Health Canada Santé Canada

RENEWING CANADA'S STRATEGY ON HIV/AIDS

SUCCESSES, BARRIERS AND LESSONS LEARNED

A SYNOPSIS, WITH PARTICIPANT VIEWS, OF A NATIONAL CONSULTATION AND PUBLIC POLICY PROCESS

Canada

A SYNOPSIS, WITH PARTICIPANT VIEWS, OF A NATIONAL CONSULTATION AND PUBLIC POLICY PROCESS

Published by authority of the
Minister of Health

This publication is available through the Internet at:
http://www.hc-sc.gc.ca/hppb/hiv_aids/

This publication can be made available in/or diskette/
large print/audio-cassette/braille upon request.

Cat. H39-448/1998E
ISBN 0-662-63790-9

Our mission is to help the people of Canada maintain and improve their health.

Health Canada

Prepared by the
HIV/AIDS Policy and Coordination Office
Strategies and Systems for Health Directorate
Health Canada

For more information on the HIV/AIDS renewal process and consultation model and/or for a copy of documents referred to by title in this paper, write to:

HIV/AIDS Policy, Coordination and Programs Division
Health Canada
Jeanne Mance Building, 18th Floor
Postal Locator: 1918B1
Tunney's Pasture
Ottawa, Ontario
Canada K1A 1B4

or fax your request to **(613) 952-3556**.

Appreciations

All players made a commitment to the process and were willing to work together toward a successful outcome of a well-informed Canadian direction for HIV/AIDS. Of significant importance was the capacity, particularly of the individuals representing the external stakeholders, to demonstrate flexibility and pragmatism on positions in light of the broader good. Through a belief in a common outcome and the capacity to influence innovative new and needed directions, the ability of Canadians to respond to HIV/AIDS has been strengthened.

"We believe a consultation does not end, but is a dialogue that continues and needs to be transparent."

Dr. Greg Robinson

EXECUTIVE SUMMARY

In the summer of 1997, the Federal Minister of Health, the Honourable Allan Rock, agreed to a national consultation process to guide the renewal of a national strategy for HIV/AIDS in Canada. This innovative process had a major challenge: to seek meaningful opinion across the country within a tight timeframe. The multi-streamed consultations were:

- broadly based;
- representative of all players in the country; and
- managed in partnership between stakeholders and government but largely steered by external stakeholders, which were primarily community groups (NGOs).

The resulting consultation process was a major breakthrough in public policy development. For the first time, stakeholder groups led a process to gather public input on a health and social issue of national and international importance. Instead of imposing policy from the top down, government acted as a facilitator and a listener. As a result, the new Canadian Strategy on HIV/AIDS is a true partnership initiative and the beginning of a new era in HIV/AIDS programming.

Following the consultations, and with a view to the future use of such an exercise, Health Canada interviewed a representative cross-section of the participants in the process. Respondents were asked for their opinions and ideas on:

- factors that influenced the success or failure of the consultation process;
- variables that influenced the process; and
- improvements needed for any similar consultation.

All of the respondents said that the successful use of large-scale, inclusive, multisectoral consultations was a major shift in defining public policy for HIV/AIDS in Canada. They credited commitment from all levels within the federal government as a key factor in that success. The consultation resulted in setting the trend for increased stakeholder involvement in decision-making and in forming the values and principles for the renewal of a national strategy for HIV/AIDS.

The respondents made several recommendations:

- any future consultations of this scale should put significantly more emphasis on organizational design and planning as well as resource allocation planning regarding consultation processes;
- all key players should be involved in planning from the outset, thereby allowing more time to be spent on the quality of the consultation rather than ongoing, energy-draining negotiations over management of the processes;
- appropriate time is needed, although some saw merit in a tight timeframe; and
- communications systems need to be in place so that each group is aware of any parallel streams of consultations.

Respondents said the consultation process resulted in many “lessons learned”, including:

- positive growth in their personal knowledge and awareness of HIV/AIDS issues;
- increased respect and appreciation for other individuals working in the field; and
- an improved understanding of the viewpoints and agendas of other organizations.

The process brought forward and increased the capacity of all players to support and develop the coordination and integration toward a change in direction. Support was unanimous for the value and usefulness of this type of consultation process that aims to represent the opinions of:

- the people affected by a public policy shift;
- those responsible for implementing the policy; and
- the major partners who will ensure that the policy direction is kept on track.

A broad-based, stakeholder-driven approach can be an effective tool in public policy development. The success of this approach depends on a number of factors, including:

- full involvement and “buy-in” by organizations and individuals affected by the policy development;
- commitment to the process by all levels of government;
- fully collaborative planning throughout the process;
- readiness and willingness of all players to change the way they do business; and
- strong communication channels and full sharing of information.

INTRODUCTION

On December 1, 1997 — World AIDS Day — the Honourable Allan Rock, federal Minister of Health, announced the renewed Canadian Strategy on HIV/AIDS. The Minister's announcement followed an intense policy development process that centred around a two-month national consultation on the future direction of HIV/AIDS programming in Canada.

