



“Entre-Nous” Forum

27 and 28 November 2004

Montreal, Quebec

The “Entre-Nous” Forum (*Between Us*), organized by COCQ-Sida (the Coalition of Quebec Community Organizations working in the fight against AIDS), was open exclusively to people living with HIV/AIDS living in Quebec. Its purpose was to promote interaction between people living with HIV and access to information from specialists on AIDS-related issues. The Forum program was established by a committee composed mainly of people living with HIV. The Forum sought to be a place to seek answers and to share concerns regarding medical treatment and the respect of human rights. It also served as an opportunity to develop new solidarity between people and communities living with HIV.

On the first day 32 information and sharing workshops on 14 themes dealt with many questions related to treatment and rights. Each workshop had a duration of one hour and unfolded according to the following 3 step formula:

1. **A brief presentation by an expert on the topic**
2. **A discussion and exchange between the participants and the facilitators.**
3. **Development of recommendations.**

Each of the participants could take part in 4 workshops by choosing among the 14 themes.

During the second day, the results of the previous day’s workshops were presented to all of the participants so that further discussion could be held. Four working groups were then held to refine and set priorities. This was, in turn, presented in plenary during lunch on Sunday.

The final recommendations from this exercise are presented in the following pages:

- Recommendations from the Saturday workshops: **pages 2 to 8**
- Recommendations from the Sunday exercises: **pages 9 to 12**

The whole of the present document is protected under the ISBN 2-922365-25-5 and deposited in the National Library of Quebec under the title "Entre Nous Forum 2004 - Recommendations"

WORKSHOP A - Access to treatments and information

Where and how to find up-to-date information on the many treatments and approaches available? By whom and where to follow treatment?

Observations:

- Lack of access to up-to-date information
- Lack of access to up-to-date treatments

Recommendations:

- Promote access to information
- Promote a more rapid access to treatments

WORKSHOP B - Access to a support network

Who do I speak to about what I am living? How do I create my support network? What are the support services available in my region?

Observations:

- The psychosocial and socio-professional needs of PHAs are not satisfactorily addressed by institutions of the Health and Social Services Network, nor by community organizations – these services are often not accessible or are inadequate.
- In the regions, those providing care are little or badly informed.

Recommendations:

- Promote meetings between PHAs in order to break their isolation.
- Promote access to services – institutional as well as community – at a faster rate.

WORKSHOP C – Treatment Guidelines

When to start treatment? What are the recommended approaches? How to know if it is working? What to do if it is not working?

Observations:

- The level of information is very different between the regions and the larger centres, and this despite a Mentorship program for Physicians, which is seldom used.
- The development of “Community Expertise” is more difficult to develop in the regions.

Recommendations:

- Be more proactive with physicians regarding the Mentorship program.
- Establish a follow-up by specialists with general practitioners treating PHAs.
- Facilitate access to Therapeutic Drug Monitoring in all medical follow-ups with PHAs.
- Consider treatment interruption as a valid therapeutic choice and not as delinquency.
- Promote greater conformity between the American and Canadian guidelines.
- Make possible the reimbursement of travel costs to facilitate access to quality care.

WORKSHOP D – Treatment Adherence

Why is it so important to adhere to treatment? What are the obstacles to good adherence? How to overcome these obstacles?

Observations:

- 95% compliance is a burdensome reality to assume.
- Doctors and pharmacists give very little information on the importance of treatment adherence.
- Important and permanent side-effects (such as lipodystrophy) are a big factor in hindering adherence. (15% of PHAs abandon treatment at the first signs of lipodystrophy).

Recommendations:

- Facilitate access to Therapeutic Drug Monitoring in all medical follow-ups with PHAs in order to reduce the quantity of drug intake and their side effects.

WORKSHOP E – Treatment side-effects

What are the most common side-effects? How can they be managed? Is it a factor to consider in the choice of therapy?

Observations:

- Doctors do not give enough information about side effects, the importance and the difficulty of adherence or on permanent or temporary undesirable side effects.
- There are often inconsistencies between what doctors, pharmacists and other health care providers say about side effects.

