



Canadian Ethnocultural Council  
Conseil ethnoculturel du Canada

CANADIAN  
LIVER  
FOUNDATION



# Engaging Ethnocultural Communities on Hepatitis C Part IV

Prepared by:

**Canadian Liver Foundation and Canadian Ethnocultural Council**

Submitted to:

**Hepatitis C Prevention, Support and Research Program,  
Public Health Agency of Canada**

**Final Report  
March 31, 2009**



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## **1.0 EXECUTIVE SUMMARY**





## 1.0 Executive Summary

- Hepatitis C is a major public health issue in Canada. While almost all newly-acquired hepatitis C infections in Canada are related to sharing of contaminated drug preparation and injection equipment, other risk factors have been implicated in parts of the world where hepatitis C is highly prevalent. These risk factors include inadequately sterilized medical equipment and certain traditional and cultural practices.
- The Canadian Association for the Study of the Liver (CASL) 2007 consensus guidelines on the **Management of Chronic Hepatitis C** state that *“The annual estimated hepatitis C-related mortality and the rate of cure on therapy is exceeded by the number of new infections and the number of infected persons immigrating to Canada, so that the prevalence of hepatitis C virus (HCV) infection is increasing and will continue to increase for the foreseeable future. Currently, approximately 65% of the estimated cases (hepatitis C) in Canada have been identified. Predictions are that by 2022, the number of hepatitis C-related deaths will increase by one-third. Approximately 20% of hepatitis C in Canada occurs in the immigrant community, where access to health care may be less than optimal. Countries with high prevalence rates for hepatitis C, and that provide Canada with immigrants, include Egypt, Somalia, Pakistan, Bangladesh and Vietnam. Almost all new HCV infections acquired in Canada are related to injection drug use (IDU) through sharing of injection equipment. However, immigration now contributes approximately 33% of all new cases of hepatitis C.”*

The report elaborates that *“In many countries from which Canada draws immigrants, large numbers of immigrants were infected with hepatitis C, 30 to 50 years ago, related to medical procedures using improperly sterilized syringes and needles.”*

- In 2006, the Canadian Liver Foundation (CLF) and the Canadian Ethnocultural Council (CEC) partnered to conduct the project entitled “Engaging Ethnocultural Communities on Hepatitis C.” This project focused on four immigrant populations:
  - Chinese
  - Egyptian
  - Filipino
  - Vietnamese

These communities were selected based on Canada’s immigration patterns, the reported prevalence of hepatitis C infection (3% or higher) in their country of origin, and modes of hepatitis C transmission.

- The overall goal of the project was to identify how to successfully engage ethnocultural communities on significant public health issues, such as hepatitis C, using a community-based approach. The objective was to identify how, where, and when the selected communities prefer to receive information on a significant health issue.
- The project was completed in four parts; Parts I, II, and III laid the groundwork for Part IV.
- Part I focused on developing community profiles for the four identified ethnocultural populations using the 2001 Census of Canada and the Ethnic Diversity Survey published by Statistics Canada in 2002; reviewing the literature on ethnicity and health to determine attitudes and beliefs towards health and diseases such as hepatitis C; developing culturally appropriate needs assessment tools; and establishing an Expert Advisory Committee (EAC) consisting of leaders and healthcare professionals from the identified communities.
- Part II focused on finalizing the project tools:
  - Invitation Letter to Organizations;
  - Invitation to Focus Group Participants;
  - Informed Consent Form;
  - Focus Group Questions.

Other aspects of Part II involved reviewing the job descriptions of the facilitators, key informants, and focus group participants; developing a list of potential participating organizations from the CEC network of contacts and those suggested by the EAC; and preparing and presenting a report to the Health Canada Research Ethics Board (REB) for their approval.

- Part III focused on translating the project tools into four languages; getting the EAC to review and approve translated project tools and to select appropriate community organizations for participation in the project; and developing an information package to distribute to participating organizations.
- Part IV involved organizing and conducting 40 focus groups and producing a report of the findings. These focus groups were conducted with members of the four ethnocultural communities in five Canadian cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver). A total of 491 individuals participated in these focus groups. After the focus groups were held, the data were collected, transcribed, and analyzed for this report. A project evaluation was also conducted.

- The information gathered in the focus groups provided insights into the social environments, culture, and social support networks in each identified ethnocultural community. These insights have, in turn, contributed to identifying the best ways to engage each community in developing, designing, and delivering culturally appropriate hepatitis C education materials. Specifically, the project increased the understanding of:
  - Best ways to deliver public health education messages about hepatitis C to each identified ethnocultural community;
  - Barriers to obtaining information on hepatitis C;
  - Role of ethnocultural communities in public health education;
  - Attitudes towards blood-borne diseases (hepatitis C);
  - Obstacles to understanding disease transmission, progression, long-term effects, and prevention measures for those infected with and affected by hepatitis C in these four ethnocultural communities.

The project also identified champions in each community who are willing to advance knowledge and awareness of this important public health issue.

**The following are the main themes from the focus group discussions:**

- Many participants in all four ethnocultural communities knew very little about hepatitis C. In fact, some participants stated that they had never heard about hepatitis C and knew absolutely nothing about it. Individuals who had any knowledge about hepatitis C had heard about it because someone they knew had the disease.
- The language in which the health information is provided is important. The communities who felt most strongly about the lack of doctors who spoke their language were the Chinese, Filipino, and Vietnamese. Focus group participants from the Chinese and Vietnamese communities, in particular, felt that a personal connection with their doctor was important, which is why they wished to go to a doctor from their community.
- All four communities held many cultural taboos regarding health issues. Participants from the Chinese, Filipino, and Vietnamese communities mentioned that even talking about diseases is a taboo in their respective culture. Many reasons were given for this reluctance to talk about health issues:
  - A fear of being stigmatized (as having the disease);
  - The difficulty in getting the community interested in health issues;
  - A fear in talking about diseases that are associated with “dirty” (sexually related) habits.

- Most participants mentioned the lack of good, reliable health information in their communities. Another common problem faced was the difficulty in knowing where to locate health information. It was suggested that this was also a problem for the general population, not just for ethnocultural communities.
- The onus was put on the Government of Canada – specifically Health Canada (HC) or the Public Health Agency of Canada (PHAC) – to help in getting health information out to ethnocultural populations. Participants suggested that the Government should prepare updated health information, as they thought that the information now available from the Government was out of date. They also felt that the Government should prepare information in different languages to best reach ethnocultural communities. Participants wanted printed information as well as information in various audio formats for those who could not read. Additionally, they suggested that the information in their own language, provided on Government websites, would be most helpful. Some thought that the Government should provide more money to help in developing TV programs on health and should also assist ethnocultural organizations in developing workshops.
- Focus group participants suggested that health information should be distributed to ethnocultural communities through the various ethnic media: community newspapers; TV (if there is not a TV network for a particular ethnic community, an existing mainstream media health channel should provide broadcasts in different languages); and radio.
- Other ways to reach communities with health information include social gatherings or as a side aspect of events marking national or cultural landmarks. At such events, it would be possible to run videos and PowerPoint presentations on hepatitis C and other health issues in one part of the room. A public awareness campaign could provide information on billboards, at bus stops, at common gathering places, etc. Other suggestions included establishing a health information group in each city, providing follow-up sessions for the focus group participants, and involving these participants in spreading health information in their respective communities. The focus group participants suggested that person-to-person contact was a good way to disseminate information.
- Several of the Egyptian focus groups participants suggested that the Egyptian embassy should have health information that particularly relates to Egyptian nationals as well as to individuals traveling to Egypt. They also noted that a website, containing health information would be very helpful for Egyptians; this website would be especially helpful as it could be accessed in both Canada and Egypt.
- The Chinese focus group participants in Toronto and the Vietnamese focus group participants in Montreal suggested that having celebrities promote specific health issues, such as hepatitis C, would get more attention in their communities. Other focus group participants suggested that community leaders should be involved in health promotion and raising awareness about health issues that might affect their communities.

- The communities recommended strongly that health care professionals (doctors, nurses, social workers, and pharmacists) required training and more information about hepatitis C.
- The Egyptian community, on the whole, seemed to be more integrated, language-wise, into Canadian society and seemed to be better educated. However, this community also had little knowledge about different health issues.
- The project received an overwhelmingly positive response from individuals in all four communities and has succeeded in generating an enormous interest in hepatitis C. This is a strong contrast to the lack of interest in and knowledge about hepatitis C displayed by focus group participants at the onset of the focus group discussions. The communities are strongly motivated to take further steps in becoming more engaged on this issue. They have specifically expressed an interest in obtaining more and up-to-date information on hepatitis C and a desire to share the information in their communities through their respective networks. It is important to keep the momentum going and not to lose the interest in hepatitis C that has been generated through focus group discussions. Communities have clearly indicated that they require help from the government if they are to be engaged meaningfully in addressing the challenges that hepatitis C poses to their communities and to the health of all Canadians.



## **2.0 BACKGROUND**





## 2.0 Background

In May 2005, representatives of the Canadian Liver Foundation and the Canadian Ethnocultural Council met with officials of the Public Health Agency of Canada to discuss the need to address a growing concern about hepatitis C in ethnocultural communities. This was the first time that representatives of the two organizations, each with a unique capacity and interest in working with ethnocultural communities, had come together.

### 2.1 Partners

#### 2.1.1 Canadian Liver Foundation

The Canadian Liver Foundation was founded in 1969 by a group of doctors and business leaders concerned about the increasing incidence of liver disease. The CLF was the first organization in the world devoted to providing support for research and education into the causes, diagnosis, prevention, and treatment of all liver diseases. Through its 30 volunteer chapters across the country, the CLF strives to promote liver health, improve public awareness and understanding of liver disease, raise funds for research, and provide support to individuals affected by liver disease. In past years, a number of initiatives were undertaken to inform and educate ethnocultural communities about liver diseases, including hepatitis C. For example, CLF conducted a needs assessment for multilingual information on hepatitis C, developed educational materials, and held educational seminars in several languages (such as Arabic, Cantonese, Mandarin, Tagalog, Vietnamese, and Italian).

#### 2.1.2 Canadian Ethnocultural Council

The Canadian Ethnocultural Council, founded in 1980, is a non-profit, non-partisan coalition of national ethnocultural umbrella organizations, which, in turn, represent a cross-section of ethnocultural groups across Canada. The CEC works toward the elimination of barriers and the advancement of equality of access and opportunity for ethnocultural populations in all segments of society. It promotes the understanding of the multicultural reality of Canada as defined in the Canadian Charter of Rights and Freedoms and the Canadian Multiculturalism Act. The CEC has carried out a variety of projects in partnership with national and regional organizations and government departments and, as a result, has developed an extensive network of contacts across Canada. Health has been a major focus in many of the projects successfully completed, and the CEC has developed culturally appropriate educational materials for diverse communities. Of particular significance is their work on type 2 diabetes in high-risk ethnocultural communities.

The CLF and the CEC became partners on this project because both organizations have a vested interest, experience, and capacity to engage ethnocultural communities on public health issues related to liver health.

## 2.2 Hepatitis C

### 2.2.1 About Hepatitis C

The hepatitis C virus, first identified in 1989, is a blood-borne virus that infects and can seriously damage the liver. HCV is transmitted through a blood-to-blood contact with an HCV-infected person. Hepatitis C is a major public health issue in Canada. Worldwide, it is estimated that approximately 170 million people are infected with HCV. In Canada, approximately 250,000 Canadians are infected with HCV and between 3,200 and 5,000 individuals are newly infected with HCV each year. Between 1960 and 1990 an estimated 90,000 to 160,000 Canadians contracted hepatitis C through infected blood or blood products.<sup>1</sup>

The risk of infection through blood transfusion has been substantially reduced in Canada by the introduction in 1990 of universal testing of blood donations for HCV.<sup>2</sup> However, current screening tests for hepatitis C are expensive, which explains why not all countries routinely screen for HCV. As a result, blood safety is not optimal in many countries.

Today, hepatitis C infection in Canada is largely associated with the sharing of contaminated drug preparation and injection equipment. In some parts of the world, other risk factors have been implicated, including inadequately sterilized medical equipment, and certain cultural practices, such as rubbing the skin with coins until there is bleeding.<sup>3</sup>

Many infected individuals do not know that they are infected, because, for some, there will be no symptoms, and, for others, the symptoms may only develop after 20 to 30 years. Therefore, many infected individuals may inadvertently spread the disease to others. Currently, there are no vaccines to prevent hepatitis C infection. However, effective treatment for hepatitis C is available in Canada.

Testing for the hepatitis C virus is a part of a larger set of activities that must take place to help those infected deal with the effects of HCV infection and to initiate treatment in order to prevent liver cirrhosis, liver cancer and death, as well as the need for liver transplants. In addition, the Hepatitis C Prevention, Support and Research Program has identified the hepatitis C information needs of ethnocultural communities as a priority and has developed brochures and posters for use by some of the larger immigrant groups. After this initial effort, it became clear that engagement with ethnocultural communities is far more complex than anticipated and that expertise in working with ethnocultural communities is needed to assess the most effective means to engage members of ethnocultural communities in promoting a better understanding of hepatitis C, its transmission, and ways to control its spread.

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<sup>1</sup>Health Canada, 2003. Get the Facts: Collection of Project Case Studies-Hepatitis C, Prevention, Support and Research Program, Mid-Term Evaluation Report.

<sup>2</sup>Canadian Liver Foundation, 2000. Hepatitis C: Medical Information Update. Can. J. Pub.Hlth, 91,1, S4-S9.

<sup>3</sup>Dev et al., 2004. Ethnic and Cultural Determinants Influence Risk Assessment for Hepatitis C Acquisition. J. Gastroenterol. Hepatol. 19:792-98.

## **2.2.2 Hepatitis C in Ethnocultural Communities in Canada**

There are about 5.5 million immigrants in Canada who arrive from many countries around the world. Some immigrants come from countries with reported high levels of hepatitis C infection. Approximately 20% of hepatitis C infection cases in Canada occur in the immigrant community, where access to health care may be less than optimal. By extrapolating data on infection rates in their country of origin, one can surmise that the immigrants from those countries will have similar rates of infection in Canada.

There is lack of information regarding hepatitis C in ethnocultural communities in Canada. Special expertise in working with ethnocultural communities is needed to work with and effectively engage members of these communities in order to promote a better understanding of hepatitis C, its transmission, and treatment.

When an infection such as hepatitis C is identified, the challenge arises on how to provide relevant and effective population health-based information, not only to an established population with a particular set of risk factors (e.g. sharing contaminated drug-using equipment), but also to vulnerable communities whose members may have become infected in other ways (e.g., childhood immunizations using contaminated equipment).

For this project, immigrant populations from China, Egypt, the Philippines and Vietnam were selected. Two of the communities (Chinese and Filipino) provide increasingly high numbers of immigrants to Canada. Immigration from Vietnam has tapered off while immigration from Egypt has continued at the same rate for the past 10 years. The selection of these four communities was based on the following criteria: (1) Canada's immigration patterns; (2) the prevalence of hepatitis C infection in their country of origin (3% or higher in the general population of their respective countries of origin); and (3) the means of hepatitis C transmission (that is reported to occur or has occurred) through cultural practices such as rubbing the skin with coins until there is bleeding, or the use of improperly sterilized hypodermic needles in the administration of vaccines and other medications.

It is hoped that by focusing on this small cross-section of communities, it will be possible to gauge a variety of attitudes regarding hepatitis C and to identify impediments to health education. Based on the information profile developed for each community (Part I of the project) - which includes immigration patterns, education levels, employment in Canada, economic status, and social structures - it is hypothesized that each of these communities requires a distinct approach to hepatitis C health education.

### **2.3 Engaging Ethnocultural Communities on Hepatitis C – Part I (January 1, 2006 to March 31, 2006)**

The CLF took the lead to work with the CEC to develop the proposal for a project entitled “Engaging Ethnocultural Communities on Hepatitis C.” Part I of the project was approved by the Public Health Agency of Canada and funding for the project was allocated.

The goal of the project was to develop a model on how to engage diverse ethnocultural communities on public health issues, such as hepatitis C. The focus was on developing an assessment tool that would identify attitudes toward diseases such as hepatitis C, as well as gaps in community health information, health concerns, and the best ways to involve and educate the community.

The identified communities were immigrant populations from China, Egypt, the Philippines, and Vietnam.

The main activities of Part I of the project included:

- The development of four community profiles;
- An Internet scan of resources on hepatitis C in English, French, and the languages of the four identified communities;
- A literature review on ethnicity and health concerning attitudes and beliefs towards health and disease, in relation to hepatitis C;
- The formation of an Expert Advisory Committee consisting of leaders and health workers from the identified communities;
- The convening of a working meeting of the EAC;
- The development of culturally appropriate needs assessment tools with input from the EAC for engaging the selected communities. These tools comprised:
  - Needs Assessment Form (Questionnaire);
  - Informed Consent Form;
  - Instruction to Interviewers;
  - Invitation Letter to Organizations;
  - Invitation Flyer to Communities.

A final project report was submitted to the PHAC on March 31, 2006.

The project team (CLF and CEC) was also required to submit an “Application for an Ethical Review” for the needs assessment tools to the Health Canada Research Ethics Board.

The REB, established in September 2002, is responsible for reviewing research involving human subjects, including that funded by Health Canada through grants and contributions to external researchers.

The review process included the following:

- Submission of the “Application for an Ethical Review;”
- Submission of the needs assessment tools;
- Attendance at the REB meeting by teleconference on May 12, 2006;
- Presentation of an overview of the project;
- Response to questions posed by the REB.

The REB recommended that the purpose of the project be clarified. The project team met a number of times to review the REB suggestions, to implement their recommendations, and to prepare for the next presentation to the REB. On June 28, 2006, the project team made their second presentation to the REB. At this meeting, the REB recommended that the project approach be clarified and the needs assessment tools be revised.

From July to September 2006, the project team continued to deliberate and act upon the REB recommendations. The team consulted with a Health Canada epidemiologist and a medical statistician to discuss the goals of the project and whether a survey methodology was the best approach to use. The consensus was that a focus group approach would best meet the objectives of the project.

As a result, the project process would be as follows:

- Hold focus groups in the four identified communities (Chinese, Egyptian, Filipino, and Vietnamese);
- Conduct two focus groups for each community in five cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver).

Therefore, 40 focus groups would be conducted with 10 individuals in each focus group, for a total participation of 400 individuals.

The focus group approach required the revision of the needs assessment tools, especially the questionnaire, in order to promote active discussion with community participants. The new approach and revised needs assessment tools were submitted again to the REB for their review and approval.

## **2.4 Engaging Ethnocultural Communities on Hepatitis C – Part II (February 2, 2007 to March 31, 2007)**

In November, 2006, a project proposal for “Engaging Ethnocultural Communities on Hepatitis C – Part II” was developed and submitted to the PHAC. The goal was to work with the selected ethnocultural communities, using a focus group approach, to identify the most effective ways to reach and engage ethnocultural communities on significant public health issues, such as hepatitis C.

Funding for the project was not approved by PHAC until February 2, 2007. Due to the curtailed time frame to implement the project (one and one half months), the project goal, activities, and budget were revised. The revised project goal was to clarify the project approach and to revise the project tools as per the REB’s request.

The main activities of Part II of the project were to:

- Set up project team, review work plan, and confirm tasks;
- Convene a meeting of the EAC;
- Submit a revised “Application for an Ethical Review” to the REB;
- Make a presentation to the REB;
- Implement the REB recommendations;
- Plan for Part III of the project.

The purpose of the EAC meeting was to:

- Finalize the project tools: Invitation Letter to Organizations, Invitation to Focus Group Participants, Informed Consent Form, and Focus Group Questions;
- Review the job descriptions for: Key Informants and Facilitators, and profile of Focus Group Participants.

On March 9, 2007, the project team made a presentation to the REB in Ottawa. On March 14, 2007, the transcript of the REB meeting was received with the statement that: *“The Board will be recommending to the Chief Scientist that this project proceed with the focus groups as submitted to the REB Secretariat on February 26, 2007.”*

A final report was submitted to the PHAC on March 31, 2007.

## **2.5 Engaging Ethnocultural Communities on Hepatitis C – Part III (December 17, 2007 to March 31, 2008)**

The project proposal for “Engaging Ethnocultural Communities on Hepatitis C – Part III” was submitted to the PHAC in September 2007. The goal of Part III was to conduct focus groups with the four selected ethnocultural communities (Chinese, Egyptian, Filipino, and Vietnamese) in five cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver) using the project tools that were approved in Part II. This would mean two focus groups per community per city for a total of 40 focus groups.

Funding for Part III was not approved until December 17, 2007. Due to the curtailed time frame, it was impossible to carry out the project as approved. The project and activities were revised to focus on assembling all the necessary materials and personnel required for the implementation of focus groups.

The main activities of Part III of the project were to:

- Identify participating community organizations from EAC, CEC members, and CEC network;
- Identify potential focus group facilitators and recorders (note takers) for each of the four ethnocultural communities;
- Prepare and submit an Annual Progress Report to Health Canada Research Ethics Board by February 26, 2008, including a request to extend the use of the project tools;
- Translate project tools (Invitation Letter to Organizations, Invitation to Focus Group Participants, Informed Consent Form, and Focus Group Questions) and hepatitis C brochure into four languages (Arabic, Chinese, Tagalog and Vietnamese);
- Convene a meeting of the EAC to review, revise, and approve translated materials;
- Review lists of participating organizations and community resources, and to suggest names for key informants (coordinators), focus group facilitators, and recorders (note takers);
- Develop an agenda for a one-day training session for focus group facilitators and recorders (note takers);
- Prepare an information package for each identified participating organization that included the following:
  - Invitation Letter to Organizations in English and in translation;
  - Invitation to Focus Group Participants in English and in translation;
  - Job descriptions of key informants and facilitators, and a profile of focus group participants;
  - Summary of project;
  - Hepatitis C brochure in English and in translation;
  - Local ethnocultural community resource list.

The Annual Progress Report to the Health Canada Research Ethics Board was submitted on February 25, 2008, for consideration at their meeting on March 13, 2008. This report included a request to approve the project tools for another year.

A final report was submitted to the PHAC on March 31, 2008.

To review the full reports on Engaging Ethnocultural Communities on Hepatitis C – Parts I, II and III, contact:

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## **3.0 ENGAGING ETHNOCULTURAL COMMUNITIES ON HEPATITIS C - PART IV**



## **3.0 Engaging Ethnocultural Communities on Hepatitis C Part IV (July 21, 2008 – March 31, 2009)**

### **3.1 Project Overview**

#### **3.1.1 Project Goal and Objective**

The goal of the project was to work with four ethnocultural communities (using a community-based approach), to identify the most effective ways to provide hepatitis C information to these selected communities.

The objective of Part IV was to find out how, where, and when the selected communities prefer to receive information on public health issues such as hepatitis C. In order to achieve the goal, 40 focus groups were conducted with the four selected ethnocultural communities (Chinese, Egyptian, Filipino, and Vietnamese) in five cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver). This meant conducting two focus groups per community in each of these five cities. The following project tools, developed and approved in Part II, and translated in Part III, were used:

- Invitation Letter to Organizations (Appendix 1);
- Invitation to Focus Group Participants (Appendix 2);
- Informed Consent Form (Appendix 3);
- Focus Group Questions (Appendix 4).

#### **3.1.2 Project Timelines**

The duration of the project was from July 21, 2008 to March 31, 2009.

The work plan included the following activities and timelines:

Project Activities	Timelines
1. Reconvene project team	July 21, 2008
2. Notify the EAC, the CEC members, and the CEC network, upon receipt of project funding	July, 2008
3. Confirm participating organizations from the EAC, the CEC members, and the CEC network	July – Aug. 2008
4. Prepare and distribute information packages to participating organizations	August, 2008
5. Follow up with each participating organization	August, 2008

6. Recruit and select 40 key informants (coordinators)	September, 2008
7. Recruit and select eight facilitators and eight recorders (note takers)	July – Aug. 2008
8. Conduct orientation session for facilitators and recorders (note takers)	August, 2008
9. Select 400 focus group participants	September, 2008
10. Prepare, organize, and coordinate 40 focus groups	September, 2008
11. Conduct 40 focus groups	Sept. – Nov. 10, 2008
12. Transcribe and translate proceedings from each focus group session	Sept. – Nov. 2008
13. Compile, synthesize, and analyze data	Nov. 2008 – Jan. 2009
14. Prepare project report	Feb. – March, 2009
15. Submit final project report	March 31, 2009
16. Disseminate results	after March 31, 2009

## **3.2 Project Activities**

### **3.2.1 Reconvened Project Team**

The project team (CLF National Director of Health Promotion and CEC Executive Director) was reconvened on July 23, 2008. A project coordinator was hired, detailed work plan developed, and the duties and responsibilities of the team members were identified. The project team, including the project coordinator, held regular weekly meetings by teleconference. Three face-to-face meetings were also held.

### **3.2.2 Notified the Expert Advisory Committee, the CEC Members, and the CEC Network upon Receipt of Project Funding**

All stakeholders were informed of the project's funding approval and the activities to be undertaken. In particular, their respective roles in the project were identified and the role of the EAC members (Appendix 5) was highlighted.

### **3.2.3 Confirmed Participating Organizations from the EAC, the CEC Members, and the CEC Network**

Contact information of participating organizations was verified. Organizations were subsequently contacted by email or telephone, and an information package was sent to each participating organization.

### **3.2.4 Prepared and Distributed Information Packages to Participating Organizations**

The information package previously developed in Parts II and III of the project included:

- Invitation Letter to Organization;
- Invitation to Focus Group Participants;
- Job descriptions for: key informants (coordinators), facilitators, and recorders (note takers), and a profile of focus group participants;
- Summary of project;
- Hepatitis C brochure;
- Local ethnocultural community resource list.

Information packages were distributed to participating organizations in the four communities (Chinese, Egyptian, Filipino, and Vietnamese) and five cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver).

### **3.2.5 Followed up with Each Participating Organization**

Each participating organization was contacted by telephone or email to ensure that the required information had been received. Participating organizations were asked to help recruit focus group participants.

### **3.2.6 Recruited and Selected 40 Key Informants**

Key informants were selected in each of the cities. The key informants requested that they be addressed as coordinators in the context of this project.

The criteria for selection (Appendix 6) were reviewed, and the names of individuals provided by participating community organizations, the EAC, the CEC membership, and other contacts were checked.

Two key informants (coordinators) were selected from each city for each community. Because there were four communities (Chinese, Egyptian, Filipino, and Vietnamese) and five cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver) a total of 40 key informants (coordinators) were selected (Appendix 7). Information regarding the project which included the project goal and objectives, and the tasks and responsibilities of the key informants (coordinators), was forwarded. This was followed by several face-to-face discussions (where possible) or telephone conversations; these communications were supplemented by information sent by email. Key informants (coordinators) were given the information package and they revised the invitation letters to the organizations and participants to include local

contact information and details of the location, the date, and the time of meeting. They also contacted each organization to re-confirm its involvement in the project.

### **3.2.7 Recruited and Selected Eight Facilitators and Eight Recorders (Note takers)**

The project team reviewed the criteria for selection of focus group facilitators (Appendix 6). Names were reviewed from the names of individuals provided by community organizations, the EAC members, the CEC members, and the CEC network; and the project team selected those who met certain predetermined criteria to be focus group facilitators. Two facilitators from each community were selected – one designated as the primary facilitator and the other as back-up (Appendix 8) – to conduct focus groups.

Recorders (note takers) were also selected to write the responses to the focus group questions and to capture the non-verbal communication among focus group participants. Due to time and budget constraints, it was decided to recruit local bilingual recorders (English and the language of the ethnocultural community) from each city with the help of the key informants (coordinators). A total of 28 recorders were selected from the four communities in the five cities (Appendix 9).

### **3.2.8 Conducted Orientation of Facilitators and Recorders (Note takers)**

A one-day orientation session was arranged for the focus group facilitators. The purpose of the session was to confirm their tasks and responsibilities and also to provide a clear understanding of the project and its goal. The session was designed to review the Informed Consent Form (Appendix 3) and the Focus Group Questions (Appendix 4) and provide a consistent approach to the focus group process. The agenda for the session is found in Appendix 10. The facilitators were asked to complete an evaluation form (Appendix 11) at the end of the session.

The recorders (note takers) did not attend the orientation session, as originally planned. This had initially been planned but due to the numbers and the fact that they were dispersed in different cities, it was expensive and difficult to coordinate and accommodate in such a short time span. However, the project coordinator and key informants (coordinators) briefed the recorders about the project prior to the focus group meetings. The Informed Consent Form and the Focus Group Questionnaire were reviewed in English. The appropriate translations were also given to the recorders (note takers).

### **3.2.9 Selected 400 Focus Group Participants**

An outreach strategy was developed with key informants (coordinators) for selecting focus group participants in each community. This included reviewing the ideal profile of focus group participants and the selection criteria. Each key informant (coordinator) used their own contacts to recruit participants. The CEC also provided a list of contact organizations. Each key informant (coordinator) was asked to select at least 12 – 14 individuals for each group to ensure that at least 10 participants attended each focus group session.

### **3.2.10 Prepared, Organized, and Coordinated 40 Focus Groups**

The project coordinator worked with the key informants (coordinators), community organizations, and facilitators to develop a schedule for focus group meetings in each city and for each ethnocultural community. The detailed schedule is shown in Appendix 12. The project coordinator notified the facilitators and made the necessary travel and accommodation arrangements.

The key informants (coordinators) selected suitable venues in each of the five cities for each of the four ethnocultural communities. They also arranged for the technical requirements for the sessions and for refreshments.

The project team prepared resource materials for distribution at each focus group. These materials included:

- The profile of the CLF (Appendix 13);
- The profile of the CEC (Appendix 14);
- Information on hepatitis C in English and in the language of the ethnocultural group (Appendix 15);
- Local health resources (Appendix 16);
- Canadian Liver Foundation offices in the selected cities (Appendix 17).

The key informants (coordinators) were responsible for contacting and confirming at least 10 participants for each focus group. They also assigned a bilingual (English and the language of the group) recorder to each focus group.

### **3.2.11 Conducted 40 Focus Groups**

Forty focus groups were conducted in the five cities for the four ethnocultural communities. The same basic format and agenda were followed for each focus group. Each focus group meeting started with attendees introducing themselves. The facilitator of the group then presented an overview of the project, the process, and the role of the participants. The Informed Consent Forms, which were available in English and the language of the focus group, were distributed to each participant. The facilitator reviewed the Informed Consent Form with the participants and clarified any questions or concerns they raised. The participants were asked to complete and return one consent form to the facilitator and keep a copy for themselves. The meeting began with the facilitator asking the participants each of the 10 Focus Group Questions in English or in the language preferred by focus group participants. The recorder (note taker) documented the responses to the questions. The entire session was recorded (verbatim) on a digital recorder.

### **3.2.12 Transcribed and Translated Proceedings from Each Focus Group Session**

To ensure that the focus group discussions were accurately recorded (verbatim), sessions were recorded on a digital recorder. The information from each focus group session was transferred onto two CDs – one was sent for transcribing and the other retained by the project team. The information from each focus group was transcribed and translated by individuals selected by the key informants (coordinators) or the facilitators in conjunction with the CEC project coordinator. Some problems were encountered in transcribing the Chinese and Vietnamese recordings. It was found that transcribing and translating verbatim took about two weeks for each focus group. Since this was not feasible due to the short timeframe of the project, the project team decided to forgo one step and have the translators to translate directly (verbatim) into English. Six of the Filipino focus groups and four of the Egyptian focus groups were conducted in English. The verbatim translations in English were sent to the CEC. The original recordings for all 40 focus group meetings are available on CDs with the CLF.

### **3.2.13 Compiled, Synthesized, and Analyzed Data**

The project coordinator compiled and categorized the information collected from the focus group discussions by the recorders and the translators. Findings from the focus group discussions for each ethnocultural community in each city were documented and the profiles for communities developed. Similarities and differences among the various ethnocultural communities and among the same ethnocultural community in the different cities were noted.