The resulting consultation process was a major breakthrough in public policy development. For the first time, stakeholder groups — primarily community groups (NGOs) — led a process to gather public input on a health and social issue of national and international importance. Instead of imposing policy from the top down, government acted as a facilitator and a listener. As a result, the new Canadian Strategy on HIV/AIDS is a true partnership initiative and the beginning of a new era in HIV/AIDS programming.

The urgent need for the strategy's renewal was driven by a number of factors, including:

- 36,000 to 42,000 Canadians are believed to be living with HIV infection (including those living with AIDS);
- each new infection will cost roughly $150,000 in direct medical costs and an additional $600,000 in indirect costs; and
- more new cases of AIDS will be diagnosed in the last five years of this century than were diagnosed during the first 15 years of the HIV epidemics.

The federal consultations leading to the renewed strategy were marked by three characteristics:

- involvement by the full breadth of organizations and individuals in the field;
- a stakeholder-driven external consultation process that provided for unprecedented public involvement in policy development; and
- an extremely tight timeframe.

The first part of this report describes:

- the main players involved in the HIV/AIDS consultation process;
- the streams of consultation;
- consultation tools, mechanisms and processes; and
- the outcome.

The second part provides a qualitative assessment of the consultations based on interviews with key participants and recipients of the process.

PART I
THE CONSULTATION PROCESSES, PLAYERS AND TOOLS

EXTERNAL STAKEHOLDER CONSULTATION — ROLES AND RESPONSIBILITIES OF THE MAIN PLAYERS

This section of the report briefly identifies the five main players in the HIV/AIDS strategy renewal process and explains their roles and responsibilities.

1. National HIV/AIDS Stakeholder Group

A National HIV/AIDS Stakeholder Group was established to lead the main public consultation process. The Group comprised 11 HIV/AIDS-focused NGOs (see Appendix for list of organizations) and advised and recommended on the following:

- goals, objectives and guiding principles for the new strategy, as well as strategic areas of work;
- the allocation of HIV/AIDS funding, management and accountability issues; and
- monitoring and evaluating the renewed strategy.

2. Stakeholder Group Steering Committee

The National HIV/AIDS Stakeholder Group established a five-person Steering Committee to act on its behalf in making day-to-day decisions and addressing rapidly emerging issues throughout the public consultation process. Although the Steering Committee played a critical role, the larger Stakeholder Group collectively addressed all major issues.

3. Special Advisor on the renewal of a national AIDS strategy

A Special Advisor, with the necessary negotiating and management skills, was appointed to coordinate the consultations and bring the various processes to a successful conclusion. The Special Advisor acted as an independent, third-party "broker" between the National HIV/AIDS Stakeholder Group, the Minister of Health, and various branches within Health Canada.

Given the extremely limited timeframe for completing the consultations, the Special Advisor was given significant latitude, flexibility and authority to make decisions, allocate resources (within a set consultation budget), and mobilize staff for the project. The Special Advisor had direct access to the Minister's Office, as well as the support of senior departmental management.

4. HIV/AIDS Consultation Secretariat

The Special Advisor established an HIV/AIDS Consultation Secretariat. Staffed by Health Canada employees and one community consultant, the Secretariat:

- worked closely with and supported the efforts of the Stakeholder Group;
- supported the work of the Special Advisor;
- contributed skills and advice to the development of the consultation process and its tools; and
- played an important logistical role in organizing consultation meetings, making necessary travel arrangements, managing the production and distribution of publications and the development of a Web page, receiving and transcribing input, etc. A toll-free line facilitated contact/dialogue with the Consultation Secretariat for groups and individuals across Canada.

5. Centre for Health Promotion

The Centre for Health Promotion at the University of Toronto was contracted to manage the public consultations on behalf of the National HIV/AIDS Stakeholder Group. Both the Stakeholder Group and Health Canada selected the Centre for its skills and experience in this area. Working with the Stakeholder Group and the Consultation Secretariat, the Centre:

- designed the consultation tools and mechanisms;
- facilitated and reported on consultation meetings;
- analyzed and summarized the information that came from the public consultation; and
- prepared a final report for the Stakeholder Group.

EXTERNAL STAKEHOLDER CONSULTATION — THE PROCESS

The main public consultation process — which became known as the External Stakeholder Consultation — was a stakeholder-driven effort to gather the opinions and views of Canadians who are either directly involved in helping to reduce the incidence of HIV/AIDS in Canada or are personally affected by HIV. This process was a direct result of the advocacy efforts of key stakeholders to secure a prominent role in the renewal of the HIV/AIDS strategy. Previous consultations for Phases I and II of the National AIDS Strategy did not include extensive stakeholder input or a public outreach process.

Consultation Tools and Mechanisms

To solicit and encourage input from as wide a spectrum of organizations and individuals as possible, the National HIV/AIDS Stakeholder Group used the following tools and mechanisms.