- There is little information available about alternative treatments and nutrition in relation to the reality of side effects.
- There is little information available about particular side effects with respect to women.
- Doctors often show little interest in lipodystrophy.

Recommendations:

- That the FORUM endorses the entirety of the activities and demands of the Lipo-Action committee.
- Facilitate access to Therapeutic Drug Monitoring in all medical follow-ups with PHAs in order to reduce the quantity of drug intakes and their side effects.

WORKSHOP F – HIV/HCV Co-infection

What are specific problems related to co-infection with HIV and the Hepatitis C Virus? What are recommended treatments and approaches?

Observations:

- There are important unanswered needs of psycho-social support for co-infected people.
- There are important unanswered needs of medical and nursing support for co-infected people (assistance to inject, etc.).

Recommendations:

- Promote the development of prevention specific to those co-infected in HIV organizations (greater openness to HCV in the organizations).
- Make the necessary contacts in the development of research in the area of HCV and HIV/HCV co-infection.
- Facilitate access and the right to transplantation for co-infected people.

WORKSHOP G – Participation in research

What are the ethical criteria in research and clinical trials and other forms of experiments? Are they really applied? How does one experience participation in research?

Observations:

- There is a very large difference between theory and practice in the area of participation in clinical trials.
- It has been noticed that the consent of people participating in clinical trials is not always / not really free and informed.

- There is a difference between the operations of private clinics and hospital centres with regard to clinical research.

Recommendations:

- Promote the establishment of a surveillance mechanism in the application of norms in ethical matters.
- Facilitate the distribution of adequate information in order to assist PHAs to better understand ethical questions in the area of participation in research.

WORKSHOP H – Challenges of the patient/doctor relationship

What kind of relationship do I want to have with my physician? How to choose a physician? How to establish a good dialogue and benefit from medical consultations?

Recommendations:

- Promote the realization that we have the right to choose our physician.
- Require a minimum allotment of time when consulting with the physician.
- Sensitize physicians to their role as counsellors (and not “decision makers”)
- Encourage the establishing of a relationship of confidence with the physician.
- Require that all physicians in regions and/or who treat a small number of PHAs subscribe to the mentorship program
- Sensitize and train physicians as to the realities specific to people from cultural communities in order to eliminate discrimination.
- Sensitize and train physicians about the specific realities of people living with complex problems.

WORKSHOP I – Discrimination

Can I be refused employment or health care services because I am HIV positive? What recourses do I have if I am a victim of discrimination?

Observations:

- Many application forms — in many fields — are discriminatory.
- There is no coherence in the different public and government bodies to which PHAs must address themselves in seeking redress for discrimination.

Recommendations:

- Encourage better collaboration between HIV groups and different public and government bodies.
- Develop accompaniment for PHAs in their recourses.
- Encourage a “positive discrimination” approach towards PHAs.
- Encourage the adaptation of the mandates of community groups so they will more adequately respond to the needs of PHAs.
- Encourage the partnership of HIV/AIDS community groups and organizations specializing in advocacy.
- Encourage legal training for community workers and volunteers in community groups.
- Act swiftly against employers in cases of discrimination against PHAs.
- Engage in a social marketing campaign in collaboration with union federations.

WORKSHOP J – Confidentiality

Is information concerning my health situation confidential? Who must respect this confidentiality (my doctor, employer, colleagues, insurance company, etc.)? In what circumstances am I obligated to divulge or reveal my status?

Recommendations:

- Promote the general use of universal precautions so as not to differentiate between treatment in hospital settings or clinics of people who are HIV positive or negative.
- Make it non-obligatory to reveal one’s HIV status/or specific state of health in order to have access to a specific service (vaccines, etc.)
- Encourage better training of physicians regarding confidentiality.
- Promote systematic confidentiality regarding benefits related to the cost of medication in the workplace.
- Promote external processes for management of benefits related to the cost of medication in the workplace.
- Promote access to community legal support.
- Produce community documentation on rights.
- Encourage the possibility of groups making complaints on behalf of individuals.
- Develop a program of intervention in the workplace.

WORKSHOP K – Insurance

Am I obligated to adhere to a private group insurance at work? Can I be refused insurance? What are the differences and similarities between private and public medication insurance?