All information was reviewed by the project team as it was being transcribed and translated, and it was compiled in a draft report. The project team picked common themes and messages and put together recommendations from each ethnocultural community.

### **3.2.14 Prepared Final Project Report and Submitted to PHAC**

This final project report contains data collected from focus group discussions with the four ethnocultural communities in the five cities.

This report provides highlights of the common themes and messages that emerged during focus group discussions. The report also outlines information concerning the best ways to engage each identified ethnocultural community on public health issues, such as hepatitis C, by identifying where, when, and how each selected community wants to receive information. It describes the best ways to deliver health education messages, how to engage communities in this process, and the barriers in existence within each community that may impede the delivery of these public health messages.

This report also includes the evaluation of the project process and the lessons learned over the course of the project. The purpose of the evaluation was to determine whether the project was conducted according to the work plan, whether the project activities met the project objectives, what was helpful in achieving the project objectives, what was difficult to achieve and why, and finally, whether the project achieved the desired outcomes.



The evaluation process comprised the following:

- Evaluation of the orientation session for facilitators. The focus group facilitators evaluated the format of the orientation session, the focus group facilitation information, and the practice session.
- Evaluation of the project process. The focus group facilitators evaluated the focus group locations, the satisfaction of participants, the lessons learned, and the similarities and differences within their respective community in the different cities.
- Evaluation of the project process. The project key informants (coordinators) provided their observations before, during, and after each focus group meeting. They specifically looked at areas such as recruitment of focus group participants, the satisfaction with focus group facilitation, lessons learned, and follow-up action by communities.
- Project team observations. The observations made by the project team included the challenges the project team faced and how these challenges were met.

This report also includes recommendations from each ethnocultural community and from the project team.

### **3.2.15 Dissemination**

The Executive Summary will be posted on the CLF website. Copies of the project report will be sent to:

- Public Health Agency of Canada;
- Members of the EAC;
- Focus group facilitators;
- Key informants (coordinators) in each of the five cities;
- CLF national and regional offices, senior volunteers, and staff;
- Health Canada Research Ethics Board.

The Executive Summary will be sent to the following:

- CEC executive;
- CEC membership;
- CLF national staff and volunteers;
- Participating community organizations;
- Participating community partners;
- Participating community leaders.

Both the CLF and the CEC will continue to share the findings of this project with their respective stakeholders and apply the lessons learned to future work with ethnocultural communities.



## **4.0 FOCUS GROUP PARTICIPANTS AND FINDINGS BY ETHNOCULTURAL COMMUNITY AND BY CITY**



## **4.0 Focus Group Participants and Findings by Ethnocultural Community and by City**

Forty focus groups were conducted with four ethnocultural communities (Chinese, Egyptian, Filipino, and Vietnamese) in five Canadian cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver). Two focus groups were conducted for each ethnocultural community in each city.

A total of 491 individuals participated in the focus groups (Appendix 18). Ottawa had the largest number of focus group participants (106). Calgary and Montreal had an equal number of participants (101), followed by Vancouver (94), and Toronto (89). The largest number of participants were from the Filipino community (130) followed by Chinese (128), Vietnamese (127), and Egyptian (106).

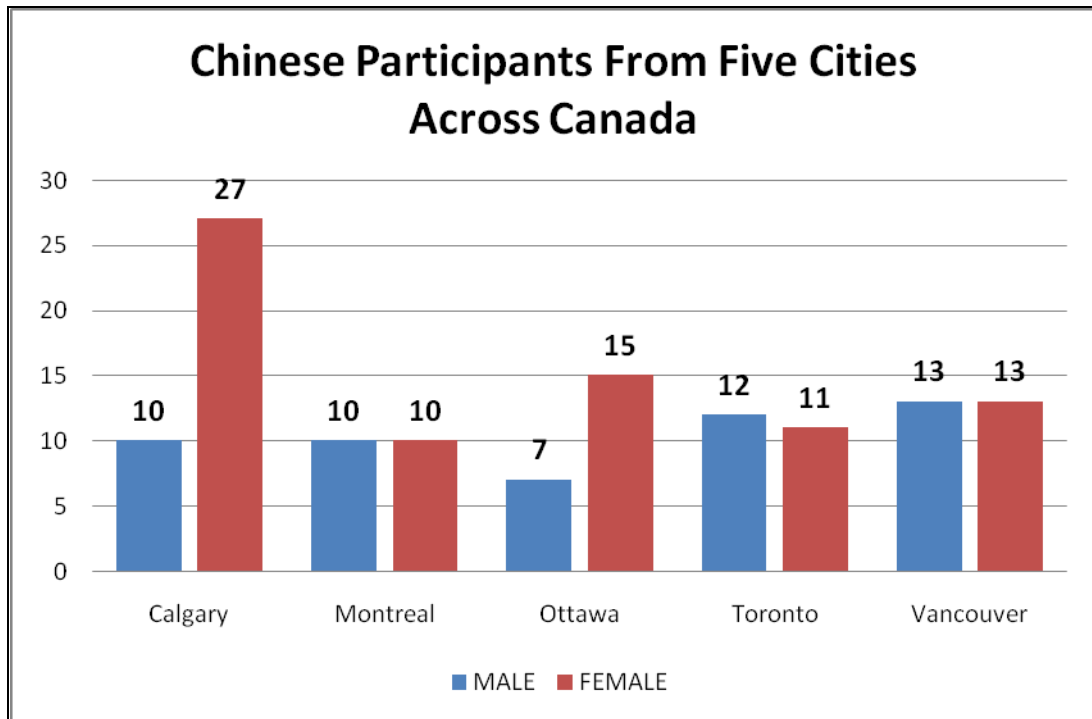
All four communities had more female than male participants. The largest difference was seen in the Filipino community, where the ratio of male (34) to female (96) participants was approximately 1:3. Among the four ethnocultural communities, the Vietnamese had the largest number of male participants (54), followed closely by the Chinese (52); Egyptians had the lowest number (41).

To ensure consistency, each focus group followed the same basic agenda, which was developed with the focus group facilitators at the one-day orientation session. The focus groups were held in locations determined to be suitable for the community representatives; these included community centres, church halls, community halls, libraries, YMCA, etc.

In each focus group, the facilitator asked the REB-approved focus group questions (Appendix 4) in sequence to obtain responses from the participants. Each focus group session was taped. After the focus groups were completed, each tape was transcribed, translated into English where needed, and analyzed. The findings from each ethnocultural community are presented in this section.

## 4.1 Chinese

### 4.1.1 Chinese: Focus Group Participants



**Figure 1. Gender Distribution of Chinese Focus Group Participants**

Figure 1 shows the Chinese focus group participants distribution by gender and by city. Female participants predominated in Calgary and Ottawa, and the gender distribution in Montreal, Toronto, and Vancouver was equal or nearly equal.

#### 4.1.2 Chinese: Focus Groups Findings

This section contains the responses to the 10 focus group questions from the Chinese focus group participants. The responses are listed at random and in no particular order of importance. In Calgary and Toronto, Cantonese- and Mandarin-speaking participants had separate focus groups because there were a sufficient number of participants for each language. In Montreal, Ottawa, and Vancouver, both Cantonese- and Mandarin-speaking participants were in the same focus group.

#### Question 1: What are the major health issues that people in your community talk about?

##### Calgary

**Cantonese group:** Cancer; contaminated milk products in China; diabetes; mental health effects of stock market turbulence; pain in different parts of the body; sports activities; exercises that improve health.

**Mandarin group:** Alzheimer's; cancer; constipation; diabetes; degenerative arthritis; eye problems, such as cataracts and glaucoma; gall stones; gall bladders; high blood pressure; hepatitis; heart disease; insomnia; kidney disease; liver disease; memory loss; obesity; pain in the joints; problems of aging; sexually transmitted diseases.

##### Montreal

Alternative therapies, such as acupuncture; Chinese herbal treatments; cancer (breast, prostate); cholesterol; diabetes; hemorrhoids; kidney diseases; long waiting time to make a doctor's appointment; long wait to see a doctor; massage therapy; Parkinson's disease; parents talk about health issues of kids, such as flu or other common ailments; supplements and health products; waiting time to see a Chinese-speaking doctor instead of a non-Chinese-speaking doctor.

##### Ottawa

Active lifestyle; blood sugar; cancer; concern about whether health information is from a trustworthy source and if community health care centre will have talks about HIV or diseases related to sex; doctors will talk about hepatitis in preparation for travel to China or when coming to Canada; diabetes; difficulty in finding a doctor and waiting time for appointments; dizziness; foods to control high cholesterol; head lice; healthy diet; heart disease; hepatitis B; high cholesterol; hypertension; language barrier and need for someone to accompany on doctor visits to bridge this; medical system; obesity; obtaining vaccines for babies that are not in the standard immunization programs for diseases such as tuberculosis; osteoporosis; palliative care; problems in health care system; prostate problems; safe sex; stroke.

## **Toronto**

**Cantonese group:** Alzheimer's; arthritis; cancer; diabetes; enough exercise; gallstones; heart disease; high blood pressure; high cholesterol; insomnia; kidney disease; stroke.

**Mandarin group:** Bird flu; cancer; dental problems; diabetes; gallstones; heart disease; high blood pressure; high cholesterol; infectious diseases; liver disease; stroke.

## **Vancouver**

Arthritis; Alzheimer's; cancer (liver, breast); dementia; diabetes; gout; heart disease; hepatitis; hypertension; kidney disease; liver disease; osteoporosis; prostate; rheumatism; stroke.



## Question 2: What health issues do people in your community *not* talk about?

### Calgary

**Cantonese group:** Aging and dementia; cancer (liver); private affairs and failure to ask for help; hepatitis, especially hepatitis B; mental problems and depression; multiple sclerosis; social issues, such as isolation, that lead to emotional and mental problems; psychological issues.

**Mandarin group:** AIDS; common colds and flu; homosexuality; mental problems and depression; sexually transmitted diseases.

### Montreal

Alzheimer's; any infectious diseases; dementia; depression; eye disease; hepatitis; HIV/AIDS; liver diseases; lung diseases; mental and psychological illnesses; skin diseases.

### Ottawa

Adult mental health problems; all kinds of abuse; dementia; child developmental and mental health problems; AIDS; sexually transmitted diseases; heart disease; HIV; homosexuality; hepatitis; hepatitis C; depression; tuberculosis; some communicable diseases; stress caused by family issues such as conflict and ineffective inter-generational communication.

### Toronto

**Cantonese group:** Death; depression; hepatitis; obesity; Parkinson's disease; sexually transmitted diseases or any disease related to sex; tuberculosis.

**Mandarin group:** AIDS; arthritis; gallstones; insomnia; kidney disease; mental and psychological problems; obesity; level of physical activity; sexually transmitted diseases or any disease related to sex.

### Vancouver

AIDS; allergies; eye diseases; epilepsy; healthy eating; hepatitis; arthritis; Alzheimer's; sexual-related issues; conditions related to genetic problems; mental health problems; depression; skin disease; Parkinson's disease.

### Question 3: What diseases are *not* talked about?

#### Calgary

**Cantonese group:** Aging and dementia; hepatitis; liver cancer; mental health problems; depression; multiple sclerosis; social issues that lead to emotional and mental issues.

**Mandarin group:** AIDS; common cold and flu; headache; sexually transmitted diseases; tuberculosis.

#### Montreal

All contagious diseases; dementia; Alzheimer's; depression; eye diseases; hepatitis; HIV/AIDS; liver diseases; lung diseases; mental and psychological illnesses; skin diseases; tuberculosis.

#### Ottawa

HIV/AIDS; Alzheimer's; depression; genetic diseases such as cystic fibrosis; hepatitis C; heart disease; homosexuality; menopause; mental and psychological illnesses; mental problems of children and some illnesses related to children; sexually transmitted diseases; tuberculosis.

#### Toronto

**Cantonese group:** Coughing; death; hepatitis; liver disease; mental illnesses; depression; Parkinson's disease; sexually transmitted diseases or any disease related to sex; skin cancer; tuberculosis.

**Mandarin group:** Hepatitis; hepatitis C; issues related to life and death; mental health issues; depression; lung disease; Parkinson's disease; sexually transmitted diseases or any disease related to sex; skin cancer; tuberculosis; respiratory diseases.

#### Vancouver

AIDS; allergies; Alzheimer's; arthritis; cancer (skin); disease related to genetic problem; diseases related to ear, throat, and nose; eye diseases; healthy eating; hepatitis; Parkinson's disease; skin diseases.

#### **Question 4: What are some reasons for *not* talking about these diseases?**

##### **Calgary**

**Cantonese group:** Members are healthy and have little contact with people who have diseases or are ill; Chinese are conservative; Chinese tend to avoid people who are sick; do not talk about a disease because of fear of contracting the disease; do not talk about diseases because there is no solution; family members who accompany patients do not always get adequate information; lack knowledge about the diseases; makes people unhappy; no time to talk about diseases in busy schedules unless someone insists; problem is that specialists are non-Chinese and interpreter does not have medical knowledge to interpret accurately; talking about disease will change the atmosphere of the group; uncomfortable in talking about diseases.

**Mandarin group:** Disease not general enough to raise public concern; disease not common and will not tell people about it; depression is something we will not talk about even if we have it because it might be self-inflicted and do not talk about self-inflicted illnesses; lack knowledge about diseases; not concerned about health issues; saving face; shame; shyness.

##### **Montreal**

Because some do not have regular checkups they are not informed about these subjects; Chinese do not discuss such subjects because they are taboo; fear of catching a disease from someone afflicted with it; do not have a platform or a chance to talk about these topics; one will have fewer friends or be isolated in small social circle of Chinese in Montreal; people lack sufficient information or understanding of such subjects; people's misunderstanding of the disease.

##### **Ottawa**

Afraid of being hurt or isolated; ashamed to talk to others; cultural difference; do not know who to talk to; feel lack of power to impact society and that no one respects what they have to say; have no solution and feel no individual power; having a disease is private and try to keep knowledge in own family; lack basic knowledge or competency to talk about the disease; not many Chinese get sexually transmitted diseases; too private; too shy to talk about health issues related to menopause.

## Toronto

**Cantonese group:** Do not want to talk about it; inadequate knowledge of the diseases; labeling effect; do not understand diseases; no proper channel or occasion to talk about these; misunderstanding that forgetfulness is related to mental illness; not understanding the nature of the disease and thinking that it will cause aggravation; talking about these diseases is a taboo in the culture.

**Mandarin group:** Cultural belief that mentioning these things will cause bad luck; distortions caused by media reports; inadequate knowledge of the diseases; labeling effect; no proper channel or occasion to talk about these; fear of being misunderstood or stigmatized; fear of being thought crazy if have depression or Parkinson's; worry that sex-related diseases and mental illness are contagious and people with mental illness are labeled as aggressive.

## Vancouver

Avoid seeing the doctor and pretend that there is no illness; cultural belief in that they do not disclose too many personal issues; disease may be hereditary so do not want to talk about it – such as depression, which a person may not know he has and society cannot help with it as it is psychological; difficult to talk about men's disease; fear of the disease due to inadequate knowledge and channels of information; talking about diseases is a taboo; the labeling effect of genetic-related issues; talking about a disease implies that the person is suffering from the disease; shy in talking about their diseases; consider their suffering as part of aging not a disease; feel it could be disgraceful to have a disease; have nobody to talk with about the disease; lack knowledge about the disease; may lose face; may not realize they have the disease.

**Question 5: What about hepatitis C? Is hepatitis C an issue in your community? What kinds of things do people say about hepatitis C in your community?**

(Explain: What is hepatitis C and how it is spread. Probe: What about other diseases spread by contact with blood? What kinds of things do people say about these diseases?)

**Calgary**

**Cantonese group:** Can be transmitted through non-sanitized dental equipment; doctor told me that I am immune to it and will not need inoculation; have never heard about hepatitis C – only hepatitis A and B; transmitted through blood; question if it can be transmitted through giving birth; related to AIDS; think it is related to sex life and to blood transfusion and donation.

**Mandarin group:** Concern about numbers who will die of it; expect to learn more about symptoms; lack knowledge of it including symptoms and causes; is transmitted through blood; know little about hepatitis C; more discussion on AIDS and hepatitis B is needed; not commonly discussed in Calgary's Chinese community; should talk about prevention of this scary illness; want to know ways of transmission and treatment methods; want to know risk factors and danger.

**Montreal**

Do not know about Hepatitis C, A, or B because it is transmittable and people are afraid of it; do not have opportunity to attend educational health talks in Montreal, unlike in Toronto or Vancouver; people have inadequate knowledge of hepatitis C and think it can be transmitted through air or in general interactions with others; talking about it is a taboo in Chinese community.

**Ottawa**

Believe that blood-transmitted diseases only happen to drug addicts and as we are not drug addicts we do not talk about it; blood-transmitted diseases spread through transfusion and blood donation; but people say nothing about hepatitis C; hepatitis may be related to a genetic problem and transmitted by mother to child; blood-transmitted diseases are scary; do not hear about hepatitis in Canada; know hepatitis A and B caused by consuming too much seafood and alcohol or through malnutrition; know a bit about A and B from China; majority said not issue in community; never talk about hepatitis C; one friend contracted it through a transfusion; another blood-transmitted disease is HIV; people with HIV have complex background and are unlucky and miserable; see information in newspaper occasionally; saw an article about it but was not certain if the information source was reliable – no control over the flow of information; transmitted via H5N1 virus.

## Toronto

**Cantonese group:** AIDS is another disease transmitted by blood; concern whether it can be contracted through donating blood; remember the tainted blood scandal in Canada; do not take it seriously when they have it and do not talk about it; lack knowledge about hepatitis C because it is not talked about much in Canada; people confuse hepatitis C with A and B; question whether this is prevalent in Canada; do not know how people get it.

**Mandarin group:** Because a higher percentage of people in China get hepatitis C do pay attention to this; know that transfusion is a means to spread hepatitis; more discussion about hepatitis C in China than in Canada; do not know how people get it except they may get it when travelling to Third World country.

## Vancouver

As symptoms do not show, people do not realize they have the disease; blood donation is a way of spreading; community does not promote screening for hepatitis C; feel a loss of self control; hepatitis C not normally discussed except when people plan to travel and talk about injection for prevention; inadequate knowledge about hepatitis C including in newspapers and health magazines; information about the disease not readily available; more discussion on hepatitis A and B than on C; only when they have blood transfusions are people concerned about hepatitis C; another disease spread through blood – AIDS; talk about hepatitis B but not much about C as a threat of contamination; worry about dentists who do not take proper infection control measures; worry about infection of blood-transmitted diseases through blood transfusion.

## **Question 6: Where do members of your community go to get information on health issues?**

(Probe: Your doctor, nurse, social worker, pharmacist, herbalist, community organization, public health office, community health centre, walk-in clinic, library, Internet, others?)

### **Calgary**

**Cantonese group:** Due to doctor shortage in Calgary we can only discuss two issues per visit and have to make another appointment to discuss additional issues; funding for workshops comes from Elder Friendly, which applies to the funding source; government health services; health talks and workshops on topics of interest such as osteoporosis; pamphlets are mostly in English; pamphlets from health authority; seldom use websites since they are in English and need to know English name of disease before using these sites; word-of-mouth sharing among friends.

**Mandarin group:** Church-organized centre; educational talks; family doctor; Internet; newspaper; pharmacy; reference materials in library; senior club; word-of-mouth sharing among friends.

### **Montreal**

Booklets; Chinese newspaper; Chinese TV; doctors and their office if we ask direct questions; disease prevention is very important; flyers; friends; health seminars in Chinatown; hospital; Internet; library; newspapers; older generation of Chinese in Montreal do not have annual checkups; relatives or those with the disease; will only be tested for Hepatitis if we look yellowish.

### **Ottawa**

Chinese newspaper; Chinese TV and radio as we do not understand English well enough to get information from English media sources; Chinese website; call my friends in China; community health centre and nurse; do not talk to Chinese herbalist since OHIP does not cover them; doctor most reliable source but in Ottawa there are not enough doctors; educational talks held in community centres are big help; family physicians; flyers; friends; health magazines; health talks; Internet; inability to understand English is a real problem; neighbors; centres providing other Chinese services; outreach health workers; pharmacy; public health; free health magazine from Toronto that is printed in traditional Chinese.

## Toronto

**Cantonese group:** Doctor's office pamphlets; documentaries on radio or TV; friends or co-workers; health fairs; health seminars at Chinese centre; Internet; magazines; newspaper; school.

**Mandarin group:** Books; Chinese health-related magazine; Chinese radio; clinics; community health fair; compared to China – which spreads Chinese language information through the workplace – there is little accessible information; doctor's office pamphlets; documentaries on radio or TV; educational talk; health booklet; family doctor; friends or co-workers; Internet; magazines; need a foundation promoting health for Chinese community in the same way that Heart and Stroke Foundation does; poster; school; seldom deal with Chinese herbalist as they deal holistically and not for a specific disease.

## Vancouver

Books; Canadian Diabetes Association; church; cancer society; Chinese version of B.C. health booklet; doctor's clinic; drugstore; educational talks/seminars; health centre; health magazine; Heart and Stroke Foundation; Internet; newspapers; pharmacists; public lectures; radio phone-in; senior club activities; TV (Chinese); workshop.



## **Question 7: In what ways would you like to receive information on health issues like hepatitis C?**

(Probe: Language spoken/written; visual – videos; in private; person-to-person; workshops  
Probe: What about the media? What format – community television, radio, brochures, newspaper, bulletin boards? Where would you like to have it – in what venues?)

### **Calgary**

**Cantonese group:** Need a system where we can go for information when we need it (cannot remember everything); Chinese newspapers but they are expensive and free papers have little health information; Chinese TV but radio is non-subscription and cheaper; Chinese-speaking doctors assisting at health workshops and materials in traditional Chinese; family doctor (reliable); free health journal such as “*Health Digest*” in Toronto; get information on diabetes from some pharmacists; health information programs on radio; need more flyers and booklets; more health workshops and health exhibitions in Chinese; people actively giving out information; small and interactive workshops not large ones with more than 100 people.

**Mandarin group:** Churches; display board in simplified Chinese; educational programs; health information pamphlets in Chinese; public health to provide Chinese materials; seniors’ groups (especially Chinatown senior’s group); social organization; social worker in home visit; TV; through pamphlets, although 99% are in English.

### **Montreal**

Canada-wide publicity campaign on health issues; desire from those not proficient in English or French for seminars on health in Chinese; Chinese newspaper; Chinese TV or radio not available because of cost; focus group for Hepatitis C patients to share experiences and expectations; from pharmacist; hotline with Chinese speakers; suggest government financially support TV channel to develop health-related program and to develop websites for health information – Taiwanese website has good information; need a Chinese-speaking staff person in community support services department of government; information from social service agencies via health promotional events; more services in Chinese – both Mandarin and Cantonese.

### **Ottawa**

Cassette tape; CDs; Chinese school; Chinese church; Chinese websites; Chinese TV channel on medical issues; community centre information in Chinese; family doctor; health fair; health information in Chinese; health talk; health telephone line; Chinese health magazines edited by Public Health Agency of Canada would provide a central guideline to screen information before distributing and also provide audio information on CDs or tapes; individual counseling by outreach nurse; government public health information in Chinese; information consultation with health professionals on TV or radio; newspaper; monthly magazine from official agencies; need to advocate for government to support the CBC in developing websites and

printing flyers in different languages; only one hour of Cantonese and one hour of Mandarin radio available daily and not many people have access to radio; one-on-one discussions so can discuss health condition privately; official website in different languages; pamphlet; phone-in questions answered at City TV; radio; radio program in Mandarin and Cantonese; TV; unlike Hong Kong where TV channel produced a number of health documentaries it is difficult to obtain health information on TV in Ottawa; videos.

### **Toronto**

**Cantonese group:** Books about the disease; Chinese-speaking health hotline; family doctor; flyers and posters; friends who have the disease; government information on Internet; multi-media format such as DVDs; newspapers; radio; school curriculum; trustworthy Internet source; TV commercials; workshops.

**Mandarin group:** Chinese health-related books and magazines; eye-catching posters in places such as subway or bus stations; family doctor; friends with the disease; health organization; booklets or pamphlets; language-specific health hotline; library; multi-media format such as DVDs; newspapers; newsletters; preventive promotional activities; radio; school plays for high school students; school curriculum; trustworthy Internet sources; TV programs and Chinese TV channels; workplace; workshops.

### **Vancouver**

Booklets; *B.C. Health Guide* in English and ethnic languages; books in library on disease; Chinese newspapers; doctors; health professionals; health-related seminars/workshops by professionals; Internet (trustworthy health sites); newspapers and free community newspapers; radio/TV; sharing experience with those who suffer from diseases (word of mouth); texts; TV – Chinese health channel.

**Question 8: Can you name any successful ways in which your community was involved in a health issue in the past?**

(Examples: CEC diabetes support groups, health fairs, media information sessions, public forum, workshops.)

**Calgary**

**Cantonese group:** Health authority that provides medical education; drug counselling; community visiting nurse with a Chinese interpreter; health workshops; new immigrant women's health organization that provides transportation; health check and health workshop; one diabetes workshop that successfully taught about self-management; self-management general workshop organized by health region (Row Your Own Boat program is a chronic disease management program that charges fees).

**Mandarin group:** Annual health carnival of Calgary organized by Chinese cultural centre that promotes health; diabetes and kidney educational booths by organizations that give health information as part of annual Chinese New Year's eve celebration; education health talk organized by senior's club; health workshop organized by senior's group and Chinese Christian mission; workshop in Mandarin organized by church group.

**Montreal**

One health talk was held by China hospital on heart disease; one health talk held by China hospital on Hepatitis C was not successful because of low attendance.

**Ottawa**

Asian heritage month; Asian health promotional week is good but too broad; diabetes education group; diabetic group studies; diabetes event by agency that used a large poster and Chinese staff to promote – Chinese-speaking person a major reason for success; essential that programs are well organized and well advertised, consistent, and held by knowledgeable professionals; flu shot clinics using posters in different languages; gambling awareness campaign held just before school term with interesting and interactive ways of promoting anti-gambling concept; health fair by Somerset West Community Health Centre; health talks; prenatal class.

## Toronto

**Cantonese group:** A DJ established a charitable foundation to help people with kidney disease; bone marrow donation campaign using TV and other media; Chinese do not express themselves well and enthusiasm cools quickly; important to use celebrities to publicize; news campaigns on West Nile virus, flu shots, and SARS; participation in Terry Fox event.

**Mandarin group:** Chinese radio star with kidney disease promoted a kidney health event and shared her experiences – important to have a star promote health to get attention; commercial promotion on use of natural medicine; education on prevention of infectious diseases; government promotion of flu shots; mainstream health program, such as breast cancer and Terry Fox run; news reports in newspapers and TV; no experience in health promotional events or health fair; public education on how to respond to SARS; publicity in mass media about listeriosis; promote health in workplace.

## Vancouver

Canadian Diabetes Association; Chinese Health Support Group; Chinese Community Health Society; Chinese herbalist suggested that people should see herbalists as they have a more holistic perspective on health and they give workshops once or twice a year; Chinese health support group; drug counter at Costco provides medicine-related information; Heart and Stroke Foundation promotes active lifestyle by sponsoring free public programs and providing free venue for health seminars; diabetes education; Joseph hospital; patients could get discount from drug store after going through four sessions of diabetes programs; pharmacy also provides blood sugar test; S.U.C.C.E.S.S. and other health-promoting organizations.

## **Question 9: What are the best ways to engage/inform your community on health issues?**

### **Calgary**

**Cantonese group:** Chinese churches who often invite health professionals to give talks such as the ones on cancer; Chinese herbalists who talk about healthy eating; Chinese newspaper; radio; senior's club that has helped to mobilize seniors and has organized health workshops.

**Mandarin group:** Chinese newspaper; distribute Chinese flyers in the street; drug store and pharmacist; family doctor; friends; Internet; involve family doctors to learn more about hepatitis C; radio; provide written information; social centre; vaccine.

### **Montreal**

Consult own doctor; emphasize health education in schools; engage doctors, nurses, and medical personnel to go into community to inform people about health issues; have CLSC – neighborhood walk-in clinic in Quebec that does not perform medical treatment – staffed with Chinese-speaking personnel; health officials can organize regular information sessions for community; increase health education budget; more information about prevention; need education talks in Chinese; organize seminars tailored to various age groups; publicity; posters in bus station and at Chinese supermarkets/grocery stores; publish articles in newspapers.

### **Ottawa**

Chinese newspapers; Chinese health magazine; community centre; family doctors do not usually have time to do health education; flyers from clinic are usually in English; government should distribute resources according to the demographic; Internet; monthly newsletter delivered to home; need more Chinese health services and more Chinese-speaking health care providers; need more community centres – especially in Chinese community; people who do not live near centres do not benefit as much so need them in more communities and serving diverse groups; need to get Chinese people to take part in political elections and attend more political activities – something they are not willing to do; need to listen to Chinese people and give them more chances to speak up; newspapers; TV and radio but money is an issue in paying for TV and radio; websites.

### **Toronto**

**Cantonese group:** Chinese churches; need data back-up; refer to health education practices in Hong Kong and China; target three different sub-groups of Chinese (from Hong Kong, Mainland China, and Taiwan); through school and Chinese language schools.

**Mandarin group:** Big poster; Chinese health magazine; Chinese organization to coordinate health promotional strategies and coordinate all the subgroups; Chinese newspaper; conducting health talks and promotional activities at public library, which Chinese love to visit; develop health promotion strategies highlighting a specific topic; develop promotional slogan and different strategies for different age groups (kids, youth, and seniors); distribute Chinese language educational flyer; download health information on MP3; information in free community newspaper; use highway billboards; Internet – health issues as the special theme; inquiry hotlines are good methods; make good use of emails; need Chinese organization to focus on health education; need strong data and statistics; through Chinese churches; TV; use TTC station for publicity; use individuals known and influential in communities; use Chinese Saturday school to teach health information; volunteers distributing flyers in community.

### **Vancouver**

Chinese health magazine; Chinese TV using physician interviews; doctor's clinics; flyers in libraries; have available a health-related consultant; health promotion and education should start at a young age; include health education in school curriculum; information should cover causes, symptoms, treatments, and prevention; information in practical format such as small cards that can be kept; involve the education of Chinese herbal medicine; recruit retired doctor to deliver volunteer health talks; presentations in both Mandarin and Cantonese; through friends and/or relatives who suffer from the disease; TV health channel with specific time for Cantonese- and Mandarin-speaking Chinese; word of mouth; workshops.

**Question 10: What, if any, barriers do you think exist to getting information on health issues such as hepatitis C to members of your community? How could these be overcome?**

**Calgary**

**Cantonese group:**

*Barriers* — Chinese medicine is not legalized, is expensive, and is not covered by health insurance; lack knowledge about health issues; lack time – community members are engaged in many activities; lack money.

*Overcoming barriers* — Improve transportation; must have information in simple and easily understood Chinese; persons who understand English have a limited vocabulary so information in English should be in easily understood language without medical terminology.

**Mandarin group:**

*Barriers* — Lack of available health information; lack of Chinese educational materials; people do not know where to go for health promotional information and activities; transportation is difficult for many.

*Overcoming barriers* — Provide more centres for new immigrants and link them to health-related seminars; provide health information in Chinese; have more government involvement in providing information; provide more resources and money for health promotion; need big banners for publicity; have health focus groups; have health promotional events at workplace; have social worker participation in health promotion.

**Montreal**

*Barriers* — Chinese are apathetic towards health, prevention of disease and take action only when diagnosed with a disease; different sub-cultural Chinese groups react differently to health issues; difficulty getting Chinese-speaking volunteers because culture does not encourage volunteering; Montreal Chinese community is not cohesive – situation in Montreal is different because of dominating French culture; lack resources.

*Overcoming barriers* — Address apathetic attitude towards health prevention; government should set up hotline with Chinese speakers; provide more services in Chinese – 50% in Mandarin and 50% in Cantonese; need more seminars in Chinese about health issues; provide Chinese-speaking personnel in hospitals; government should increase budget for public education on health issues; need more involvement by private health sector; provide more informational flyers and booklets in pharmacies; provide referral services, especially for medical specialists; provide support groups; have a publicity campaign across Canada in different languages to promote awareness of health issues; recruit more volunteers and coordinators to go into community to inform about health issues; social service agencies should provide information on preventive measures.

