been identified since 1973. These include HIV, Ebola, hepatitis-C, the Hanta virus, new variants of Creutzfeldt-Jakob disease and the Nipah virus. *"In the opinion of the US Institute of Medicine, the next major infectious disease threat to the United States may be, like HIV, a previously unrecognized pathogen."*⁸⁵

The challenge, therefore, is to invest in the research, policy development and capacity that will address HIV/AIDS today and new pathogens tomorrow. Similarly efforts to promote condom use and safe sex, for example, will help to protect people from HIV and other sexually transmitted infections. Lowering HIV rates will help to reduce the spread of tuberculosis among non-HIV positive people. Efforts to improve the way in which the government system copes with HIV/AIDS will help build capacity to fight other pathogens in the future.⁸⁶

⁸⁴ Kaiser Family Foundation, 2002.

⁸⁵ US National Intelligence Council, 2000.

⁸⁶ Bloom, 2002:3.

Canada should invest more because there are no viable alternatives to government funding for HIV/AIDS.

The Government of Canada needs to invest more because it remains the only viable source of funding for many components of the effort to address the HIV/AIDS epidemic. Private and philanthropic support is severely limited, in part because of the stigma and discrimination associated with HIV/AIDS.

AIDS Walks, for example, have long been an important fund raiser for HIV/AIDS organizations in Canada and in 2002, 7,000 people participated in Vancouver, 14,000 in Toronto and 20,000 in the province of Quebec.⁸⁷ Yet, as illustrated in Figure 17, the amount of money raised has declined significantly since 1997/98.

Fig. 17, AIDS Walk Revenues, 1996-2002 (\$million)

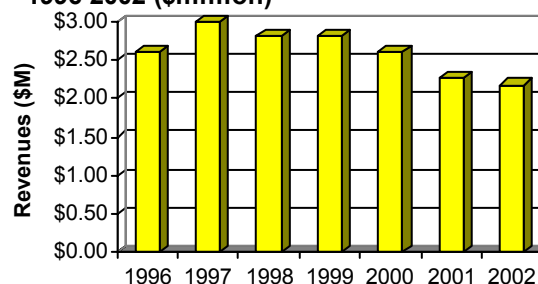


Fig. 18, CAS Revenues from Fundraising

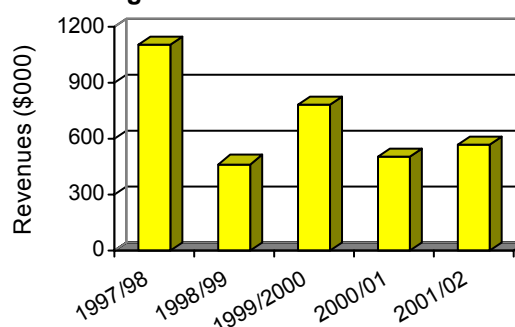


Table 5, Funding Sources, Canadian AIDS Society (\$000)

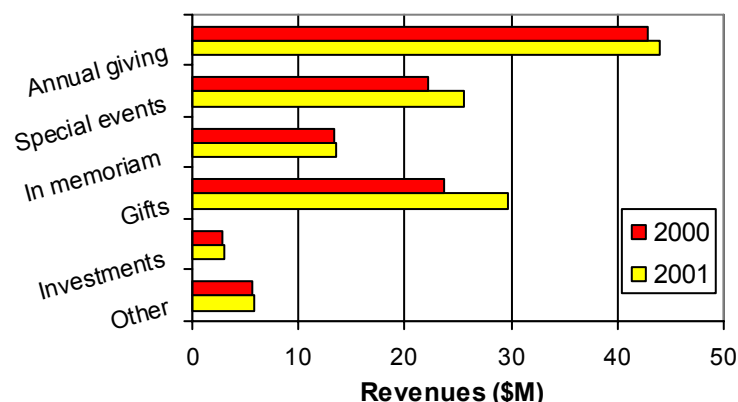
Revenue Source	1997/98	1998/99	1999/2000	2000/01	2001/02
Health Canada	\$1,759	\$1,583	\$1,953	\$1,542	\$1,330
Other Government	134	46	107	183	197
Fundraising	1,100	466	784	503	571
Total	\$2,993	\$2,095	\$2,844	\$2,228	\$2,098

⁸⁷ In total almost 130 communities and over 50,000 people participated in these events.

In contrast, in Ottawa alone, the Canadian Cancer Society has more than 5000 volunteers who raised over \$800,000 from their residential canvass. In Ontario as a whole, the Society raised almost \$10M in its residential campaign.

Nationally in 2002, the Society's 250,000 volunteers raised \$104.9 million, with over \$93 million coming from the public and the remainder from a variety of other sources, including \$12 million from In Memoriam contributions and bequests. It had two "platinum donors," each contributing more than \$100,000, i.e. Manulife Financial and the Royal Bank Foundation. And it had over 210 corporations, employee groups, foundations and associations contributing \$10,000 or more in 2002.

Fig. 19, CCS Revenues, 2000 & 2001 (\$M)



Canadian Cancer Society revenues were such that it could invest \$45M – more than the entire CSHA budget – in cancer research and in eighty-nine new leading edge cancer research projects. Furthermore, it committed almost \$27 million to health promotion alone, equivalent to 64% of the entire CSHA budget.⁸⁸

Similarly the Canadian Diabetes Association had over 200,000 direct mail donors in 2001⁸⁹ along with almost 600 physicians, researchers and health professionals working as volunteers in its Clinical & Scientific Section and 2,200 more in its Diabetes Educator Section. In 2002, it contributed over \$5 million to research. The Association's Banting Circle consists of individuals who contribute over \$1000 per year to the Association and in 2002, its membership doubled to 235 donors. The Association also had sixty-one organizations or individuals contributing more than \$5000.

⁸⁸ Canadian Cancer Society, 2001. (<http://www.cancer.ca/ccs/internet/cancer/0..3172.00.html>)

⁸⁹ Canadian Diabetes Association, 2002.

Canada should invest more because the current funds are being used responsibly.

It certainly appears that the CSHA funds are being well spent. The Health Canada Corporate Services Branch “regards the CSHA financial management as well structured with a good system for tracking expenditures. CSHA’s obligation to sound public accountability has created the incentives for timely reporting of expenditures by regions and responsibility centres to the Ministerial Council on HIV/AIDS.”⁹⁰

Similarly independent evaluators “found that partners and stakeholders see [the Health Canada] International HIV/AIDS Program as credible, valuable and a very good use of resources.... Stakeholders also believe that [the] international HIV/AIDS activities are delivered cost-effectively.” The evaluators concluded that the Health Canada international program has provided leadership and supported a number of important activities using very limited resources (\$300,000 annually).⁹¹

Similarly, the Year Three CSHA Evaluation also concluded that “*The [CSHA] investment strategy appears to be effective, given the resources which are currently available, and the available evidence suggests that resources are being well used. Lack of funds, however, makes it difficult to assess questions as to the ‘best’ or most efficient use of resources.*”⁹²

10. What Outcomes Will Flow from Investing More?

By all accounts, the CSHA funds have been well used in the past and Canada has made tremendous strides through the past two decades, for example:

- community awareness has been enhanced and different communities – Aboriginal people, those living with HIV/AIDS, immigrant women – have been engaged in the effort to address the epidemic;

⁹⁰ Legowski, 2000:4.

⁹¹ Canada, Health Canada, International Affairs Directorate, 2003:1-2.

⁹² SPR Associates, 2002:56.

- HIV transmission via the blood supply and from mother-to-infant have been virtually eliminated, and people are living longer with HIV/AIDS and continuing to work and participate in community life; and
- considerable progress has been made toward developing a vaccine and there is a fuller appreciation of interdependence of efforts to address the epidemic in developing and developed countries.

Thus, much has been accomplished with \$42.2 million annually. However key informants and the literature emphasize that Canada and the world will lose the fight against HIV/AIDS if they do not invest more in the effort. Importantly they also identify what concrete outcomes could reasonably be expected by 2008 if Canada substantially increased its CSHA investment.

Perhaps the most dramatic of these outcomes is the key informant suggestion that the life span of those infected with HIV would be extended by decades. The person infected at age 30 could continue to live, work and participate in community life well into their 60s. The following identifies other outcomes that can reasonably be expected to flow from a more appropriate financial commitment to addressing the epidemic.

Research

An enhanced investment would:

- allow Canadian researchers to undertake intensive cohort studies of injection drug users and of young people who are vulnerable to HIV infection. This knowledge would result in new program models that would effectively reduce HIV transmission rates among these populations. Cohort studies are expensive to undertake but vital for understanding behaviour, the factors influencing behaviour and the impact of various treatments.
- allow Canadian researchers to understand the relationship between HIV vulnerability and the social determinants of health, and to contribute their knowledge to new policy and new programs that reduce the risk of infection for Aboriginal people and other communities. This research would ensure that Canada has the evidence-based knowledge required to address new issues and new epidemics as they arise.