Observations:

- Breach of confidentiality on insurance issues is more than frequent.
- There is more and more pressure placed on PHAs in relation to group insurance premiums in the workplace.

Recommendations:

- Encourage the establishment of universal medication insurance for all Quebeckers.
- Promote the establishment of severe penalties for insurance companies who breach confidentiality.
- Encourage putting in place structures which permit partial return to work.
- Encourage the elimination of obligatory membership in group insurance plans (allow choice).
- Encourage legal and administrative changes so that the individual's state of health will be evaluated according to objective criteria and information.

WORKSHOP L – Disability Status

What are the applicable rules on disability in regards to: 1) private insurance; 2) the Quebec Insurance Board; and 3) revenue security?

Recommendations:

- Encourage a revision of the missions of community groups in relation to the specific needs of PHAs and the reality of disability (support, accompaniment, etc.)
- Encourage the improvement of legal knowledge in community groups in relation to the specific needs of PHAs and the reality of disability
- Make the necessary representations in order to facilitate a return to work of PHAs.
- Make the necessary representations/pressure with the College of physicians in order to sensitize its members with regard to disability plans.
- Adapt to the particular needs of people who must receive complex and difficult treatments (Co-infection, etc.).

WORKSHOP M – Criminalization of HIV Transmission

What sexual behaviour to adopt in order to avoid any criminal responsibility? Must I reveal that I am HIV+ to my sexual partner? What is the signification in criminal law if there is protected sexual activity?

Observations:

- In the current legal context the weight of responsibility regarding transmission rests on the shoulders of PHAs.
- It is vitally important to make PHAs conscious of this legal situation.

Recommendations:

- Initiate sensitization and education campaigns in the general population so that all will understand that they are first and foremost responsible for their own health and that each individual must take responsibility for their choices in this area.

WORKSHOP N – Dying with Dignity

Can I choose the way I want to die? How do I ensure that my wishes are respected when I am approaching death? Where are we now in matters regarding access to palliative care at home, hospices and hospital?

Recommendations:

- Facilitate the distribution of information on legal protection, interests, autonomy and well-being at the end of one's life.
- Encourage a more widespread knowledge and sensitivity (general, social and institutional) on the specific reality of the end of life with regard to HIV.
- Promote adequate financing as well as the coordination of home care services, community hospices, palliative care and short term convalescence units.
- Promote the adoption of laws accepting euthanasia, assisted suicide and access to therapeutic drugs.

SUNDAY WORKSHOPS – SPECIFICATIONS AND PRIORITIES

WORKSHOP 1

- **Access to treatment and information**
- **Treatment guidelines**
- **Treatment adherence**
- **Side effects of treatments**

Recommendations:

PHAs participating in this workshop wanted to express their expectations clearly and precisely, so the following recommendations are stated in form of demands:

1. We demand the same access to treatments in all of Quebec's regions as in larger urban centres, as well as access to specialists within a reasonable delay, particularly in the area of gynaecology.
2. We demand that the Quebec guidelines concerning anti-retroviral treatment be updated at the same time as American guidelines as well as that the Quebec Mentor Program forward these directives to all physicians who treat people living with HIV/AIDS.
3. We demand that all travel costs be reimbursed so that people living with HIV/AIDS throughout Quebec can have access to quality care.
4. We demand that treatment Interruptions be considered as a valid and clear therapeutic choice, with the support of treating physicians.
5. We demand information that is current, adapted, vulgarized, in French and according to specific pathologies and groups (women, etc.) with regard to treatment, clinical trials and side-effects.
6. We demand the approval of medication at the same time and according to the same delays as the United States.
7. We demand the abolition of "Exception Drug Status" as well as "Patient Exception Drug Status".
8. We demand that the FORUM "Entre-Nous" endorse all of the activities and demands of the Comité Lipo-Action.
9. We demand universal access to reparative treatments for lipodystrophy, lipoatrophy and lipoaccumulation.
10. We demand the establishment of a post-approval surveillance system for all medications.
11. We demand access to therapeutic drug monitoring in all medical treatments of people living with HIV/AIDS in order to adjust the quantity of medicinal dosing and reduce undesirable side-effects.
12. We demand that medical teams take the time needed to explain what is involved in therapeutic adherence before the patient begins taking medication.