## Ottawa

*Barriers* — Language biggest problem – even if speak good English do not know medical terms; difficult to use Telehealth hotline because not all interpreters speak Cantonese well; hard to find translator in health system because of difficulty communicating some medical terminology.

*Overcoming barriers* — Government needs to put more resources into developing Chinese services and health information in Chinese; distribute health information through grocery store; individuals should speak up to let the public and politicians know Chinese health needs; need more resources for Chinese health workers – MDs, nurses, and outreach workers; need to get information to people who speak different dialects including Taishan; need a politician, such as city councilor, to speak out for Chinese; use radio and TV to reach wider audience.

## Toronto

### **Cantonese group:**

*Barriers* — Diversity in Chinese community – three different groups (from Hong Kong, Taiwan, and Mainland China); people are busy and do not have time to attend health or educational programs.

*Overcoming barriers* — Educate teachers and medical professionals (such as doctors) about health problems (such as hepatitis C) for this specific community; increase manpower and money for health issues; must have print materials in Chinese language; need long-term sustainable strategy; need one organization with professional knowledge to promote health issues; need support from government in distributing health information; raise knowledge of the public through: (1) placing information in plazas and restaurants, (2) promoting through places where people congregate, such as churches, and (3) using volunteers to increase awareness.

### **Mandarin group:**

*Barriers* — Language is main barrier – need Chinese information (not necessarily simplified Chinese) because more people know traditional Chinese than English; do not know where health promotional activities are held; due to long working hours people are too tired after work to make extra effort to attend health talk or related activities.

*Overcoming barriers* — Need better publicity about health-related activities in Chinese community; educate students in schools; hold programs after office hours or in workplace or churches; must have print materials in Chinese language; information should be given in English and Chinese, not English and French; need Chinese column giving health information on Internet; provide one Chinese organization to coordinate all health promotional events and use health professionals to provide information; encourage community organizations to do more prevention work; target different age groups; use Chinese TV and radio channels to spread health information.



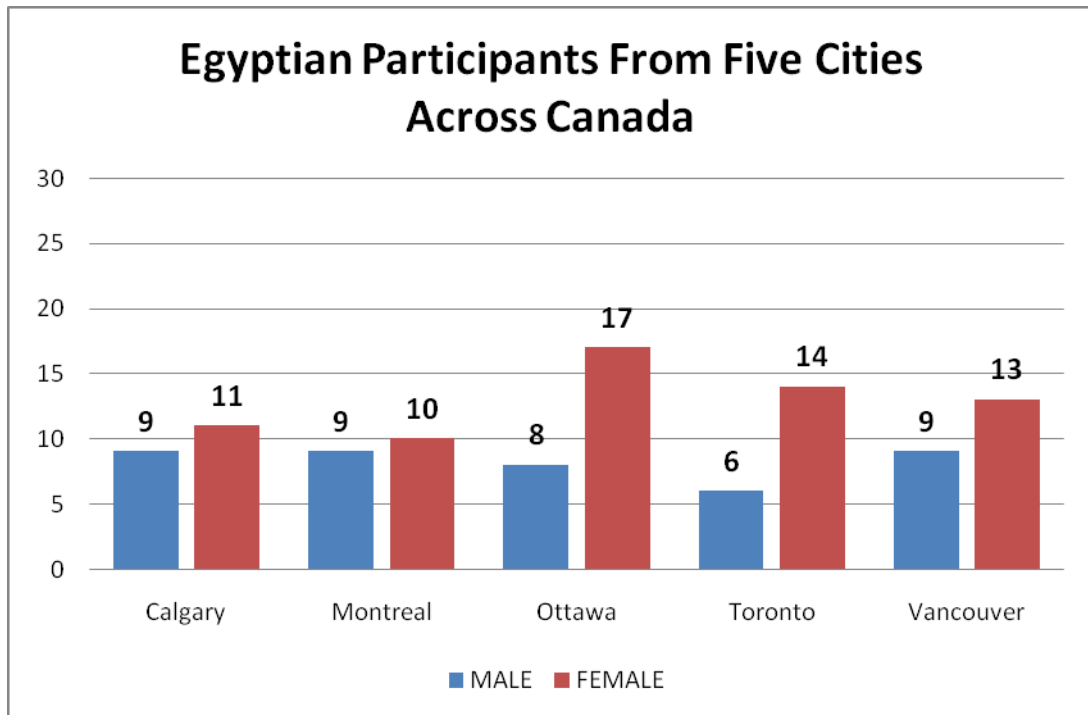
## Vancouver

*Barriers* — Do not know where to get health information; when find information there is too much and unsure whether it is from trustworthy sources; language – information in Chinese is important; lack organization to centralize coordination of health promotion strategies; people not motivated to obtain health information; lack printing resources and finances to rent venues for seminars.

*Overcoming barriers* — Provide Chinese (both Mandarin and Cantonese) version of information sheets; consult health professionals to verify information accuracy; health officials need to emphasize and promote disease prevention instead of only remedial; must explain medical terminology in both English and Chinese; have one centre to coordinate health promotion strategies and screen relevant materials for distribution; have lectures and forums; provide pocket-sized health alert booklets; work to enhance public health awareness; target audience through specialist clinics; target population sectors.

## 4.2 Egyptian

### 4.2.1 Egyptian Focus Group Participants



**Figure 2. Gender Distribution of Egyptian Focus Group Participants**

Figure 2 shows Egyptian focus group participants distribution by gender and by city. In all five cities, there were more female focus group participants as compared to male participants. However, the distribution of male to female focus group participants was nearly equal in Calgary, Montreal, and Vancouver.

#### **4.2.2 Egyptian: Focus Groups Findings**

The following are the responses to the 10 focus group questions discussed at the Egyptian focus groups in each city. The responses are given in random order and in no particular order of importance.

#### **Question 1: What are the major health issues that people in your community talk about?**

##### **Calgary**

Arthritis; Alzheimer's; allergies; backache; blood clots; cancer; cholesterol; diabetes; hepatitis C; heart problems; high blood pressure; hearing loss; menopause; overweight; old age; Parkinson's disease; strokes; strokes with diabetes.

##### **Montreal**

AIDS; Alzheimer's; arthritis; cancer; colds; cholesterol; diabetes; heart, kidney, and liver diseases; mad cow disease; high blood pressure; importance of food and exercise; psychological problems; stress; talk more about the value of food – food that is “*good for you*” – as opposed to health; the community needs to know more about health.

##### **Ottawa**

Alzheimer's; anxiety attacks; arthritis; asthma; cancer; cholesterol levels; colds and flu; depression; diabetes; daily diet; heart diseases; hepatitis; high blood pressure; kidney failure; mental illness; obesity; osteoarthritis; osteoporosis; sexually transmitted diseases; senility; shingles (herpes); tuberculosis.

##### **Toronto**

Arthritis; balancing a style of healthy living; balanced way of raising kids; blood diseases; blood pressure; bone density; cancer; cholesterol; community health; depression; diabetes; diets (anti-oxidants); food and nutrition; heart attack; heart disease; kidney problems; matters of social health and awareness for newcomers; osteoporosis; psychological health; sexually transmitted diseases; stress; the bureaucracy of the health system; Viagra; weather effects on children (rhinitis, flu, etc., from temperature changes).

##### **Vancouver**

Bone density problems; cancer; chemicals in food; diabetes; growing old; hypertension; heart disease; hepatitis C; kidney problems and failure; misdiagnoses; multiple sclerosis; overweight; obesity; diabetes.

**Question 2: What health issues do people in your community *not* talk about?**

**Calgary**

Addictions; AIDS; cancer; hepatitis C; HIV; mental and psychological problems; sexual diseases; vaginal diseases.

**Montreal**

Alcohol addiction; AIDS; cholesterol; health in general is not talked about; high blood pressure; mental and psychological or psychiatric illness; obesity; sexually transmitted diseases.

**Ottawa**

AIDS and HIV; abortion; any hereditary diseases; any infectious diseases; conception; cancer; coma; depression and mental illness; epilepsy; erectile dysfunction and sexual dysfunction; menopause; obesity; psychological problems; schizophrenia; sexually transmitted diseases; suicide attempts; syphilis; tuberculosis.

**Toronto**

Addictions; anything about gays and lesbians; AIDS; bronchitis (tuberculosis); drugs; hepatitis (and its presumed link to HIV); hereditary diseases; HIV; mental health; sex education; sexual diseases.

**Vancouver**

Alcoholism; AIDS; cancer; depression; drug addiction; high blood pressure; erectile dysfunction; stigma attached to hepatitis C; life problems; menopause; sexually transmitted diseases; psychological problems; psychiatric problems.

### **Question 3: What diseases are *not* talked about?**

#### **Calgary**

Addictions; AIDS; cancer; hepatitis C; HIV; mental and psychological problems; sexual diseases; vaginal diseases.

#### **Montreal**

Drugs and alcohol; health in general; mental or psychological illnesses; multiple sclerosis; addictions and pregnancies in families; sexually transmitted diseases.

#### **Ottawa**

Abortion; AIDS and HIV; anxiety; Alzheimer's; any infectious diseases; cancer; coma; conception-related issues; dementia; depression and mental illness; epilepsy; erectile dysfunction and sexual dysfunction; hereditary diseases; menopause; multiple sclerosis; polio; Parkinson's disease; psychological problems; schizophrenia; sexually transmitted diseases; suicide attempts; tuberculosis.

#### **Toronto**

Addictions; AIDS; bronchitis (tuberculosis); drugs; hepatitis (and its presumed link to HIV); hereditary diseases; HIV; mental health; lack of communication between sexes; sex education; sexual diseases.

#### **Vancouver**

AIDS; alcoholism; cancer; drug addiction; erectile dysfunction; hepatitis C; menopause; psychiatric problems; psychological problems; depression; sexually transmitted diseases.

#### **Question 4: What are some reasons for *not* talking about these diseases?**

##### **Calgary**

Cultural and religious background; believe cannot tell doctor; fear of being deserted or isolated; do not want pity; fear of high insurance costs; fear of losing a job (as happened to neighbor who had breast cancer and job not renewed at contract end) or of not getting a job; no benefit to disclose since there is no cure; not wanting to disclose information to marriage partner; pessimism; privacy; superstition in that one will catch it from talking about it – fear it is contagious; sensitivity about the disease; talking about others may bring punishment or “sins” to the individual or individual’s family; this is taboo in Arab culture and religion.

##### **Montreal**

Avoid talking about health problems because of a lack of education; have a lot of misinformation; believe that diabetics will lose their jobs if it is known that they have diabetes; believe that a child who is mentally handicapped is just kept at home in hiding since there is no support for the parents – this is slowly changing with an organization called the *Right to Live*; cancer is also taboo; community gives no support to persons with mental illness although this is changing in Egypt; consider it shameful; cultural – sexually transmitted diseases are taboo since do not talk about sex in general; do not talk about health issues because they are taboo; do not talk about health problems because they worry about marriage or jobs; do not talk about mental illness because of stigma; do not want to disclose having a disease for fear of being ostracized or out of embarrassment; fear of catching the disease from shaking hands; fear of consequences; generational gap where younger persons may discuss this with friends but not parents – a barrier or gap between the way of thinking of older and younger generations; mental illness is equated with madness; stigma attached to some illnesses such as AIDS; they will only talk about Alzheimer’s when they start to show signs of it; this avoidance could be lack of communication but also do not think that these illnesses will attack them one day; talking about health problems is considered a bad omen; want to keep such information confidential.

##### **Ottawa**

Anything related to morals is not discussed; taboo or cultural reasons; do not want people to know that they have a contagious disease; economic impact and stigmatization; family concerns; fear of being judged in a judgmental culture; fear immigration papers to Canada will be rejected if they tell about having this illness and also do not want to tell before getting married; family does not want to be labeled as having a member with an illness, such as manic depression; ignorance; job opportunity limitations if cancer known; low education or lack of knowledge about that health issue; shy.

## **Toronto**

Background; community does not talk about gay or lesbian issues; cultural reasons; discussing diseases is unpleasant unless a person wants to share own suffering with others; embarrassment; family relations – to open up or not; fear; knowledge that a person has a disease may affect retention of jobs or getting a job; lack of confidence; lack of education; lack of information; people do not find it beneficial; personal pride; persons who die of HIV are said to die of another ailment, such as cancer or heart attack (because it is not detected earlier); religious beliefs; shy to talk about diseases that are related to sexual behavior such as sexual activity or what reflects on character; social acceptance.

## **Vancouver**

Assumption is that the community has awareness of the disease; a problem for our culture as we tend to marry from within families (marry relatives and so should be tested before marriage); cultural issue; do not talk about openly because it worries them; in denial and only talk about when someone has the disease; morality; if a person has a disease in our culture people think that he is not complete or has some defect – but not diseases such as heart disease or cancer; not familiar with disease (lack of education); people are ignorant of health issues; people are shy or think it is not a problem; pride – they do not want sympathy; privacy; sensitivity; stigma prevents people from talking about hepatitis C; stigma and morality issues relating to how people get diseases such as AIDS; worry about infectious or contagious diseases.

**Question 5: What about hepatitis C? Is hepatitis C an issue in your community? What kinds of things do people say about hepatitis C in your community?**

(Explain: What is hepatitis C and how it is spread. Probe: What about other diseases spread by contact with blood? What kinds of things do people say about these diseases?)

**Calgary**

An issue in Egypt but not among Egyptian Canadians although cases do exist in Calgary; important for people to communicate about this; not a health issue during immigration process or with Canadian missions (consulates); lack information on hepatitis C; learned that it is more common in Egypt than thought; may have gotten from parents who had; may not learn reasons for which a visa is denied – a positive test for hepatitis C is one reason because someone with renal failure will be a burden on the health care system; *“my dad died from this disease but I was young and did not know the cause;”* must learn about treatment; need much greater awareness; not informed about transmission – maybe through sex or by shaking hands with another individual; may be transmitted by barber and his equipment.

**Montreal**

About 600 million people with communicable blood diseases worldwide; believe that they can get at the dentist, barber, or manicure; belief that it spread in government-sponsored vaccination campaigns that used inadequately sterilized needles or injections; think that prevalence in Canada is 1 to 2% – in Egypt 25% and in some areas as high as 50% among those over 40, but figures not totally believed; community does not know about it because symptoms are not visible; confusion among hepatitis A, B, and C; do not talk about it unless there is a problem in Egypt with a relative; fearful of getting this in trip to Egypt; hepatitis C mostly prevalent in countryside; do not know if there is a vaccine for hepatitis C; medical students report a paper being published about it and research on a therapy; no accurate survey about its origins in Egypt; numbers are not accurate but believe it is underestimated; people coming from Egypt have a lot of misinformation about illnesses; problems of the poor people who die silently in the countryside are not reported; patients do not realize they have it because of lack of symptoms and testing not being required; sharing needles as among addicts; some people do not know they have the virus as it can take 20 to 30 years to manifest itself; tattooing and body piercing; tourism; treatment is expensive and effective in 50% of cases especially among younger patients; worry about getting it from blood transfusion; worry about persons immigrating from Egypt since are not tested for this and it can take years before symptoms show.



## **Ottawa**

Are a high-risk group; afraid of surgery and contracting hepatitis C during surgery; blood transfusions between 1980 to 1985 did not include information about hepatitis C; can get infection from Egyptians living in Canada; companies and factory workers think they will be less efficient or weak and do not talk about illnesses; danger of immigrant population being carriers if come from high risk areas; dentists do not talk about it to prevent people from worrying or so they do not lose patients; know a little about hepatitis A and B and do not know how it is spread; do not know if it leads to cancer and how we are susceptible to it; do not want to know about it since it has no cure; easy to discover; husbands and wives try to hide it from each other; Egyptians discovered it by chance; has four different genotypes; important that dentists and barbers follow sterilization techniques; know more about AIDS and it is sometimes confused with AIDS; many people know nothing about it; necessary for international travelers; not part of life insurance testing; one person had blood transfusion of blood that tested positive for hepatitis C; people in government jobs and those who travel outside the country try to hide it to avoid being banned from traveling; part of immigration testing 10 years ago; people are not aware of it; people do not talk about it; persons with hepatitis C do not get as much attention because it does not kill as fast and they can carry it for a long time; some friends who had it 10 to 15 years ago now have cancer – believe they got it in Egypt; some private insurance will deny insurance to people with hepatitis C.

## **Toronto**

A major disease in Egypt – Bilharzias – leads to hepatitis; also believe that make-up and chemicals can make the liver sick; community as a whole does not talk about hepatitis C; liver disease in Egypt is a major issue; mentioned Pamela Anderson who got hepatitis from sharing needles with boyfriend; others said it was serious and dangerous and has the same effects as HIV – tend to combine these concepts; some attendees did not know what hepatitis C is; some persons do not have symptoms but others do; spread through substance abusers sharing syringes; type C is transmitted by blood but A and B by food or blood to blood.

## **Vancouver**

Aware that hepatitis C is an issue from two very successful sessions that brought people in the field to speak; can be transmitted through razors at barber shops and at manicure places; cirrhosis develops in chronic cases and medicines can help stabilize the condition; costs of routine check and of treatment may be daunting; do not believe that their community needs to deal with AIDS; do not think they should talk about hepatitis C; for acute infections patient treated by doctor; may be transmitted through menstrual blood and from sharing toothbrushes; people on low income or welfare cannot pay for expensive treatment – extended health care (not Government coverage) will cover it; proposal to research hepatitis C transmission between Egypt and Canada was not accepted; should involve youth; this and the dormant nature of symptoms means that patients should be checked for hepatitis C.

## **Question 6: Where do members of your community go to get information on health issues?**

(Probe: Your doctor, nurse, social worker, pharmacist, herbalist, community organization, public health office, community health centre, walk-in clinic, library, Internet, others?)

### **Calgary**

Aerologist, although not common for Egyptians to go to someone without degree in medical science; Calgary health region unit; do not think of community health or social workers; family doctor; family member who is doctor; Internet; Mayo Clinic; nurses; only look for information when it is an issue; peer with same issue; pharmacists more than doctors; some people go to religious leaders (imams) for anything but the younger generation feels a barrier between themselves and the imams who are older and of the old school and may be judgmental about health issues; will get information on hepatitis C from doctors only if already have it – doctors do not give general information; walk-in clinics.

### **Montreal**

A friend in Egypt, although some visiting Egyptians go to Canadian doctors for drugs because they trust them more than in Egypt; some use natural products as an alternative but others question this alternative; ask someone; books; cautious about pharmacies as they want to hook patients on their medications; community health centre; different age groups use different sources of information; doctors although they are too busy to talk and not all doctors are honest; trust the recommendation of the pharmaceutical industry that pushes drugs in an attempt to make money; family doctor; friends; Health Canada website; Internet – although not all information there is correct; pharmacists and doctors; Ralph Nader's list of bad pills; school nurse; social services centre; TV; young use Internet and older ask friends.

### **Ottawa**

Adult children; Arabic magazines; Arabic schools; ask around; booklets; brochures in doctor's office; community organizations; drug information centre in hospital; family member who is physician; family physician; flyers in shawarma places; friend; friend who is a doctor; health food stores; Internet; pharmacist and pharmacies; prefer to read instead of watch TV; prophetic medicine book; religious and places of worship; schools; TV.

### **Toronto**

Ask friends; clinic; community centres; doctor; drugstores; family physician; Internet; library books but this is very limited; pharmacist; radio; TV; Telehealth Ontario.

## **Vancouver**

*B.C. Health Guide*; call-a-dietitian; doctor; health centre; hospital direct call line for information; Internet; media – radio and TV; newspapers; pharmacy; sometimes do self medication using brochures in clinics because doctors do not have time to explain everything; walk-in clinics.

**Question 7: In what ways would you like to receive information on health issues like hepatitis C?**

(Probe: Language spoken/written; visual – videos; in private; person-to-person; workshops. Probe: What about the media? What format – community television, radio, brochures, newspaper, bulletin boards? Where would you like to have it – in what venues?)

**Calgary**

Airport; awareness week program; trains and buses; Canadian embassies abroad; CDs and DVDs; churches; community pharmacist; dental offices; faith book; family doctor offices or waiting rooms; hospitals; Internet; laboratory waiting rooms; LRT; libraries; passport office; PowerPoint presentation; presentation in mosque (although in this multicultural community the mosque is also for other cultures, during the khutbah speech because the imams are influential); schools and universities; travel agency and guides; expanded travel Canada booklet information; TV and radio; universities; walk-in clinics through presentations on various issues; x-ray waiting rooms.

**Montreal**

All media especially local Arabic newspapers; cafés; churches; community centres; community local newspapers; ethnic TV programs; Facebook especially for youth; flyers; lectures and workshops; mosque; nurses; points of travel; passport office or travel doctor; public citizen's groups; pharmacists; radio; satellite – dish-network; religious places; seminars; shopping centre in area with high concentration of Arabs; special media such as satellite channels in Arabic; specialty stores like the Middle Eastern stores; TV ads during Egyptian soap operas and sports; where people hang out; visual – both spoken and written information.

**Ottawa**

Brochures; booklet and pamphlets; churches and mosques; CHIN Radio; community and faith leaders; documentary; Egyptian associations; Egyptian Canadian Cultural Association of Ottawa; Egyptian embassy (although then it becomes a political issue); ethnic celebrations; Egyptian TV program; Egyptian website; email list; events held by both Christian and Muslim Egyptians; Facebook group; feast or Eid time gatherings; interactive forum presentation; interview doctor; mosque; programs with incentives to get people to attend; radio; talk presented at social gathering; TV; *“tell me and I will forget, show me and I will remember, involve me and I will understand”*; satellite channels such as the Egyptian Channels; social gathering with food; YouTube; workshops; written information sheets; websites with information in Arabic.

## **Toronto**

Airports; Arabic journals; available online; awareness sessions; brochures; CDs; flyers in each language when blood donated; community centres; explained in own language at worship places; flyers in clubs; hospitals; information (immigration) packages about major health issues such as hepatitis C, HIV, and sexually transmitted diseases; Internet; jails; malls; Ministry of Health newsletter with statistics; trends and latest diseases; newspapers; online video from health organizations; public library; public shelters; radio; rehab places; schools; simplified and detailed information; sports clubs; transit stations; TV ads; videos; verbal information; visual methods are fastest and easiest; worship places; written material; workshops.

## **Vancouver**

Advertising; *B.C. Health Guide* information; doctors must inform those who have disease; email – in secret otherwise people will say that all Egyptians have hepatitis C; Facebook; from family doctors and good speakers in schools; good TV programs on health on the community channel; pharmacy; lectures by health professionals; online website; social services; talks; TV documentary; visually presented in sessions; talks by experts.

**Question 8: Can you name any successful ways in which your community was involved in a health issue in the past?**

(Examples: CEC diabetes support groups, health fairs, media information sessions, public forum, workshops.)

**Calgary**

Moral support; financial and other support provided individually for friends; breast cancer awareness in community at large; consider that Egyptians in Canada are very highly educated and do not need more information (some focus group participants); donating to health causes like breast cancer; donations for cancer ribbon that create more awareness.

**Montreal**

Examples from other places: (Ottawa – mothers organized an information session for girls approaching puberty; Toronto – Canadian Islamic Congress sponsored walk-a-thon for breast cancer victims); Montreal – awareness campaign for blood donation in Brossard; Muslim student association at Concordia and McGill involved in breast cancer awareness campaign – a walk-a-thon organized by Islamic group; no specifically Egyptian initiative as Arabic-speaking Egyptians integrated well into the community.

**Ottawa**

Egyptian Canadian Cultural Association of Ottawa; high schools – as we do for AIDS and smoking but doing it to general public as opposed to communities; blood donation sessions; breast cancer drive by the association and another by the mosque; CHIN Radio 97.9 talked about leukemia and advertised blood donation drives; fundraising dinner for money for cancer in Egypt; lecture about girls and maturity; multiple sclerosis; pharmacists that are now retired used to go to high schools and give public lectures about AIDS and smoking; TV program; workshop exercise on what we are doing.

**Toronto**

Community helps on individual but not systemic level; gathering places; information in community centres; hospitals; in Ottawa Egyptian community asked a doctor to give lectures for growing girls about body changes they will encounter; jails; malls; public libraries; public shelters; schools; transit stations.

**Vancouver**

Cancer survivor walks for donations to cancer research; community organized to send medications to earthquake victims in Egypt; doctors spoke to community about hepatitis C; food banks; ongoing blood donation drive every five months by Muslim students that is so effective that more students show up than can be handled; two successful lectures on hepatitis C.

## **Question 9: What are the best ways to engage/inform your community on health issues?**

### **Calgary**

A social gathering with health issues as an advertised part of the gathering will probably not attract people nor would they like to have health issues added to what they thought was purely social; use Egyptian doctors to lecture on health issues; give presentations to your people; give incentives to encourage people to participate; Public Health Agency of Canada should distribute more information; if friends get sick people get engaged; Internet; larger-scale workshops; make information available at places of work; motivate people to know about the health issues – one-on-one communication; negatives may stop Egyptians from seeking jobs outside Egypt because they may not get work visas; not enough awareness even among the doctors; places of worship; religious institutions – mosques and churches – because religious leaders are influential; invite a speaker to religious places; tell how they can protect their kids; TV; workshops to educate the public and prevent the disease from spreading.

### **Montreal**

Address the issue in specialized media; awareness should not be only directed to ethnic groups – in other words *“my barber should know since I could get infected through him”*; be sensitive to generational differences; doctors and nurses should give time to community – meet members individually and give advice; Egyptian consulate in Montreal should be involved – for example, during the special day of Ramadan that they organize for all the Egyptians; Egyptians have a very high risk of getting it since it is all around; government has a role to play in educating – need more aggressive education about hepatitis C; give information on where screening is done; motivate people; give data on the disease; get people’s attention and raise interest and awareness by explaining why this is important; explain that our priority is ourselves; emotional approach, such as asking people close to you who have it; need doctors from within community who are aware of the prevalence of a disease within the community – not native Canadian doctors; need doctors who know terms in Arabic; potluck dinners; teach the young people about this at an early age – ethnic or even public schools; people confuse the different types of hepatitis (A, B, and C); use Sunday schools for awareness campaign; use understandable language – not jargon; use websites aimed at Arab communities and Egyptians.

### **Ottawa**

Catch their attention through handouts; encourage early testing to enable suppressing the disease; should be a routine test during checkup; for drug addiction prevention target children and youth; general information will reach our community; hepatitis C needs to have strong activist telling about the disease; increase awareness about infections and their transmission and vaccination to prevent; may become a law by immigration to have test for hepatitis C prior to approval to immigrate; must increase awareness and not just find out whether people have hepatitis C; non-governmental group to launch campaign against virus; it will always be

on the back burner unless we have a strong advocate group to campaign about it; people are hesitant to find out about disease or get tested because they worry about jobs, immigration, and marriage; public service use the large umbrella that the Heart and Stroke Foundation does to ensure that Egyptians are included; start by educating kids at young age; through religious places; TV ads.

### **Toronto**

Arabic schools; awareness should start early; community centres; focus on teenagers and youth; include incentives; lectures – train-the-trainer model; Saturday schools for language classes; schools; university; word of mouth; workshops; places of worship.

### **Vancouver**

Dinners and social gatherings – people like to socialize around food and people who are motivated and passionate on the issue should be involved; doctors all over Canada should know to test Egyptians at large for hepatitis C; Egyptian associations; Egyptian community in Vancouver is highly educated and can access information on their own (see no need to target Egyptian community) so education should target society at large; have doctor from the community give information on health issues such as hepatitis C; people who are knowledgeable about the issue; social gatherings – a speaker at dinner who talks about issues; some do not want to involve religious leaders while others feel that talks at the Burnaby mosque have been successful; target large Chinese population in Richmond because they will be potential risk for society; through education; travel doctors; work with embassy for those who travel to and from Egypt.



**Question 10: What, if any, barriers do you think exist to getting information on health issues such as hepatitis C to members of your community? How could these be overcome?**

**Calgary**

*Barriers* — Language barrier – need someone from Egypt to explain in the language; lack awareness; cultural barrier – people are not concerned about prevention and only react when it happens to them; denial – do not want to know and believe there is no cure so will not worry; lack time to attend lectures; have no information because it is not a sexually transmitted disease; many superstitious people keep quiet because they believe that talking about something too much will bring it to you; pride in country important – do not want to believe that Egypt is a bad country because of such a disease.

*Overcoming barriers* — Translate information into Arabic; give adequate information about benefits of seeking treatment; give statistics about the disease; information should be in a spoon-feeding mode or through Internet; need more effective marketing plan to spread information; parents need knowledge to educate kids; include health information in landing process and at embassies; need detailed information on transmission; need more information sessions and lectures on general health issues at universities; a friend who went to China for treatment after being given three months to live is now fully recovered; use the media; community needs to be frank about health situation with ourselves.

**Montreal**

*Barriers* — A great language barrier in Canada and an illiteracy barrier in Egypt; believe that testing should be done prior to coming to Canada before individuals start to mingle with Canadian society; belief that it will not happen to individual; cultural barriers such as shame in illnesses like this; community not disposed to deal with this information; denial; difficulties in finding Egyptians in Montreal – the associations are not very active; do not ask because not certain source will be confidential; fatalistic or ignorant attitude; hepatitis C testing not required for students; want to keep country's reputation unsullied; lack information on how hepatitis C is spread; lack interest in health issues; stigma or fear in just seeking this information; government neglect – tourism offices will not talk about the disease as that could give Egypt a bad reputation and drive away tourists.

*Overcoming barriers* — Can overcome fear by having a trusted source of information who keeps things private and confidential; detection of hepatitis C should be part of testing for immigrants – some want this and others fear discrimination; concern about visitors who might be carriers so infect others – should test visitors first; have awareness campaigns in places such as restaurants, gymnasiums, and Arabic cafés; have to raise awareness for everyone and form committees; provide information in Coptic churches; provide information on church and mosque websites; have information and awareness campaigns; provide screening on routine basis; religious leaders are a respected source of information but no Egyptian mosque in Montreal as there is in Ottawa; information through websites and TV.

## Ottawa

*Barriers* — Major barrier is language; all communities need awareness, not just Egyptians; community is complacent; cost of treatment, as injections are expensive; denial; government does not screen for HIV if from a different country because screening tests vary by country; fear of infection; fear losing job opportunities and insurance; financial problems – cannot reach some with information and some do not have family doctors; ignorance about health issues; do not know if cure exists for carriers with no symptoms; no information campaigns or sense of urgency on situation; OHIP does not cover treatment; there is no cure or vaccine, treatment is lengthy and ugly, and success rate is low; parents and grandparents are at increased risk; people worry about marriage; political refugees are not tested for HIV; statistics do not show that Egyptian population in Canada has increased risk; stigma.

*Overcoming barriers* — Need flyers in Arabic; provide brochures at doctor's office and information through dentists; CHIN Radio station has physicians; Egyptian satellite channel with daily health issues should give talk in a Canadian context; Egyptians doctors have big role in educating; need recommendations about cost of treatment; health care professionals should talk to different generations; believe that hepatitis C virus spread by blood contact, tattooing, pedicure, toothbrushes, and household items; increase awareness as it is not a big issue in Egypt and Canadians do not know prevalence of hepatitis C; provide information in café or local magazines such as *Metro* and *Muslim Link*; keep telling about it; give information about why they should be tested – most people with disease have no symptoms but can transmit the disease; clarify method of transmission; need to be tested before marriage and provide general medical history; need to know relationship between bilharzias and hepatitis C; provide information through schools, radio, journals, brochures, pamphlets, free newspapers, telephone information, and regular mailings; family member who learns should tell others; need TV commercials to spread information.

## Toronto

*Barriers* — Some care about hygiene and cleanliness but not many are careful; language a major barrier; lack of interest in topic based on probability of getting it; cultural barriers; people do not give health priority – only care about what they get or suffer from; financial problems; hesitation to talk about; lack awareness about topic; fear of not getting insurance; too busy with work; traditionally not interested in health issues.