The Consultation Package
To provide a framework for the consultations, a consultation package was developed and distributed across Canada to organizations and individuals identified by stakeholders as

potential participants in the renewal process. The package also was made available on request to any other organizations/individuals who wanted to provide input to the new strategy.

The package contained the following components:

- a 70-page **Consultation Workbook** entitled *Tell Us Your Views.* Available in a print version and on the Internet, the Workbook was designed to help groups and individuals in making their opinions known on a wide range of issues. Respondents were also encouraged to provide input on issues not addressed in the Workbook.
- a **Consultation Meeting Guide** which helped groups in planning and holding local meetings, and provided guidance on how to encourage multisectoral dialogue.
- a **Health Canada discussion paper,** entitled *Towards a Canadian Strategy on HIV/AIDS*, which provided background information on the multiple HIV epidemics in Canada, outlined the current federal response, and highlighted key issues and challenges for future HIV/AIDS programming.

Consultation Meetings
To achieve the dual goal of a multisectoral dialogue on renewal of HIV/AIDS programming and the participation of "hard-to-reach" communities and vulnerable populations, major one-day consultation meetings were held in five Canadian cities. Members of the National HIV/AIDS Stakeholder Group helped identify potential participants. The Centre for Health Promotion developed the agenda for each meeting and acted as dialogue facilitator.

In addition to these city meetings, five focus groups were held in four cities to encourage the involvement of vulnerable population groups that would be unlikely to participate in large public gatherings. The specific population groups included injection drug users, gay youth, HIV-positive women, AIDS-affected children and families, and various multicultural groups. The Consultation Secretariat and, in some cases, regional offices of Health Canada, provided logistical arrangements for both the city-based meetings and the focus group sessions.

The Centre for Health Promotion monitored the proceedings and prepared summary reports for each of the large-city meetings and focus group sessions (the latter reports were treated as confidential). As well, more than 20 community organizations conducted their own constituency-based consultations and submitted a brief or discussion paper to the Consultation Secretariat.

Targeted Outreach Efforts
At the beginning of the public consultation process, the Consultation Secretariat staff started an aggressive outreach initiative to reach "unheard" populations, including:

- AIDS-affected children and families;
- HIV-positive women;
- the homeless;
- youth (particularly gay youth);
- ethnocultural and multicultural communities;

- the mental health communities;
- people with disabilities;
- the Deaf and hearing-impaired communities;
- spiritual and religious groups;
- prison populations;
- injection drug users; and
- sex trade workers.

The Web Site
The Centre for Health Promotion also established a Web site to outline the consultation process, distribute information electronically, and receive input.

The Information Management and Analysis Framework

The Centre for Health Promotion, with input from the National HIV/AIDS Stakeholder Group, developed an Information Management and Analysis Framework. Based on this framework, the Centre developed an Information Management and Analysis Protocol that described in detail how the consultation data would be analyzed and presented in summary form to the Stakeholder Group. Since a computer-assisted analysis was not possible within the established time constraints, the Protocol set out "a practical and targeted analysis" process that was approved by the Stakeholder Group.

The Public Response

Respondents were not restricted to the consultation tools or mechanisms outlined above, although they were encouraged to use the Workbook as a basis for discussions and input. Some organizations chose to submit written position papers (briefs) as their input, while others wrote directly to the Minister.

By the October 17 deadline, the Consultation Secretariat received 57 briefs (representing approximately 10,000 people) and 217 completed Workbooks (representing about 2,500 people).

After transcribing all input based on the approved Information Management and Analysis Protocol, the Consultation Secretariat then turned over all the information to the Centre for Health Promotion, which produced a 50-page summary report *(National AIDS Strategy: Phase III Consultation. A Summary Report and Results*) around three basic questions:

- What should the renewed strategy continue to do?
- What should the renewed strategy do differently?
- What needs to happen in the renewed strategy to ensure that it is effective?

Recommendations to the Minister

The summary report prepared by the Centre for Health Promotion was used by the National HIV/AIDS Stakeholder Group to produce recommendations to the Minister on:

- the goals, objectives, themes and guiding principles of the renewed strategy;
- priorities and the policy focus; and
- management of the new National AIDS Strategy.

On October 31, the Stakeholder Group presented the Minister with *Recommendations For Phase III of the National AIDS Strategy*, which set out more than 70 detailed recommendations.

PARALLEL CONSULTATION PROCESSES

In addition to the External Stakeholder Consultation, seven other parallel consultation processes were undertaken to ensure input was sought and received from the entire HIV/AIDS community.

1. Aboriginal Peoples

A parallel consultation process was undertaken with Aboriginal peoples, who face unique challenges and issues related to HIV/AIDS. The Canadian Aboriginal AIDS Network (CAAN) led this process and was supported by a separate Workbook that contained questions directed especially to Aboriginal peoples. CAAN hired consultants to manage the process, and the Consultation Secretariat provided logistical support when requested. The National HIV/AIDS Stakeholder Group endorsed and supported this Aboriginal consultation, the results of which were integrated into the Group's recommendations to the Minister of Health.