- ensure that researchers are attracted to working in the HIV/AIDS field and are contributing to the country's ability to address this epidemic now and other epidemics in the future. During the recent SARS outbreak, the talent and capability of the Canadian research community was amply displayed, for example at the National Microbiology Laboratory in Winnipeg.⁹³
- ensure that world class researchers continue to work in Canada rather than migrate to the United States or elsewhere. Their presence contributes to the success of clinicians in treating HIV/AIDS and to ensuring that HIV/AIDS-related research is sensitive to the sometimes unique Canadian context.

Clinical Trials

An enhanced investment would:

- expand Canadian participation in clinical trials and allow Canadians to continue simplifying treatments, reducing toxicity and enhancing access.
- allow researchers to find the most efficient and effective use of the various treatment drugs and thereby create important savings by avoiding ineffective or wasteful practices. Researchers with the pharmaceutical industry cannot be expected to focus on efforts to reduce the cost of treatment.

Vaccines

An enhanced investment would:

- enable organizations such as CANVAC to develop vaccines for HIV/AIDS and other viruses. The Canadian Network for Vaccines and Immunotherapeutics is a federally funded Centre of Excellence whose objectives are to enhance the Canadian economy and quality of life through the development of new knowledge and its transfer to concrete applications. An enhanced commitment to developing a vaccine would help to ensure that Canada has

⁹³ See Bernstein, 2003.

the capacity not only to contribute its expertise to the world but also to address other pathogens when they appear.

Prevention

An enhanced investment would:

- enable Canada to eradicate mother to infant transmission entirely.
- enable Canada to reduce HIV infection rates, as well as rates for other health conditions including hepatitis-C and tuberculosis, by addressing the social determinants placing some groups at risk.
- enable Canada to reduce HIV transmission by focusing new prevention efforts on those who are already HIV-positive, including the 15,000 people who currently are not aware that they are carrying the virus.
- enable Correctional Service Canada to implement peer education and counselling programs in all rather than half of its institutions. This would help reduce the rate of HIV transmission in prisons and reduce also the risk of people carrying the virus from the institutions back into the community.
- encourage the provinces and territories to partner more fully in the CSHA and to work toward its common prevention, care, treatment and support objectives. It could allow these jurisdictions to significantly increase the proportion of infected people who are connected to an appropriate program of care and treatment.
- enable ACAP to greatly increase the number of innovative, community-based programs that it supports and to ensure that the lessons learned from these projects are shared across the country.

Surveillance

An enhanced investment would:

- improve the current system of national HIV/AIDS case reporting so that it is more timely and includes complete information on all cases, thus allowing the data to be more useful for prevention and care programs.

- allow Canada to build a second-generation HIV surveillance system that monitors risk behaviours as well as infections and includes effective partnerships among epidemiologists, public health officials and community service providers. Transferring knowledge, experiences and insights across sectors in this way would allow Canada to respond more quickly to new trends and to get out in front of the epidemic.

Community Capacity

An enhanced investment would:

- enable AIDS Service Organizations to more effectively address the epidemic by increasing community participation in their activities. It would enable them to undertake more policy development and social research, build partnerships with other government agencies including CIDA, and achieve a higher level of consistency in their services by retaining staff.
- enable community-based organizations to more effectively prevent HIV transmission by developing peer mentoring programs and creating population-specific support and prevention programs. It would enable them to use their network of volunteers more effectively and to provide better training for their staff.

International Awareness and Prevention

An enhanced investment would:

- permit organizations to engage youth more fully in the international effort to address HIV/AIDS, for example through a HIV/AIDS youth ambassador program. The program would encompass both Canadian and overseas placements of young people in HIV/AIDS-related organizations. It would enhance youth awareness on both domestic and international HIV/AIDS issues and would have a positive impact on both prevention and the behaviours that place youth at risk.
- enable Canadian AIDS Service Organizations (ASOs) to incorporate lessons learned from international experiences by giving them access to the most up

to date information on prevention, care, treatment and support initiatives. This would improve their ability to implement high quality programming in Canada.

- enable ASOs to develop training materials and workshops to reduce stigma and discrimination, and to create positive and supportive working environments for people living with HIV/AIDS. This would enable Canadian firms working internationally to be leaders in addressing HIV/AIDS-related workplace issues.

Cost Savings and Economic Spin-offs

An enhanced investment would:

- generate very significant savings in the health care sector and throughout the economy, in both the short and the long term.⁹⁴
- contribute directly to the Canadian economy, for example through the development of new vaccines or by enabling people who are HIV-positive to remain in the paid labour force.
- support the business sector. In the United States, the Centers for Disease Control and Prevention has reported that large employers incurred costs ranging from \$17,000 to \$32,000 (\$US) for each worker living with HIV. The CDC asserts that “*Supporting prevention programmes makes good economic sense.*”⁹⁵

11. What Amount Should Canada Invest in the Renewed CSHA?

11.1 What approaches can be used to determine the funding levels?

There are two approaches to identifying options for the level of CSHA funding to be invested by the Government of Canada. The first is *bottom up* and endeavours to use available evidence to

⁹⁴ UNAIDS, Report on the global HIV/AIDS epidemic, 2002:51,54. See also the presentations, for example by Dr. Martin Schechter, to the Parliamentary Standing Committee on Health, March 2003.

⁹⁵ UNAIDS, Report on the global HIV/AIDS epidemic, 2002:55.

identify how much is needed in order to achieve certain goals and objectives. This approach is eminently viable in the case of new *programs* where needs, service level goals and potential outcomes can be identified. It may involve, for example, estimating the cost of training a certain number of counsellors in a program offering care and support, or purchasing so many condoms for a sex education program in high schools. This approach has characterized only a few of the other federal initiatives in the health sector, for example the Tobacco Strategy and the Hepatitis-C Program.

This approach is difficult to apply for comprehensive, multi-sectoral strategies whose goals and objectives, of necessity, are both long-term in nature and more general in character. It cannot be used for the CSHA, at least in the short term, because:

- the Strategy does not yet have concrete objectives; and
- the federal role, for the most part, is not oriented toward direct service.

The bottom up approach may be more feasible for provincial and territorial health authorities whose focus is treatment, care and support.

The second, top-down approach is for government to identify what budget is available to support the strategy given a range of considerations, for example historical funding levels, an assessment of current and future needs, consideration of fiscal issues and the level of public and political will. Stakeholders are then left with the task of allocating that budget in an equitable manner that is consistent with the strategy's goals and priorities. This approach has been widely used for HIV/AIDS strategies both in Canada and elsewhere.

It is this latter, top-down approach that has to be used to determine the CSHA budget for the period 2004-2008. In the future, as concrete objectives are incorporated into the Strategy and as its components are rigorously evaluated for effectiveness and impact, it may be possible to adopt the bottom up approach.

11.2 What premises should underlie federal funding decisions?

The following premises, based on the preceding sections, provide a foundation for considering the most appropriate investment level:

-
- the money invested to date in the CSHA has been well spent and has contributed to Canada's success in addressing the epidemic both nationally and internationally.
 - the current CSHA budget is inadequate given the epidemic's spread into new and harder-to-reach communities, the increasing complexity of HIV/AIDS, the significantly higher number of people living with HIV/AIDS and the impact of inflation since 1994 when the \$42.2 million budget was established.
 - the response to the HIV/AIDS epidemic must be inter-sectoral and intergovernmental, and must acknowledge both:
 - that HIV/AIDS will remain a public health threat for an extended period of time yet, and
 - that, increasingly, it must be treated as a chronic and episodic condition for those who are infected.
 - an enhanced investment would prove to be cost-effective as a result of avoiding both:
 - higher costs in the health care system, and
 - new costs in terms of lost productivity.
 - an enhanced investment would produce very significant benefits in terms of intellectual development, the capacity to address other viruses when they appear, economic spin-offs and the avoidance of human suffering.
 - Canada can afford a more significant investment, both nationally and internationally, given its economy, its fiscal situation, its budget surpluses and its wealth relative to much of the world.

11.3 What goal should underlie federal funding decisions?

Federal funding decisions should reflect the federal goal outlined in Section 4.2 (above) for its role in the CSHA, 2004-2008. Central to that goal is the determination *"to anticipate the epidemic's course – and to get out in front of it – rather than simply react to its manifestations."*

This federal goal speaks to the abundant evidence, acquired through the past two decades, that in spite of medical advances, viruses remain a serious health and economic threat to Canada. The recent experience with Severe Acute Respiratory Syndrome, for example, has shown how:

- viruses can skip from one vulnerable population into the community as a whole;
- communities can very quickly lose control of an epidemic if it is not effectively contained and controlled;
- investments in public health and in both intellectual and community capacity are vital for enabling Canada to respond effectively to the threats posed by viruses; and
- sustained effort is required to manage viruses that cannot be entirely eradicated.