*Overcoming barriers* — Arab doctors should start awareness campaign to educate community; becoming aware and cautious helps prevent it; monthly lectures at high schools conducted by specialized doctor about a serious disease with a brochure or handout; have children bring information home from school; need Arabic community centre to get community together; need reach-out programs – volunteer is not enough; do not know what to do about it; open up and speak to doctors; social awareness important.

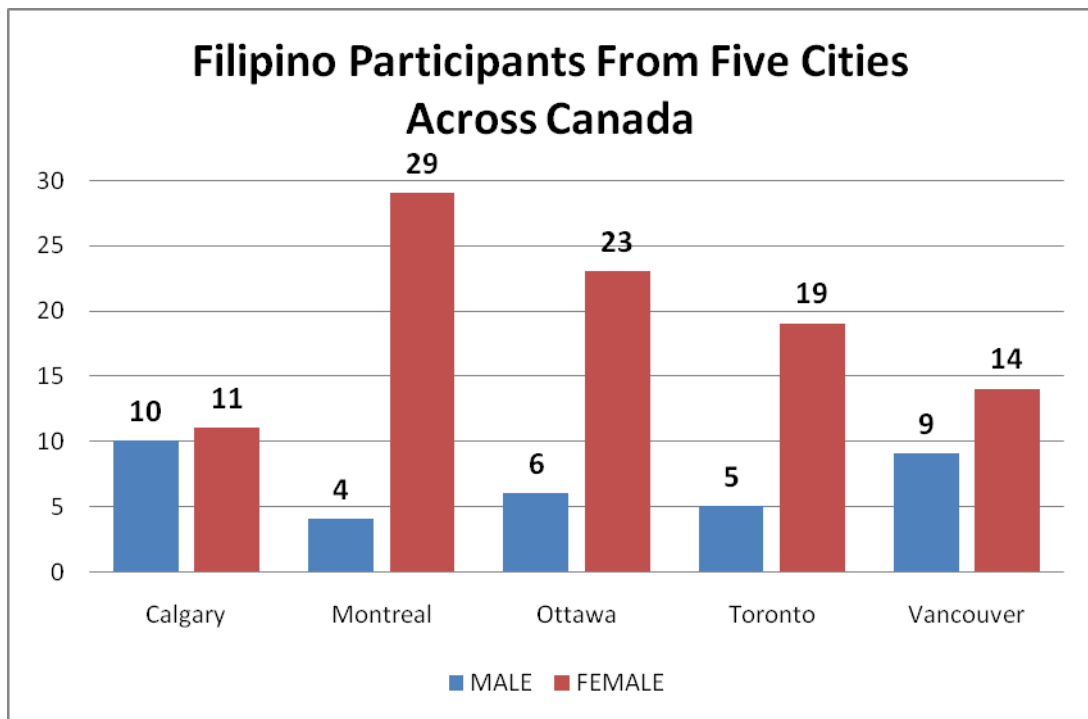
## Vancouver

*Barriers* — Stigma – fear being ostracized or shunned by community; lack awareness; cultural – will deal with it when it happens; do not read about hepatitis C if do not have it; fear – do not know if can be treated so do not want to know; financial; Government of Canada does not hold conference on hepatitis C; health professionals do not promote prevention; persons who read about it fear that they have the disease – do not want to know; language problems; people are lazy – why should they know everything; older immigrants do not believe in preventive medicine; privacy – certain topics, such as health issues, are taboo; screening for diseases has failed with immigrant groups because will go to doctor only when sick; will not disclose having hepatitis C to prevent being ostracized; would be offended if doctor wants them to be tested because of nationality.

*Overcoming barriers* — Communication and education; children and youngsters should educate older people by taking information from school to parents; ethical obligation to learn if have hepatitis C so can prevent spreading it; physicians should talk to patients but do not have time and a lot of misdiagnosis; health professionals should combine efforts – pharmacists have different disease days for promotions such as a hepatitis C day or diabetes day; need visual communication instead of printed; awareness and sensitization are important especially in suggesting that it is a good idea to be tested; test persons from countries with high incidence of hepatitis C, but this may prevent immigration.

## 4.3 Filipino

### 4.3.1 Filipino: Focus Group Participants



**Figure 3. Gender Distribution of Filipino Focus Group Participants**

Figure 3 shows the gender distribution of focus group participants from the Filipino communities in the five cities. The female to male ratio of focus group participants was disproportionately higher in Montreal, Ottawa, and Toronto; the number of female focus groups participants was also higher in Vancouver. In Calgary, the distribution of male to female participants was nearly equal.

### **4.3.2 Filipino: Focus Groups Findings**

The following are the responses to the 10 focus group questions discussed at the Filipino focus groups in each city. The responses are given at random and in no particular order of importance.

#### **Question 1: What are the major health issues that people in your community talk about?**

##### **Calgary**

Anxiety; the aging population; adjusting to the way of life in a new country; cancer (breast, lungs, and ovaries); diabetes; depression; eating habits; fibroids; heart disease; high blood pressure; high cholesterol; high cost of insurance for those with high cholesterol; hepatitis; hepatitis C leading to cancer of the blood and liver; lifestyles; Lipitor usage affecting the liver; psychological factors; physical disability; tuberculosis; work-related stress.

##### **Montreal**

Alcohol and drug abuse; allergies and skin problems (psoriasis); Alzheimer's; old age; arthritis; cancer; cholesterol; cardiac disease; depression due to cultural crisis (cultural shock); dementia; diabetes; diet and nutrition and ignorance about these; economic problems; eye problems; gambling; highly salted foods; hypertension; hepatitis; families have no social life together and experience marital problems and loneliness; food – diet food and junk food; incest; isolation; lack of physical activities resulting in obesity; mental problems; most youth seem to be wearing glasses; osteoarthritis; osteoporosis; physical fitness; psychiatric problems related to family separation and lack of bonding; social problems; stroke; seniors have no social life; thyroid problems.

##### **Ottawa**

Allergies; arthritis; aging; cancer (prostate, reproductive system); depression; diabetes; elevated cholesterol; heart problems; high blood pressure; liver disease; nutrition; obesity; old age; osteoporosis; over-medication; stress; too much drinking; tuberculosis.

##### **Toronto**

Allergies such as pollen and ragweed; Alzheimer's; arthritis; constipation; cancer in general; liver cancer; cost of medications not covered by OHIP; diabetes; problems with digestive system; gout; hearing impairment; heart problems; high blood pressure; high cholesterol; joint pains and body aches; liver problems; medications; memory loss; obesity; problems when new immigrants can not receive OHIP cards before the mandatory three months wait; sandwich generation; sharing experiences; sleeping problems; type 2 diabetes; taking herbal medicines without understanding side effects such as constipation; waiting time for some

treatments; weight – need for exercise and balanced diet; over-prescription of different drugs that may interact and produce negative side effects.

### **Vancouver**

Alzheimer's; arthritis; cancer (colon, intestinal, ovarian, and breast); costs – for drugs to treat these conditions and lack of money to pay amount not covered; decrease in activity and exercise; diabetes; especially afraid about the disease and a need to know more about that disease; gout; heart problems – elevated cholesterol, heart attacks, hypertension; kidney problems – increase in numbers of persons with problems and late diagnoses that result in treatments needed quickly; malnutrition and decreased awareness of nutritional content/values of food available in the market; obesity and increase in patients with weight problems; sexually transmitted diseases; venereal diseases and AIDS.

**Question 2: What health issues do people in your community *not* talk about?**

**Calgary**

AIDS; Alzheimer's; cancer (uterus); drug addiction; hepatitis (A, B, and C); HIV; insanity; leprosy; mental disabilities; mental health issues; physical disabilities; sexually transmitted diseases; skin diseases; depression; leprosy; tuberculosis.

**Montreal**

AIDS; Alzheimer's; cerebral palsy; drug use; emotional problems; extramarital relationships; gambling; HIV; mental problems; obesity; Parkinson's disease; sexually transmitted diseases; social problems.

**Ottawa**

AIDS; age; alcohol; cancer; drugs; gonorrhea; hepatitis; mental problems; stress; obesity; sexually transmitted diseases – social diseases.

**Toronto**

Cancer (colon, breast, lung, and pancreatic); erectile dysfunction; hepatitis; liver problems; mental health issues; psychiatric issues (such as depression, schizophrenia, or bipolar).

**Vancouver**

AIDS; anorexia; bulimia; hepatitis C; mental problems; psychological problems; depression; sexual dysfunctions; sexually transmitted diseases; tuberculosis.

### **Question 3: What diseases are *not* talked about?**

#### **Calgary**

Abortion; AIDS; drug addiction; hepatitis (A, B, and C); HIV; leprosy; mental disabilities such as slow mental development; physical disabilities; mental health issues such as depression; sexually transmitted diseases; skin diseases such as leprosy; tuberculosis.

#### **Montreal**

Alcoholic addictions; AIDS; autism; attention deficit disorder; battery or abuse; cancer; cerebral palsy; drug use; erectile dysfunction; economic problems; hepatitis C; gambling; incest; mental problems such as depression; obesity; tuberculosis.

#### **Ottawa**

AIDS; alcohol; Alzheimer's; cancer; dementia; drugs; hepatitis; HIV; mental illness – schizophrenia, mental problems, and stress; obesity; tuberculosis.

#### **Toronto**

AIDS; attention deficit disorder; Chlamydia; cancer in general; breast cancer; gonorrhea; hepatitis; HIV; liver failure; psychiatric issues such as depression; kidney failure; syphilis; sexually transmitted diseases; tuberculosis.

#### **Vancouver**

AIDS; hepatitis; hepatitis C; mental problems; psychological problems and depression; sexual dysfunctions; sexually transmitted diseases; tuberculosis.



#### **Question 4: What are some reasons for *not* talking about these diseases?**

##### **Calgary**

Cultural sensitivity; discussing diseases may be offensive; do not want to talk about contagious diseases such as leprosy for fear of being excluded or isolated from the group; too personal; may bring shame to family; moral issues; not enough knowledge about the disease; some issues are very sensitive; too shy to talk about it.

##### **Montreal**

Denial; feeling ashamed of having hepatitis C; other socially unacceptable things such as gonorrhea and HIV are kept quiet – there is embarrassment and stigma to having these diseases; feeling of guilt; isolation; parents are ashamed because of the stigma – they do not want anybody to know.

##### **Ottawa**

Ashamed to talk about it; confidential; do not want to worry loved ones; fear of transmitting communicable diseases; ignorance of the problem; inadequate information about the disease; jobless mother will not report incest; lack of communication; lack of knowledge; limited education; personal; scared; social stigma; tend to ignore; to be forthcoming about the presence of an illness could affect eligibility for insurance coverage.

##### **Toronto**

Afraid to discuss; community and family do not talk about diseases; belief that psychiatric diseases are inherited; do not want to be recipient of pity; fear and shame in discussing these issues at work; fear of sharing disease with co-workers in day-to-day encounters and shame of having disease; having illness is personal; ignorance about disease; individuals do not want to have people talking about them; keep knowledge of having disease private; lack of education and awareness; little understanding of HIV and fear of being shunned if one has it; pressure from work or family not to share information; stigma (especially around mental health issues) or shame attached to disease; diagnosis of breast cancer is like a death sentence; stigma related to liver diseases; talking about these things is embarrassing.

##### **Vancouver**

Are in denial and refuse to learn about the disease or medical problems; cultural reasons; do not believe they are sick because have no symptoms; do not see priests in hospital unless giving last rites – people who have faith have no problems with suffering; do not want to talk about negative things; hepatitis C is not talked about because do not know any Filipino people who have it; embarrassed to have this illness; health issues are avoided because they are uncomfortable; must cheer up others and give positive ideas and support rather than discussing topics of illness; they support ill persons by their presence; religious individuals do not want to see a priest as this connotes death; stigma attached to mental problems; they do not want others to be upset so ignore discussions of disease or related issues; topic is depressing.

**Question 5: What about hepatitis C? Is hepatitis C an issue in your community? What kinds of things do people say about hepatitis C in your community?**

(Explain: What is hepatitis C and how it is spread. Probe: What about other diseases spread by contact with blood? What kinds of things do people say about these diseases?)

**Calgary**

Liver disease spread by direct contact with the blood or an infected person; it is a sensitive issue; disease of liver generally contracted by blood transfusion and associated with inadequately sterilized medical equipment; do not talk about hepatitis C or HIV; fear of hepatitis C because it is severe, contagious, affects persons in their later years, and can progress into cancer of the liver; hepatitis A is spread through eating or drinking contaminated food or water; hepatitis B is spread through blood contact with any body fluid of an infected person; hepatitis C can be serious but is preventable; only transmitted by person-to-person contact; other diseases transmitted by blood – AIDS and tuberculosis; people do not talk publicly about disease; prevent by avoiding blood to blood contact; some know of hepatitis C through the media and others lack information about it.

**Montreal**

Confidentiality of Canadian Government focus group on hepatitis C awareness and prevention questioned; denial and ignorance on subject in community; have brochures with more information; hepatitis C has no vaccination and is transmitted by blood; is the root of infection for HIV; takes 20 years to appear; other diseases spread through blood are venereal diseases; vaccination for hepatitis B, which can be transmitted by body fluids.

**Ottawa**

AIDS and tuberculosis are other diseases spread by blood; HIV; hepatitis is supposed to be airborne; Jehovah's witnesses refuse to have blood transfusions; is not an issue in our community.

**Toronto**

Community does not have enough information about hepatitis C; hepatitis C is barely discussed in community and not advertised as compared with vaccination against hepatitis A and B; hepatitis C is not talked about much in Filipino community; know that people with yellowish skin have liver disease; only use term hepatitis when have symptoms such as jaundice or yellow discoloration of skin; know of other diseases spread by contact with blood (AIDS, HIV, and hepatitis B) but people also do not talk about these; other diseases spread through blood are spread by blood transfusion and tattooing; people do not know they have the disease; said that HIV/AIDS is spread by contact with blood and by sex; some say that hepatitis C comes from contaminated food and too much alcohol; they may be stuck at home because it is very contagious.

## **Vancouver**

Hepatitis A and B are somewhat familiar but persons who hear about hepatitis C downplay or ignore it; because symptoms are not felt, even those who are diagnosed refuse to accept it; have misinformation about it; community does not know probably because they do not hear much about it (when did they first discover this hepatitis C, anyway?); doctors do not list it as the cause of death; no Filipino health or community units are available; not many know about hepatitis C; some confuse hepatitis A and B when persons actually die with hepatitis C.

**Question 6: Where do members of your community go to get information on health issues?**

(Probe: Your doctor, nurse, social worker, pharmacist, herbalist, community organization, public health office, community health centre, walk-in clinic, library, Internet, others?)

**Calgary**

Community health centres; family doctors; family health clinics; Filipino association; flyers; herbalists; hospitals; Internet; library; magazines; newspaper; nurses; pharmacies; social worker; TV.

**Montreal**

Associations; CLSC; community workers; doctors especially family doctors; friends or close family members; health workers; Health Canada; herbalist; Internet; media; newspapers; nurses; pharmacy; public health clinic; TV.

**Ottawa**

Brochures; Canadian websites; computers; doctors' offices; family physician; focus group meetings; health ministry; encyclopedia; health professionals; Internet; medical clinics; public health centres; school flyers sent home with kids.

**Toronto**

Community groups; family; family doctor; Filipino nurses; focus group; friends; health care centres; hospital/health care workers; Internet; pharmacist; public health; seniors; seniors' organizations and other community groups; walk-in clinics.

**Vancouver**

Books; brochures; community newspapers are available at Filipino restaurants or stores – these sources are better for people who do not use computers; family doctors if they have time; family doctor's office – both visits and brochures; Internet; magazines; mainstream community health centre; media – radio; papers; pharmacy waiting area; social events; TV; walk-in clinics.

### **Question 7: In what ways would you like to receive information on health issues like hepatitis C?**

(Probe: Language spoken/written; visual – videos; in private; person-to-person; workshops. Probe: What about the media? What format – community television, radio, brochures, newspaper, bulletin boards? Where would you like to have it – in what venues?)

#### **Calgary**

Associations; brochures; bus terminals; church groups and bulletins; concern expressed that information should not be limited to hospitals but also available in schools; email; food courts; forums; government involvement; groceries and stores; individual help; information in airports; media; multi-lingual approach; mail; newspapers including Filipino newspaper and publication; offices; personal information (from doctors, seminars, and workshops); pharmacies; radio; shopping centres; train station; TV; videos.

#### **Montreal**

Brochures; doctors; groups that can communicate in dialect through Filipino nurses association; information targeting the ethnic community; interactive health workers; lectures; media; medical group; newsletter; newspapers (local English, Tagalog, French); one-to-one basis; seminars; TV; workshops.

#### **Ottawa**

Brochures; bulletin; mail; community newspaper; discussion groups; email; focus groups; family doctors; flyers; Internet; local news; newspapers; one-on-one with health professional; pamphlets; phone; radio; TV; workshops; would like to receive in French.

#### **Toronto**

Ads in Filipino newspapers; brochures; Canadian Liver Foundation; TV show (*Citypulse*); community newspapers; different community centres; discussion groups; email; government-sponsored TV; group discussions in places accessible by public transportation or get volunteers to transport seniors to sessions; hold focus groups; hotels; information in English is all right; in Filipino associations; Internet; lectures; library; media; newspapers like *Toronto Star*; person-to-person; presentations in first language; seminars; TV; use graphics and drawings to educate younger generation; workshops.

#### **Vancouver**

Announcements on Filipino radio station; brochures; captions in Filipino shows; commercials during Filipino shows or programs; educate students in classrooms; Filipino nurses to give community talks to raise awareness; hepatitis education sponsored by public health (a preventative approach by doctors); family doctors; focus groups; get information verbally because many do not read; health ads placed on regular basis; health care workers spreading

information in community; social or cultural events or in short medical ad; information in church bulletins; information in Filipino magazine or newspaper; information sessions in schools; information sessions or focus group on topic; information sheets or brochures in Filipino stores; need a strong group of volunteers dedicated to making a difference; nurses or other health care providers speaking in communities on regular basis; social gatherings with a TV playing information about hepatitis C for those who want to watch; TV; videos or CDs or unidentifiable person speaking about the experience with illness.

**Question 8: Can you name any successful ways in which your community was involved in a health issue in the past?**

(Examples: CEC diabetes support groups; health fairs; media information sessions; public forum; workshops.)

**Calgary**

Community newspapers and newsletters; diabetes association event with seminar speakers such as a Filipino doctor; health fairs such as annual fair conducted and sponsored by Filipino-Calgarian Rotarians that is advertised in the parish newsletter of Holy Trinity Parish; Radio Filipino; spearheaded information and examinations given at a church.

**Montreal**

Broadcasting health information; community to come together when there is an identified problem as has happened in the past; brochures; diabetic sugar and blood testing by Filipino Nurses Association of Quebec (FNAQ) for seniors; media information; nurses health awareness for community; nurses volunteered at a blood pressure clinic at the centre but very few people came as there was little interest; focus groups; Filipino papers – language is an issue; Federation of Filipino Canadian Association of Quebec (FFCAQ) and FNAQ passed a resolution giving priority to health issues.

**Ottawa**

No one ever heard about, was aware of, or involved in hepatitis C; senior members of Filipino Canadian Association of the Ottawa Valley were involved in a study regarding medications for seniors; treatment of seniors in hospitals and handling of referrals.

**Toronto**

Held healthy eating seminars/workshops with invited guest speakers; Heart and Stroke Foundation gave a lecture on nutrition; hold group meetings and workshops; invited police to talk about drugs and bullying in schools; helpful to share experiences in informal groups; ongoing workshop on various topics (such as andropause, menopause, and Alzheimer's); our senior's groups use pamphlets from CEC on diabetes as guide for exercises and proper diet; seminars at Filipino centre on health issues; speakers (including people from CNIB and CCAC) on how we can access assistive devices (such as wheelchairs, walkers, and hearing aids for seniors); Philippine Heritage Band and CEC held focus groups with older adults and youth on diabetes (youth play in a band and parents come to practices and socialize).

**Vancouver**

Currently no Filipino support groups on health; health and health issues are generally not talked about and there are no support groups where these issues are talked about (only perhaps in alcoholic and non-alcoholic groups); information (but not about health) comes from immigration offices; no Filipino support group known for hepatitis C – it has a social stigma attached.

## **Question 9: What are the best ways to engage/inform your community on health issues?**

### **Calgary**

Activities such as fun walk or fun run; bingo socials – part of awareness program before beginning to play because there is a captive audience; brochures; community papers; commercial and TV ads; concerts for a cause; concerts for young people; Filipino radio and TV programs; giving out flyers; house-to-house campaign; media – particularly TV and Internet; jazz and rock bands; multicultural media; newsletters; pamphlets; parties – they will come where there is food and then disseminate information; using volunteers; visuals.

### **Montreal**

A Filipino to coordinate different organizations; focus groups and follow-up on the focus group issues; flyers; government should provide infrastructure support to get the community engaged; involve local newspapers and churches where most of the community goes; include information on hepatitis C with FFCAQ and other associations; information on prevention of hepatitis C; make hepatitis C a part of agenda in meeting; media to focus on health issues; need a focused health study – a continuity of focus group to get community leaders to educate members of the community; need more funding for other groups such as the voluntary group *Panday Tinig*; newspapers; networking among organizations to make a core group; organize session of health issues like taking blood for testing; resource persons on different topics; regular workshops; testing for hepatitis C must be mandatory so that they can get accurate statistics – although that can be viewed as an infringement of personal rights; the community is not centralized and each organization must be specifically approached; need to continue funding the focus group; use WHO statistics to explain why we are only now learning about hepatitis C.

### **Ottawa**

Biblical perspective – taking care of your body because it is the temple of God; brochures or pamphlets; church groups; distributing pamphlets; encourage friends to participate; information sessions; media (newspaper *Pinoy Eh!*, radio program *Tinig Pinoy*); physical health follows spiritual health; praying; seminars; sharing information; spiritual dimension – only God can prolong life; seminars; sharing groups; telephoning; teach information at schools or send information home from schools; TV ads; video presentations; workshops.

### **Toronto**

Committee on education and health; informal groups with intimate friends to share experiences and knowledge; invite guest speakers; invite guest speakers on health issues; sharing with parents while children are in group activities; workshops; work with other ethnocultural groups (Africans, Chinese, Caribbean) on health issues.



## Vancouver

Add hepatitis C to hepatitis B screening as part of immigration process and as part of yearly blood tests – make family doctors aware of this; advertise health information about hepatitis C on the Internet or in PowerPoint form; ask Filipino associations or organizations to include a short information announcement about hepatitis C – talk to president of group; booth at Filipino events with snacks and a PowerPoint presentation running; brochure or posters in doctors' offices; contact pastor of church organizations; devise proper education to decrease occurrence of hepatitis C; Filipino doctors or dentists to be more aware and doctors to include testing for hepatitis C in their yearly check-up; flyers; have church announcement after mass about information sessions on hepatitis C; health care workers spreading information in community; through social events or short medical ad; information in church bulletins; information sessions or focus group on topic; make health issues a part of social gatherings or events to increase awareness; newspapers with brief articles; nurses or other health care providers speaking in communities on regular basis; posters with captivating pictures/message; send PowerPoint presentation by email; TV; video.

**Question 10: What, if any, barriers do you think exist to getting information on health issues such as hepatitis C to members of your community? How could these be overcome?**

**Calgary**

*Barriers* — Family culture and values; fatalistic attitude; lack funding – need budget to disseminate information; lack knowledge about subject; lack of transportation; lack someone to advocate for health issues; lack personal involvement; not interested in the subject; people are extremely busy; some are not interested enough to go to information sessions and seminars; tight work schedule or a conflicting schedule.

*Overcoming barriers* — Having a social for a cause; increase community awareness by telling about sources of health information; overcome reluctance to attend information seminars by bringing food and having a support group committed to this work; educate younger generation; develop more ways of spreading the information.

**Montreal**

*Barriers* — Attitude towards the illness; tend to be secretive; busy; get information only when sick; denial; Filipinos are not health conscious, lack interest and knowledge about health, do not openly talk about disease, and only obtain help after becoming sick; fear of being singled out on an issue; language problem – flyers are only in French and English; fear of gossip; mobility problems; lack proper resources; not properly educated by doctor; problem getting family doctor and use health clinic, which can lead to neglecting health.

*Overcoming barriers* — Early education important; FFCAQ should work with FNAQ and coordinate with CEC on public health issues; health awareness could increase if an organization with a core group works to spread knowledge; CLSC should tackle the problem; should write to MPs about lack of doctors.

**Ottawa**

*Barriers* — Language; apathy – do not want to get involved; need child care so parents can attend information sessions; busy schedules – lack time to share information; fear isolation from friends; fear of becoming an outcast if people know about illness; lack finances to print information; inadequate information about disease so ignore it; lack of communication; procrastination; secrecy – people do not want to talk about it or for people to know because of shame and social stigma.

*Overcoming barriers* — Need education to increase interest; could raise money through fund raisers; need to encourage people to join; get involved and invite others; have playgroups or social groups to educate parents and give them correct information; have focus groups such as this one; make information sessions appealing – use visual aids such as video or movie in our own language so information can be easily understood; have community leaders encourage their members by offering carpooling; need to know so can protect others from contracting

disease; need seminars and groups where people could talk openly about their disease; need to be honest and educate people about the disease.

### **Toronto**

*Barriers* — Apathy – think information not personally applicable; do not know about existing programs or resources; everybody is busy or working; lack time to attend if work two jobs; financial problems; lack brochures and other written information; have other priorities; insufficient information and access to information; isolation – live alone; lack motivation or interest; lack health insurance; think information sessions have an ulterior motive such as selling a product; timing – only have weekends free if work; too shy to find out on their own; three-month wait for OHIP coverage; lack transportation.

*Overcoming barriers* — Provide educational sessions to share information; invite resource speakers from Filipino community; overcome isolation by telephone communication; increase motivation by integrating other activities, such as line-dancing and cooking demonstrations; have one-stop shopping information on health such as Services Canada; NGOs, such as Trillium in operation years ago and New Horizons, helped; networking and teamwork help involve people but these present real challenges; have health fairs with doctors as speakers; encourage people to get information; volunteers to help with transportation.

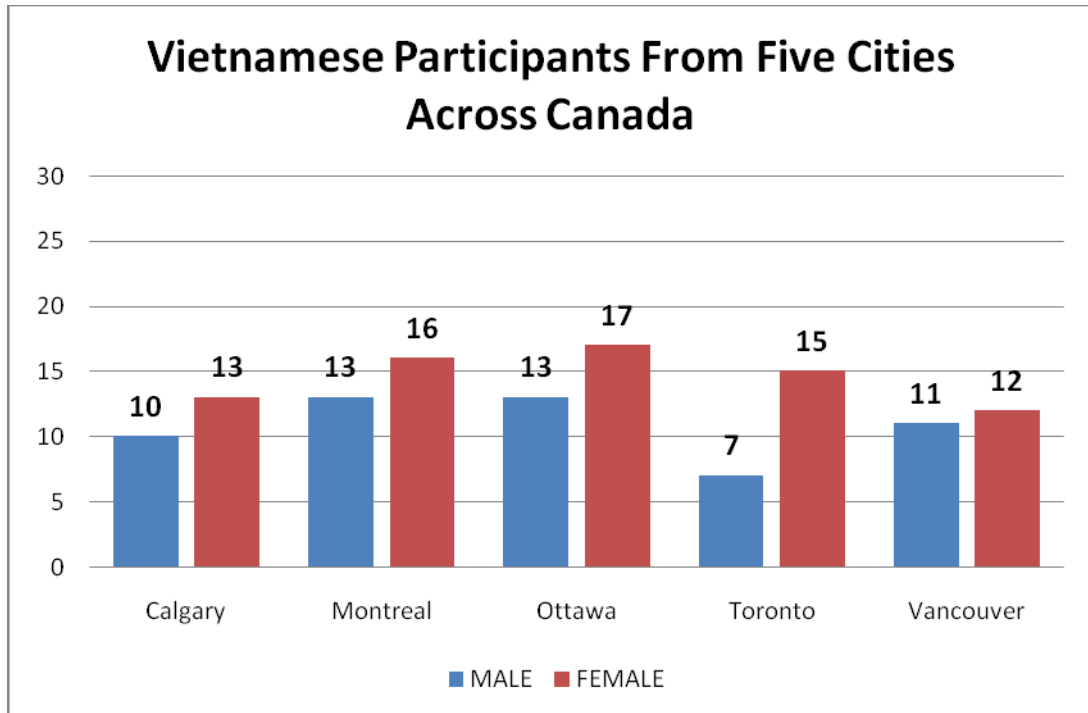
### **Vancouver**

*Barriers* — Decreased manpower to increase public awareness; language barriers; denial that they have the disease or need to know about it; information not accessible to person without a computer; lack knowledge and even awareness about this disease; cultural sensitivity about hepatitis C can cause social isolation and feelings of unworthiness.

*Overcoming barriers* — Provide information in languages other than English – in Tagalog and other dialects at about grade 5 to 7 level and not too lengthy; provide more health personnel to help in education.

## 4.4 Vietnamese

### 4.4.1 Vietnamese: Focus Group Participants



**Figure 4. Gender Distribution of Vietnamese Focus Group Participants**

Figure 4 shows the Vietnamese focus group participants distribution by gender and by city. In all five cities, there were more female participants than male participants. The female to male ratio was significantly greater in Toronto than in Calgary, Montreal, Ottawa, and Vancouver.

#### 4.4.2 Vietnamese: Focus Groups Findings

The following are the responses to the 10 questions discussed at the Vietnamese focus groups in each city. The responses are given at random and in no particular order of importance.

### **Question 1: What are the major health issues that people in your community talk about?**

#### **Calgary**

Alzheimer's; memory-related issues; arthritis; cancer (lung, breast, and prostate); diabetes (high blood sugar); gout; high cholesterol; high blood pressure; leukemia; mental illness; pain in the foot; stomach illness.

#### **Montreal**

Adhering to a daily schedule; arthritis; cancer; diabetes; diet; dizziness; exercise and activities (ping-pong, walking, or swimming); hepatitis; forgetfulness; getting a proper amount of sleep; diseases of the lungs; maintaining good habits; mental health; pain in the bones; selecting healthy food; sleeping habits; special ideas about ways to keep healthy; tai chi; walking.

#### **Ottawa**

Alzheimer's; arthritis; bone fractures – especially in old people; blood disorders; cancer (breast, stomach, liver, and blood); cholesterol-related issues; diabetes; digestive diseases; eating fatty foods; eating disorders; hepatitis; hepatitis C (which can turn into a cancer); high blood pressure; high blood sugar; joint pains; lack of physical activity; liver diseases; migraines/headaches; smoking and damage to lungs; healthy living and eating well.

#### **Toronto**

Cancer (breast and cervical); depression; digestive disorders; emotional problems; healthy living and eating; liver; obesity; sicknesses of the elderly; hepatitis B and C – treatments and how to cope with them; osteoporosis.

#### **Vancouver**

Cholesterol; diabetes; hepatitis A and B; hepatitis C – talked about by some but many do not know much about it; high blood pressure.

**Question 2: What health issues do people in your community *not* talk about?**

**Calgary**

AIDS; arthritis; cancer (breast, cervical, and lung); depression; high blood pressure; hepatitis C; HIV; leprosy; leukemia; loneliness; painful joints; sexually transmitted diseases; stress.

**Montreal**

AIDS; arthritis; body aches; coughing; cold; cancer; diabetes; high cholesterol; high blood pressure; hepatitis C; sexually transmitted diseases.

**Ottawa**

Addictions – alcohol, smoking, and drugs; AIDS; age; Alzheimer’s; anorexia; bone deficiencies; bulimia; heart diseases; depression; disabilities; eating disorders; fitness issues; high blood pressure and high fat levels in diet; hepatitis (A, B, and C); leprosy; liver and its relation to hepatitis A; mental health issues; multiple sclerosis; obesity; venereal diseases.

**Toronto**

AIDS; Alzheimer’s; depression; emotional illnesses; diabetes; hepatitis; high blood pressure; mental health issues.