2. Provincial/Territorial Consultations

Health Canada officials held a series of (primarily bilateral) meetings with provincial/territorial health department officials. The agenda was often structured around Health Canada's discussion paper. Among other issues, the meetings with provincial/territorial officials focused on identifying possible goals and objectives for HIV/AIDS programming, strategic areas of effort, roles, monitoring, evaluation and accountability. This stream of consultations informed and influenced Health Canada's internal recommendations to the Minister.

3. Research Consultations

An ad hoc group — led by Health Canada's National Health Research and Development Program, the Canadian Association for HIV Research, and the National Planning Forum for HIV/AIDS Research — developed a report which was distributed to the research community and others for comment. Entitled *AIDS Research in Canada: Recommendations for Research Funding*, the report summarized the work and recommendations of several previous efforts to establish a national framework for HIV/AIDS research in Canada. Feedback received by the ad hoc group was sent to the National HIV/AIDS Stakeholder Group, which integrated the information into its research recommendations to the Minister.

4. AIDS Community Action Program Consultations

The AIDS Community Action Program (ACAP) of Health Canada held consultations to discuss proposed federal funding guidelines to support HIV/AIDS-related projects at the community level. The ACAP consultations were held after the External Stakeholder Consultation, thereby allowing all ACAP partners to participate fully in the External Stakeholder Consultation. Discussions focused on such issues as models for delivery of community support, funding eligibility, and an appropriate balance between operational funding and project funding. These consultations involved grassroots organizations in communities across Canada, and also informed Health Canada's internal recommendations to the Minister, contained in *The AIDS Community Action Program Consultation Final Report*.

5. Private Sector Workshop

Fifteen corporate representatives participated in an HIV/AIDS workshop which was designed to engage HIV/AIDS "champions" from Canadian companies in an informal dialogue resulting in statements confirming the business community's commitment to HIV/AIDS programming. Following the workshop, Health Canada produced a report entitled *HIV/AIDS and Canada's Private Sector... the next five years*.

6. The Federal Government's Internal Process

Health Canada led an interdepartmental consultation involving more than 15 federal departments and agencies that were contributing or could potentially contribute to the federal response to HIV/AIDS. More than half of the participating departments identified strategic areas where they support HIV/AIDS-related programming or activities. In addition, they recognized the need to provide an ongoing forum for interdepartmental consultation and discussion to integrate and harmonize HIV/AIDS policy and program efforts among departments.

To develop the department's own input to the renewal process, Health Canada also formed a group, chaired by the Special Advisor on HIV/AIDS, which drew on individuals with knowledge of health promotion, protection, policy and research as well as Aboriginal AIDS programs. Strongly influenced by the work being done in parallel consultation processes, the group focused on:

- lessons learned from Phase II of the National AIDS Strategy;
- possible goals and objectives for the renewed strategy;
- possible roles and responsibilities; and
- governance and accountability issues.

7. Professional Associations

The work of Health Canada's internal group was influenced by *National Professional Organizations and HIV/AIDS in Canada: A Discussion Paper*, produced by 13 professional groups representing pharmacy, occupational therapy, social work, nursing, community care, dentistry, dietetics, medicine, psychiatry, physiotherapy and psychology.

PART II
ASSESSMENT OF THE CONSULTATIONS

OUTCOME OF THE CONSULTATIONS — THE CANADIAN STRATEGY ON HIV/AIDS

The consultation process had a clear objective: to shift the emphasis away from developing "Phase III" of a federally controlled strategy and toward a strategy that is owned by all governments and stakeholders and that encourages the involvement of a broad spectrum of players across the country. All of the consultation streams discussed earlier in this report fed into the development of the goals, priorities and budget allocations for the new strategy. Epidemiological trends and current scientific evidence, from the final evaluation of Phase II of the National AIDS Strategy, were also taken into account.

On December 1, 1997 — World AIDS Day — the Minister announced the Canadian Strategy on HIV/AIDS, with funding of $42.2 million annually. The new pan-Canadian approach is designed to address the expanding face of HIV/AIDS epidemics, based on the results of the extensive consultation process. It includes more emphasis on programs for at-risk populations such as Aboriginal peoples, women, injection drug users and marginalized youth, including young men who have sex with men. Other features include open and public accountability as well as the establishment of mechanisms to enhance relationships with all new and existing partners in the fight against this disease.

Strategic elements identified during the consultation process and reflected in the strategy are the need to:

- provide education and prevention;
- support community action;
- ensure the availability of care, treatment and support;
- support HIV/AIDS research;
- build and enhance HIV/AIDS surveillance;
- provide an enhanced focus on Aboriginal communities; and
- address the legal, ethical and human rights issues related to HIV/AIDS.