Federal funding decisions for the CSHA should reflect this experience and knowledge. One lesson that can be drawn is the importance of stopping epidemics in their tracks, and of getting out in front of an epidemic before it gets out of control. That implies investing both heavily and early in those efforts that will enhance our understanding of HIV/AIDS – in both its social and biologic manifestations – and our ability to prevent its spread, to reduce vulnerability, to strengthen capacity, to ensure appropriate treatment, care and support and to minimize the adverse personal, social and economic impact of HIV/AIDS on individuals, groups and communities.

11.4 What funding levels have been recommended?

As described earlier, there is both a broad consensus that a greater investment is needed to support the CSHA and its various activities, and sound reasons for doing so. Few, however, have suggested how much more is needed. The Year Three CSHA evaluation, for example, did not offer a figure. Nor did the Fair Findings evaluation of the Health Canada international effort although it did note that *“Carrying out some of the activities envisaged in this plan will require additional resources.”*⁹⁶

In 2000, the Canadian AIDS Society recommended \$85 million as an amount that would represent a strong federal commitment to addressing the HIV/AIDS epidemic. This figure was then highlighted by the *Taking Stock* report prepared for the Ministerial Council on HIV/AIDS. The report itself did not recommend a specific figure as being *adequate*. Instead it

⁹⁶ Health Canada, International Affairs Directorate, 2003:2.

suggested amounts ranging from \$44 million to \$70 million as *appropriate* given both inflation and changes in the epidemic since 1990 and 1994.

More recently, in March 2003, the Canadian AIDS Society suggested to the Parliamentary Standing Committee on Health that a much more significant Canadian investment was required. The government, it said, needs:

to invest millions of dollars to change social behaviours.... When we look at the scope of HIV now in our country [and at] putting ads in all newspapers, we're looking at a quarter to three-quarters of a million dollars, to put ads not only in The Globe or The National Post. We need to involve all the media of all the communities.... We were looking at a campaign annually of \$1 million just to do some awareness. And awareness is the beginning of a process of education and prevention. So in order to reach out there, the money has to be available.⁹⁷

Other experts appearing before the Standing Committee also offered estimates. Dr. Mark Wainberg, Past President and Director of the McGill AIDS Centre and the International AIDS Society, recommended doubling the CSHA budget *"to \$85 million. It's something we keenly feel is necessary ... [to enable] us to do a proper job at home ... [and] to develop research exchanges with countries outside our own borders.... The United States ... probably still spends approximately eight times more money per capita on HIV research of all types than we do in this country.⁹⁸*

Dr. Martin Schechter from the BC Centre for Excellence in HIV/AIDS also recommended \$85 million as an appropriate amount as did the Executive Director of the Canadian HIV/AIDS Legal Network. The latter suggested that *"with \$85 million per year and additional funding for HIV vaccines we would have a chance to make the difference we so desperately want to make."⁹⁹*

These comments were reinforced by the Past President of the Canadian Association for HIV Research, Dr. Kenneth Rosenthal. He contrasted the Canadian government's commitment of perhaps \$1 million for vaccine development to that of the United States (\$400 million) and

⁹⁷ Canada, Parliamentary Standing Committee on Health, March 2003. (Paul Lapierre, Executive Director, Canadian AIDS Society)

⁹⁸ Canada, Parliamentary Standing Committee on Health, March 2003. (Dr. Mark Wainberg)

⁹⁹ Canada, Parliamentary Standing Committee on Health, March 2003. (Ralf Jürgens)

France (\$8 million Euros).¹⁰⁰ He also drew attention to the \$50 million Canadian contribution to International AIDS Vaccine Initiative for work that will be done in other countries.

In June 2003, the Standing Committee itself recommended that:

- the federal government increase its funding for the renewed CSHA to \$100 million annually;
- this increased federal funding specifically designate \$5 million annually to each of the two at-risk sub-populations (First Nations and Inuit as well as inmates) falling under federal jurisdiction;
- this increased federal funding specifically designate \$5 million annually to Canadian researchers engaged in vaccine development; and
- this increased federal funding be reviewed in two years to ensure that it is appropriate to changes in the status of the disease and its economic, physical and social impact on Canadians.¹⁰¹

Whatever the precise amount, the literature warns that *“Half-measures bring, at best, partial results. Interventions that do not achieve sufficient coverage will simply fail to have a significant impact.”*¹⁰²

11.5 What funding options are available?

The following presents three options representing different levels of federal financial investments in the renewed CSHA. It assumes that the current level of \$42.2 million annually is the absolute floor since any lesser amount would result in Canada:

- losing control of the HIV/AIDS epidemic and losing the capacity to respond to this or future epidemics;
- inviting irreparable health, social and economic consequences; and

¹⁰⁰ Canada, Parliamentary Standing Committee on Health, March 2003. (Dr. Kenneth Rosenthal)

¹⁰¹ Canada, Parliament of Canada, Standing Committee on Health, June 2003, Report.

¹⁰² UNAIDS, Report on the Global HIV/AIDS epidemic, 2002:80.

- abrogating its responsibilities to vulnerable populations both within Canada and in the developing world.

**Annual Level**

- \$42.2 million

Message

- Canada is committed only to administering what exists currently as a response to the HIV/AIDS epidemic.

Rationale

- could be said to reflect the country's success to date in controlling the number of new infections
- could be presented as "reasonable" given the amounts allocated to other diseases and strategies
- assumes that the country's commitment to the international effort will be addressed through the Canadian International Development Agency

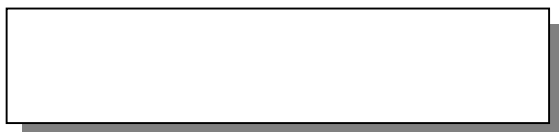
Implications

- is inconsistent with the goals articulated for the federal role in the renewed CSHA and with the premises upon which these options are founded
- does not represent federal leadership or a federal commitment to the CSHA in terms of the effort or coordination required across sectors and jurisdictions
- will not allow Canada to meet the responsibilities identified in its new Federal Role Discussion Paper
- ignores the advice of all those community and academic organizations engaged in the effort to address the epidemic as well as the advice and recommendations of the Parliamentary Standing Committee on Health
- does not reflect the changes in the epidemic since 1994 and 1998, for example
 - the epidemic's increasing complexity, and
 - its spread into the heterosexual population and into harder to reach groups on the margins of Canadian society

- does not reflect the impact of inflation since 1990 or the increasing number of people now living with HIV/AIDS
- overlooks the recent increase in the number of newly reported HIV-positive cases
- does not permit Canada to build upon lessons learned from its own and the international experience

Anticipated Outcomes

- diminished capacity to address HIV/AIDS among AIDS Service Organizations and the research community as well as within the Aboriginal and other vulnerable communities
- diminished capacity to address other viruses and epidemics when they appear
- enhanced vulnerability for all Canadians and particularly for Aboriginal people and those incarcerated in federal prisons
- compromised partnership between Health Canada and the community organizations playing a vital role in the effort to address the epidemic
- none or few of the new and much needed prevention initiatives will be implemented
- Canadian researchers and clinicians may continue to leave Canada



Annual Level

- \$85 million

Message

- The federal government is committed to restoring funding to the levels established in 1990 and 1994, adjusted for inflation¹⁰³ (\$47.5M), for the increasing number of people now living with HIV/AIDS¹⁰⁴ (\$71.9M) and for the country's dramatically improved fiscal situation (\$85M+)
- The federal government intends to actively manage the epidemic

¹⁰³ See Statistics Canada, Consumer Price Index, 1971-2002.
<http://www.fp.ucalgary.ca/oia/cpi/tables/Canada.pdf>

¹⁰⁴ http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/epiu-aeipi/hiv-vih/estime_e.html. See also Spigelman, Taking Stock, 2001:iii. Prevalence numbers for 2002 have not yet been determined. It is estimated, however, that there are 55,000-60,000 people currently living with HIV/AIDS.