**Vancouver**

Addiction to medicine; AIDS; depression; diabetes; drugs; exhaustion and low energy; gambling; heart disease and high blood pressure; hepatitis (not many know about it); HIV; malnutrition; obesity; weight – too fat or too skinny; sexually transmitted diseases.

### **Question 3: What diseases are *not* talked about?**

#### **Calgary**

AIDS; autism; arthritis; cancer (breast and lung); Down syndrome; drug addiction; eating disorder; HIV; joint pain; pain in different parts of the body; mentally challenged or mental retardation.

#### **Montreal**

Addictions – alcohol and smoking; AIDS; Alzheimer’s; amnesia; anorexia; bone deficiencies; bulimia; high blood pressure; high fat levels in diet; depression; disabilities; eating disorders; fitness issues; hepatitis C; HIV; liver and its relation to hepatitis; mental health issues; multiple sclerosis; obesity; STDs; venereal diseases.

#### **Ottawa**

Addictions – alcohol and smoking; AIDS; Alzheimer’s; anorexia; bone deficiencies; bulimia; cardio-related diseases such as high blood pressure; depression; disabilities; eating disorders; fitness issues; hepatitis C; liver and its relation to hepatitis; mental health issues; multiple sclerosis; obesity; diseases of the sex organs; venereal diseases.

#### **Toronto**

AIDS; bone diseases; brain diseases; cancer (leukemia and bone); colds; diabetes; headaches; flu; hearing disability; heart problems; mental health issues; sexually transmitted diseases; stroke.

#### **Vancouver**

AIDS; cancer (lung); depression; health issues such as diet (eating too much food or too much fat); leprosy; leukemia; mumps; recurrence of disease; sexually transmitted diseases; smallpox; tuberculosis.

#### **Question 4: What are some reasons for *not* talking about these diseases?**

##### **Calgary**

Avoid stigma; do not discuss with neighbors because they are scared of what others may think or that it may be contagious; do not want to worry others; fear or prejudice; fear of embarrassment; isolate them when beginning therapy for a disease; main issue is privacy – most people learn only after someone dies; no reason to tell others; persons in treatment for cancer stay at home; value their face/pride.

##### **Montreal**

Do not talk about their disease because it is a secret or a taboo; embarrassed to talk about something that they do not know about; human nature to hide bad news; they are afraid that if people in the community know about it they might be mistreated or judged; they are ashamed of having the disease and do not want others to know they have it as it might be attributed to dirty (sexually related) habits.

##### **Ottawa**

Afraid of social stigma and judgement by friends that they might transmit a disease to friends; although cholesterol is more harmful than high blood pressure – do not talk about it; being sick is considered bad and is not discussed within the community; cultural taboos; do not discuss other person's illnesses out of respect (for example; Alzheimer's – do not talk about it because they say confusion is normal and they do not want to complain); do not have a scientific viewpoint about diseases; do not know about certain illnesses or health issues such as mental health; do not like talking about issues relating to sex (sexually transmitted diseases, AIDS, or VD); do not notice it or do not know if they are sick; do not speak about diseases that are hard to understand or grasp; embarrassing to talk about a disease you have because people may judge them (for example; people who have AIDS have bad sexual habits); hepatitis is not spoken about because of fear of transmission and social exclusion; hide own illnesses for fear of being excluded; lack knowledge of hepatitis (A, B, and C); in our culture may consider mental health problems as being imaginary disease; may be embarrassing to speak about diseases; mental illnesses may be associated with possession by a spirit or ghost; disease progresses to cancer; smoking can lead to pneumonia; lung cancer and TB; speaking of diseases may convince ourselves that we are sick; shame; talk to doctors after tests have confirmed having a disease.



### **Toronto**

Do not worry about disease until it impacts them; do not know about them and are not interested; embarrassment; fear of affecting family; non-transmittable and therefore not talked about as much; people are scared to let others know about their diagnoses and only confide in doctors; protect themselves; stress.

### **Vancouver**

AIDS is spread by homosexuals; needles; tattoos; blades for shaving and blood transfusions; AIDS is considered a man's problem not to be talked about and it is also shameful; afraid of ridicule; afraid wife will leave if she hears about it; careless about self; cultural – community members may blame parents; do not want to reveal illnesses such as mental; do not want to ask for information so disease spreads; do not understand the importance of talking about health problems and diseases so they can get help; fear public opinion if own condition is known; hide to protect happiness of family; lack updated information; need health education; need public education; psychological reason; shame; shameful for homosexual people to talk about problems; shy; social and psychological reasons.

**Question 5: What about hepatitis C? Is hepatitis C an issue in your community? What kinds of things do people say about hepatitis C in your community?**

(Explain: What is hepatitis C and how it is spread. Probe: What about other diseases spread by contact with blood? What kinds of things do people say about these diseases?)

**Calgary**

Do not know if it is curable; do not talk about it because they do not know about it; have only heard about hepatitis A and B – not hepatitis C; is not discussed in the community; patients do not follow doctor's advice to have blood tests for hepatitis A and B.

**Montreal**

A cultural taboo; are ashamed to tell the doctor that they have hepatitis C; do not talk about hepatitis C; will go and talk to doctor if necessary.

**Ottawa**

One participant believes that hepatitis was transmitted by a marriage partner; mostly only know about A and B; hepatitis C is not spoken about because of fear of transmission and being judged (social stigma); differences between hepatitis B and C are not clear; do not know what kind of hepatitis they have and it does not seem to make a difference – can still eat and sleep as normal; discussed differences among the different types of hepatitis; hepatitis C is an issue but B is more spoken about; many do not know about the various types of hepatitis; one believes hepatitis C is the third stage and that it leads to cancer; one person's relative who has C believes it started as B and there is potential for it to turn into cancer; the easy transmission through blood and saliva means that persons (especially those who have it) are reluctant to speak about it; they learn from doctors.

**Toronto**

Community may talk about it but does not have much information such as about prevention or what to do if diagnosed as having it; group knows nothing about hepatitis C and wants to know how the virus affects the liver.

**Vancouver**

AIDS spreads through blood; hepatitis C is a problem in community; is important to have more discussion on subject in community or in groups; know little about what hepatitis C is and how it spreads; need more education on it; talk about hepatitis A and B but not much about C (especially not publicly); spreads through tattoo needle; spread by dental tools.

**Question 6: Where do members of your community go to get information on health issues?**

(Probe: Your doctor, nurse, social worker, pharmacist, herbalist, community organization, public health office, community health centre, walk-in clinic, library, Internet, others?)

**Calgary**

Family doctor; Vietnamese newspaper; nothing in community centre; pamphlets and brochures in English only; pharmacy; presentations; TV; word of mouth; workshops.

**Montreal**

Community centres; doctors – more than 200 Vietnamese doctors in Montreal; Internet; medical association.

**Ottawa**

Community health centre; doctor; family members; friends; Internet (Google search); information through Vietnamese TV; pharmacy; seminars by Vietnamese doctors.

**Toronto**

Discuss with friends or read books; family doctors; focus groups; foundations; Internet; local newspapers; newspaper articles written by physicians; specialists; *Thoi Bao* or *Saigon Times*; Vietnamese radio; workshops.

**Vancouver**

Family doctor; friends who have knowledge; hospitals; Internet; media – TV; reading about health issues; social agencies group.

**Question 7: In what ways would you like to receive information on health issues like hepatitis C?**

(Probe: Language spoken/written; visual – videos; in private; person-to-person; workshops. Probe: What about the media? What format – community television, radio, brochures, newspaper, bulletin boards? Where would you like to have it – in what venues?)

**Calgary**

Churches; computers; doctors; doctors' offices; Internet; information printed in Vietnamese that could be brought home; meetings after church to attract large number of people – 500 to 600; Vietnamese community newspaper.

**Montreal**

Articles in Vietnamese in *Thoi Bao* – weekly magazine; embedded within the community newspapers; Internet; information available in Vietnamese; information at community centres; publications sent to different community members; TV and paper documentation in Vietnamese; Vietnamese newspapers; Vietnamese-speaking doctors to talk to; weekly magazines with information in Vietnamese.

**Ottawa**

Brochures available in places such as the Vietnamese community centre; books and documents; Buddhist magazines; community newspaper in doctor's office; courses/seminars; direct mail; distributing information through various community groups (churches, temples, community centre); doctor's office; emailed newsletters; grocery stores; health information days with a nurse to answer questions; information available in both English and Vietnamese; Internet; people do not understand hepatitis C; radio; TV; Vietnamese newspaper and *Thoi Bao* magazine; Vietnamese pharmacies; Vietnamese doctors offices.

**Toronto**

Churches; confidential telephone line; focus groups; group information sessions; information from Canadian Liver Foundation; local grocery markets; mailing; pamphlets in family physician's office and Vietnamese associations; sessions on different health issues sponsored by Vietnamese associations; temples; Vietnamese newspaper; Vietnamese community centres; Vietnamese radio; word of mouth; workshop by health specialists.

**Vancouver**

Agencies; brochures to be placed in neighborhood houses; brochures in community centres; doctor's office; emails; health fair; home mailings; Internet; medical news to read; Moon Festival; New Year's festival; schools; social agencies; Vietnamese TV.

**Question 8: Can you name any successful ways in which your community was involved in a health issue in the past?**

(Examples: CEC diabetes support groups, health fairs, media information sessions, public forum, workshops.)

**Calgary**

Meeting on diabetes brought in a large crowd last year; stated a need – to advertise in newspaper and doctor’s offices to help people learn about and attend workshop.

**Montreal**

Health sessions or meetings organized to educate public on availability of new drugs and medications; once-a-year health day with topics such as diabetes; osteoporosis; hepatitis B and C; diseases of gastrointestinal tract; organized focus groups and meetings at Vietnamese centre with physicians to speak who are from Vietnamese community; pharmacists talk to them about new medications; existing programs (every Thursday) meet at centre to talk about different issues of interest to community during existing weekly programs; three to four times a year community centre organizes information sessions on various health issues (such as diabetes, hepatitis, Alzheimer’s disease); use lab technicians as source of information.

**Ottawa**

Both Oriental and Western medicine; free eating events where health information is presented; health days; information about disease prevention; need information in Vietnamese – translation takes too much time; Master taught Tai Chi classes and every session he gave was very well attended; physical activities such as volleyball; planned physical activities that promote prevention and health; successful collaborations with government that helped get information on various health issues; through the “*Health is Wellness*” fair; workshops.

**Toronto**

Every Tuesday an information session at health centre in Parkdale about different diseases and health issues – held in English and need information session in Vietnamese; every few months there is a field trip; need an association to organize workshops and fundraisers to give more information; Vietnamese association had group information session about intestinal illnesses.

**Vancouver**

Although health fair is effective have no budget for that; community has participated in health issues in the past including diabetes screening workshops; request for funding to organize workshops and public education events, including parents support group on health care issues; most successful workshop is for community to organize public education and have health issues in local newspaper; seniors workshops; workshops organized in Vietnamese community with doctors discussing diseases.

**Question 9: What are the best ways to engage/inform your community on health issues?**

**Calgary**

Church announcements; distribute brochures and other media in Vietnamese; information session with health professionals; Kerby Centre is main office for distributing information; language barrier is main issue in preventing people from getting the information – pamphlets should be translated into Vietnamese and sent by mail; need to advertise in Vietnamese newspaper; placed in doctor’s offices; TV; Vietnamese association and Vietnamese seniors association; Vietnamese newspaper – *Saigon Times* – which generally has no health column but does discuss healthy eating; Vietnamese video.

**Montreal**

Focus groups with speakers (such as doctors, pharmacists, lab technicians); have celebrities disseminate information; have shared information on diabetes and staying healthy; pamphlets in Vietnamese distributed through different centres; publications on different health issues in Vietnamese.

**Ottawa**

“*Health is Wellness*” fair; brochures available in places such as the community centre; Canadian Liver Foundation; courses and seminars; direct mail; doctor’s office; health information days with a nurse to answer questions; hotline for health issues; information available in both English and Vietnamese; information sessions with face-to-face communication with health care professionals; Internet – especially government websites; meetings; magazines; major community events such as *hoi cho tet* or Vietnamese New Year festival; need information in Vietnamese; news; newspapers – community newspapers and those of various religious or community groups; parties; Paris by Night (a popular music production); physical activities, such as volleyball, that included information about disease prevention; radio; successful collaborations with government that helped get information on various health issues to Vietnamese community; TV; Vietnamese channels and Vietnamese radio programs.

**Toronto**

Family physician; hotline with choice of Vietnamese language; newspaper (*Thoi Bao, Saigon Times*); providing group information; radio; TV *VietTien* (local Vietnamese broadcasting).

## **Vancouver**

Communicate with people verbally or in writing; disseminate information through radio or TV at least three times a week; distribute materials to public; encourage people to discover and learn more about health issues; need a contact person to put ads in newspaper about upcoming workshops or public education events; newspaper; organizations need to reach out because many people do not know how to search for information; people dealing with mental problems need support of community; post notices at pharmacies; ads in magazines; public education such as reading information on the radio in Vietnamese; support groups; workshops.

**Question 10: What, if any, barriers do you think exist to getting information on health issues such as hepatitis C to members of your community? How could these be overcome?**

**Calgary**

*Barriers* — Only talk about the disease with doctor, but doctors only give details, not general information; Vietnamese seniors are not proactive and only go to doctor if they are sick; language barriers – need health information in Vietnamese; people know of hepatitis A and B but not about C; people are busy with work and family; many do not take care of their health and do not want to take medication; transportation problems.

*Overcoming barriers* — Need brochures with information on diseases in Vietnamese; need to get more information out and younger generation needs to explain to parents; disseminate information through many different channels; a routine blood test to learn whether individual has disease would allow early treatment to prevent death or extend life; distribute pamphlets or brochures at Vietnamese grocery stores, Vietnamese temples, and Vietnamese church; use *Viet Tieng TV*, or video, to give information, possibly through a health program once or twice a week.

**Montreal**

*Barriers* — Discussion with doctors – doctors in Montreal often only speak in French and language is major barrier; fear – they have heard about hepatitis C but are afraid and do not want to know anything about it; lack knowledge about hepatitis C testing; not proactive and do not worry about disease unless have symptoms; transportation is an issue; young people may be too complacent about health issues or too busy.

*Overcoming barriers* — Even with Vietnamese doctors and Vietnamese interpreters accessing information is still difficult; get information from the Internet; it is easy to have blood tested and they need to ask their doctor for this; organize sessions with a Vietnamese doctor speaking and have outside speakers address issue; increase awareness and better education on hepatitis C, especially through publications in Vietnamese.

**Ottawa**

*Barriers* — Believe they are immortal; do not understand severity of hepatitis or take all medical conditions seriously; do not care enough to obtain information or are in denial; lack of Vietnamese doctors; language – information available in English but not in French or Vietnamese; learn about health issues and diseases when it is too late (when hepatitis C becomes cancer) and only see end result; not aware of symptoms and will not look for health information unless impacted in some way; psychological – do not want to think of unhappy things, such as sickness, or worry about their health; do not understand technical vocabulary.



*Overcoming barriers* — “*Health is Wellness*” fair; educate about a health issue and how to remedy it; have a hotline in Ontario in every language including Vietnamese; successful collaborations with government (such as a sporting event) could include information about disease prevention; teach about technology and using Internet for information.

### **Toronto**

*Barriers* — Language barriers and difficulties with scientific terminology when translated from English to Vietnamese; no one organization to organize vigorously and develop details on specific illnesses; people are scared and shy in talking about issues to others; transportation is a barrier – many cannot drive or elderly find it hard to use public transit; weather a barrier in winter, but can easily travel in summer; individuals with children cannot find day care.

*Overcoming barriers* — Announcements to community; do not know what they will get out of sessions so afraid of coming; for health sessions include map also showing bus route to location; provide day care during information sessions; need information on protecting families of those with hepatitis C; share information through word of mouth; give information about prevention, coping with disease, and treatments.

### **Vancouver**

*Barriers* — Are afraid of disease and of the truth; afraid to seek help when they have a disease due to religious beliefs; language a barrier as they have limited English; work hard and do not have time for health issues; believe only in God not in medicine; conservative and hesitate to have doctor checkup that might lead to “*harmful*” information; do not get examination if they think they have the disease or go for examination too late; irresponsible about own health care; lack knowledge about hepatitis C (symptoms, treatment, and prevention) and symptoms of health problems; people do not know about the government program to compensate victims of hepatitis; trust in family doctor rather than research; unaware of seriousness of health problems; low level of understanding.

*Overcoming barriers* — Encourage to go for exams – the sooner the better; disseminate information on health issues; *B.C. Health Guide* is an excellent source of health information; need brochures, publications, and health education in Vietnamese; place materials on diseases in doctor’s office, travel agencies, social agencies, and schools.



## **5.0 FOCUS GROUP DISCUSSION HIGHLIGHTS**



## 5.0 Focus Group Discussion Highlights

The highlights of the project are based on the responses of the focus group participants to the 10 questions (Appendix 4) and the observations made by the focus group facilitators and key informants (coordinators). Many noticeable similarities and differences were evident among the four ethnocultural communities. The following is a brief description of the similarities and differences among the ethnocultural communities:

### 5.1 Similarities Among the Four Ethnocultural Communities

- The focus group discussions showed that participants of all four ethnocultural communities knew very little about hepatitis C. Some participants even stated that they had never heard about it. Most individuals with any knowledge about hepatitis C had heard about it because someone they knew had the disease. Some had heard about hepatitis A and B, but the questions that they asked showed that most of these individuals had incomplete or inaccurate knowledge of these two diseases.
- The communities, in general, held many cultural taboos regarding health issues. Some of the reasons given for the reluctance to discuss hepatitis C are:
  - A fear of being stigmatized as having the disease;
  - Health is just not talked about in the community;
  - It is difficult to get the community interested in health issues;
  - Community members do not like to talk about diseases that are associated with “dirty” (sexually related) habits.
- Among the four communities, only a few Chinese focus group participants said that their community was interested in health. The Vietnamese focus group participants said that health was not discussed much among Asians, nor did their community consider regular medical checkups to be important. The Egyptian focus group participants said that health and health status received very low priority in their community unless someone had a very serious illness. Filipino focus group participants suggested that members of their community were not health conscious and only sought help when they were sick.
- Most of the focus group participants from the four ethnocultural communities across the country also mentioned the lack of good, reliable health information and knowledge about where to locate health information. They noted that this was a problem for the Canadian population, in general, and not just for ethnocultural communities.

- For a majority of those who attended the focus groups, language was a barrier to receiving information about health. This was particularly true of the Chinese, Filipino, and Vietnamese communities. The issue of language may have been so important because the participants in the focus groups were disproportionately older; the younger generation may not have considered a language to be a problem. However, it is imperative that the older ethnic population receive health information in the language they are most comfortable with. This is the most effective way to reach them. Even those who know some English and can read health information in English do not have an adequate grasp of medical terminology.
- Focus group participants of all the four communities suggested that health information should be disseminated through the various ethnic media – newspapers (local and community), TV (if there is no TV network for a particular ethnic community an existing mainstream health channel should introduce a program in the different languages), and radio.
- The communities put the onus on the Government of Canada – Health Canada or the Public Health Agency of Canada – to disseminate health information to ethnocultural populations. They suggested that the Government should prepare updated health information in different languages. They wanted printed information as well as information in various audio formats for those who could not read. Additionally, they suggested that information on websites provided by the Government, especially in the different languages, would be very helpful.

Other salient points:

- Key informants (coordinators) noted that as focus group participants began to understand the purpose of the project they became engaged in the discussion and eager to respond to the questions that were asked.
- Focus group facilitators noted that the focus group participants were eager and willing to participate and curious about the purpose of the sessions. A majority of the participants from all the communities seemed to be interested in knowing more about hepatitis C and how it affects their communities. Facilitators also reported a similarity in the questions that were raised by focus group participants in all the cities and communities. Additionally, they reported that they observed similar cultural issues across all communities.
- A majority of focus group participants from all four communities were women – 63% women to 37% men. Many of the focus group participants were older individuals. Nevertheless, the older individuals represent a significant population that needs to receive appropriate health information.

## 5.2 Differences Among the Four Ethnocultural Communities

- Two ethnocultural communities, the Filipino and Vietnamese, mentioned that their communities had a fatalistic attitude towards illnesses: “*whatever happens is God’s will*” (Filipino). This appeared to be one reason that health concerns were not strong topics of discussion in these communities.
- The level of knowledge on health issues was different in different communities. The Chinese community appeared to be more knowledgeable about diseases and the importance of diet and exercise in staying healthy.
- Although language was an issue for three communities, their language needs varied. This was particularly true of the Chinese and Filipino communities where individuals from the same community spoke different dialects. Most members of the Egyptian community did not mention language as a problem. However, some indicated that information in Arabic would be useful for those with limited knowledge of English.
- It was identified that different cities provided different health resources for communities. For example, Toronto and Ottawa residents benefitted from Telehealth Ontario, an open telephone line from which callers can get health information. British Columbia has the *B.C. Health Guide*, a book containing reliable health information that is available to all B.C. residents. Additionally, the Chinese groups in Vancouver mentioned the S.U.C.C.E.S.S. programs, which serve many needs of the Chinese community. Vancouver has an 809 number, known as “*Call-A-Dietitian*”, that individuals can call for information about diet. The Vietnamese community reported that in Montreal, as contrasted with Ottawa, Vietnamese specialists attend health information sessions and give health information in Vietnamese. Additionally, the Vietnamese in Montreal have their blood tested annually.
- Some communities wanted printed information in their language while others thought that talks in their language would be more effective, as some of the older persons could not read. Others wanted radio or TV health information in their language. Some suggested that the information should be in different dialects so that different members of the same community could be reached more effectively. This was true of the Chinese and Filipino participants.
- Some Chinese and Vietnamese focus group participants mentioned that there were seniors groups in their cities that held health discussions on issues of interest to seniors. They felt that interactive focus groups are effective in reaching communities with health information.
- The communities varied in the ways that they thought information on health topics should be disseminated to their particular ethnic group. The facilitators said that focus groups which included community leaders showed enthusiasm to disseminate information; however, the emphasis placed on the role of community leaders was different from community to community.

- Many suggested that existing ethnocultural organizations were the logical places to disseminate this information, and some said that the once yearly health talk by a local organization had very limited space to accommodate larger number of participants. Others, while agreeing that this was the best way to disseminate information, said that they do not have an organization in their community that could do this. The Ottawa Egyptian focus groups suggested that the Egyptian Canadian Cultural Association of Ottawa would be a good place for information dissemination. Also, the Montreal Filipino focus group participants mentioned that because their communities were not centralized it would be necessary to approach each organization separately; they also suggested that their community needs to work together to organize health initiatives.
- Since members of the Chinese community liked to visit libraries, this was a good place to have health information in order to reach this community.
- The Chinese focus group participants in Toronto and the Vietnamese focus group participants in Montreal suggested that having celebrities promote specific health issues, such as hepatitis C, would get more attention in their communities. One example given was of a local ethnic TV personality who went public with her struggle with a specific disease. Other focus group participants suggested that community leaders should be involved in activities that promote health and knowledge of illnesses to which the community might be susceptible.
- Several focus group participants from the Chinese and Filipino communities suggested that one organization should coordinate all health promotion strategies and activities to help meet the needs of their diverse sub-groups. The Chinese sub-groups, for example, include those from Mainland China, Hong Kong, and Taiwan.
- One Chinese focus group suggested that establishing a foundation for hepatitis C that would operate in a manner similar to the Heart and Stroke Foundation would be a good way to bring more attention to all aspects of this disease.
- Several of the Egyptian groups suggested that the Egyptian embassy should have health information that particularly relates to Egyptian nationals as well as to individuals traveling to Egypt. They also noted that a website containing health information, which could be accessed in both Canada and Egypt, would be very helpful for Egyptians.
- The communities also demonstrated a difference in terms of their inner cohesion. The Chinese and Vietnamese communities seemed especially cohesive and mentioned a greater number of group activities and centres that addressed some of their needs in various ways. The one exception to this seemed to be the Montreal Chinese community, which was noted as being rather small. The Egyptian community, a highly educated group, seemed to be much more integrated into the larger Canadian culture in terms of group activities and religious services. However, even though highly educated, this group also lacked knowledge about hepatitis C and other health issues.



And some Egyptian focus group participants in Vancouver noted that a social event involving food would attract members of their community; however, it was suggested that they might not respond positively if such an event had a “hidden” agenda, such as dissemination of health information.

Other salient points:

- Cities selected for this project varied a great deal with regard to the existence of organizations that represented different ethnocultural communities. Vancouver has a strong organization – S.U.C.C. E.S.S. – for the Chinese community but the Vietnamese, Filipino, and Egyptian communities do not have an equivalent organization. In Toronto, the Vietnamese (e.g., Vietnamese Association of Toronto), Chinese, and Filipino communities have good organizations. In Montreal and Ottawa, the focus group participants from all four communities stated that there were no strong organizations for their respective communities. This does not mean that these communities had no organizations. Most ethnic communities have organizations, but many of these organizations have a narrow focus that does not include a mandate to provide health information to the larger community, or they have a limited budget that does not allow involvement in additional issues. In Calgary, organizations such as the Calgary Catholic Immigrant Society were active in bringing communities together and providing education and services. The Filipino and Vietnamese communities in Calgary, Ottawa, and Vancouver appeared to meet in churches and organize their community events after church service.
- Reasons given for lack of an organization that provides health information to ethnic communities were lack of resources to maintain an organization and finding a location in a part of the city where a large number of individuals reside. For example, in some cities, such as Vancouver and Montreal, the focus group participants from Filipino communities mentioned that members from their community were spread out in the city. One community that particularly lacked any organizations that provided health information was the Egyptian community. They tended, on the whole, to be more integrated into the larger community and were very sensitive to being singled out as a community particularly affected by hepatitis C. Additionally, some organizations provided help to ethnocultural communities in one area of need – settlement, for example – but did not get involved in health issues.
- Focus group facilitators noted that age differences mattered in the response of participants, especially in the enthusiasm that they showed and the speed of vocalization. The key informants (coordinators) also noticed that the younger participants were more vocal than the older members.



## **6.0 RECOMMENDATIONS**



## 6.0 Recommendations

Focus group participants suggested that the most effective way to provide health information was through interactive workshops. One person said: *“Tell me and I will forget, show me and I will remember, and involve me and I will understand.”*

Focus group facilitators suggested that health professionals (physicians, nurses, pharmacists, social workers) from each of the selected communities should have more training on hepatitis C. They suggested using the train-the-trainer model to train individuals in communities to promote awareness and provide information on hepatitis C in ethnocultural communities across Canada.

### 6.1 Recommendations from the Focus Groups

#### 6.1.1 Recommendations from the Chinese Focus Groups

- Continue to have small focus group meetings so members can ask questions and interact better.
- Hold separate sessions in Mandarin, Cantonese, Taishan (some focus group discussions were slowed down by a need to translate into different dialects), as well as in English for youth and young adults.
- Involve government in getting updated health information and also information in different languages.
- Put health information in Chinese and community newspapers; use Chinese TV channel, Chinese radio programs in Cantonese and Mandarin, Chinese websites, and churches for disseminating information on health issues such as hepatitis C.
- Select an organization representing the community to take the lead in developing community health promotions.
- Develop a Chinese-speaking health hotline.
- Provide incentives (e.g., honoraria, transportation, parking, child care) to the public for attending health events to attract more individuals to these events.

### **6.1.2 Recommendations from the Egyptian Focus Groups**

- Target all Canadians, not just ethnocultural communities, in a campaign for awareness of hepatitis C.
- Create an association to raise awareness of health-related issues in the Arabic community.
- Provide weekly information sessions on health issues at high schools and hold information sessions for the general community at universities.
- Provide incentives to youth, teenagers and members of the community for participating in workshops and in information dissemination.
- Involve the Egyptian embassy in giving out information about hepatitis C to Egyptians in Canada and persons traveling to Egypt.
- Provide information on hepatitis C through TV ads, in mosques, Coptic churches, Egyptian websites, YouTube, Facebook, points of travel (airports, train stations), and travel agencies.
- Develop videos and TV documentary on health issues; use health professionals to give lectures on hepatitis.
- Need an aggressive campaign to raise awareness about hepatitis C.

### **6.1.3 Recommendations from the Filipino Focus Groups**

- Provide information in brochures and pamphlets about hepatitis in many different places, such as hospitals, schools, churches, associations, offices, pharmacies, grocery stores, and shopping centres.
- Have short public service announcements mentioning hepatitis C and suggesting that people see their doctor or go to a website for more information.
- Involve Filipino organizations in the cities to give out health information.
- Develop TV ads in Tagalog that have a person, face in shadow, telling about experience with having hepatitis C.
- Develop PowerPoint presentations, posters with captivating pictures and messages on hepatitis C.
- Use Filipino radio, Filipino newspapers and workshops with health professionals to educate the Filipinos and disseminate health information.

- Work in partnership with other ethnic groups in disseminating health information.
- Have something like a walk-a-thon to raise money and spread information about various health issues.

#### **6.1.4 Recommendations from the Vietnamese Focus Groups**

- Distribute health information brochures in Vietnamese after church and at various Vietnamese festivals.
- Write articles in Vietnamese newspaper and send publications to the Vietnamese organizations, schools, social agencies, and temples in the various cities.
- Use celebrities to disseminate health information, which would get the attention of the public.
- Use Vietnamese radio, TV, websites, and Internet to disseminate information on health issues like hepatitis C.
- Conduct health workshops with Vietnamese doctors, nurses, and pharmacists and allocate sufficient time for questions and answers.
- Provide information on ways hepatitis C is spread in their community, in addition to sharing needles by drug users.
- Encourage Vietnamese community centres and Vietnamese organizations in the cities to have information sessions on all health issues common to Vietnamese community with pamphlets on these issues that attendees could give to others not present.
- To ensure participation, provide some financial incentives, such as free bus tickets or free parking, and child care.

## 6.2 Recommendations from the Project Team

In this first joint project that took four years to complete, the CLF and CEC each contributed its own set of unique skills in order to determine the best ways to engage ethnocultural communities on public health issues such as hepatitis C. The project team consisted of Billie Potkonjak, the CLF National Director of Health Promotion and Patient Services, Anna Chiappa, the CEC Executive Director, and the Project Coordinator, Sucy Eapen.

The strong contribution of the communities involved in this project was based on the respect and trust they have developed over the years working on many projects with the CEC. This trust paved the way for community participation and leadership in focus group discussions and helped provide the project team with information that will enable communities to continue engaging in health issues that affect them. This community-based research has been a learning process for the communities involved and for the project team. The team developed the following recommendations based on their observations during the project:

- Creation of a national health network of Canadian Ethnocultural Council stakeholders and volunteers to sustain dialogue and community-based research focusing on issues affecting high-risk ethnocultural populations.
- Development of a long-term strategy to continue the existing productive partnership between the Canadian Liver Foundation and the Canadian Ethnocultural Council to build community capacity on issues around hepatitis C.
- Creation of public awareness to the high-risk ethnocultural populations and social marketing campaigns on hepatitis C with the information and expertise gained through this project.
- Implementation of a two-day follow-up forum to share the results of this project and disseminate hepatitis C information and awareness packages to ethnocultural communities.
- Provision of on-going training for healthcare professionals (physicians, nurses, social workers, pharmacists) on hepatitis A, B and C using the train- the-trainer model.
- Implementation of follow-up discussion group sessions on hepatitis C with the four communities in the five cities to sustain the interest and engage leaders in the communities in designing future work.
- Development of a hepatitis C awareness package in multiple languages for dissemination in communities across Canada.



## **7.0 PROJECT EVALUATION**



## 7.0 Project Evaluation

The evaluation plan was to conduct a formative evaluation by documenting the project process as it evolved. In preparing this report, the project team had the following in mind: whether the project was conducted according to the work plan, what was helpful and what was difficult in achieving the project objectives. The following comprised the evaluation process:

- Evaluation of the orientation session for facilitators by the focus group facilitators;
- Evaluation of the project process by the focus group facilitators;
- Evaluation of the project process by the key informants (coordinators);
- Project team observations.