To ensure an ongoing relationship with stakeholders, the Minister of Health also agreed to appoint a Ministerial Council on HIV/AIDS. The Council members are a representative group which includes scientists, health care workers, people infected and affected by HIV/AIDS, and major stakeholders. The provincial Co-Chair of the Federal/Provincial/Territorial Advisory Committee, who holds an ex-officio position on the Ministerial Council, provides a strong linkage to provincial and territorial HIV/AIDS work. The Council will advise the Minister in a number of crucial areas, including:

- keeping the Canadian Strategy on HIV/AIDS flexible and responsive to the changing nature of the epidemic;

- promoting alliances and joint efforts;
- reaching and responding to the needs of groups at risk; and
- assisting in the development of long-term plans for future action on HIV/AIDS.

The Minister will meet with the Council at least once a year to review its recommendations, and will report annually on the progress of the Canadian Strategy on HIV/AIDS.

OPINIONS ON SUCCESSES, BARRIERS AND LESSONS LEARNED

The remainder of this report attempts to synthesize the viewpoints expressed during interviews with nine individuals who were either directly involved in creating, managing and delivering the consultation process or were persons living with HIV/AIDS (participants) of the consultations. All respondents were asked the same basic questions, which focused around the following themes.

> "I think it was a qualified success. It was certainly the best we could do in the circumstances, and it was an improvement on previous processes. On the positive side, the collaboration was very successful. I felt our positions were respected, our advice was sought and acted on."
>
> *Russell Armstrong, Executive Director, Canadian AIDS Society and Co-Chair of the National HIV/AIDS Stakeholder Group*

Was the renewal process a success?

> "One of the things that I thought was a success was that people who needed to be involved felt they were — both internally and externally. Groups outside government made it clear that they had to be involved; they were instrumental in making it happen. Government at the highest levels listened."
>
> *Elaine Scott, Special Advisor on the renewal of the Canadian Strategy on HIV/AIDS*

To varying degrees and with some qualifications, all respondents agreed that the national consultations were a success. Although some respondents were enthusiastic in their statements of endorsement (notably those who reflected a government viewpoint), others acknowledged success more grudgingly. Success was measured primarily in the fact that stakeholders were involved in the policy development process in a meaningful and unprecedented way.

What were some of the key positive outcomes?

The consultation process resulted in the following key positive outcomes:

- **The announcement of a new pan-Canadian HIV/AIDS strategy**. The new strategy will be based on the strategic elements identified by stakeholders and others.
- **A new level of mutual respect and understanding among stakeholder groups and between these groups and Health Canada.** The intense, collaborative process resulted in organizations that had previously been at loggerheads gaining a new awareness and appreciation of each others' viewpoints, how they work, and

> "Given the way the process unfolded and everyone worked together, it might create a better climate for implementation of the new strategy."
>
> *Darryl Sturtevant, Manager of the research component of the consultation process*

the different pressures and demands placed on community and government workers. This new level of respect and understanding bodes well for the future work of the pan-Canadian approach to HIV/AIDS programming.

- **The realization that "the scene has changed" for HIV/AIDS programming and organizations over the past five years.** Given the ever-changing nature of the epidemics, established HIV/AIDS groups will be required to "share their power" with new organizations that may have a strategic role to play in reaching at-risk population groups.
- **A recognition of the need to more directly involve mainstream health and social service organizations in the Canadian response to HIV/AIDS.**

What factors influenced success?

Most respondents said the success of the consultation process was a direct result of:

- **advocacy on the part of the HIV/AIDS community.** Many respondents cited the community groups' belief in their right to be involved in designing the strategy as well as the capacity of key organizations to continue to advocate as members of the National HIV/AIDS Stakeholder Group.
- **political commitment at the highest levels of government.** The personal commitment of the Minister of Health and his political staff, strengthened by stakeholder advocacy, ensured that the consultation process was broad, inclusive and stakeholder- driven. This commitment filtered down through Health Canada and was sup- ported, in both words and action, by the department's senior management team.

> "Without the (political) commitment at a higher level, we would not have had this success."
>
> *Russell Armstrong, Executive Director, Canadian AIDS Society, and Co-Chair of the National HIV/AIDS Stakeholder Group*

- **a shift in thinking and approach within the Health Canada bureaucracy.** Most stakeholders acknowledged a "real effort" within government to work cooperatively, listen to others and make changes where necessary. Those within government also noted that "the system allowed us to do what we needed to do." With the support of senior management, bureaucratic barriers were removed. Emerging issues were addressed quickly and effectively with the aid of a direct line of communication established between the Minister's Office and the Special Advisor.

> "There was cultural change within Health Canada. There were people who could influence the process internally who understood the issues and the problems."
>
> *Greg Robinson, Co-Chair, AIDS ACTION NOW!*

- **the ability of stakeholders to put aside their differences and work toward a common goal.** Although the 11 member organizations of the National HIV/AIDS Stakeholder Group all work in the HIV/AIDS area, they do not necessarily share similar viewpoints or agendas. The organizations' ability to avoid dissension, while managing to forcefully represent the interests of their constituents, was crucial in keeping the process focused and on-time.