Rationale

- represents a constructive government response to a clear community and academic consensus around what level of funding would be appropriate
- will infuse new money to address the diversity inherent in the HIV/AIDS epidemic
- would represent a determination to address and control HIV/AIDS before it sinks even deeper roots in Canada and in other countries

Implications

- would enable government to undertake some very significant efforts that promise to pay handsome dividends while, at the same time, meeting current needs and compensating for the lack of new investments since 1994
- could be combined with a priority-setting process that flows significant dollars into a small number of priorities and effective measures that promise to have the greatest impact
- renews and updates the current government commitment to address the epidemic and allows it to at least begin addressing new challenges as they arise
- will enable government to begin addressing, at least minimally, the needs of particularly vulnerable communities and communities in crisis

Anticipated Outcomes

- meets pent-up demand and restores capacity in the ASO and research sectors to 1998 levels
- creates some room for policy development and innovative programs with proven efficacy
- allows for a modest expansion of what exists currently in both Canada and the international sector

**Option 3 – Getting Ahead of the Epidemic:
\$106 Million****Annual Level**

- \$106 million

Message

- The federal government has a clear, strong and visionary commitment to “getting ahead of the epidemic,” to preventing its further spread and to ameliorating its impact on people and communities both in Canada and internationally
- The federal government is committed to the pan-Canadian approach embedded in the CSHA
- The federal government is strongly committed to addressing the epidemic in all its diversity

Rationale

- represents a constructive and positive government response to the advice received from community organizations, research and academic institutions and the Parliamentary Standing Committee on Health
- indicates the government is building upon two decades of experience with HIV/AIDS and from the recent experience with Severe Acute Respiratory Syndrome (SARS)
- represents a clear and renewed commitment on the government’s part to the CSHA, to a pan-Canadian approach and to intergovernmental and inter-sectoral initiatives

Implications

- conceivably the level of funding could be reduced over time as Canada gets ahead of the epidemic and brings it fully under control, and as the impact of its proactive measures is felt
- would enable government to undertake some very significant new efforts – both in Canada and internationally – for which there is strong evidence of efficacy and cost-effectiveness
- would enable the government to address the social determinants that increase vulnerability to HIV infection
- will allow Canada to head off the epidemic before it become irreparably rooted in the Aboriginal, prison and other populations
- provides seed money for more fully engaging the provinces, territories and the range of federal departments and agencies in the CSHA
- would represent a significant investment in building the capacity required to address a host of other health conditions and threats, including hepatitis-C, SARS and West Nile
- could be combined with a priority-setting process that flows significantly increased funds into priorities that promise to have the greatest impact
- provides the government with the flexibility required to address its three realms of responsibility

-
- provides the government with the flexibility required to address new challenges as they arise
 - allows Canada to enhance its commitment to the global fight against HIV/AIDS
 - allows Canada to invest in the search for an effective vaccine

Anticipated Outcomes

- will allow for a heavy, up-front investment to enable Canada to get ahead of the epidemic
- will enable the virology and HIV/AIDS sectors to attract world class researchers and to retain its clinicians and biomedical scientists in Canada
- will allow the government to achieve its CSHA goals relative to prevention, care, treatment and support, etc.
- will enhance the partnerships among the Government of Canada and a host of community and other organizations addressing the epidemic in Canada and internationally
- will create significant short and long-term cost savings and other economic, social and intellectual spin-offs

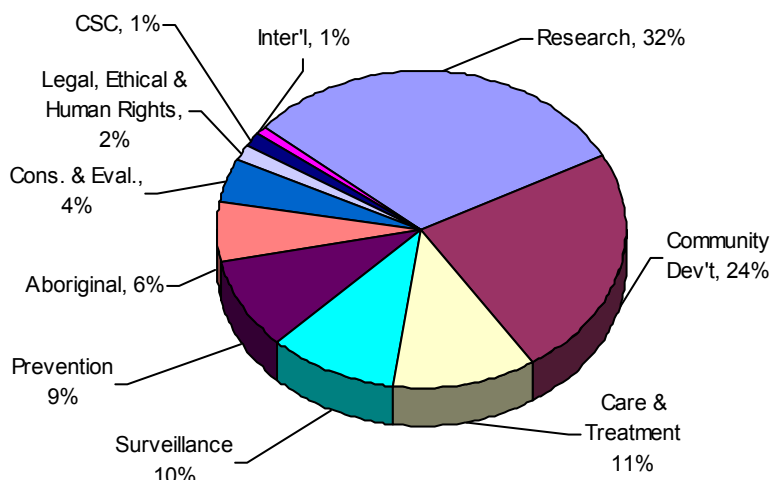
12. What Will Be the Federal Government's Funding Priorities?

Priorities refer to a limited number of areas deserving of strengthened focus, increased effort and enhanced resources. *"These are areas which hold a potential for significant changes ... [or] areas where we see a real opportunity to act."*¹⁰⁵

The 1997/98 CSHA allocation process assigned the largest share of available funding (32%) to the research sector. Subsequently it has proven to be exceedingly difficult to identify priorities in part because of the difficulties inherent in measuring the impact and effectiveness of current activities. The literature, for example, suggests that the process for establishing priorities should include an understanding of both what works and what is needed.¹⁰⁶

At the same time, however, there must be realistic expectations about what the research and

Fig. 20, CSHA Funding Allocation, 1998-2003 (\$M)



¹⁰⁵ Birch, 1993.

¹⁰⁶ World Health Organization, 1999.

evidence can indicate. Rarely in the health system, where behaviour is an important variable, is such precision available. Furthermore:

- all of the Strategy's current areas of activity are both vitally important for addressing the epidemic and interdependent. International experience, for example, contributes to the national effort while surveillance contributes to prevention and prevention to the care, treatment and support continuum; and
- establishing priorities may be practical only when there is adequate funding available for those priorities.

The difficulties inherent in allocating the federal investment, 2004-2008, will be compounded since such processes invariably are "*made in a highly charged environment, [and] subject to numerous competing influences including politics, advocacy, scientific evidence, personal values and community norms.*"¹⁰⁷

Furthermore there are few models available to provide such guidance and fewer still that are directly applicable or entirely practical. In Australia, for example, the Commonwealth/State Funding Agreements incorporate laudable but vague principles respecting equity and access, best practice, participation and partnership, government commitment to infrastructure and integration with primary health care.¹⁰⁸ Similarly in Scotland, the allocation of funding for the health care system incorporates principles relating to fairness, equal access, a commitment to addressing deprivation and inequities, reliance upon evidence-based practices, and transparency.¹⁰⁹

The American literature also offers some suggestions for allocation principles. In its proposed prevention strategy, the National Institute of Medicine suggested that funding allocations should be based upon estimates of new HIV infections, program evaluations, the need to promote prevention among those already infected, the need to strengthen local capacity and education around harm reduction strategies.¹¹⁰ It also recommends avoiding efforts that are not evidence-based, for example the expenditure of \$440 million on abstinence-only sex education programs for which there is no evidence of efficacy.

¹⁰⁷ National Institute of Medicine, 2000:20.

¹⁰⁸ Australia, n.d.

¹⁰⁹ Scotland, Fair Shares for All.

¹¹⁰ National Institute of Medicine, 2000.

The National Institute of Medicine also emphasizes the importance of cost effective approaches. It contrasts the \$7.5 million cost per infection avoided associated with safeguarding the blood supply with the \$50,000 per HIV infection prevented for needle exchange programs.¹¹¹

Finally, the Institute recommends rewarding success and allocating only a portion of total funding on the basis of HIV/AIDS prevalence or incidence numbers. The remaining funds would be discretionary and allocated on the basis of effective practice and infections avoided. This approach is consistent with that recommended by provincial auditors in Canada who suggest that health administrators should “move consistently toward relatively higher benefits and relatively lower costs, incorporating the best available knowledge about the links between treatments and health outcomes.”¹¹² Quality more than quantity should guide the allocation process, with monitoring, outcome evaluation and knowledge determining effective and best practices.

In Canada also, a C.D. Howe Institute Commentary on Medicare offered four criteria for establishing allocation priorities, i.e.:

- limited resources should be used in a manner that produces maximum benefit;
- the process for setting priorities should be open and explicit;
- principles of both equity and efficiency should be considered; and
- the process should be evidence-based wherever possible.¹¹³

¹¹¹ National Institute of Medicine, 2000:25.

¹¹² Mitton 2002:2/29.

¹¹³ Mitton 2002:18/29.

12.1 Public Priorities

Canadians have a sense of what priorities should characterize the federal effort.¹¹⁴ Figure 21 illustrates that they see public education followed by research as their highest priorities. The international effort ranks very low in spite of its importance for and contribution to the national effort in Canada itself.

The subsequent Figures indicate that the public ranks prevention higher than treatment. It also ranks education and research as almost equally important. They also prioritize efforts targeted to all Canadians over those targeted to specific groups.