### 7.1 Evaluation of Orientation Session for Facilitators by the Focus Group Facilitators

The orientation session for focus group facilitators was held in Ottawa on August 29, 2008. An expert facilitator was hired to conduct the one-day session. The agenda for the session is shown in Appendix 10. At the end of the session, the participants were asked to complete an evaluation of the session. (The evaluation form developed by the project team is provided in Appendix 11.)

Eight facilitators, an equal number of males and females, attended the orientation session. Four of them work for their respective community organization, two work in Social Service Agencies, one works in a Nursing Home, and one works in a multicultural organization.

Two facilitators each came from the four communities selected for this project. Four of the eight facilitators were from Ottawa, three from Toronto, and one from Winnipeg.

In the evaluation, the facilitators were requested to rate the facilities for the orientation session. Five found the location to be “*very good*” and three stated that it was “*excellent*.” Three out of the eight felt the meeting room was “*excellent*” but the remaining five rated it as “*very good*.” One facilitator rated the food served to be “*excellent*,” six considered it as “*very good*,” and one rated it to be “*good*.”

Participants were also asked to rate the effectiveness of the format – both agenda and process – of the orientation session. All the participants rated the session as “*excellent*.”

In evaluating the focus group facilitation information, one stated that “*it confirms what I already know*.” Others stated that it “*provides ways of promoting discussion on health issues in my community*” and “*offers new information*.”

Seven participants of the orientation session rated their facilitator “*excellent*” and one participant rated the facilitator “*very good*.” In addition, seven agreed that she “*was very*

*knowledgeable about issues related to facilitation.*” Six thought that she “*offered good guidelines for facilitation*” while five stated that she “*reviewed all the materials to be used by the facilitator at the focus groups.*”

When asked to comment on the focus group practice session, three participants rated it as “*excellent.*” Four participants rated the practice session as “*very good*”, and one participant rated it as “*good.*”

Overall, the orientation session was rated as “*excellent*” by four participants and “*very good*” by the remaining four.

The following comments show what participants liked most about the session:

- “*The spirit in which the information was provided*”
- “*The positive environment*”
- “*The practice focus group session*”
- “*The facilitator's guidelines*”
- “*Learning new facilitator skills*”
- “*The charts used in the presentation*”
- “*The participation by everyone*”
- “*The lively discussions*”
- “*The arrangements.*”

In answer to the question about what they did not like at the session, five had no comments. However, one thought that the room was “*noisy,*” one did not like the food, and one considered the timeframe to be too short.

When asked for suggestions to improve future sessions, four had no comments. The other four gave the following suggestions:

- “*Have it on weekends*”
- “*Have a shorter session*”
- “*Allow a longer time to cover specifics*”
- “*Use slides and/or a video.*”

When asked whether they would recommend this session to others, all eight participants said that they would.

## 7.2 Evaluation of Project Process by the Focus Group Facilitators

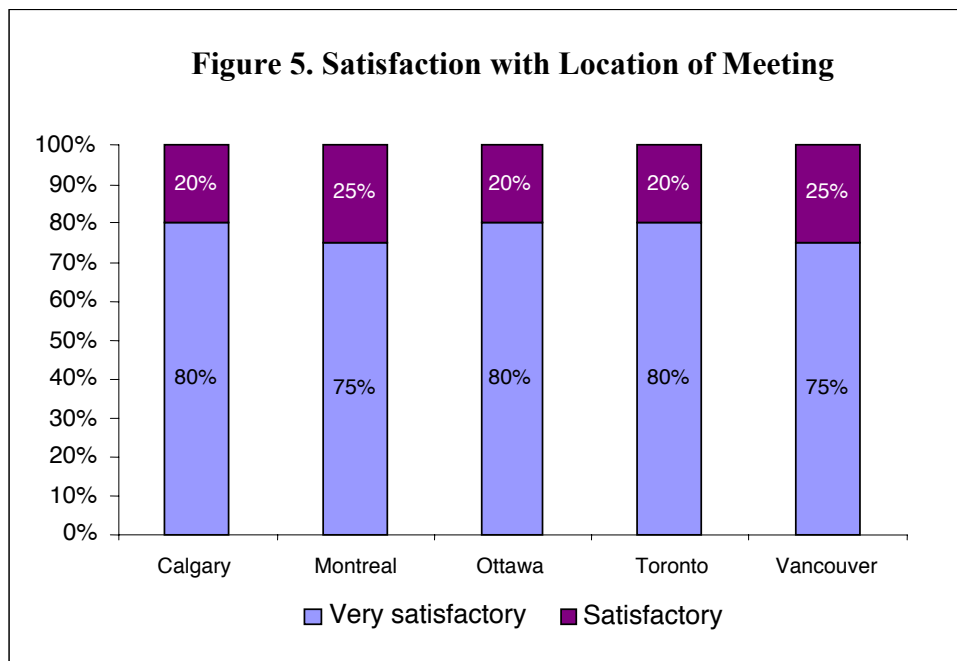
The focus group facilitators were asked to evaluate the project process and, in particular, the focus groups they conducted for their respective communities in the different cities. The evaluation form (Appendix 19) developed by the project team focused on gathering information on the focus group location, satisfaction of focus group participants, lessons learned in conducting focus groups, their role as facilitator, similarities and differences among the groups in the different cities, and steps to keep the momentum going on hepatitis C.

### Background of the Focus Groups

In total there were eight focus group facilitators and all responded to the questionnaire. Two facilitators from each of the selected communities (Chinese, Egyptian, Filipino, and Vietnamese) facilitated the focus group discussions in their respective community in five cities (Calgary, Montreal, Ottawa, Toronto, and Vancouver). Facilitators (one per focus group) were assigned the cities and the number of focus groups based on their place of residence and availability.

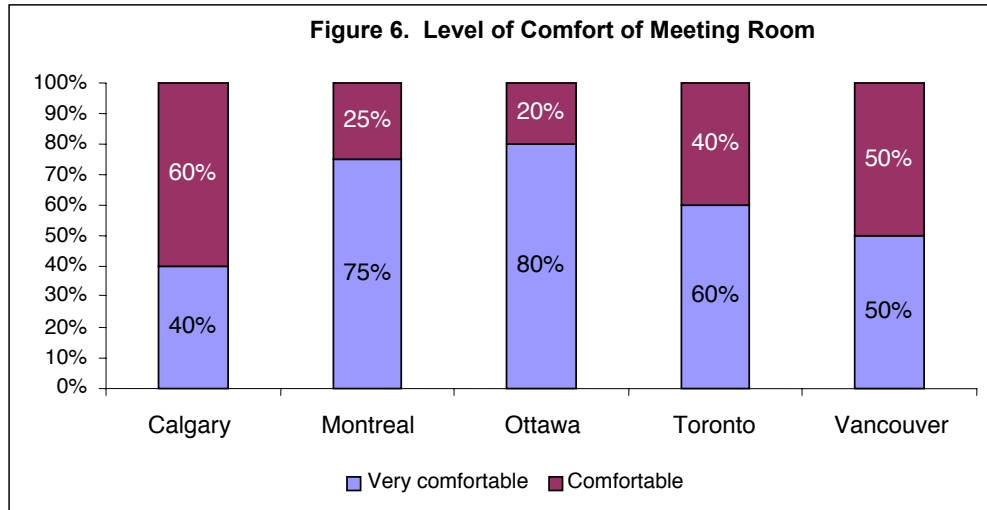
### Location of Focus Group Meeting

The focus group facilitators found the locations where the meetings were held to be satisfactory or very satisfactory (Figure 5).



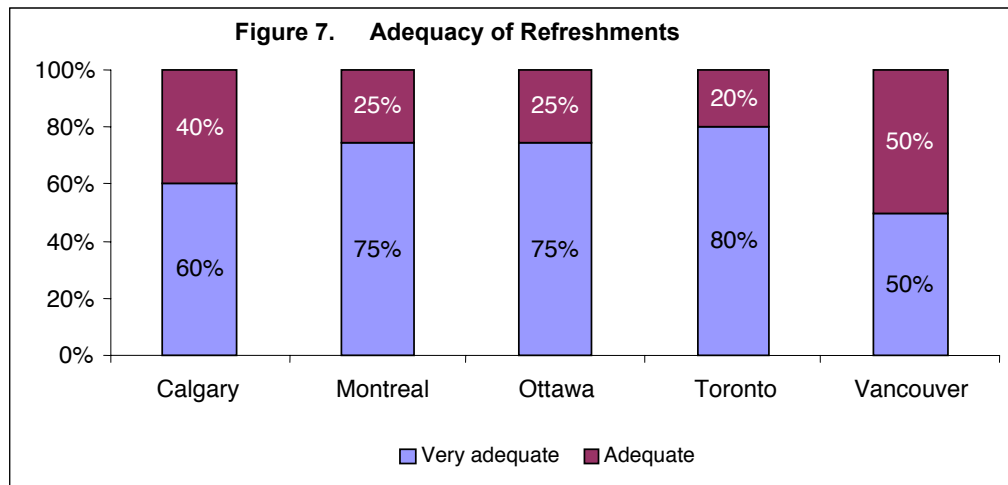
## Focus Group Meeting Rooms

The focus group facilitators found the meeting rooms to be comfortable or very comfortable (Figure 6).



## Refreshments

The focus group facilitators found the refreshments provided at the focus group sessions to be very adequate or adequate (Figure 7).



## Number of Focus Group Participants

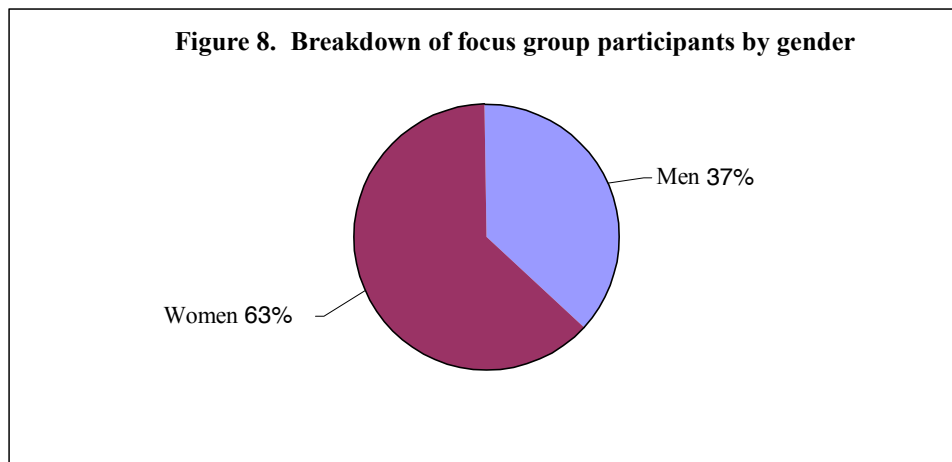
In total, the focus group participants numbered 491. The number of focus group participants from the four communities in the five cities are given in Table 1.

**Table 1. Number of Focus Group Participants**

	Chinese	Egyptian	Filipino	Vietnamese
<b>Calgary</b>	37	20	21	23
<b>Montreal</b>	20	19	33	29
<b>Ottawa</b>	22	25	29	30
<b>Toronto</b>	23	20	24	22
<b>Vancouver</b>	26	22	23	23
<b>Total</b>	<b>128</b>	<b>106</b>	<b>130</b>	<b>127</b>

## Gender Composition of the Focus Group Participants

The majority of the participants were women (Figure 8).



### **Size of Focus Groups**

All but one focus group facilitator felt that the size of the focus groups was appropriate. This facilitator felt that there were too many participants, including many drop-ins who happened to be present at the site and wished to participate.

### **Time Allotted to Meetings**

All the focus group facilitators felt that the time allotted (two hours) for each focus group was sufficient.

### **Interest and Satisfaction of Focus Group Participants**

It appears that the focus group facilitators felt that the majority of focus group participants were interested in the issue. Six of the facilitators felt that the participants were “*very interested*” while two commented that they were “*interested*.” Yet all stated that the participants provided the information needed from them. All facilitators stated that the focus group participants actively engaged in the discussions. Five of the facilitators felt that the participants were “*very satisfied*” with the focus group process and three felt that the participants were “*satisfied*.” None felt that any participant was dissatisfied.

### **Tasks, Responsibilities, and Training**

All the focus group facilitators felt that they were clear in their tasks and responsibilities. This indicates that the orientation session for facilitators was useful. All the facilitators noted that the training session helped them in terms of conducting the focus groups. One of the facilitators stated: “*it was a very useful training session and ensured all facilitators understand the role and responsibility in focus groups.*” While the majority of the facilitators did not wish for other facilitation materials, three of the facilitators would have liked additional resources. These included:

- AV materials (video, PowerPoint) on subject to make it more interesting;
- Copies of the consent form distributed before the focus group meeting (it appears that participants raised questions);
- A primer on how to handle difficult questions from participants.

Three facilitators experienced problems or concerns during their facilitation of the focus groups. In two instances, participants lacked understanding of the purpose of the focus groups, believing that the focus group session was actually to be a health talk. One community expressed concern as to why they were initially targeted to participate. The third problem may have arisen due to inexperience in facilitating groups. The facilitator found that it was hard for participants to wait their turn to speak.



## **Focus Group Improvements**

Overall, the majority (five of the eight) of the focus group facilitators felt that there were things that could be done to improve the focus groups. Several suggestions to improve the focus groups concerned the key informants (coordinators). One facilitator recommended that the key informants (coordinators) participate in an orientation session, as it was felt that they did not seem to understand the background of the project (and that may possibly have affected the selection process of focus group participants). Another focus group facilitator recommended that participants be better briefed on the objectives of the session (this may be connected to the first recommendation) since it was the coordinator's role to recruit and, as such, to clarify the goal of the focus group session. It was also suggested that the key informants (coordinators) and recorders (note takers) should be familiar with the community to improve group dynamics (help create more openness).

Other suggestions include:

- Inviting community leaders who are in positions of authority to participate so that they can more easily pass on information to their community;
- Allocating more time to complete the project;
- Reviewing the terminology used in developing the focus group questions; it was felt that they seemed redundant or the meanings were too obscure. For example, the difference between health issues and disease was not clear to participants.

## **Lessons Learned from Conducting the Focus Groups**

Some of the lessons learned include:

### **Focus group facilitating skills**

- One focus group facilitator felt a need to learn more about facilitation to gain mastery of the process of facilitation (e.g., reading ground rules first), to learn how to encourage people to speak, and know how to control the flow of dialogue; Others felt that they had acquired some of these skills through the process.
- Planning is important;
- People will cooperate when objectives are clear.

### **Greater knowledge/insights**

- Learned more details about hepatitis C (myths, importance as a health issue);
- Gained a better understanding of health services;
- Learned more about people's needs with respect to health issues;
- Learned that health awareness among the community, even among well educated people, was not always high;
- The same cultural community in different cities has different interests.

## Observed Similarities and Differences Among Focus Groups in Different Cities

<i>Similarities</i>	<i>Differences</i>
<ul style="list-style-type: none"> <li>• Eager and curious participants/willingness to participate;</li> <li>• Lack of knowledge of disease;</li> <li>• Language was a common difficulty for seniors;</li> <li>• Similar questions raised by participants;</li> <li>• Cultural issues were similar;</li> <li>• Gender mix was similar;</li> <li>• More seniors than youth participated.</li> </ul>	<ul style="list-style-type: none"> <li>• Level of knowledge differed;</li> <li>• Difference in attitudes towards seeking health information across cities;</li> <li>• Language needs varied;</li> <li>• Groups with community leaders showed enthusiasm to disseminate information;</li> <li>• Different health resources (info/services) across cities;</li> <li>• Different emphasis placed on community leaders to engage people;</li> <li>• Groups had different preferences in seeking out information even within same community;</li> <li>• Age mix made a difference in focus group meetings in terms of enthusiasm and vocalization speed.</li> </ul>

## Role as Focus Group Facilitator – Likes and Dislikes

The predominant thing that the focus group facilitators enjoyed in their role was meeting and interacting with the focus group participants (six of the eight respondents mentioned this).

Two of the eight facilitators stated that there was nothing they did not like in their role as facilitator. The following shows the likes and dislikes:

<i>Likes</i>	<i>Dislikes</i>
<ul style="list-style-type: none"> <li>• Meeting and interacting with participants;</li> <li>• Helping people in own community with public health promotion issue;</li> <li>• Improving facilitating skills – listening and probing;</li> <li>• Level of responsibility.</li> </ul>	<ul style="list-style-type: none"> <li>• Waiting to see if enough people showed up;</li> <li>• Isolation felt from travelling to facilitate these groups;</li> <li>• Juggling busy schedule;</li> <li>• Explaining why communities were targeted;</li> <li>• Speaking other dialects in order to communicate with group.</li> </ul>

## **Keeping Momentum Going on Hepatitis C**

Half of the focus group facilitators felt that participants of the focus groups should be kept informed of any new developments. This could be accomplished by involving the facilitators, coordinators, and networks. The same number felt that there should be continued follow up – i.e., public health education on hepatitis C. They recommended the following:

- Provide more training (train-the-trainer model) to health care professionals for promoting hepatitis C information in different ethnic communities;
- Engage community leaders in designing the next steps;
- Establish an information group for each city;
- Translate health information into different languages, not just the two official languages (English and French);
- De-briefing session for facilitators.

## **Focus Group Meetings as Means of Reaching the Community**

Seven of the eight facilitators agreed that the focus group meetings were the best way to reach their respective community. Other forms of reaching the community can include social gatherings, other events of national significance, etc.

Facilitators had positive comments about the experience, CLF, CEC, and the project coordinator, in particular.

### 7.3 Evaluation of Project Process by the Key Informants (Coordinators)

The key informants (coordinators) were asked to evaluate the project process and, in particular, the focus groups they coordinated for their respective communities in their city. The evaluation form (Appendix 20) developed by the project team focused on gathering information on their observations before, during, and after each focus group meeting.

#### Background

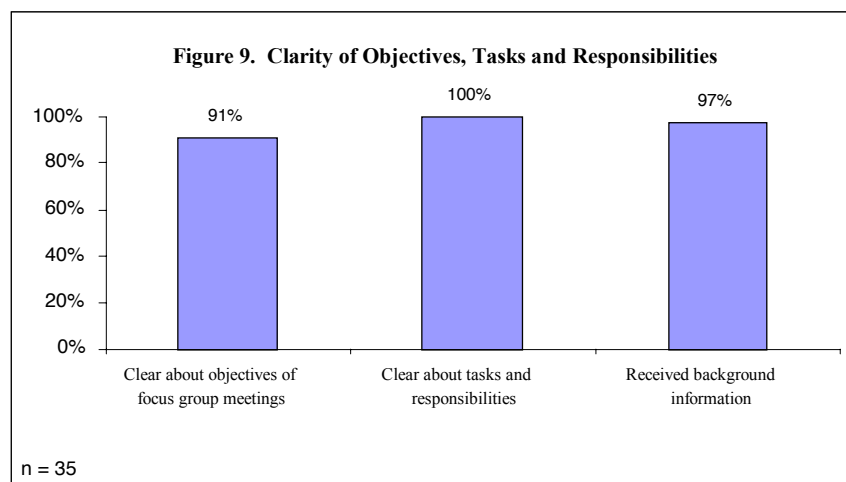
Thirty-five key informants (coordinators) completed the evaluation forms. Barring a few exceptions, there were two key informants (coordinators) for each of the four ethnocultural communities (Chinese, Egyptian, Filipino, and Vietnamese) in each of the five major cities across Canada (Calgary, Montreal, Ottawa, Toronto, and Vancouver). The exceptions were the following five instances in which the communities concerned deputed only one key informant (coordinator) to work with their members: Egyptians in Calgary; Filipinos in Montreal; and Vietnamese in Ottawa, Montreal, and Vancouver.

The key informants (coordinators) were from a variety of occupational backgrounds: health care providers, community development workers, coordinators of centres, and prominent members of the community.

#### Before the Focus Group Meeting

##### Clarity of Objectives, Tasks, and Responsibilities

The majority (32 out of 35) of the key informants (coordinators) stated that they were clear about the objectives of the focus group meeting. Three of the key informants (coordinators) felt that they were not clear (Figure 9). Yet, all of them mentioned that they were clear about their tasks and responsibilities. Only one key informant (coordinator) did not seem to receive the background information on the project ahead of time. The organization was forced to replace the original coordinator who was unable to carry out the tasks due to unavoidable circumstances.



## Difficulties with Recruitment

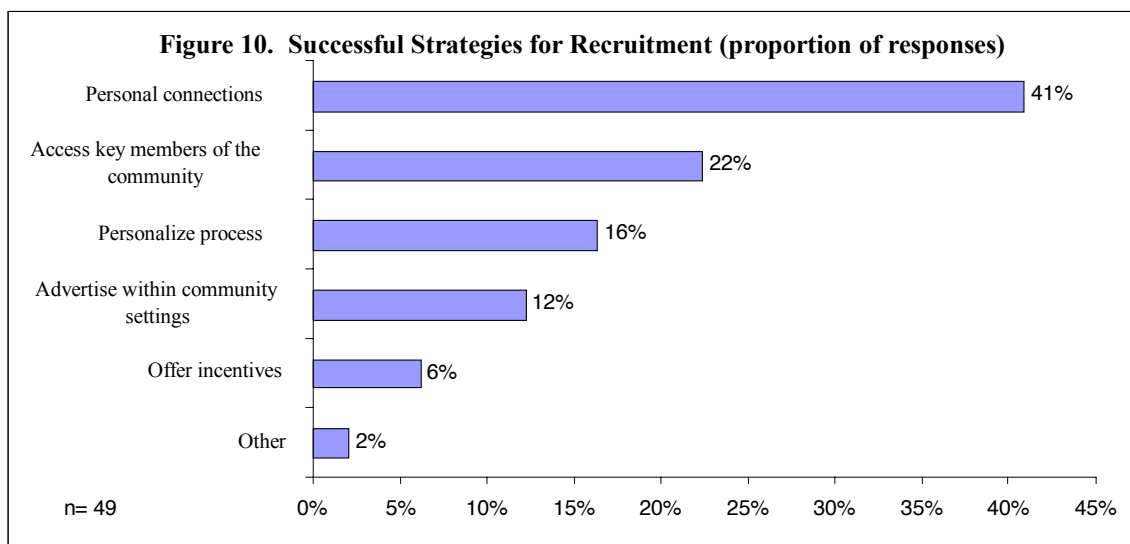
Almost one-quarter (23%) of the key informants (coordinators) encountered difficulties in recruiting participants for the focus group meetings. (Respondents were allowed to provide more than one response to the question.)

Out of the total of 35 responses received, the largest proportion (37%) indicated that the biggest problem key informants (coordinators) noted was scheduling difficulties; would-be participants had prior commitments on the date and time, they worked, there were religious holidays, etc. Other problems included:

- Uncertainty about participating/fear of participating (fear of being labeled with a disease, uncertain of process and what to expect, not used to discussing these issues; not sure of having anything to say) (31% of all responses);
- Lack of commitment/lack of interest of participants (not willing to commit, felt that they knew about the topic) (20% of all responses);
- Honorarium/incentives to participate were not offered (6% of all responses);
- Difficulty in meeting selection criteria and not having an organized/established cultural community to draw upon (3% of all responses).

## Strategies to Overcome Barriers to Recruitment

The most successful ways to recruit participants included a variety of strategies. It is evident from the responses that the key informants (coordinators) included what they believed to be best practices but not necessarily strategies that they employed. Figure 10 shows that the use of *personal connections* was the most common strategy of all the suggestions. (Respondents were allowed to provide more than one response to the question.)



**Details of the successful strategies for recruitment are as follows:**

**Personal connections:**

- Calls/emails to friends (asking them to recruit)/members of community;
- Network with the community;
- Recruit from clients (e.g., seniors' daycare centres).

**Recruit community leaders and key professionals:**

- Recruit community leaders;
- Contact family doctors because of the number of people they come in contact with, and they are also aware of others who can spread the word.

**Personalize the process:**

- Send personal invitations to different organizations in the community;
- Find convenient time for busy people;
- Ensure clarification purpose of focus group meeting and its link to the participants /Explain health education especially regarding hepatitis C;
- Coordinate with other ethnic group coordinators.

**Advertising/invitations through local community organizations/common areas:**

- Posters in common places such as bulletin boards at places of worship, grocery stores, schools, drugstores, and doctors' offices;
- Short clips/advertisements in the local cultural newspapers/media;
- Make announcements at cultural activities – mass gatherings, etc.;
- Email marketing;
- Invitation letters distributed through places of worship, friends, and organizations.

**Incentives:**

- Offer honorariums and/or food.

**Other:**

- Email marketing.

## **Venue for Meeting**

Of the key informants (coordinators), 78% had no difficulties in finding a satisfactory venue for the meetings. Those that did (22%) experience difficulties stated that the most common ones were availability of an appropriate venue and the cost of the available venue (given the limited budget). The solutions to finding a satisfactory venue included (Respondents were allowed to provide more than one response to the question):

- Making do with a smaller and not the original venue that had been intended (44% of all responses);
- Collaboration with other communities to find an appropriate venue (33% of all responses);
- Looking around until able to find a venue (22% of responses).

## **During the Focus Group Meeting**

### **Clarity of Facilitator**

The majority of the key informants (coordinators) felt that the presentation by the focus group facilitator was very clear (58%) or clear (39%). A few (3%) stated that the presentation was not clear.

### **Satisfaction with Presentation**

Approximately 69% of the key informants (coordinators) agreed that the pace of the presentation was very satisfactory and 31% felt it was satisfactory. The majority (91%) of the key informants (coordinators) felt that enough time was allocated for each focus group meeting. Of the 9% that disagreed, the common response was that the allocated time was too short (partly due to having to explain the focus group procedures, the goal of the focus group, and that confidentiality would be maintained).

### **Satisfaction with Distributed Materials**

Many (87%) of the key informants (coordinators) felt that the materials distributed to the participants were useful (very useful to useful). The remaining (13%) felt that they were not.

### **Project Reach**

A majority (84%) of the key informants (coordinators) felt that the project did reach a wide variety of participants. Of the 16% who did not feel that this project reached a wide variety of participants, the reasons given were that the demographics of the participants were not varied enough (i.e., old vs. young; newly arrived immigrants vs. long-term immigrants).

## **After the Focus Group Meeting**

### **Effectiveness in Gathering Information, Satisfaction with Groups**

The majority of the key informants (coordinators) felt the focus group meeting was a very effective way to gather information on the best ways to reach the community – 97% felt it was effective to very effective. The rest (3%) felt that this approach was not effective.

### **Key Informants (Coordinators) Suggestions for Improving the Meetings**

However, when asked whether the focus groups could have been better, 55% of the key informants (coordinators) felt that there could be improvements.

They recommended the following ways to improve the focus group meetings:

- Provide more information on hepatitis C. This includes valid and important medical information that can help participants take care of their health, i.e., more data and research material;
- Solicit the help of professional facilitators and members of the medical community on a voluntary basis to conduct and participate in the meeting;
- Offer incentives for individuals from the community to attend;
- Schedule – take into account that people have jobs and try to organize some of the events at times that would be accessible;
- Have a better representative demographic mix;
- Offer more focus group sessions;
- Offer documents in different dialects;
- Allow focus group participants to submit written questions to be compiled by note taker to get input from those who remained silent;
- Focus on recruiting community leaders and leaders from organizations so that they can share information with others.

The most frequent response was the need to provide more health information.

### **Key Informants (Coordinators) Views on Whether the Participants were Satisfied**

In their own mind, however, the majority of the key informants (coordinators) felt that the focus group participants were satisfied: very satisfied (51%) to satisfied (48%) with the focus group meetings. Only 1% said that they were not satisfied. Some focus group participants were disappointed that discussion on hepatitis C was not on the agenda; others stated that they should have been given some monetary compensation for their time and effort in attending the focus group.



## **Key Informants (Coordinators) List of Lessons Learned**

Key informants (coordinators) provided the following list of lessons learned (they are not in any order of importance; the groupings were developed to have similar items together). The most frequent responses were that recruiting more people than needed was necessary because of “no shows”; understanding the project was necessary to be able to explain it to others; personal contacts are the best way to recruit, and the recruits need to be sent reminders/messages to attend.

### **Planning:**

- Planning is important;
- Coordination needs to be done well in advance to reduce last minute replacements for last minute cancellations;
- Location of meetings should be close to where the majority of the community lives;
- The details are important – food, transportation, etc.;
- Need to ensure a convenient date and time;
- Promotion of the event is important;
- Conduct separate focus groups with people of the same community who speak different dialects;
- Ensure written materials are easy to understand and have definitions available.

### **Recruitment:**

- Get more participants than needed. It is inevitable that there will be no shows;
- Contact people by phone and place email/reminder calls particularly for those who cannot commit. Confirm and remind everyone by phoning again before the event;
- Personal contacts are the best way to recruit for any event;
- Acknowledge any of the community's concerns;
- Important to include other community leaders;
- Research and reach out.

### **Getting buy-in:**

- Understand that the project is important – need to be able to explain it well to the participants;
- Must be able to explain why the project is important and why their involvement is essential;
- Be able to communicate that the issue has a high level of importance: this shows the importance of being educated in order to be able to act.

**Personal Learnings:**

- Learned more about the disease;
- Personal success – a sense of satisfaction, and a confidence in communication, facilitation, and coordination skills;
- Learned more about process of focus groups – barriers, facilitation, etc.;
- Success in coordinating a group comes from sincerity and personal energy before you can persuade others;
- Required more time and effort than expected;
- Patience required.

**Incentives:**

- High level of apathy – need non-monetary incentives to persuade them to participate.

**Other impacts:**

- Creating a pleasant, warm environment for people to get together and socialize - a good way to reduce isolation.

**Key Informants' (Coordinators) Likes and Dislikes**

Key informants (coordinators) enjoyed several aspects about coordinating the focus groups. The most frequent responses included: the discussions and participation with the group; learning about the CEC in Ottawa and meeting the project coordinator; the educational opportunities afforded through the project (that is learning more about hepatitis C; and learning about the cultural perspective towards different diseases, etc).

**Other things that were enjoyed:**

- Getting to know people from the community;
- Seeing the sincere concern of participants about issues from the way participants contributed their ideas and interacted in the process;
- Having a chance to advocate for my community;
- Happy to be contributing in a small way to policy making in area of public health;
- Seeing the satisfaction of the participants;
- Learning of the continued interest of focus group participants, i.e., having people call back to find out outcomes.
- Receiving give-aways, e.g., cloth bags and pens (*AMI NUMBER 12.org?*).

**In terms of what they liked least, the following responses were offered:**

- Learning enough about the project to be able to explain it to focus group participants and other non-participants;
- Trying to convince people in the community that this was an important activity and having to deal with their disappointment afterwards when they did not learn anything new. Participants wanted more information on hepatitis C;
- Looking for and finding a satisfactory venue for the focus group meeting;
- Calling focus group participants at the last minute/trying to get reassurances that they would show up;
- Dealing with the no shows – people bailing out;
- Dealing with long presentations (considering seniors' age);
- Having meetings scheduled on a Sunday;
- Being uncomfortable with the statements of one of the focus group participants;
- Dealing with the recruitment process;
- Getting requests for reimbursements one week after the meeting;
- Accommodating the time limits of the session;
- Adjusting to the short timeframe;
- Dealing with the long coordination process – too much time wasted.

**Key Informants' (Coordinators) Views of Similarities and Differences of the Focus Groups**

Some of the key informants (coordinators) provided comments on the similarities that they observed:

- Focus groups were made up of different professions and working groups;
- Groups were similar in enthusiasm, level of understanding, contribution of ideas, and interaction;
- More women than men were willing to participate in the groups;
- The focus group process – the way meetings were conducted was similar;
- Some focus groups were more openly expressive than others;
- The medical concerns in all groups were very similar;
- All groups had constructive discussions;
- The groups freely shared knowledge;
- Focus group participants had little knowledge about hepatitis C;
- A majority of the focus group participants need information in their own language;
- The focus group participants became more interested as they began to understand the project better.