> "Our ability to compromise contributed to the success. We knew we had to make compromises — and we made them."
>
> *Russell Armstrong, Executive Director, Canadian AIDS Society, and Co-Chair of the National HIV/AIDS Stakeholder Group*

- **the openness and transparency of the process.** Open lines of communication between the Stakeholders Group, the Special Advisor, the Consultation Secretariat and the Centre for Health Promotion promoted a sense of inclusiveness. Hiring a respected, broadly skilled person from the HIV/AIDS community to work within the Consultation Secretariat was also applauded as a demonstration of an open process and as a way to build bridges between Health Canada and the community.

> "None of the stakeholders and no one from government or the consultants tried to take control of the process. Everyone understood their role and worked together."
>
> *Kevin Barlow, National Coordinator, Canadian Aboriginal AIDS Network*

- **strong, cooperative and shared leadership.** Respondents praised the cooperative relationship among the leaders, particularly between the Special Advisor and the community leaders from the Stakeholders Group. Both community leaders and government employees put the national interests of the process ahead of their respective organizational/ departmental interests, demonstrating objective leadership and diplomacy skills.
- **flexibility on the part of all players.** The clear framework of roles and responsibilities was able to evolve as the process unfolded. When confusion arose, the different players consulted each other to determine who could best fulfill the role in question and get the job done quickly and effectively. As well, the process was sufficiently flexible to allow Health Canada and the Centre for Health Promotion to shift resources in response to new (and often unforeseen) requests and directions from the Stakeholder Group. The negotiation of a separate Aboriginal process was an example of this flexibility.
- **the limited timeframe allowed for the consultations.** Despite considerable criticism of the limited timeframe (see next section), some respondents saw it as a factor contributing to success. The firm deadline established by the Minister required participants to focus their energy on getting the job done. Several respondents believed that an extended process might have lost direction and intensity.

Were there any barriers to success?

Respondents said that the success of the consultation process was marked by a number of barriers:

- **the severe time constraints**. Many argued that a two-month window of opportunity to organize and conduct consultations, analyse data and develop meaningful recommendations was unrealistic, jeopardized the quality and integrity of the process, and placed undue stress on the individuals involved. Some stakeholders stated forcefully that the time constraints were an impediment to widespread and meaningful participation by community-level organizations and by at-risk and hard-to-reach population groups. However, the general consensus was that the best work possible had been done within the allotted time.

> "Elements of the process should be retained. But there were far too many constraints."
>
> *Russell Armstrong, Executive Director, Canadian AIDS Society, and Co-Chair of the National HIV/AIDS Stakeholder Group*

- **a perceived lack of inclusiveness**. Some community organizations in provinces or regions that did not host one of the city-based meetings felt disconnected from the process. There was also some concern that, in an effort to be all-encompassing, the

consultations lost sight of the fact that gay men continue to be the primary group affected by HIV/AIDS. Respondents identified homophobia as an ongoing contributing factor to the exclusion of gay men in addressing HIV/AIDS issues. They also expressed concern that HIV/AIDS issues in rural and remote areas were not given sufficient consideration.

- **gaps in the flow of information**. Some groups at the regional level expressed frustration at not receiving sufficient and timely information on the consultations. Representatives from the Stakeholder Group remarked that they were often unaware of what was happening in the parallel consultation processes, or how these processes would contribute to the development of the strategy. Many participants, including individuals within the HIV/AIDS Consultation Secretariat, were not aware that Health Canada had made a strategic decision to not encumber the External Stakeholder Process with issues related to parallel processes.
- **the lack of preliminary planning**. In the words of one individual, "The piece that was missing was an overall strategy for conducting the consultations."

Individual respondents noted **other barriers**:

- the assumption that participants in the consultations would have knowledge of the work completed under Phases I and II;
- the assumption that the communities consulted would have knowledge about the complex issues being addressed in the Consultation Workbook;
- the lack of planning and marketing to address a distressing level of apathy in the HIV/AIDS community, attributed in part to the effectiveness of new treatment therapies;
- problems in producing and distributing French-language materials in a timely fashion;
- the failure of certain Aboriginal groups to participate in the Aboriginal consultation process, which may have reflected discomfort in dealing with HIV/AIDS issues; and
- the inability of Health Canada to overcome internal "turfism" and research politics to achieve an integrated, coordinated research component for the new strategy.

What were the key decision-making points?

Respondents identified the following as the consultation's key decision-making points that made the consultation process a success:

- holding a national, stakeholder-driven consultation process, within an extremely tight timeframe, that had sufficient funding and other resources;
- involving the National HIV/AIDS Stakeholder Group in leading the External Stakeholder Consultation, which resulted in a more comprehensive and authentic process;

> "I think we did a damned good job as Health Canada employees to get the job done in the time frame. We went out to stakeholders and asked them how they wanted to see the next phase. This was more comprehensive than in the past."
>
> *Robert Shearer, Acting Director, HIV/AIDS Division, Health Canada and Co-Chair of the National HIV/AIDS Stakeholder Group*

- appointing a co-chair from the Stakeholder Group, which empowered one individual to negotiate and act as a facilitator on the Group's behalf;
- establishing a Steering Committee of the National HIV/AIDS Stakeholder Group, thereby ensuring that administrative and process decisions could be made quickly by a representative group of stakeholders who had the support of their colleagues from the wider community;