Fig. 21, Public Views on Federal Priorities, 2003

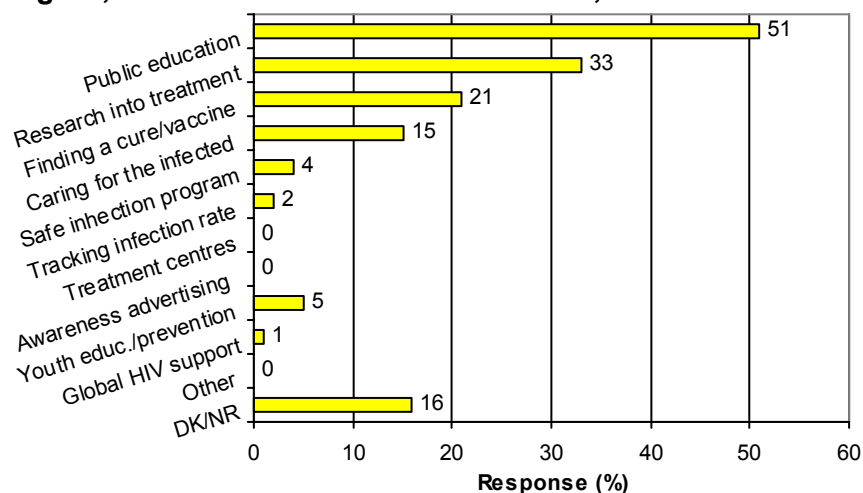


Fig. 22, Public Priorities - Prevention or Treatment

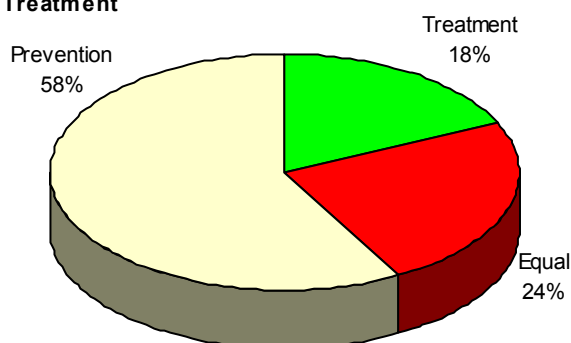
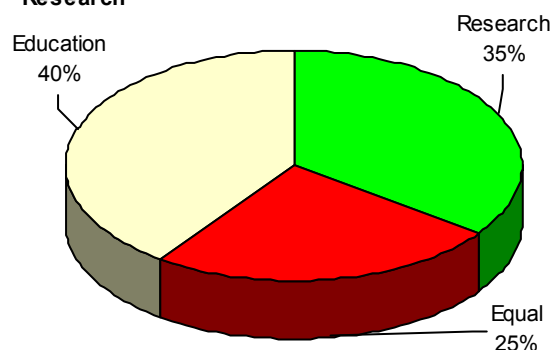
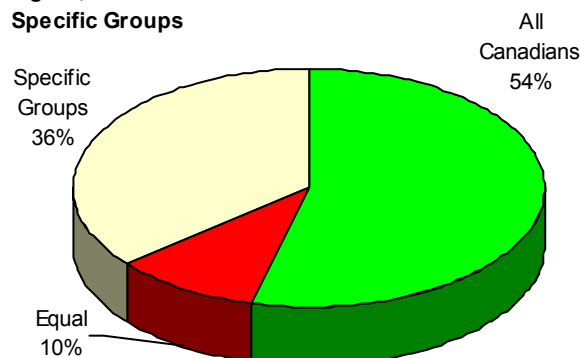


Fig. 23, Public Priorities - Education or Research



¹¹⁴ Ekos, 2003.

Fig. 24, Public Priorities - All Canadians or Specific Groups



12.2 Proposed Priorities

The *Getting Ahead* process has developed funding priorities based on an understanding of both what works and what is needed to fill gaps or respond to emerging threats as well as upon a number of principles, i.e.:

- Allocation decisions should endeavour to maximize the benefits that flow from the investment. The investment should be used in the most efficient and effective manner possible in terms of outcomes. Outcomes and impact should be measured and assessed on an on-going basis.
- The allocations should acknowledge the impact which the health determinants have on HIV vulnerability and on the ability of individuals to manage their HIV/AIDS.
- The allocation process should acknowledge the importance of the knowledge that has been acquired through the past decades, in Canada and other countries, as well as the need for continuing and sustained efforts to build capacity, prevent infection, provide care, treatment and support, and enhance community infrastructure.
- The allocation process should support at least a minimally acceptable level of activity in each area recognized as a federal government responsibility or priority. Instead of funding to a level that threatens an activity's viability, it may be advisable to withdraw funding entirely and divert it to other purposes where the enriched investment will have the greatest impact. At the same time, the federal government's smaller

allocation to some activities should not preclude other jurisdictions from treating it as a funding priority.

- Relatively small allocations to certain responsibilities and activities are not intended to convey a message that they will not be afforded a higher priority and a larger allocation sometime in the future, in accordance with the epidemic's changing character. Indeed addressing the HIV/AIDS epidemic should not be static but rather an evolving, dynamic progression in which areas of activity can move up or down the priority hierarchy depending upon circumstances.
- The allocations should be arrived at through a process that is fair, equitable and transparent. They should reflect the Government of Canada responsibilities and priorities as developed through the Five-Year Review Process and the companion CSHA Strategic Planning Process. The reasons for the allocations must be readily understood even if not entirely agreeable to all stakeholders. Transparency will also help to avoid creating expectations that cannot or will not be met.

As illustrated in the following Figures, the funding allocations being proposed represent a modest shift from what exists currently. Importantly these allocations are intended to be **preliminary only** and should be modified as the federal government's responsibilities, roles and activities are further refined through the broader CSHA strategic planning process. It may well be, for example, that the following allocations assign somewhat more dollars than are needed in a particular realm or somewhat fewer dollars than are required to achieve a particular objective. It may well be that dollars will have to be shifted, for example from "access" to "leadership" or from "capacity" to "knowledge" as specific expenditure plans are developed.

These priorities and shifts reflect a variety of considerations, including:

- the goal of "getting ahead" of the epidemic and of preparing Canada to address both HIV/AIDS and new epidemics as they arise;
- the importance of ensuring that knowledge and the best available evidence permeate every aspect of the effort to address the epidemic;
- the pent-up demand that currently exists as a result of the federal financial commitment remaining unchanged through the past decade;

-
- the importance of developing partnerships, across sectors, across orders of government, and across departments within the federal government;
 - the importance of both rebuilding capacity, given the exhaustion evident within community organizations, and building new capacity given the changes in the epidemic;
 - the cost of promoting prevention among the general population, among those already infected and among specific populations that are particularly vulnerable to HIV infection,
 - the cost of sustaining prevention efforts so as to prevent a resurgence of the epidemic as evident recently during the SARS outbreak in Toronto; and
 - the potential for significant cost savings in the health system and for leveraging greater investments, particularly through efforts to develop a vaccine and to develop research capacity.

The following also assumes that CSHA partners will develop whatever implementation or administrative structures are needed to administer the funding in a responsible, effective, efficient and accountable manner, for example through a new system for planning research and managing knowledge, or a modified Health Canada delivery system.

12.4 Realms of Responsibility Allocations

Realms of Federal Responsibility

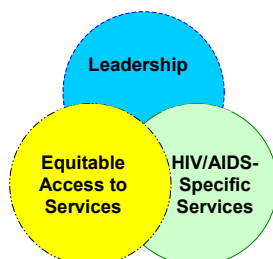


Fig. 25, Current Allocation (\$42.2M)

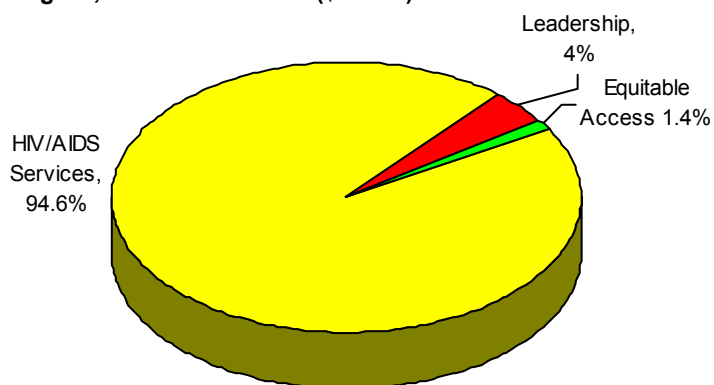


Fig. 26, \$85M Allocation Option

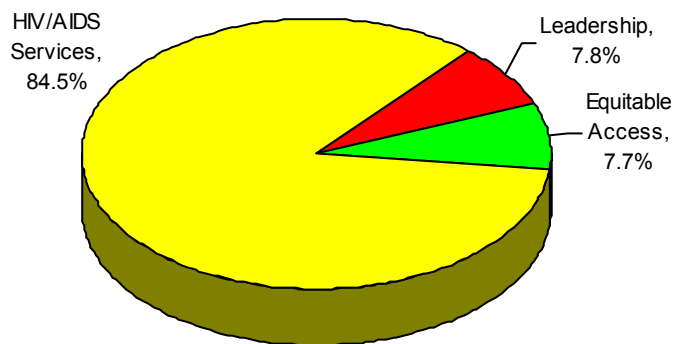
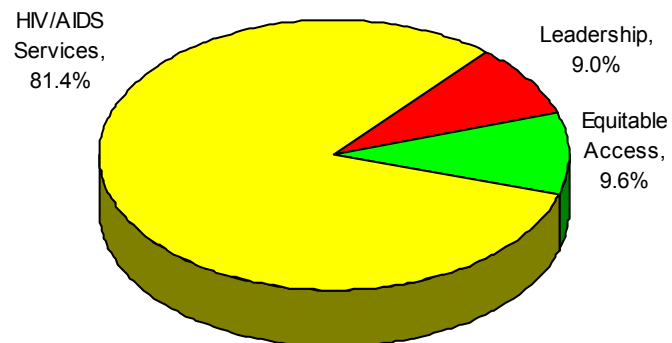