They also provided comments on any differences that they observed among the focus groups:

- There were gender differences in the make-up of different focus groups;
- The success of the meeting depended on the skills of the focus group facilitator;
- The subject matter discussed varied;
- Groups that included participants who spoke different language/dialect required more time for translation;
- Some participants were more vocal than others, notably, the young were more vocal than older members;
- The level of awareness of the topic varied;
- The groups targeted varied;
- Not all age groups were well represented across the different focus groups.

It should be noted that for both the similarities and differences, the most frequent responses, which were not captured in the paragraphs above, were either no response to those questions or the statement that there were no discernable differences.

### **Action Planned as Follow-up**

The majority (62%) of the key informants (coordinators) did not have any follow-up planned after the meetings. Of those that were planning a follow-up, the most frequently mentioned action plan involved *reporting back to the community when the final report was completed* (47% of the action plans reported).

Other planned activities included:

- Future health education presentations to further discuss hepatitis C (in one instance, they are planning on inviting a health professional to respond to questions arising from the focus groups) (33% of the action plans);
- Currently thinking of planning a follow-up to this meeting (20% of the action plans).

### **Key Informants (Coordinators) and New Contacts**

Of those who responded to the question, some (45%) of the key informants (coordinators) stated that new contacts were made as a result of the focus group meetings. These included the facilitators, community members, CEC members, and new organizations. One coordinator stated that the process of recruitment allowed them to get their foot in the door of new organizations.

## **Key Informants' (Coordinators) Recommendations for Future Work**

Twelve of the key informants (coordinators) provided recommendations for future work. The suggestions can be roughly placed into three broad groupings – improvements to focus group meetings, follow-up work to these meetings, and new topics.

### **How to improve focus group meetings:**

- Provide more training for facilitators;
- Include the medical community as volunteers (as facilitators);
- Include community leaders;
- Offer honoraria.

### **Follow-up work:**

- Follow-up with discussion of results from the hepatitis C focus group meetings;
- Continue to involve the focus group participants;
- Extend the study to other communities and across Canada;
- Produce a video;
- Provide more information on hepatitis C: possibly in other languages.

### **New topics:**

- HIV/AIDS;
- Any information sharing sessions on health education topics;
- Develop new health awareness packages – information for dissemination.

## **Reaching the Community – Are Focus Groups the Best Way?**

The majority (76%) of the key informants (coordinators) felt that the focus group meetings are the best way to reach their community. Those who felt that the focus group meetings were not the best way offered the following suggestions and complaints:

### **Suggestions:**

- Couple the focus groups with an activity that the community already participates in – places of worship, schools, etc.;
- Use person-to-person contacts;
- Target the ethnic newspapers, radio stations, and TV stations;
- Host workshops. Participants had wanted more information on the disease and to have the potential to ask questions;
- Provide videos and open forums which will reach more persons.

**Complaints:**

- Focus groups have a function but a community cannot be reached by gathering 20 people. You can only get an idea about the community and think on a certain issue.
- Focus groups too costly for the amount of information shared.

**Other Comments:**

Several coordinators provided other suggestions or comments in the following areas:

**Post Focus Group Sessions:**

- Need follow-up to the focus groups;
- Need to evaluate findings;
- Participants hope that focus groups can be organized twice a year to reach more people in the community.

**Dissemination ideas (disseminating information about the disease):**

- Create public awareness campaigns – short videos, billboards, common gatherings, bus stops, etc.;
- Offer hepatitis C materials that are accessible and easy to read in different languages.

**Other benefits to these meetings:**

- These types of focus group meetings are useful to groups of people, particularly ethnic minority seniors who are relatively isolated.

**Work by CEC and CLF:**

- Great work on part of CEC and CLF managers.

## 7.4 Project Team Observations

The project team faced several challenges during the course of the project. A brief account of how the challenges were met is as follows:

- The first major challenge was to schedule and conduct 40 focus groups from September 1 to October 31, 2008, involving four ethnocultural communities, in five cities across Canada. Care had to be taken to ensure that they could be conducted in sequence and completed in the shortest period of time with limited resources. The allocated and approved budget for travel and accommodation did not permit any flexibility. It should be noted that the facilitators accepted the stringent conditions because of their dedication to helping and working for their communities and because of their cordial relationship with the CEC, a non-profit organization that they knew also had very limited resources.
- Meetings had to be scheduled on weekends and weekdays during the months of September and October to accommodate all 40 focus groups. In some cases, two focus group meetings were scheduled on the same day because alternate dates were not available within the two-month timeframe.
- Initially notes and proceedings of the focus groups were done verbatim from the transcribed tapes in the language of the focus group. They were then translated into English. This process took far more time than allocated. For example, the Chinese and Vietnamese translators each took more than 20 hours to transcribe one session into the respective language and an equal amount of time to translate into English. As a result, it took them more than one month to complete two sessions. Therefore, it was decided to translate verbatim recordings directly into English. The CDs with the original language are available should anyone want to refer to focus group discussions in the original language.
- According to the project work plan, all 40 focus groups had to be completed in two months (September and October). The focus groups in Ottawa, Montreal, and Toronto were scheduled for the month of September, and the focus groups in Vancouver and Calgary were planned for October. In 2008, Ramadan, a religious observation for devout Muslims, took place during the month of September. Many of the potential participants who are Muslims, particularly from the Egyptian community, were unwilling to participate in the focus groups because they were fasting during the day. No food is to be served/consumed between sunrise and sunset. Special accommodation and steps had to be made to accommodate focus group participants of the Muslim faith for the entire month of September. The key informants (coordinators) in Montreal, Ottawa, and Toronto quickly found ways to accommodate the participants. Each group adopted its own methods to overcome these challenges. The Ottawa Egyptian group agreed to have their meetings late in the evening, starting with supper. The Montreal key informants (coordinators) decided to provide each participant a box of food or sweets instead of serving refreshments during the meeting. In Toronto, two locations where individuals

generally congregate to attend regular community programs were used to conduct focus groups.

- The location for the focus groups in Montreal presented its own challenges. The Filipino association in Montreal that normally works with the CEC on health projects refused to host the focus groups. They had wanted to have their own focus group facilitator from Montreal. Instead the project coordinator approached a Filipino professional association, which had also worked with the CEC on previous projects. This group was told by the Montreal association that they should have a Montreal-based facilitator. The CEC sent a letter to both contacts explaining the criteria used for the focus groups as required by the project mandate, approved by the Health Canada Research Ethics Board. All focus groups were required to have the same facilitators for each of the four communities. They were reminded that the criteria for selection were based on qualifications that had been approved and outlined in the previous parts of the projects. All facilitators had to undergo an orientation workshop. The Filipino business and professional group was satisfied with the explanation provided and the organization proceeded with organizing the focus groups. However, for future projects, they felt strongly that only facilitators from Montreal should conduct focus groups in Montreal.
- Also in Montreal, the Egyptian key informant (coordinator) wanted the focus group facilitator to be fluent in French because some of the Egyptians who have lived there for many years speak French rather than Arabic. Fluency in French should have been one of the criteria for selecting facilitators if focus groups are to be conducted in Montreal. The key informant (coordinator) personally accommodated this request by taking on the additional task of interpreter, in French, for the Egyptian community. As a result of this challenge the project team took steps with the other three cultural groups to be ready for this request in case focus group participants wanted to speak French. It was noted by some of the Montreal participants, that in the future, provision should be available to conduct focus groups in French.
- As there is no national Egyptian Canadian organization, the key informants had difficulty communicating with Egyptian communities in all cities across Canada except Ottawa. The CEC has worked closely with the local Egyptian community but a national network did not exist. However, through informal channels and through the contact list developed earlier in the project as well consultation with the CEC membership they were able make contacts and maintain communication to organize the focus groups there by creating an informal network.



- The Egyptian focus group participants, on average, were better educated and had to be approached differently. Participants questioned the use of the consent form, wanted to see the questions that they had to respond to before filling out the consent forms; and felt that they could get the information on hepatitis C if they wanted because they had no language or literacy barriers. However, once the discussion started they were very enthusiastic and provided the required information for the project. A few of them went to the extent of asking for more such focus group meetings on hepatitis C with healthcare professionals.
- The project evolved over a four-year span. The stop-and-start nature of the project, although outside the control of the funding agency, is very difficult on non-profit organizations such as the CLF and the CEC. The CEC does not have sustained funds to keep the operations going between approvals or to keep the interest and the community stakeholders informed. It was difficult to resume discussions and negotiations with the four ethnocultural communities without knowing whether the funding for the continuation of the project would be approved.
- The request from the Health Canada Research Ethics Board to conform to their requirements was a new challenge for non-profit, community-based organizations such as the Canadian Liver Foundation and the Canadian Ethnocultural Council. Community-based organizations do not normally conduct academic or medical research, although they may fund it. Having to submit the community-based research to the Health Canada Research Ethics Board criteria was a new experience for all concerned.



## **8.0 CONCLUSIONS**



## 8.0 Conclusions

Focus group participants recruited from the four ethnocultural communities selected for this project demonstrated a uniform lack of knowledge about hepatitis C. This is a concern because of the crippling effects of the disease on individuals, families, and communities, and also on the Canadian healthcare system.

In these focus group discussions, the communities who felt most strongly about the lack of doctors who speak their language were the Chinese, Filipino, and Vietnamese. Focus group participants from the Chinese and Vietnamese communities, in particular, felt that a personal connection with their doctor was important, which is why they wished to go to a Chinese or Vietnamese doctor. The Egyptian community on the whole seemed to be more integrated, language-wise, into Canadian society and seemed to be better educated. However, this community also had little knowledge about various health issues.

Many individuals from all four communities stated that they had difficulty in obtaining health information from their doctors, especially preventative information. They indicated that they could only get information from their doctor if they had a disease. In some areas, a visit to a doctor is limited to talking about only one or two health issues per visit; individuals who have more concerns need to make multiple visits to cover their concerns. Others mentioned the difficulty in finding any doctor, not just one from their own ethnic community, as a problem in getting good health information; additionally, their doctor was often just too busy to give out information. If they did get an appointment with a doctor from their ethnic community, there was usually a long waiting time.

In all four communities, many cultural taboos exist with regard to health issues. Focus group participants – particularly from the Chinese, Filipino and Vietnamese communities in the five cities – mentioned that talking about diseases is a taboo in their culture. They are also reluctant to talk about a disease for fear of being stigmatized and labeled. Focus group participants from all four communities felt that it would be difficult even to get their communities interested in health and health issues. In addition, many of the focus group participants have little knowledge about health and health issues. Some, in fact, are not at all health conscious and only become interested in a disease when they have that disease. This attitude could possibly be changed for future generations by early education on health. Quite a few believed that the schools should be involved in health education and they suggested that health education should be a part of the high school curriculum. Additionally, they thought it would be a good idea for universities to host health talks.

Several focus group participants from the Chinese, Filipino, and Vietnamese communities were fearful that talking about a disease might somehow lead to their getting this disease. This superstition may be a reflection of the fact that knowing more about a disease might help them to identify their own symptoms. On the other hand, the Egyptian community, which is fairly integrated into the larger Canadian society, thought that an emphasis on hepatitis C in their communities was a form of stereotyping of their community, which they considered an insult. The Egyptian community stressed that information about hepatitis C should not focus on any one community, but should focus on the larger Canadian society. Additionally, one Egyptian focus group suggested that health is simply not a topic of concern in the Arab community. Many focus group participants from the Filipino and Vietnamese communities discussed a deeply ingrained fatalistic attitude that meant that they should not worry about the future and accept whatever happens.

Communities – especially the Chinese, Filipino, and Vietnamese – expressed concern over difficulties in obtaining health information and, in addition, that the information they were getting was not up-to-date or accurate. They favored receiving information from the government, as they deemed that to be the most reliable information available. In Vancouver, the *BC Health Guide* was used by many of the Egyptian focus group participants, and in Toronto the Egyptian focus group participants used Telehealth Ontario, the health information telephone line of the Ontario Government. Focus group participants from all four communities in the five cities suggested that health information should be spread through the various ethnic media: newspapers, TV, radio, etc. Other ways to reach communities with health information include social gatherings or when events of national significance are marked. Videos and PowerPoint presentations on hepatitis C and other health issues could be running in one part of the room during such an event. A public awareness campaign could provide information on billboards, at bus stops, at common gathering places, etc. Focus group facilitators suggested establishing a health information group in each city. Key informants (coordinators) agreed with the focus group participants that follow-up sessions were needed for the focus group participants, and suggested that it was important to get them involved in spreading the health information in their respective communities. The focus group participants mentioned that person-to-person contacts were the best way to spread information.

This project was plagued from start to finish by the fact that approval was granted quite late in each fiscal year. This meant that time to completion had to be speeded up and that there was less flexibility in times and dates of meetings. This late approval of project funding necessitated holding the meetings in September and October, which created a problem for the Egyptian community, whose Muslims celebrated Ramadan in September. Creative ways had to be found to involve many of these individuals, particularly those from the Egyptian community, in these meetings. Because it was hard to find a date and time that were convenient to the majority, some who would otherwise have come to the focus groups were unable to do so. Key informants (coordinators) also found that this short timeframe meant that they had less time to do a great amount of preparatory work. The limited budget created

difficulty in finding satisfactory venues for the meetings; in some cases coordinators had to spend an inordinate amount of time to find an appropriate and available venue for the meeting.

Another difficulty that the project team faced was that the approved budget did not allow for honoraria to be given to focus group participants. This meant that participants of the focus groups came simply out of goodwill with no compensation for their time. This, and the difficulty in scheduling times to meet in this shortened timeframe, may have contributed to the fact that the demographics of the groups were heavily weighted in favor of older individuals. The key informants (coordinators) in each city who spent weeks working to organize the focus groups, could only be paid a token amount that was not at all adequate for the amount of time and effort that they spent in organizing focus groups in their communities.

The limited budget and short timeframe placed both the Canadian Liver Foundation and the Canadian Ethnocultural Council under tremendous pressure. Uninterrupted and consistent funding throughout the project would have allowed for considerable money and time savings. As it was, the project team was under tremendous stress to accommodate restrictions in both budget and time. The allocated and approved budget for travel and accommodation permitted no flexibility. It should be noted that the facilitators accepted the stringent conditions because of their dedication to helping and working for their communities and because of their cordial relationship with the CEC, a non-profit organization that they knew also had very limited resources. Conforming to the additional requirements from the Health Canada Research Ethics Board added to the challenges faced in this project.

The project took four years to complete as it moved along in a stop-and-start modus operandi not knowing whether funding would be secured from one stage to the next. Although funding availability was outside the control of the funding agency, this situation placed great stress on the non-profit organizations, which do not have sustained funds to keep operations going between approvals. Maintaining the respect and trust of the four ethnocultural communities was difficult when the continued funding, and therefore project completion, was in doubt. This respect and trust are essential to working with ethnocultural communities. The fact that the project succeeded in achieving its goals and objectives in spite of the irregular and uncertain nature of the funding, is due almost solely to the trust and loyalty to the CEC engendered by earlier projects with these communities.

The project has had a positive impact on all four communities. Most people really wanted to participate and an enormous interest has been generated by this project. In some cases, the organizers had to turn down would-be participants. It is imperative to build on the goodwill and interest generated in the communities through this project. Not being able to do so now that this interest has been generated, would mean losing momentum in providing necessary and useful information about a major public health issue that affects these communities and all Canadians. Awareness and knowledge about hepatitis C and engagement of the communities are crucial in our efforts to increase capacity in ethnocultural communities.





## 9.0 APPENDICES

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## **APPENDIX 1**

### **INVITATION LETTER TO ORGANIZATIONS**



## Appendix 1

### Invitation Letter to Organizations

\_\_\_\_\_, 2008

(Name/Organization here)

Dear \_\_\_\_\_:

Following our telephone conversation, the Canadian Ethnocultural Council (CEC) and the Canadian Liver Foundation (CLF) cordially invite the (name of organization here) to participate in the project “Engaging Ethnocultural Communities on Hepatitis C”. Funding for this project is being provided by the Public Health Agency of Canada.

The purpose of the project is to involve ethnocultural communities in building an understanding and awareness of hepatitis C, a liver disease caused by the hepatitis C virus (HCV), which is found only in persons who have this infection. (More information on hepatitis C is enclosed with this letter.)

In order to do this, we are seeking input from your community. We will be holding focus group sessions in Calgary, Montreal, Ottawa, Toronto and Vancouver with individuals from four communities - Chinese, Egyptian, Filipino and Vietnamese. These were selected because, according to the World Health Organization, China, Egypt, the Philippines, and Vietnam reported levels of hepatitis C infection at 3% or higher in the general population of these countries.

We are aiming to find 10 women and 10 men from your community to participate in two focus groups. We would like to invite participants from among health care workers, members of your organization, and individuals interested in health issues such as hepatitis C. Information from the focus groups will be used to help us develop a process to approach communities and engage them in health issues such as hepatitis C.

All information provided in the focus groups will be kept strictly confidential, including the names of individuals. Each focus group session will take about 2 hours, participants will be reimbursed for out-of-pocket expenses (taxi, parking, child care), and refreshments will be served. There is no fee for participation.

If you wish to participate in this project or need any clarification, please contact:

(Name/information of local contact here:)

Anna Chiappa, CEC, (613) 230-3867 ext. 224 (collect); Email: [cec@web.ca](mailto:cec@web.ca), or

Billie Potkonjak, CLF, 1-800-563-5483; Email: [bpotkonjak@liver.ca](mailto:bpotkonjak@liver.ca)

We appreciate your help in this important work. Your organization’s participation in this project will help improve the health of our communities. We look forward to hearing from you by (date here).

Yours truly,

Anna Chiappa, Executive Director, CEC



## **APPENDIX 2**

### **INVITATION TO FOCUS GROUP PARTICIPANTS**





## Appendix 2

### Invitation to Focus Group Participants

We need you. Help improve health in your community.

The Canadian Liver Foundation and the Canadian Ethnocultural Council are working together on a project to reach out and involve diverse communities to learn how to build understanding and awareness around health issues such as hepatitis C.

Hepatitis C is a liver disease caused by the hepatitis C virus (HCV), which is found only in persons who have this disease. It is serious for some people, but not for others and it can take up to 10 to 20 years to show any signs or symptoms.

Today, many people who are infected with the virus that causes hepatitis C may not be aware that they have this disease. They do not know that they can easily be checked for hepatitis C and that there is treatment available for some. Also, if tested by their health care provider for HCV, people could learn how to protect their liver from further damage if they have this infection.

We are planning two focus group sessions in your city. A total of ten women and ten men from your community will be selected and each will be invited to participate in one of the two focus group sessions. If you are a health care worker, member of a (name community) organization or individual interested in health issues like hepatitis C, we need your help. Your information will be used to find out how and where your community prefers to receive information on health issues such as hepatitis C and will help to improve the health of our communities.

All information you provide, including your name, will be kept confidential.

The focus group session will take approximately 2 hours of your time, you will be reimbursed for out-of-pocket expenses (taxi, parking, child care) to attend the focus group, and refreshments will be served. There is no fee for your participation.

If you would like to participate, please call us by (date here):

(Contact of local organization here):

Anna Chiappa, CEC: (613) 230-3867 ext. 224 (collect); E-mail: [cec@web.ca](mailto:cec@web.ca)

Billie Potkonjak, CLF: 1-800-563-5483 ; E-mail: [bpotkonjak@liver.ca](mailto:bpotkonjak@liver.ca).

If you know of anyone else who may be interested in participating, please feel free to share this invitation and ask him or her to give us a call, too!

Thank you

*Funding for this project is provided by the Hepatitis C Prevention, Support and Research Program, Public Health Agency of Canada.*



## **APPENDIX 3**

### **INFORMED CONSENT FORM**



## Appendix 3

### Informed Consent Form

**Title of Project:**

Engaging Ethnocultural Communities on Hepatitis C

**Purpose of the Project:**

The purpose of the project is to find ways of reaching out and involving ethnocultural communities in building understanding and awareness about public health issues such as hepatitis C.

**Background:**

The Canadian Ethnocultural Council (CEC) and the Canadian Liver Foundation (CLF) are working together on this project because of their experience in public health education. The funding for this project is being provided by the Hepatitis C Prevention, Support and Research Program of the Public Health Agency of Canada.

Hepatitis C is a liver disease caused by the hepatitis C virus (HCV), which is found only in persons who have this disease. The disease is serious for some people, while for others it can take 10 to 20 years to show any signs or symptoms.

While the need for public education on hepatitis C exists among all communities in Canada, four ethnocultural communities - Chinese, Egyptian, Filipino and Vietnamese were selected because, according to the World Health Organization (WHO), China, Egypt, the Philippines, and Vietnam reported levels of hepatitis C at 3% or higher in the general population in these countries.

**Description of the Project:**

A total of 40 focus group sessions are being held in the cities of Calgary, Montreal, Ottawa, Toronto and Vancouver. Individuals from four communities - Chinese, Egyptian, Filipino, and Vietnamese - have been selected to participate. Ten women and ten men were selected to participate in each city from each of these four communities.

Information from these focus groups will be used to find ways of reaching and involving ethnocultural communities to learn how to build an understanding and awareness around health issues such as hepatitis C.

**Your part in the Project:**

If you decide to accept the invitation to participate, the information that you share in the focus group will help us to find out how and where your community prefers to receive health information, including information on hepatitis C.

An invitation was sent to organizations in your community asking for their help in informing potential participants to take part in a focus group. They were asked to share information about this project and invite you to contact us if interested.

Ten participants have been chosen for each of two focus group sessions. The composition of the focus group aims to have representation from individuals who are 18 years of age and over, as well as a gender (male/female) and age balance.

**About the Focus Group:**

The questions you and other group participants will be asked deal with the best ways to involve your community to build understanding and awareness of health issues such as hepatitis C.

We anticipate that the focus group session will last about 2 hours and the information will be audio taped. The information on the audiotapes will be transcribed and a written transcript of the focus group discussion will be prepared.

**Participation:**

Participation in the project is voluntary. If you do choose to participate in the project, you may withdraw at any time without penalty or any loss of benefits or services to which you are entitled and receive.

**Confidentiality:**

Confidentiality will be respected and any information that discloses your identity will not be shared or revealed to any individual or organization. Other than signing this consent form showing that you agree to participate in the focus group, no information about you, not even your name, will be collected. This consent form cannot be linked to the information and opinions you may express in the focus group discussion and the results of the discussions will only be presented in future in anonymous group form.

If you participate in this focus group, you are asked not to discuss outside this room what individual people say in the group.

All completed consent forms, the focus group audiotapes, as well as the typed transcriptions made from the tapes will be accounted for and kept in a secure locked cabinet and be available only to the project staff of the Canadian Liver Foundation, the Canadian Ethnocultural Council and the Hepatitis C Prevention, Support and Research Program of the Public Health Agency of Canada. The audiotapes will be destroyed after the transcription has been completed, reviewed, and verified, and all other project materials will be destroyed within three years after completion of the project.

**Potential Risks:**

Potential risk is minimal as we seek only information from you to help us in future to develop ways to involve your community to build awareness on health issues such as hepatitis C. As a result of participating in the focus group discussion, you could experience discomfort, fear or anxiety if you or a loved one has been exposed to the hepatitis C virus. If you would like to speak to someone, support is available. Please contact the Canadian Liver Foundation by telephone at: 1-800-563-5483 (toll free).

**Potential Benefits:**

You will not personally benefit directly from participating in this focus group; however, your contribution is important and will be valued. The findings will be used to develop culturally appropriate ways of reaching your community to better inform them about health issues such as hepatitis C. Your participation may:

- improve the quality of life for those infected by the hepatitis C virus;
- help decrease the spread of the virus;
- encourage community support for educational programs that will provide a better understanding of the disease;
- provide new information on hepatitis C; and
- encourage members of your community to seek medical help, and prevent the progression of the disease through treatment.

**Reimbursement:**

There is no financial compensation for your participation in the project. Out-of-pocket expenses, such as costs for taxi, parking, and child care will be reimbursed. This will be reimbursed even if you don't answer all the questions asked or even if you decide to withdraw your participation before the focus group ends.

**Contact:**

If you have any questions about the project, please contact:

- Anna Chiappa, Canadian Ethnocultural Council: (613) 230-3867 ext. 224 (collect calls accepted) or
- Billie Potkonjak, Canadian Liver Foundation: 1-800-563-5483 ext. 4932 (toll free)

If you have questions about your rights as a project participant, you may contact:

The Research Ethics Board Secretariat

Office of the Chief Scientist

Health Canada

Holland Cross, Tower B

1600 Scott Street, Room 410, A.L. #3104A

Ottawa, ON

K1A 0K9

Phone: (613) 941-5199 (collect calls accepted)

Fax (613) 948-6781

Email: [reb-cer@hc-sc.gc.ca](mailto:reb-cer@hc-sc.gc.ca)



## CONSENT

By signing this form, I agree that:

This project has been explained to me..... Yes  No

My questions about this project were answered..... Yes  No

The possible risks and discomforts and the possible benefits (if any) of this project have been explained to me..... Yes  No

I understand that I have the right not to participate and the right to stop at any time..... Yes  No

I have a choice of not answering any specific questions..... Yes  No

I am free now, and in the future, to ask any questions about this project..... Yes  No

I have been told that my personal information will be kept confidential..... Yes  No

I understand that no information that would identify me will be released or printed..... Yes  No

I understand that I will receive a signed copy of this consent form..... Yes  No

I hereby consent to participate..... Yes  No

---

Signature

---

Date

Name of person who obtained the consent: \_\_\_\_\_

---

Signature

---

Date



## **APPENDIX 4**

### **FOCUS GROUP QUESTIONS**



## Appendix 4

### Focus Group Questions

1. What are the major health issues that people in your community talk about?
2. What health issues do people in your community **not** talk about?
3. What diseases are **not** talked about?
4. What are some reasons for **not** talking about these diseases?
5. What about hepatitis C? Is hepatitis C an issue in your community? What kinds of things do people say about hepatitis C in your community?

**Explain:** What is hepatitis C and how it is spread.

**Probe:** What about other diseases spread by contact with blood? What kinds of things do people say about these diseases?

6. Where do members of your community go to get information on health issues?

**Probe:** Your doctor, nurse, social worker, pharmacist, herbalist, community organization, public health office, community health centre, walk-in clinic, library, internet, others?

7. In what ways would you like to receive information on health issues like hepatitis C?

**Probe:** Language spoken/written; visual (videos); in private; person-to-person; workshops.

**Probe:** What about the media? What format? (Community television, radio, brochures, newspaper, bulletin boards.) Where would you like to have it? (In what venues?)

8. Can you name any successful ways in which your community was involved in a health issue in the past?

**Examples:** CEC diabetes support groups, health fairs, media information sessions, public forum, workshops.

9. What are the best ways to engage/inform your community on health issues?

10. What, if any, barriers do you think exist to getting information on health issues such as hepatitis C to members of your community? How could these be overcome?



## **APPENDIX 5**

### **MEMBERS OF THE EXPERT ADVISORY COMMITTEE**





## Appendix 5

### Members of the Expert Advisory Committee

#### Chinese Community

1. Ms. Maria Chu, Program Manager, Community Support Services, Yee Hong Centre for Geriatric Care, Toronto.
2. Mr. K.Y. Liu, Director, Social Services, Yee Hong Centre for Geriatric Care, Toronto.
3. Ms. May Yip, Nurse Educator, Somerset West Community Health Centre, Ottawa.
4. Ms. Miriam Yu, Chair, Chinese Cultural Centre of Greater Vancouver, Vancouver.
5. Ms. Lucy Zhao, Registered Nurse, Somerset West Community Health Centre, Ottawa.

#### Egyptian Community

1. Ms. Zaineb Al-Kutoby, Multicultural Health Promoter, South East Ottawa Community Health Centre, Ottawa.
2. Ms. Huda Bukhari, Coordinator, Arab Newcomers Centre, Toronto.
3. Ms. Susie El-Saadany, Egyptian Community Representative, Ottawa.
4. Ms. Safaa Fouda, Head, Egyptian Cultural Association, Ottawa.
5. Ms. Nahid Gawad, Teacher, Ottawa Muslim Association, Ottawa.
6. Mr. Art Hagopian, Past-President, Canadian Ethnocultural Council, Toronto.
7. Ms. Nivin Sharaf, Representative, Egyptian Community, Ottawa.

#### Filipino Community

1. Mr. Flaviano Agpalza, Philippine Association of Manitoba, Winnipeg.
2. Ms. Carol Banez, Clinical Nurse Specialist, University Health Network, Toronto.
3. Mr. Salvador Cabugao, Representative, National Council of Canadian Filipino Associations, Montreal.
4. Ms. Laarni Casiple, Registered Nurse, Ottawa Filipino Association, Ottawa.
5. Ms. Nejie Escares, Registered Nurse, Ottawa Filipino Association, Ottawa.

#### Vietnamese Community

1. Ms. Hoa Duong, Nurse Educator, Somerset West Community Health Centre, Ottawa.
2. Ms. Tuyet Lam, Information Specialist at Peter Lougheed Hospital, Calgary and Board Member, Multicultural Cancer Prevention Project – Vietnamese community, Calgary.
3. Mr. Can D. Le, Commissioner, External Affairs, Vietnamese Canadian Federation, Ottawa.
4. Mr. Antoine Nguyen, Vice-President, External, Calgary Vietnamese Canadian Association, Calgary.
5. Mr. Mong Q. Nguyen, Manager, Vietnamese Newcomer Settlement Program, Ottawa.
6. Ms. Hien Duc Tran, ESL Teacher, Vietnamese Buddhist Association, Winnipeg.
7. Mr. Diep V. Trinh, Advisor, Vietnamese Canadian Federation, Ottawa.

## **Terms of Reference**

### **Guiding Principles**

The committee shall work within the following principles:

- Community awareness
- Cultural sensitivity
- Community involvement in public health education
- Partnership.

### **Role of the Members**

To advise on the project process and implementation.

### **Representation**

Individuals are selected from four ethnocultural communities: Chinese, Egyptian, Filipino and Vietnamese based on their experiences as health professionals, community leaders, and individuals interested in health issues.

### **Duties**

Duties are to provide advice on:

- Focus group approach
- Focus group tools
- Terms of Reference for key informants, focus group facilitators, and recorders
- Method of recruiting focus group participants
- Translation of project materials
- Criteria for facilitator training
- Recommendations for the next steps.