> "Hearing from the grassroots level has told us we need to listen to other voices and opinions. Not that much good has come from the AIDS epidemic, but it has taught us the values of other ways of doing business."
>
> *Dr. Bryce Larke, Co-Chair of the Federal/Provincial/Territorial Advisory Committee on HIV/AIDS*

- consulting the provinces and territories (which was not done during development of Phases I and II of the National AIDS Strategy);
- appointing a Special Advisor who came from outside the HIV/AIDS field and didn't have a vested interest in the outcome, and giving her *carte blanche* to manage all the processes;
- establishing the HIV/AIDS Consultation Secretariat as a group within Health Canada dedicated to making the consultations a success;
- contracting with the Centre for Health Promotion — a third party organization with the required expertise and knowledge — to manage the External Stakeholder Consultation;
- having a separate consultation process for Aboriginal peoples, which enabled Aboriginal peoples to have a strong influence on the final recommendations to the Minister;

> "I believe that allowing access for Aboriginal people to provide input to this process was a key success. Definitely the receptivity of the bureaucracy and the government to make this not just a massive paper exercise was important."
>
> *Kevin Barlow, National Coordinator, Canadian Aboriginal AIDS Network*

- holding meetings in large cities as a means of encouraging a multisectoral dialogue while also seeking the involvement of hard-to-reach and often unheard population groups;
- conducting an assertive outreach program to reach unheard voices; and
- remaining firm on the deadline for an announcement on December 1, 1997, which kept the process on track and required organizations to put aside their individual agendas in the interests of a broad national strategy.

In addition to the above points, respondents frequently referred to the personal decisions made by those involved in managing the process, as well as those being consulted, to remain involved in the face of extraordinary work demands and pressures. This was true for both government and non-government participants. The consultation process was tremendously stressful, and often strained longstanding working relationships within organizations and between organizations. Virtually all participants made personal and professional sacrifices to ensure the success of the overall process. Many organizations were forced to set aside their own agendas and priorities for the sake of collaboration with the wider stakeholder community. Participants made difficult compromises to maintain an environment of collaboration and progress toward a common goal.

Was the management process inclusive and effective?

The management process and framework for the consultations generally received high marks from all respondents, who:

- said the breakdown of roles and responsibilities was balanced and effective;
- endorsed the range of stakeholder representation on the National HIV/AIDS Stakeholder Group; and
- believed that everyone involved in the management process had a valid role.

> "The process was comprehensive and inclusive — the stakeholders owned the process. The provinces and territories defined how they wanted to be consulted, and we did what they asked."
>
> *Isabel Romero, Coordinator, HIV/AIDS Consultation Secretariat*

Respondents viewed the involvement of the Centre for Health Promotion — an objective third party which managed the consultations — as a unique and effective approach. However, they stressed that finding consultants with the right mix of knowledge, experience and expertise as facilitators was critical to the success of this approach.

Were the consultations themselves inclusive?

Most respondents believed that the consultations were as inclusive as possible within the limited consultation period. At the same time, several respondents stressed that a lengthier consultation would have resulted in even broader participation, particularly from community groups and hard-to-reach populations.

> "The main success in my mind was that the process actually reflected public participation in policy development."
>
> *Darryl Sturtevant, Manager of the research component of the consultation process*

The respondents identified a number of critical population groups that may not have been adequately heard during the consultations, including:

- inmates in a correctional environment (federal and provincial/territorial institutions);
- injection drug users;
- young gay men;
- HIV-positive individuals and families; and
- HIV/AIDS researchers.

> "Inclusiveness was one of the compromises. We did well within the time frame and funding constraints, but I don't think we achieved what we wanted to."
>
> *Russell Armstrong, Executive Director, Canadian AIDS Society, and Co-Chair of the National HIV/AIDS Stakeholder Group*

At the same time, it was recognized that the large-city meetings and smaller focus groups allowed the participation of populations that had not previously been considered part of the HIV/AIDS community, such as housing groups, minority women's groups, and prisoners. In this sense, the consultation process reached beyond the traditional boundaries of the HIV/AIDS world.

Is this consultation process transferable?

All respondents agreed that the consultation process used to support renewal of a national AIDS strategy could be transferred to other health issues and other areas of public policy development. However, several respondents qualified their comments by stipulating that improvements and modifications would have to be made to the process, primarily to address the need for more preliminary planning and more time for the consultations themselves.

Other specific transferable aspects of the process included:

- the concept of a stakeholder group and steering committee to lead external consultations;
- the appointment of a special advisor and establishment of a secretariat whose collective role is "to make things happen;"
- a consultation workbook (though in a shorter and simplified form);
- the multisectoral city meetings and focus group sessions; and
- the hiring of experienced and knowledgeable consultants to manage the external process.