Fig. 27, \$106M Allocation Option



12.2 HIV/AIDS-Specific Supports and Services

HIV/AIDS-Specific Supports and Services

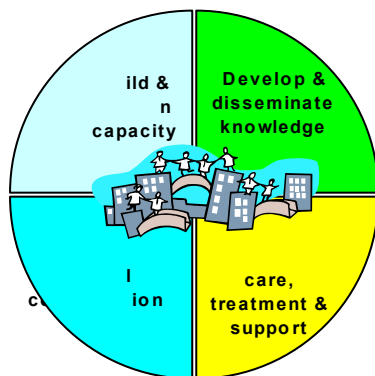


Fig. 29, \$85M Allocation by Activity Area

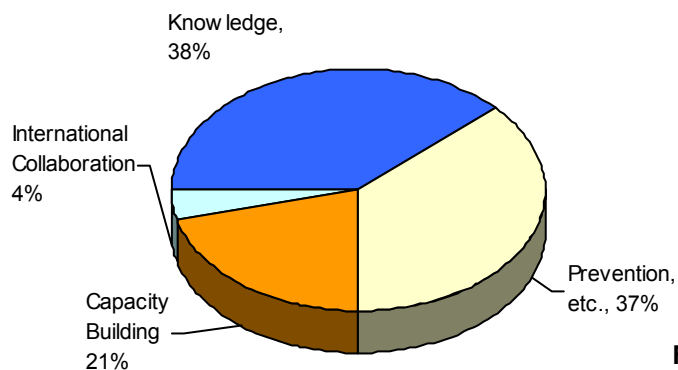


Fig. 28, Current Allocation (\$42.2M) by Activity Area

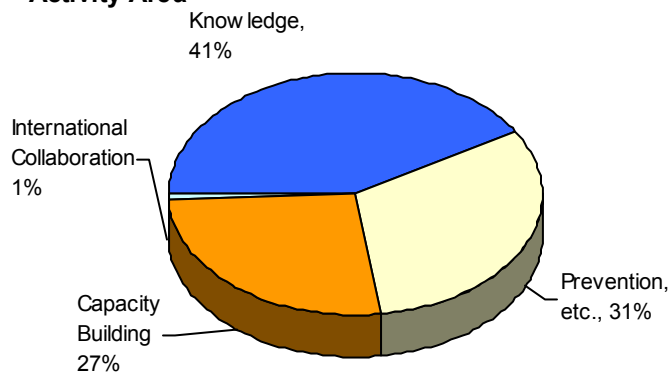
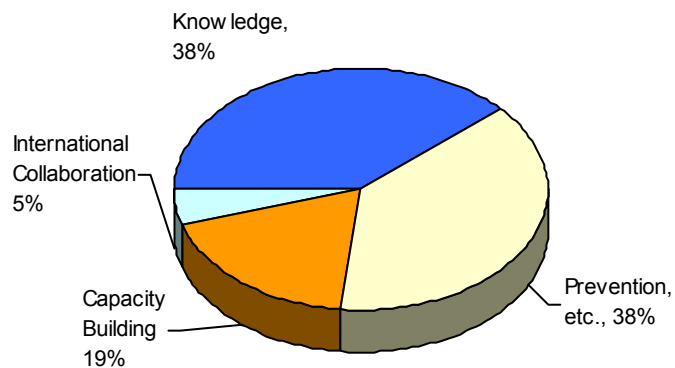


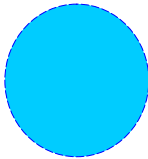
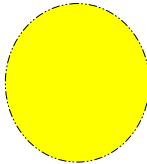
Fig. 30, \$106M Allocation by Activity Area

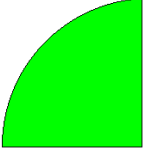


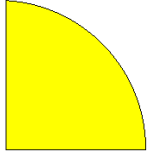
13. Overview of the Federal Role at the Different Funding Levels

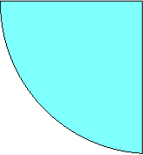
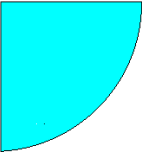
Table 6 below describes the changes that would occur in the federal role under the different funding options and allocations outlined above. Importantly, maintaining the current funding level (\$42.2M) may well involve some reductions in the different realms of responsibility and in each activity area as organizations endeavour to accommodate funding levels that have not changed in more than a decade.

Table 6, The Federal Role by Funding Level

Realm of Responsibility	Funding Options		
	Administering the Epidemic: \$42.2M	Managing the Epidemic: \$85M	Getting Ahead of the Epidemic: \$106M
Leadership 	<ul style="list-style-type: none"> maintain status quo periodic meetings or consultations with stakeholders little funding to the Ministerial Council on HIV/AIDS or other organizations to support policy and program development limited efforts to foster intergovernmental cooperation through the Federal/Provincial/Territorial Advisory Committee 	<ul style="list-style-type: none"> build intergovernmental and non-partisan support for the federal role and the CSHA. model strategic approaches demonstrate leadership on controversial issues decentralize leadership responsibilities where appropriate 	<p>In addition to the \$85 million initiatives:</p> <ul style="list-style-type: none"> use seed money to build intergovernmental and inter-sectoral partnerships and support promote an action agenda based on concept of population health and social justice undertake policy and program development addressing needs implement harm reduction pilot and demonstration projects decentralize leadership responsibilities where appropriate
Equitable Access to Services 	<ul style="list-style-type: none"> maintain status quo effective working relationship with the Correctional Service Canada little policy coherence with CIDA weak links with other departments including Indian and Northern Affairs Canada 	<ul style="list-style-type: none"> use seed money to build interdepartmental support link related strategies, for example CSHA and hepatitis-C program promote population health ensure that INAC and the First Nations and Inuit Health Branch (FNIHB) are full and active partners in the CSHA. 	<p>In addition to the \$85 million initiatives:</p> <ul style="list-style-type: none"> promote an action agenda based on concept of population health, human rights principles and a commitment to social justice develop partnership and policy coherence with CIDA and DFAIT build action partnerships with INAC and the FNIHB

Realm of Responsibility	Funding Options		
	Administering the Epidemic: \$42.2M	Managing the Epidemic: \$85M	Getting Ahead of the Epidemic: \$106M
HIV/AIDS-Specific Services			
Develop, analyze and disseminate knowledge 	<ul style="list-style-type: none"> maintain current surveillance and reporting systems, based on sometimes inconsistent provincial and territorial data continue with current research activities including some clinical trials and community-based social research abandon effort in Canada to develop vaccines or to undertake cohort studies limited efforts to engage in knowledge exchanges at the international level adjust efforts to reflect funding limits and impact of inflation and prevalence 	<ul style="list-style-type: none"> standardize data collection across jurisdictions and enhance data completeness enhance efforts to monitor risk behaviours enhance bio-medical and other research capacity and activities including cohort studies develop effective mechanisms for transferring knowledge between sectors, jurisdictions and countries promote best practices based on the Canadian and international experience promote media and public awareness of research findings and conclusions. develop rigorous, outcome-based evaluation protocols for all federally-funded pilot projects and other initiatives 	<p>In addition to the \$85 million initiatives:</p> <ul style="list-style-type: none"> build partnerships with community agencies as part of an early warning sentinel surveillance system link data relating to HIV, HCV, STIs and TB improve means for disseminating knowledge and ensuring its application at the provincial, territorial and community level more extensive vaccine research and development monitor population health developments and their links to HIV vulnerability redirect larger portion of CIHR funding to strategic research enhanced efforts to develop research capacity re HIV/AIDS and other infectious diseases

Realm of Responsibility	Funding Options		
	Administering the Epidemic: \$42.2M	Managing the Epidemic: \$85M	Getting Ahead of the Epidemic: \$106M
Prevention, care, treatment and support in areas (i) of federal jurisdiction or (ii) having national significance 	<ul style="list-style-type: none"> limited efforts among those populations for whom the federal government has a fiduciary or particular responsibility limited efforts to fill service or resource gaps in particular regions and communities limited public education adjust efforts to reflect funding limits and impact of inflation and prevalence, for example relative to grants to community-based agencies 	<ul style="list-style-type: none"> enhance initiatives to meet federal responsibilities to First Nations people and the Inuit build public support for evidence-based harm reduction initiatives expand prevention research and disseminate knowledge about innovative programming expand the prevention/care/treatment/support continuum with increased engagement of people living with HIV/AIDS. 	<p>In addition to the \$85 million initiatives:</p> <ul style="list-style-type: none"> expand harm reduction initiatives in federal correctional institutions in partnership with the provinces and territories, use "seed money" to fund prevention and harm reduction initiatives in provincial correctional institutions build knowledge management infrastructure to inform policy and program development expand prevention and harm reduction initiatives for injection drug users, women and other vulnerable populations undertake special efforts directed at those 15,000 people who are HIV-positive but not aware of their condition undertake prevention initiatives among those who are HIV-positive