SUNDAY WORKSHOPS – SPECIFICATIONS AND PRIORITIES

WORKSHOP 2

- **Access to a support network**
- **HIV/HCV co-infection**
- **Participation in research**
- **The challenges of the patient/doctor relationship**

1. That the complementarity and integration of services be assured, in the public sectors and in the community in order to encourage access in the shortest delays possible, without discrimination in regard to the different groups of people living with HIV/AIDS (men, women, gays, heterosexual, cultural communities, injection drug users, etc.)
2. That meetings between people living with HIV/AIDS be encouraged, taking into account their particularities and needs in order to break isolation.
3. That the Resource Guide be updated on a regular basis, as well as made accessible on the internet.
4. That it be required that any physician who is practicing in a region and/or treating a small number of PHAs be registered in the Mentorship Program.
5. Train and sensitize physicians to the specific realities of people from cultural communities as well as aboriginals in order to combat discrimination.
6. Train and sensitize physicians to the specific realities of people living with complex difficulties.
7. Recognize the problem of HIV/HCV co-infection in all organizations involved in the fight against AIDS, in such a way as to develop appropriate support services.
8. Make the necessary pressures towards the development of research in the area of HCV and HIV/HCV co-infection.
9. Demand access and the right to organ transplantation for those co-infected.
10. Put into place a surveillance mechanism in the application of norms in ethical matters.
11. Encourage the distribution of adequate information in order to assist PHAs to better understand ethical questions in the area of participation in research.
12. Demand the implantation of Phase IV in clinical studies and the distribution of their results to the public.

SUNDAY WORKSHOPS – SPECIFICATIONS AND PRIORITIES

WORKSHOP 3

- **Discrimination**
- **Insurance**
- **Disability status**

1. Engage in a concerted and positive social marketing campaign by associating with, among others, labour federations and by using/adapting successful examples from other areas.
2. Encourage closer cooperation between ASOs and government and public agencies (Employment Quebec and other ministries) and provide accompaniment for PHAs in their dealings with these agencies (look at the allocation of resources in ASOs).
3. Act swiftly against employers (penalties, education) in cases of discrimination and look at closer cooperation between ASOs and organizations specializing in human rights/advocacy.
4. Allow a free choice in adherence to private or public medication insurance plans in order to avoid any discrimination.
5. Put into place very severe penalties on insurance companies in cases of breach of confidentiality.
6. Encourage the adoption of legal and administrative changes so that the health condition of people living with HIV/AIDS will be evaluated based on objective criteria and information.
7. Encourage the setup of a structure and a supple mechanism which will allow a return to work without penalty (portability of insurance, partial or long term return, etc.)
8. That there be a concerted updating of the mission of ASOs in order to respond to the specific needs of people living with HIV/AIDS in the face of the realities of disability (adequate support, accompaniment, etc.)
9. Encourage a re-enforcing the legal knowledge of ASOs to be better able to respond to the specific needs of PHAs and the realities of disability.

SUNDAY WORKSHOPS – SPECIFICATIONS AND PRIORITIES

WORKSHOP 4

- Confidentiality
- The Criminalization of transmission
- Dying with dignity

1. Have a general systematic application of universal precautions in order that there be no difference between the treatment received in hospitals or clinics for people who are seronegative or seropositive.
2. Develop access to information on the rights of people living with HIV/AIDS, particularly in the development of a provincial tool for legal aid.
3. Initiate sensitivity and education campaigns directed at PHAs on the legal aspects in regards to the criminalization of HIV transmission (which should also be part of the work mandate of community legal workers)
4. Initiate sensitivity and education campaigns directed at the general public so that all citizens understand that they are first and foremost responsible for their health and that everyone must take responsibility for their choices in this area.
5. In collaboration with other concerned groups, lobby to obtain adequate financing as well as coordination of homecare, community housing, palliative health care and short term respite care units.
6. In collaboration with other concerned groups, participate actively in discussions on the adoption of laws in respect to euthanasia, assisted suicide and access to drugs (e.g. marijuana) which have a therapeutic use.