Some respondents noted that this model is transferable "if the systems and infrastructure are there" in the form of a broad and diverse range of national stakeholder groups, a committed unit within government, informed provincial/territorial players, and effective leaders. Perhaps most importantly, support must exist for the process at the highest political levels, as well as among senior department managers.

Lessons learned

When asked about "lessons learned" through the consultation process, the most common response — from both government and non-government participants alike — was that they had:

- experienced positive growth in their personal knowledge and awareness of HIV/AIDS issues — even though most had been involved in the field for many years;
- increased their respect and appreciation for other individuals working in the field; and
- improved their understanding of the viewpoints and agendas of other organizations.

As for the process itself, the following were identified as lessons learned:

- Stakeholders need to be consistent and persistent in their advocacy roles.
- Stakeholders must be made partners with government in a fundamental way to ensure the success of such a national consultation process.
- Preliminary planning is needed to develop the process, define roles and responsibilities, and establish an initial level of trust and partnership.

> "I think it was a success just having the consultation. The fact that we could bring people together to discuss issues that were important to us in the AIDS community was very empowering for the community and very beneficial to the government."
>
> *Wilson Hodder,*
> *Chair of The AIDS Coalition of Nova Scotia*

- If parallel consultation processes are to take place exclusive of each other, management decisions must be made — and communicated to all participants — at the outset on the parameters for the different processes, the relationship between processes, and how the processes will come together at the end of the consultation period.
- Significant effort is often required to convince people of the importance and benefits of participating in the process.
- Public servants involved in the process need the confidence of senior management in order to make decisions "on the run." This requires a "release" from bureaucratic attachments.

> "We made decisions on what was practical based on our understanding of what needed to be done. We were very pragmatic as to what could be done in the time frame."
>
> *Robert Shearer, Acting Director, HIV/AIDS Division, Health Canada and Co-Chair of the National HIV/AIDS Stakeholder Group*

- Central agencies (e.g., Treasury Board) need to be kept informed of what is happening (and why) to facilitate both governmental and financial approvals.
- A dedicated group within the department is needed to coordinate the internal input and feed information to the branches. This is key to limiting interbranch issues that can cause problems.
- To minimize barriers to success (such as time constraints, lack of inclusiveness, and gaps in the flow of information), all of the organizations involved need to have the capacity (systems and readiness) to participate in such a consultation process.
- To ensure that time and energy are not taken up with frequent negotiations on the capacity of the consultation process, all organizations and players need to have reached prior agreement on budgetary allocations and limits.

RECOMMENDATIONS FOR FUTURE PROCESSES

With regard to changes and/or additions to the process, respondents made the following recommendations:

- More preliminary planning is needed. Stakeholder input should be sought from the outset — even before the consultations are announced — to ensure that the recipients of the consultations can better influence how the process takes place.
- Planning must begin earlier in the cycle. The final year of a multi-year strategy should be a time of assessment and planning for the future.
- Senior management must support the process from the outset. Problems internal to the department (e.g., interbranch issues) must be addressed at the highest possible level.
- Depending on the issue, non-mainstream organizations need to be involved in the consultations to garner their support in addressing the issue, to educate them, and to get their views.
- While a firm and realistic deadline must be established, national consultations of this nature require more time than was allotted. Proper consultations, and the development of reasoned and responsible input, is time-consuming but worth the effort.
- All participants should be kept informed of what is happening in parallel processes (if applicable). Streams of consultation should not be isolated from each other.
- An overall strategy is needed to explain how the various processes will come together at the end of the consultation to inform ministerial decision-making.
- A clearer understanding of how data will be analyzed, as well as sufficient time for the data analysis process, is essential.
- Plans should be made for an ongoing, interactive dialogue in the post-consultation period.

> "There was a lot of coalition building and enthusiasm around issues. There was some really hard work on a strategy everyone could live with and that would take us forward."
>
> *Darryl Sturtevant, Manager of the research component of the consultation processes*

CONCLUSION

Ultimately, the success of the Canadian Strategy on HIV/AIDS renewal process — a major breakthrough in public policy development — will be measured in the progress made over the next five years in: preventing the spread of HIV; finding and providing effective vaccines, drugs and therapies; finding a cure; ensuring treatment, care and support for persons living with HIV/AIDS, their caregivers, families and friends; minimizing the adverse impact of HIV/AIDS on individuals and communities; and minimizing the social and economic factors that increase individual and collective risk for HIV.

> "Being part of the process has empowered us."
>
> *Wilson Hodder,*
> *Chair of The AIDS Coalition of Nova Scotia*

APPENDIX

The Stakeholder Group comprised the following organizations:

- the Canadian Aboriginal AIDS Network;
- the Canadian AIDS Society;
- the Canadian Association for HIV Research;
- the Canadian Foundation for AIDS Research;
- the Canadian Hemophilia Society;
- the Canadian HIV Trials Network;
- the Canadian Public Health Association;
- the Canadian Treatment Advocates Council;
- the Community AIDS Treatment Information Exchange;
- the Federal/Provincial/Territorial Advisory Committee on AIDS; and
- the Interagency Coalition on AIDS and Development.