Realm of Responsibility	Funding Options		
	Administering the Epidemic: \$42.2M	Managing the Epidemic: \$85M	Getting Ahead of the Epidemic: \$106M
Build and sustain capacity as part of a broad, integrated and effective response to the epidemic 	<ul style="list-style-type: none"> ▪ endeavour to sustain capacity in national HIV/AIDS-related organizations ▪ limit effort to sustain capacity in community-based organizations ▪ sustain current research capacity ▪ adjust efforts to reflect funding limits and impact of inflation and prevalence, for example relative to building new capacity 	<ul style="list-style-type: none"> ▪ build funding partnerships with the provinces and territories so as to simplify the funding process, avoid duplication and fill gaps relative to community-based agencies. ▪ enable national HIV/AIDS-related organizations to respond to the epidemic's expanding demographic scope and impact ▪ foster links between HIV/AIDS-related organizations, at the national and community level, and the federal government's Voluntary Sector Initiative 	<p>In addition to the \$85 million initiatives:</p> <ul style="list-style-type: none"> ▪ enhance capacity to respond to the epidemic within particular communities, for example among Aboriginal people, women, those from countries in which HIV is endemic, those who are HIV-positive and youth ▪ enhance Health Canada capacity to lead and coordinate national efforts ▪ enhance capacity of community organizations to monitor and evaluate their efforts and to apply new knowledge ▪ enhance capacity in the research and scientific communities
International collaboration 	<ul style="list-style-type: none"> ▪ represent Canada internationally ▪ endeavour to meet international obligations and commitments ▪ facilitate knowledge transfers ▪ adjust efforts to reflect funding limits and impact of inflation and prevalence, for example relative to building new capacity 	<ul style="list-style-type: none"> ▪ encourage partnerships between organizations in Canada and other countries. ▪ maintain the current Canadian contribution to the international effort to address the pandemic ▪ encourage knowledge transfers across countries 	<p>In addition to the \$85 million initiatives:</p> <ul style="list-style-type: none"> ▪ expand the Canadian contribution to the international effort ▪ build partnerships between Canadian and international AIDS Service organizations ▪ develop policy coherence between the CSHA and CIDA

C. Getting Ahead

14. Conclusions

HIV/AIDS may well be the most devastating infectious disease since the bubonic plague decimated Europe in the 14th century. In some countries the HIV/AIDS epidemic has turned back the development clock by several decades while in Canada it has cut a swath through vulnerable communities and has left thirteen thousand dead and very many thousands of others coping daily with its effects and impact.

The Government of Canada has responded to the epidemic in a consistent manner, endeavouring to build commitment, partnerships, knowledge, awareness and capacity. Need shaped the government's response and it addressed the epidemic by making long-term commitments and by raising for public discussion issues previously considered taboo. It enabled a host of organizations and individuals to reach out to different communities including those who are immigrants and newcomers to Canada and those who have to struggle every day to survive their addictions. It supported research of all sorts and built a base of knowledge and experience that will continue to benefit those living with HIV/AIDS both in Canada and elsewhere in the world.

These efforts have paid important dividends. The number of AIDS-related deaths has declined very considerably through the past decade and Canadians have been assured of a safe supply of blood and blood products. HIV transmission to infants has been virtually eliminated. And some of the rigid behaviours, attitudes, beliefs and prejudices that made people particularly vulnerable to HIV infection have been softened. This portends well for the future.

However Canada's success is neither adequate nor secure. HIV/AIDS remains a deadly disease for which there is no vaccine and no cure, and for which none are anticipated in the near future. The virus' ability to mutate, to re-emerge and to race ahead means there is no place for complacency. The status quo – simply maintaining the past or continuing with the present – is not an adequate response for the future.

The federal government's response to HIV/AIDS, therefore, must continue to evolve and must continue to adapt to the epidemic's harsh realities. This requires a willingness to enlarge the federal government's role. It will require continuing efforts to work cooperatively across jurisdictions and sectors.

Continued success will also require the government to expand upon and to improve what it is already doing. More and better research as well as enhanced capacity in non-governmental organizations will strengthen the Canadian effort to prevent HIV infection and to provide treatment, care and support to those living with HIV/AIDS. They will also enable the government to respond more adequately to the vulnerability of particular communities, for example Aboriginal people and those incarcerated in federal prisons.

At the same time, the government's response and role must be broadened. HIV/AIDS is not simply a health issue. Nor is it simply a Health Canada responsibility. A broad array of federal departments and agencies must become more active partners in the federal and Canadian effort to manage the epidemic. CIDA, INAC, HRDC, the CMHC, Justice Canada, Industry Canada and others can all make an important contribution. Importantly their involvement will break down barriers and enable the government to address more fully the inequities, discrimination, stigma, exclusion, violence and other social determinants that are at the root of HIV vulnerability. Herein lies the long-term solution to HIV/AIDS.

Finally and importantly, a commitment to providing strong and effective leadership must be at the very centre of the future federal role in addressing the epidemic. Its leadership responsibilities will mean confronting barriers and engaging in efforts that may put the government out in front of the Canadian public, for example in terms of its international commitments or its willingness to support important, effective and evidence-based harm reduction initiatives. It will mean efforts to inform, educate and evaluate, and to serve as a model for other institutions. It will mean efforts to forge partnerships and to ensure cooperation. It will mean political will and public willingness.

But will and willingness are not enough. These expressions must be accompanied by dollars and sufficient dollars both:

- to compensate for the static level of investment through the past decade; and
- to enable Canada to get ahead of the epidemic and stop its spread within Canada and its devastation elsewhere in the world.

This will require a significant investment.

“The fact is that we know what to do about care and we know what to do on prevention, and we know what to do on treatment, and we could turn this pandemic around in a few years if we were able to summon the energy and mobilize the resources and the response....it is partly a matter of human resources, partly a matter of infrastructure, but it is overwhelmingly a matter of financial resources.”¹¹⁵

A status quo investment of \$42.2 million will result in Canada losing the fight against HIV/AIDS and not having the capacity to address new epidemics as they arise. This level of investment will send a clear but disappointing message to those addressing HIV/AIDS in Canada and to those concerned with public health and well being. A larger investment – of \$85 million annually – will significantly strengthen the country’s response but represents only the equivalent of what was invested in 1990 adjusted for inflation and prevalence. It represents a commitment only to managing the epidemic and living with the epidemic.

A larger investment – of \$106 million – represents a clear and strong commitment to fighting HIV/AIDS and other epidemics, in Canada and around the world. This amount, allocated equitably on the basis of knowledge and need, will allow Canada to get ahead of the epidemic and, very possibly and very soon, prevent its further spread. It would enable Canada to show leadership and to reduce the stigma, discrimination and exclusion that underlies HIV vulnerability. It would support an intergovernmental and multi-sectoral approach that signals to all Canadians that preventing infectious diseases is a national priority and not a problem to be avoided.¹¹⁶

Enhancing the public investment in this way, and to this level, is an eminently practical option given the country’s fiscal situation, budget surpluses, spending in other sectors, social conscience and commitment to public health and well being. It is eminently practical given the financial costs that will be avoided in the future.

Importantly, the new Canadian funds must be invested effectively and wisely, in leadership, equitable access and HIV/AIDS-specific supports and services, and in knowledge, prevention,

¹¹⁵ Lewis, 2003.

¹¹⁶ Bollinger, 1999:10.

care, treatment and support, capacity and international collaboration. It also has to be invested in good governance and the monitoring and evaluation that are fundamental to good governance. A genuine multi-sectoral approach requires judgements to be made about the competing claims of quite different interventions. Only careful monitoring and evaluation can provide the evidence for these determinations and can ensure that future funding decisions are firmly rooted in our understanding of what works and what is needed to get ahead of the epidemic.¹¹⁷

¹¹⁷ Bloom, 2002:5.

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Martin Spigelman Research Associates Ltd. assumes full responsibility for the analysis and conclusions presented in this report. That analysis and those conclusions do not necessarily represent the views and policies of Health Canada, the Government of Canada or any organization participating in the research process.

Appendix A

Advisory Group and Other Contributors

Five-Year CSHA Review, Advisory Committee

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Appendix B

Five-Year CSHA Review Working and Discussions Papers

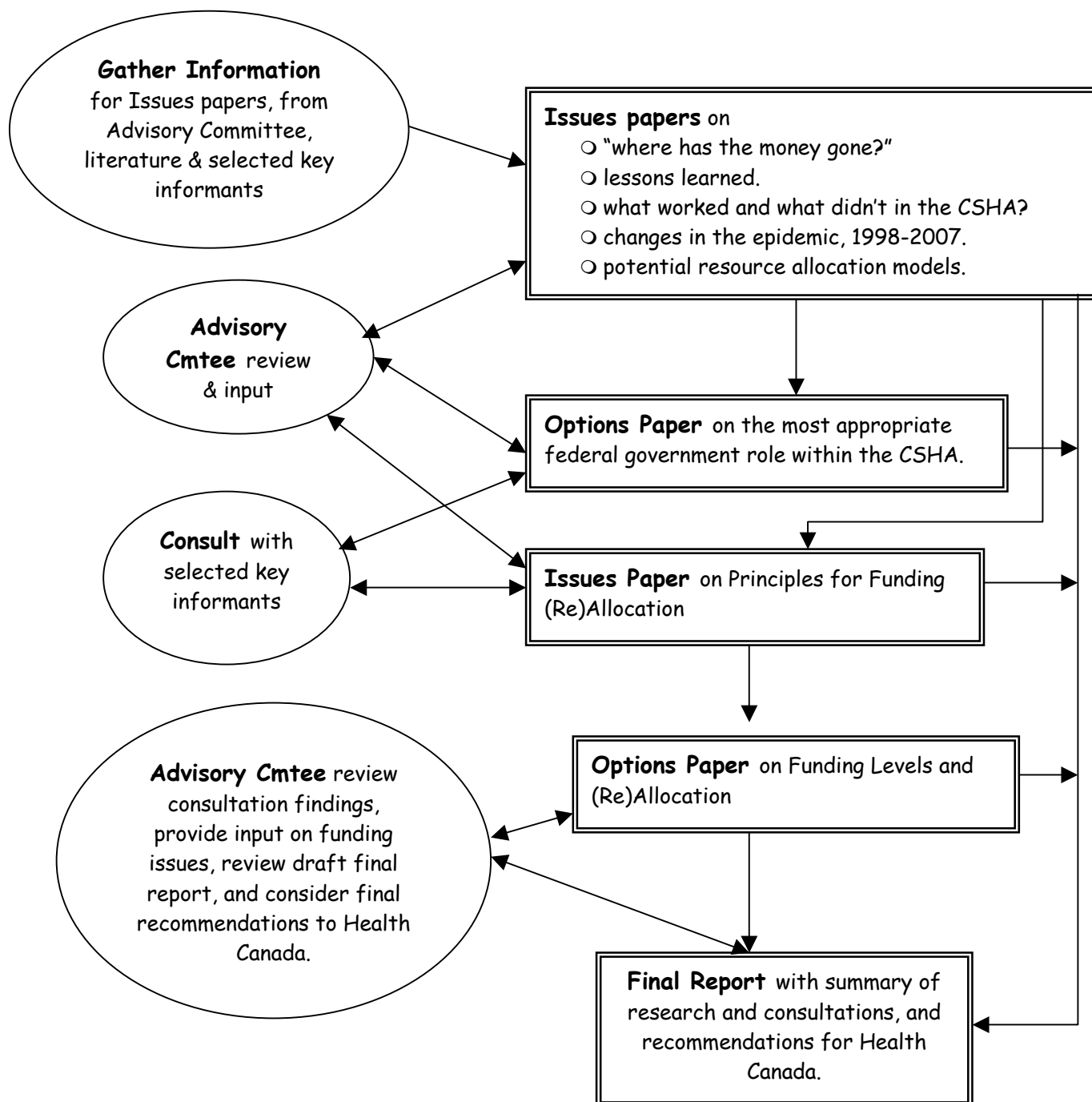
1. Government of Canada Expenditures on HIV/AIDS, 1998-2003
2. A Working Paper on Strengths and Shortcomings
3. A Working Paper on Effective Practices
4. A Working Paper on Epidemiological Data and Trends
5. A Discussion Paper on the Government of Canada Role in the CSHA
6. A Working Paper on Funding Issues

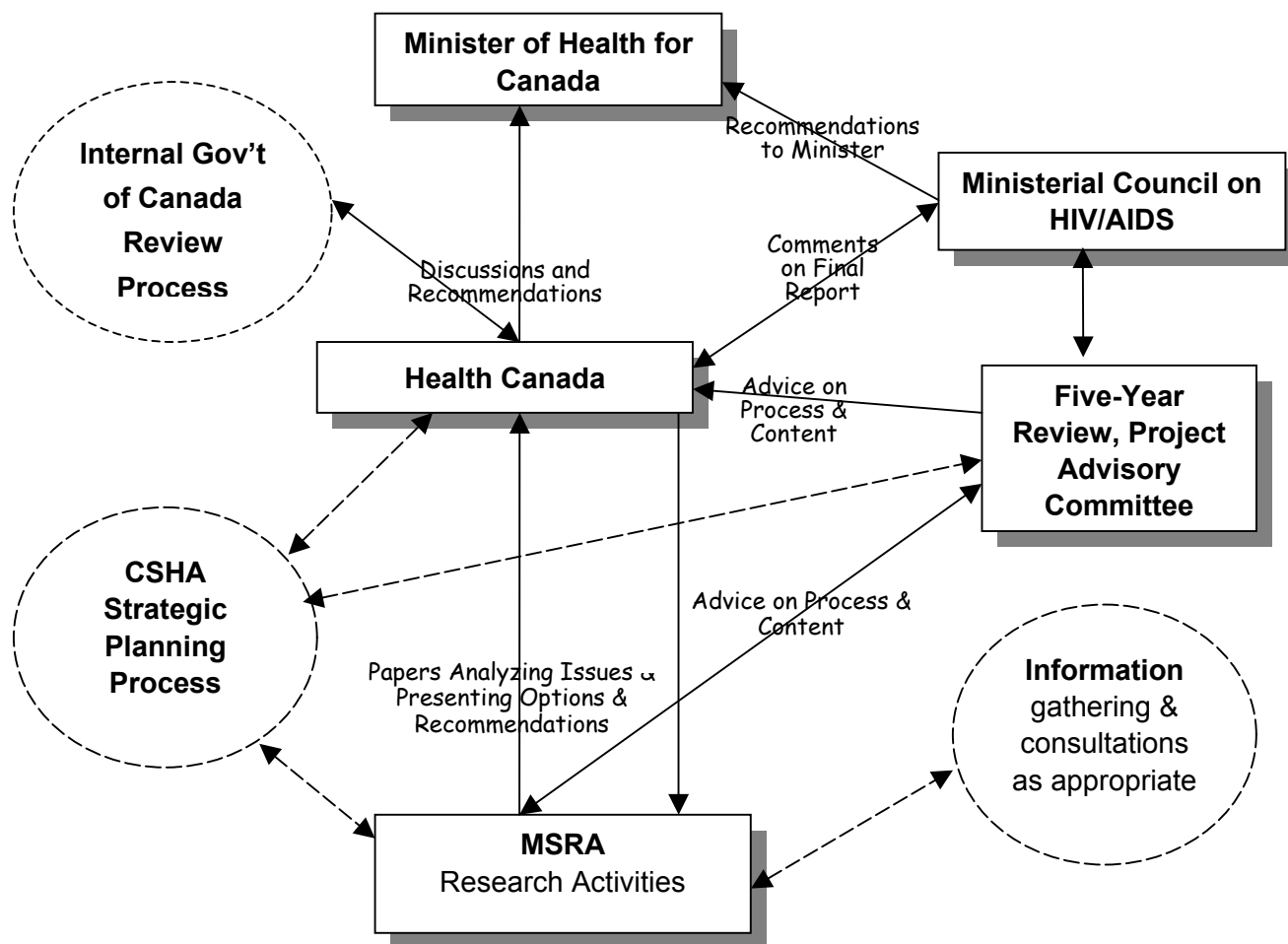
These reports are available under separate cover from Health Canada.

Appendix C

Workplan

Five-Year Review Research Process



Five Year CSHA Review – Reporting Lines

Appendix D

Canadian Strategy on HIV/AIDS Policy Directions, Goals and Priorities

Policy Directions

- enhanced sustainability and integration
- increased public accountability
- an increased focus on those most at risk

Goals

- to prevent the spread of HIV infection in Canada
- to find a cure for HIV/AIDS
- to ensure care, treatment and support for Canadians living with HIV/AIDS, their families, friends and caregivers
- to find and provide effective vaccines, drugs and therapies
- to minimize the adverse impact of HIV/AIDS on individuals and communities
- to minimize the impact of the social and economic factors that increase individual and collective risk for HIV¹¹⁸

Priorities

- Research
- Community Development & Support to National NGOs
- Care, Treatment & Support
- Surveillance
- Prevention
- Aboriginal Communities
- Consultation, Evaluation, Monitoring and Reporting
- Legal, Ethical & Human Rights
- Correctional Service Canada
- International Collaboration

¹¹⁸ Health Canada. "The Canadian Strategy on HIV/AIDS: Moving Forward Together." www.hc-sc.gc.ca/hppb/hiv_aids/.

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