## **APPENDIX 6**

### **JOB DESCRIPTION OF KEY INFORMANTS**



## Appendix 6

### Job Description for Key Informants

Key Informants: 40 (2 per ethnocultural community; 4 groups: Chinese, Egyptian, Filipino, Vietnamese)

Cities: 5 (Calgary, Montreal, Ottawa, Toronto, Vancouver)

#### Tasks and Responsibilities

- Serve as a link to specific ethnocultural community
- Assist in identifying appropriate individuals for participation in all aspects of the project including focus groups
- Liaise with the project coordinator
- Liaise with focus group facilitator

#### Skills Required

- Ability to communicate in either Mandarin and Cantonese, Tagalog, Vietnamese, and Arabic, as well as English or French (as required)
- Thorough knowledge of their local communities
- Knowledge of local media and community organizations/associations
- Experience in recruiting participants for group sessions in their community

### Job Description for Facilitators

Facilitators : 8 (2 per cultural group)

Ethnocultural Communities: 4 (Chinese, Egyptian, Filipino, Vietnamese)

Cities: 5 (Calgary, Montreal, Ottawa, Toronto, Vancouver)

Focus Groups: 40

#### Tasks and Responsibilities

- Facilitate and conduct focus group meetings
- Clarify the content of transcribed focus group discussions
- Available to travel across Canada
- Liaise with the project coordinator

#### Skills Required

- Ability to communicate in either Mandarin and Cantonese, Tagalog, Vietnamese, and Arabic, as well as English or French (as required)
- Ability to work under direction
- Good listening skills
- Thorough knowledge of the community

## **Profile of Focus Group Participants**

Focus groups: 40

Number of participants per group: 10

Total participants: 400

### **Profile**

- Representatives from the community (health professionals, leaders, individuals interested in health issues like hepatitis C)
- Adults 18 years or older
- Equal male and female participation
- Ability to communicate in English or French

## **APPENDIX 7**

### **KEY INFORMANTS (COORDINATORS)**





## Appendix 7

### Key Informants (Coordinators)

City	Chinese	Egyptian	Filipino	Vietnamese
Calgary	Anita Chow Huamei Chen	Zeinab Al-Kady Adel Khalil	Sherrisa Celis Nora Dista	Fong Do Sabita Basnet
Montreal	Alice Choy Howard Tan	Samaa Elibyari Nagliaa Shoukri	Grace Yip Sharard Yip	Chung Mai-Lien Thu Van Lam
Ottawa	May Yip Emma Peng	Nivin Sharaf Safaa Fouda	Nejje Escares Laarni Casiple	Nhung Nguyen Vietnamese Canadian Centre
Toronto	K.Y. Liu Maria Chu	Nawal Al-Busaidi Fida Qulaghasi	Rose Bustamante Carol Banez	Lucy Nguyen Manh Nguyen
Vancouver	Michael Tang Ivy Tang	Salwa El-Ramly Fatma Taha	Alice Cabarlo Vincente Francisco	Ngoc Dung Nguyen Vietnamese Community Society



## **APPENDIX 8**

### **FOCUS GROUP FACILITATORS**



## Appendix 8

### Focus Group Facilitators

#### *Chinese Community*

##### **Maria Chu**

Program Manager, Community Support Services  
Yee Hong Centre for Geriatric Care  
2311 McNicoll Avenue  
Scarborough, ON M1V 5L3  
Tel: (416) 321-6333 ext. 2632

##### **Kwong Y. Liu**

Director of Social Services  
Yee Hong Centre for Geriatric Care  
2311 McNicoll Avenue  
Scarborough, ON M1V 5L3  
Tel: (416) 321-6333 ext 1160

#### *Egyptian Community*

##### **Safaa Fouda**

Past President, Egyptian Cultural  
Association of Ottawa  
2 Swans Way  
Ottawa, ON K1J 6J2  
Tel: (613) 884-2411

##### **Nivin Sharaf**

Volunteer, Egyptian Canadian  
Association of Ottawa  
6 F Europa Private  
Ottawa, ON K2E 7R6  
Tel: (613) 808-9929

#### *Filipino Community*

##### **Flaviano Agpalza Jr.**

Member, Philippine Association of Manitoba,  
San Augustin and Isabella Association of  
Manitoba and Society for Manitobans  
with Disabilities  
403 Burnell Street  
Winnipeg, MB R3G 2B1  
Tel: (204) 788-1048

##### **Laarni Casiple**

Member, Filipino Canadian Association  
of Ottawa Valley  
and Himig Pilipino Chorale Ensemble  
40 Goldora Private  
Kanata, ON K2T 1K7  
Tel: (613) 270-9325

#### *Vietnamese Community*

##### **Mong Nguyen**

Manager, Vietnamese Settlement Program,  
Vietnamese Canadian Centre  
249 Rochester Street  
Ottawa, ON K1R 7M9  
Tel: (613) 230-8282 (w) (613) 828-3156 (h)

##### **Stephen Nguyen**

Volunteer, Vietnamese Association of Toronto  
6780 Longview Place  
Mississauga, ON L5W 1V3  
Tel: (416) 629-9603



## **APPENDIX 9**

### **RECORDERS (NOTE TAKERS)**





## Appendix 9

### Focus Group Recorders (Note takers)

<b>Name</b>	<b>Community</b>	<b>City</b>
Adam Abdalla	Egyptian	Calgary
Alice Cabarlo	Filipino	Vancouver
Alice Choy	Chinese	Montreal
Anita Chow	Chinese	Calgary
Charles Goeldner	Filipino	Calgary
Chung Mei Lien	Vietnamese	Montreal
Dung Ngoc Nguyen	Vietnamese	Vancouver
Emma Peng	Chinese	Ottawa
Fatma Taha	Egyptian	Vancouver
Fida Qulaghasi	Egyptian	Toronto
Fong Do	Vietnamese	Calgary
Grace Yip	Filipino	Montreal
Howard Tan	Chinese	Montreal
Humei Chen	Chinese	Calgary
K.Y. Liu	Chinese	Toronto
Lucy Nguyen	Vietnamese	Toronto
Maria Chu	Chinese	Toronto
May Yip	Chinese	Ottawa
Michael Tang	Chinese	Vancouver
Nawal Al- Busaidi	Egyptian	Toronto
Nejie Escares	Filipino	Ottawa
Nhung Nguyen	Vietnamese	Ottawa
Nivin Sharaf	Egyptian	Ottawa
Rose Bustamante	Filipino	Toronto
Roselyn Bernardo	Filipino	Calgary
Safaa Fouda	Egyptian	Ottawa
Salwa El-Ramly	Egyptian	Vancouver
Samaa Elibyari	Egyptian	Montreal



## **APPENDIX 10**

### **ORIENTATION SESSION FOR FACILITATORS AGENDA**



## Appendix 10

**Orientation Session for Facilitators**  
**Capital Hill Hotel & Suites, Ottawa ON**  
**August 29, 2008**

### **Agenda**

- 9:00 Continental Breakfast
- 9:30 Welcome  
Billie Potkonjak, Canadian Liver Foundation  
Anna Chiappa, Canadian Ethnocultural Council  
Susan Lilley, Facilitator  
Overview of Project:  
Background Information  
Workplan and Steps  
Project Tools:
  - Invitation Letter to Organizations
  - Invitation to Focus Group Participants
  - Focus Group Questions
  - Informed Consent Form
  - Hepatitis C Brochure
- 10:15 Review of Focus Group Process:
  - Role of Facilitators
  - Sample Focus Group Agenda
  - Focus Group Tools:
    - o Informed Consent Form
    - o Focus Group Questions
    - o Hepatitis C Brochure
    - o Local Health Resources
  - Preparation and Set-up of Focus Groups
- 10: 45 Break
- 11:00 Facilitation Tips: Susan Lilley
- 12:00 Lunch
- 1:00 Focus Group Practice: Susan Lilley
- 2:30 Break
- 2:45 Focus Group Practice
- 3:45 Final Questions and Instructions
- 4:00 Evaluation and Wrap-Up



## **APPENDIX 11**

### **EVALUATION FORM FOR ORIENTATION SESSION**





## Appendix 11

### Canadian Liver Foundation and Canadian Ethnocultural Council Orientation Session for Facilitators August 29, 2008

#### Evaluation Form

1. Are you:            Male                    Female

2. Where do you work? *(please check all that apply)*

Hospital

Nursing home

Community health centre

Multicultural organization

Unicultural organization

Public health department

Settlement agency

Social service agency

Other, please specify \_\_\_\_\_

3. Which community do you represent?

Chinese

Egyptian

Filipino

Vietnamese

4. In which city do you live? \_\_\_\_\_

5. How would you rate the facilities for the Orientation Session?

	Excellent	Very good	Good	Fair	Poor
Location					
Room					
Food					

6. In general, how effective was the format (agenda and process) of the Orientation Session?

Very effective

Somewhat effective

Not effective

**7. This training workshop offers focus group facilitation information which:**

- confirms what I already know
- provides ways of promoting discussion on health issues in my community
- offers new information
- is not useful

**8. In general, the facilitator of this workshop is:**

- Excellent
- Very good
- Good
- Fair
- Poor

**9. The facilitator: (please check all that apply)**

- was very knowledgeable about issues related to facilitation
- offered good guidelines for effective facilitation
- reviewed all the materials to be used by the facilitator at the focus groups

**10. How would you rate the focus group practice session?**

- Excellent
- Very good
- Good
- Fair
- Poor

**11. Overall the Orientation Session was:**

- Excellent
- Very good
- Good
- Fair
- Poor

**12. What did you like most about the Orientation Session?**

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**13. What did you like least about the Orientation Session?**

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**14. How could we improve the Orientation Session in the future?**

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**15. Would you recommend this Orientation Session to others?**

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*Thank you!*

## **APPENDIX 12**

### **FOCUS GROUPS SCHEDULE**



## Appendix 12

### Focus Groups Schedule

Date	Time	Community	City	Location	Facilitator	Coordinator
Sep 1	2 - 4 pm	Chinese	Toronto	2311 McNicoll Avenue (Yee Hong Centre)	Maria Chu (416) 321-6333	K. Y. Liu
Sep 1	4:30 - 6:30 pm	Chinese	Toronto	2311 McNicoll Avenue (Yee Hong Centre)	K. Y. Liu (416) 886-6671	Maria Chu
Sep 7	2 - 4 pm	Filipino	Ottawa	320 Olmstead St (Assumption Parish)	Laarni Casiple (613) 270-9325	Nejje Escares (613) 592-8757
Sep 8	11-1:30 pm	Egyptian	Ottawa	3A Europa Private	Nivin Sharaf (613) 808-9929	Safaa Fouda
Sep 9	7 - 9 pm	Egyptian	Ottawa	2 Swans Way North	Safaa Fouda (613) 749-1889	Nivin Sharaf
Sep 11	6:30 - 8:30 pm	Vietnamese	Ottawa	249 Rochester Street (Vietnamese Canadian Centre)	Mong Nguyen (613) 828-3156	Nhung Nguyen (613) 276-2188
Sep 13	2 - 4 pm	Vietnamese	Ottawa	249 Rochester Street (Vietnamese Canadian Centre)	Mong Nguyen	Nhung Nguyen
Sep 14	2:30-4:30 pm	Filipino	Ottawa	307 Richmond Road (Baptist Church)	Laarni Casiple	Eduardo Escares (613) 592-8757
Sep 15	12 - 2 pm	Chinese	Ottawa	55 Eccles St, 3rd Floor (Somerset West Community Health Centre)	Maria Chu	May Yip (613) 238-8214
Sep 17	12- 2 pm	Chinese	Ottawa	55 Eccles St., 3rd Floor (Somerset West Community Health Centre)	Maria Chu (613) 298-0472	Emma Peng
Sep 18	11:30 -1:30 pm	Filipino	Toronto	1151 Denison St. #10/11 (Markham Fed.of Filipino Cdns)	Laarni Casiple	Rose Bustamante (905) 881-7363
Sep 18	6 - 8 pm	Filipino	Toronto	1441 Clarke Ave. W.Thornhill (Dufferin Clarke Library)	Laarni Casiple	Carol Banez (416) 453-9348

## Focus Groups Schedule (Cont'd)

<b>Date</b>	<b>Time</b>	<b>Community</b>	<b>City</b>	<b>Location</b>	<b>Facilitator</b>	<b>Coordinator</b>
Sep 19	11 – 1 pm	Egyptian	Toronto	209-555 Burnhamthorpe Rd. (Arab Newcomers Centre)	Safaa Fouda	Nawal Al-Busaidi (416) 231 - 7746
Sep 19	1:30-3:30 pm	Egyptian	Toronto	209-555 Burnhamthorpe Rd (Arab Newcomers Centre)	Safaa Fouda	Fida Qulaghasi (416) 231-7746
Sep 21	11-12:30 pm	Vietnamese	Toronto	1364 Dundas Street (Vietnamese Assoc. of Toronto)	Stephen Nguyen (416) 629-9603	Lucy Nguyen (905) 670-3991
Sep 21	2 – 3:30 pm	Vietnamese	Toronto	3585 Keele Street, N. York (Vietnamese Assoc. of Toronto)	Stephen Nguyen	Manh Nguyen (416) 536-3611
Sep 23	1 - 3 pm	Egyptian	Montreal	1440 Stanley St.6th Fl (YMCA)	Safaa Fouda	Samaa Elibyari (514) 288-8609
Sep 23	4 - 6 pm	Egyptian	Montreal	1440 Stanley St.6th Fl (YMCA)	Safaa Fouda	Naglaa Shoukry
Sep 26	11 - 1 pm	Vietnamese	Montreal	6655 Cote des Neiges (Centre for Vietnamese Old Age Citizens in Montreal)	Mong Nguyen	Chung Mai Lien (514) 341-6777
Sep 26	2 - 4 pm	Vietnamese	Montreal	6655 Cote des N., 2nd Fl. (Centre for Vietnamese Old Age Citizens in Montreal)	Mong Nguyen	Chung Mai Lien
Sep 27	10 - 12 noon	Filipino	Montreal	6767 Cote des Neiges	Laarni Casiple	Grace Yip (514) 683-3111
Sep 27	1 - 3 pm	Filipino	Montreal	6767 Cote des Neiges	Laarni Casiple	Grace Yip
Sep 28	1-3 pm	Chinese	Montreal	1088 Clarke Street	Maria Chu	Alice Choy (514) 781-2688
Sep 28	4 - 6 pm	Chinese	Montreal	1088 Clarke Street	Maria Chu	Howard Tan (514) 726-7781

## Focus Groups Schedule (Cont'd)

<b>Date</b>	<b>Time</b>	<b>Community</b>	<b>City</b>	<b>Location</b>	<b>Facilitator</b>	<b>Coordinator</b>
Oct 3	2 - 4 pm	Chinese	Vancouver	1100 Minoru Gate (Richmond Cultural Centre)	K. Y. Liu	Michael Tang 778-893- 9306
Oct 3	6:30 – 8:30 pm	Chinese	Vancouver	1100 Minoru Gate (Richmond Cultural Centre)	K. Y. Liu	Ivy Tang (604) 275-5899
Oct 4	1:30 – 3:30 pm	Filipino	Vancouver	17475 59th Ave, Surrey (Precious Blood Roman Catholic Church)	Flaviano Agpalza	Alice Cabarlo (604) 813-6975
Oct 4	5 - 7 pm	Filipino	Vancouver	2881 Main St, Vancouver (St. Patrick's Parish)	Flaviano Agpalza	Vincente Francisco (604) 813-6975
Oct 5	12 - 2 pm	Vietnamese	Vancouver	1720 Grant Street (MOSAIC, Community Room)	Stephen Nguyen	Ngoc Dung Nguyen (604) 708-0646
Oct 5	4 - 6 pm	Vietnamese	Vancouver	1720 Grant Stret (MOSAIC, Community Room)	Stephen Nguyen	Ngoc Dung Nguyen
Oct 5	8 - 9:30 pm	Egyptian	Vancouver	3140 Springford Av. Richmond	Safaa Fouda	Salwa El-Ramly (604) 275- 9691
Oct 6	7 – 9 pm	Egyptian	Vancouver	2982 Cliffrose Crescent	Safaa Fouda	Fatma Taha (604) 552-9484
Oct 14	10-12 noon	Chinese	Calgary	4030 Maryvale Dr. NE (Cantonese Church of Christ)	K. Y. Liu	Humaiei Chen (403) 262-2006
Oct. 15	5:30 - 7:30 pm	Filipino	Calgary	120 17th Ave. SW 3rd (Calgary Catholic Immig. Services)	Flaviano Agpalza	Sherissa Celis (403) 290-5755
Oct 16	10.45-12:45 pm	Chinese	Calgary	108 3rd Ave. SW, suite 201 (Chinese Christian Mission)	K. Y. Liu	Anita Chow (403) 262-2006
Oct. 16	7 - 9 pm	Filipino	Calgary	3633 Westwinds Dr. NE (Superstore Community Room)	Flaviano Agpalza	Nora Dista (403) 454-7941

## Focus Groups Schedule (Cont'd)

<b>Date</b>	<b>Time</b>	<b>Community</b>	<b>City</b>	<b>Location</b>	<b>Facilitator</b>	<b>Coordinator</b>
Oct 17	10-12 noon	Vietnamese	Calgary	6100 Penbrooke Dr SE (Community Hall)	Stephen Nguyen	Carolyn Arrell (403) 290-5756
Oct 18	3-5 pm	Vietnamese	Calgary	1405 8th Av. SE (St. Vincent Liem's Church)	Stephen Nguyen	Do Tieu Muoi (403) 630-6166
Oct 19	2 - 4 pm	Egyptian	Calgary	1520 B Northmount Dr. NW (Brentwood Community Hall)	Safaa Fouda	Zeinab Al- Kady (403) 640-1810
Oct 19	4:30 – 6:30 pm	Egyptian	Calgary	1520 B North Mount Dr. NW (Brentwood Community Hall)	Safaa Fouda	Zeinab Al-Kady



## **APPENDIX 13**

### **CANADIAN LIVER FOUNDATION – PROFILE**



## Appendix 13

### About the Canadian Liver Foundation

Founded in 1969 by a group of doctors and business leaders concerned about the increasing incidence of liver disease, the Canadian Liver Foundation (CLF) was the first organization in the world devoted to providing support for research and education into the causes, diagnoses, prevention and treatment of all liver disease.

Through its chapters across the country, the CLF strives to promote liver health, improve public awareness and understanding of liver disease, raise funds for research and provide support to individuals affected by liver disease.

#### Research

- The CLF actively supports approximately one third of the leading liver researchers across the country.
- To promote the continuing study of hepatology, the CLF provides funding to undergraduate & graduate students for research projects in hepatology and related fields.
- The Foundation has contributed to several significant scientific breakthroughs including the discovery of the genes responsible for Wilson disease and hemochromatosis as well as various new treatments for hepatitis C and other forms of liver disease.
- Over its history, the CLF has awarded over \$10 million in research funding.

#### Education & Prevention

Recognized by medical practitioners and policy makers as Canada's authoritative voice on liver disease, the CLF is often the first place both patients and physicians turn for the most current information.

- The CLF has developed comprehensive and multi-lingual educational materials, presentation kits and communication tools covering signs, symptoms and treatments of liver disease, as well as wellness and prevention advice.
- Our National Help Line fields thousands of inquiries each year from individuals, families and health care professionals seeking assistance and information.
- We offer a 'Living with Liver Disease' program which help patients and families learn how to cope with liver disease through guided group sessions.
- We coordinate educational conferences across Canada that encourage discussion and knowledge sharing among health professionals, researchers, support groups and patients.

**For more information on liver disease or the Canadian Liver Foundation,  
please call 1-800-563-5483 or go online at [www.liver.ca](http://www.liver.ca).**



## **APPENDIX 14**

### **CANADIAN ETHNOCULTURAL COUNCIL PROFILE**



## Appendix 14

### THE CANADIAN ETHNOCULTURAL COUNCIL

Established in 1980, the Canadian Ethnocultural Council is a non-profit, non-partisan organization representing over 30 national ethnocultural organizations that in turn represent over 2,000 local chapters across Canada. Its mandate is to work towards equality of access and opportunity for all Canadians and to promote the understanding of the multicultural reality of Canada as defined in *The Canadian Charter of Rights and Freedoms* and *The Canadian Multiculturalism Act*.

The CEC conducts programs and activities to support the vision of an inclusive and multicultural Canada. These projects include organizing events, conferences, seminars, and workshops, or developing community-based research and training resource material. It also advocates for ethnocultural communities on common issues and concerns to affect change and policy development.

The CEC has worked in partnership with national and regional organizations, government departments, and the private sector. The following is a sample of organizations the CEC has partnered with:

- Alternative Dispute Resolution Centre (Ottawa)
- Association for Canadian Studies
- Affiliation of Multicultural Societies and Service Agencies of British Columbia
- Canadian Food Inspection Agency
- Canadian Liver Foundation
- Carleton University Center, Research Resource Division for Refugees
- Correctional Services Canada
- Department of Justice
- Department of Canadian Heritage
- Elections Canada
- The Quilt of Belonging – a national project
- O'Brien Publishing: The Canadian Technology and Business Magazine
- Public Health Agency of Canada
- YOUCAN

The CEC has also produced manuals, training materials and reports. Some examples include:

- Intergenerational Dialogue and Conflict Resolution: Resource Guide
- Preventing Type 2 Diabetes in Ethnic Youth: Strategies and Resources
- Capacity Building and Strengthening for Ethnocultural Communities: A Tool Kit
- Bias Free Parenting: A Resource Guide
- Ethnic Seniors and Healthy Aging: Perceptions, Practices, and Needs

The CEC is the sole distributor of *Transforming Our Organization: A Tool Kit for Planning and Monitoring Anti-Racism Multicultural Change*.

The CEC has developed an outreach capacity based on the following contacts:

- CEC member organizations with over 2000 provincial and local chapters across Canada
- A database of over 3,500 organizations including new Canadian communities
- A database of over 300 social and health services across the country

### **Canadian Ethnocultural Council - Initiatives and Projects 2004 –2008**

**A Pilot Model on Engaging Ethnocultural Communities on Hepatitis C:** Three reports in partnership with the Canadian Liver Foundation for the Public Health Agency of Canada.

**Resolving Conflict Through Intergenerational Dialogue and Cross-Cultural Understanding:** A Community Training Initiative, in partnership with YOUCAN and funded by Canadian Heritage. Training of youth and adults on conflict resolution and production of resource guide for action plans.

**Strategic Engagement of Youth in Ethnocultural Communities on Diabetes Awareness:** Community symposium and briefing, demographic analysis, community awareness report, resource guide, youth forum and YOUTUBE video.

**Strategies for Outreach to Ethnocultural Communities on the Reintegration of Offenders:** A national consultation and report for Correctional Services Canada

**An Outreach Plan for Ethnocultural Communities on the Travelers Awareness Campaign:** Research on ways to reach ethnic communities in Canada for the Canadian Food Inspection Agency

**Cultural Diversity Special** for the *Canadian Technology Business Magazine*, and insert in major newspapers distributed to over a million households across Canada.

**Capacity Building and Strengthening for Ethnocultural Communities:** three-year project that included: a Training Tool Kit - *Capacity Building and Strengthening for Ethnocultural Communities: A Guide*; National Conference: *Looking back, Looking Forward: Building Strong Ethnocultural Communities*; and Training workshops with communities across the country

**Forum on Trafficking in Persons, Especially Youth, Children and Women:** the CEC held a forum in conjunction with Status of Women and the Justice Department to inform communities and develop strategies to deal with trafficking of women and children.

**Diabetes and Ethnic Older Adults: Best Practice Models for Prevention and Management Project:** provides a basic working model for the implementation of an autonomous “Diabetes Self-Directed Support Group” for aging ethnic adults in Canada.

**Elections Canada Outreach:** a project on behalf of Elections Canada to determine the effectiveness of the multilingual/ethnic advertising and outreach campaign before the 38th general election.

**Culturally Appropriate Best Practices for Healthy Aging:** includes a province-wide list of health care agencies providing successful and innovative service programs for ethnocultural seniors.



## **APPENDIX 15**

### **HEPATITIS C BROCHURE**



## Appendix 15

### Hepatitis C Brochure

#### CANADIAN LIVER FOUNDATION

*HEPATITIS C - a liver disease*

#### **What is hepatitis C?**

Hepatitis C is a liver disease caused by the hepatitis C virus (HCV) which was first identified in 1989. Hepatitis C is spread by direct contact with the blood of an infected person. Hepatitis C differs from hepatitis A, which is spread through eating or drinking contaminated food or water; and hepatitis B, which can be spread through blood contact with any body fluid of an infected person.

#### **Who is at risk?**

People at risk for hepatitis C include the following:

- Blood transfusion recipients prior to 1990
- People who use injection drugs or share drug-related equipment
- People with tattoos and body piercing acquired with non-sterile equipment

#### **How does someone get hepatitis C?**

The most common means of transmission is through injection drug use, even if the drug use was many years ago or happened only once. Sharing needles or any drug-related equipment is enough to spread hepatitis C.

Another way of getting hepatitis C is through a blood transfusion from a donor who has hepatitis C – especially for those people who received a blood transfusion prior to 1990. The risk of getting HCV in this way is now extremely low because of the universal testing of all blood donors.

Activities such as tattooing and body piercing, which may be performed without sterile precautions, sharing toothbrushes and razors, or any kind of blood-to-blood contact with an infected person can also spread the hepatitis C virus. The risk of getting HCV infection through ordinary household or workplace interactions is extremely low.

#### **Could I get hepatitis C from having unprotected sexual intercourse?**

The rate of transmission by sexual contact - either heterosexual or homosexual - is considered to be very low. In spite of the low risk, long-term monogamous couples must decide for themselves about routine condom use. They should, however, avoid unprotected intercourse during menstrual periods if the woman is HCV positive. People with multiple sexual partners should always practise safe sex, not only to decrease the small risk of hepatitis C transmission, but to minimize the risk of acquiring other infections.

### **Can I have children or breastfeed if I have hepatitis C?**

The risk of passing hepatitis C to your newborn is approximately 5 %. Cesarean section is not recommended to prevent HCV infection. Breastfeeding does not appear to transmit hepatitis C unless nipples are cracked or bleeding.

### **What are the symptoms of hepatitis C?**

Most people with hepatitis C have no symptoms and may feel quite healthy. Others may develop fatigue, jaundice (yellowing of the eyes and skin), abdominal and joint pain, nausea and loss of appetite.

### **How do I know if I have hepatitis C?**

Most people with hepatitis C are unaware they have it and can carry it unknowingly for decades. Only a blood test can detect the hepatitis C virus infection. If you think you may have been exposed to HCV through high-risk behaviour, major surgery, a blood transfusion or blood products and are concerned, you should see your physician and discuss whether or not you should be tested.

### **What happens if I test positive?**

If you test positive for antibodies to HCV, your physician should do a follow-up blood test to see whether actual viral material can be found in your blood, along with blood tests to check the state of your liver. Approximately 15-25% of people infected with HCV have a mild, brief disease and get rid of the virus completely. In this case, the antibodies to HCV usually remain detectable in the blood but the actual viral material does not. However, most people who get hepatitis C will have HCV infection for a long time, and possibly for the rest of their lives.

Your family physician may refer you to a specialist to determine whether or not you require treatment. You may wish to contact the Canadian Liver Foundation to learn about support groups and education materials available through this organization.

### **How do I live with hepatitis C?**

It is important for people living with hepatitis C to implement lifestyle changes, including:

- Maintain a healthy body weight
- Eat a well-balanced, nutritious diet
- Exercise regularly
- Avoid alcohol
- Avoid high-risk behaviours
- Get vaccinated against hepatitis A and hepatitis B.

For some hepatitis C patients drug treatment may be appropriate and must be administered after careful assessment by a physician. The current standard of care is a combination of pegylated interferons taken by injection once a week plus ribavirin pills taken daily. Depending on the HCV genotype, cure rates range from 50 to 90%. New drugs are being developed. No herbal remedies have been shown to be useful.

## **What happens as the disease progresses?**

Most people with chronic hepatitis C feel well for many years. In 10% - 20% of patients, chronic hepatitis C leads to cirrhosis – irreversible and potentially fatal scarring of the liver. In severe cases, hepatitis C may lead to liver cancer or liver failure. Hepatitis C is one of the most common reasons why people need to have liver transplants in Canada. The earlier you find out that you have hepatitis C, the more likely it is that treatment could be successful.

## **How can I protect others?**

If you have been diagnosed with hepatitis C there is no need to become socially isolated, but there are common-sense precautions you should take to avoid spreading the virus:

- Do not give blood
- Do not share razors or toothbrushes
- If you use drugs, do not share needles or other drug-related equipment
- Inform health professionals who care for you and may be exposed to your blood that you have hepatitis C
- Although sexual transmission is rare, inform your sexual partner(s) that you have hepatitis C and take appropriate precautions
- There is no vaccine for hepatitis C prevention.

Established in 1969, the Canadian Liver Foundation (CLF) was the first organization in the world devoted to providing support for research and education into the causes, diagnosis, prevention and treatment of liver disease. CLF provides information and education programs for patients, families and the general public through more than 30 volunteer chapters across the country.

Because hepatitis C is a liver disease, the Canadian Liver Foundation is committed to providing information and education about this increasingly prevalent infection. This is a rapidly changing field of medicine; information in this pamphlet is current for October 2006.

For more information about hepatitis C or other liver diseases, please call 416-491-3353 or 1-800-563-5483.

Canadian Liver Foundation National Office  
2235 Sheppard Avenue East, Suite 1500  
Toronto, Ontario M2J 5B5  
Tel: 416.491.3353 Fax: 416.491.4952  
Toll-free: 1-800-563-5483  
www.liver.ca E-mail: clf@liver.ca

Canadian Charitable Registration No. 10686 2949 RR0001

Ce dépliant est également disponible en français.



## **APPENDIX 16**

### **LOCAL HEALTH RESOURCES – HEPATITIS C**





## Appendix 16

### Local Health Resources - Hepatitis C

#### Vancouver

Vancouver, North Vancouver-Coast Garibaldi  
11th Floor, 601 West Broadway  
Vancouver, BC, V5Z 4C2  
Tel: (604) 736-2033

Vancouver Coastal Health Information Line  
Toll Free: 1.866.884.0888 (for residents outside  
the Lower Mainland)  
Website: [http://www.vch.ca/facilities/  
community/](http://www.vch.ca/facilities/community/)

Gilwest Clinic  
7000 Westminster Hwy.  
Richmond, BC, V6X 1A2  
Tel: (604) 233-3135  
Fax: (604) 233-3198  
Website: [www.richmondhealth.ca](http://www.richmondhealth.ca)

#### Calgary

Calgary Health Region  
10101 Southport Road SW  
Calgary, AB, T2W 3N2  
Tel: (403) 943-1111

Health Link  
Calgary Health Region  
10101 Southport Road SW  
Calgary, AB, T2W 3N2  
Tel: (403) 943-LINK (5465)  
Toll Free: 1-866-408-LINK(5465)

#### Toronto

Toronto Public Health  
277 Victoria Street, 5th Floor  
Toronto, ON, M5B 1W2  
Tel: (416) 392-7401  
Fax: (416) 392-0713  
Website : [www.toronto.ca/health/index.htm](http://www.toronto.ca/health/index.htm)

Toronto Health Connection  
Monday to Friday  
8:30 a.m. to 4:30 p.m.  
Translation services are available  
Tel: (416) 338-7600

#### Ottawa

Ottawa Public Health  
100 Constellation Cres  
Ottawa, ON, K2G 6J8  
Tel: (613) 580-6744  
Toll: 1-866-426-8885  
TTY: (613) 580-9656

#### Montreal

Montreal Public Health  
1301 Sherbrooke Est  
Montréal, QC  
H2L 1M3  
Tel: (514) 528-2400  
email: [webmaster@santepub-mtl.qc.ca](mailto:webmaster@santepub-mtl.qc.ca)



## **APPENDIX 17**

### **CANADIAN LIVER FOUNDATION OFFICES**



## Appendix 17

### Canadian Liver Foundation Offices

<b>City</b>	<b>Address</b>	<b>Telephone</b>	<b>Toll Free</b>
<b>Vancouver</b>	Suite 109 828 West 8th Ave Vancouver, BC V5Z 1E2	(604) 707-6430	800-856-7266
<b>Calgary</b>	Suite 309, 1010-1 Avenue N. E. Calgary, AB T2E 7W7	(403) 276-3390	888-557-5516
<b>Ottawa</b>	1729 Bank St Suite 309 Ottawa, ON K1V 7Z5	(613) 733-1433	
<b>Greater Toronto Region</b>	2235 Sheppard Avenue East Suite 1500 Toronto, ON M2J 5B5	(416) 491-3353	800-563-5483
<b>Montreal</b>	Section de Montréal 1000, rue de la Gauchetière Ouest Bureau 2830 Montréal, QC H3B 4W5	(514) 876-4171	

For more information on hepatitis C or other liver diseases, please call the Canadian Liver Foundation, National Office, 1-800-563-5483 or (416) 491-3353. Website: [www.liver.ca](http://www.liver.ca)



## **APPENDIX 18**

### **FOCUS GROUP PARTICIPANTS BY GENDER AND BY COMMUNITY IN THE CITIES**





## Appendix 18

### Focus Group Participants by Gender and by Community in the Cities

City	Chinese		Egyptian		Filipino		Vietnamese		Total
	M	F	M	F	M	F	M	F	
<b>Calgary</b>	10	27	9	11	10	11	10	13	<b>101</b>
<b>Montreal</b>	10	10	9	10	4	29	13	16	<b>101</b>
<b>Ottawa</b>	7	15	8	17	6	23	13	17	<b>106</b>
<b>Toronto</b>	12	11	6	14	5	19	7	15	<b>89</b>
<b>Vancouver</b>	13	13	9	13	9	14	11	12	<b>94</b>
Sub-Total	52	76	41	65	34	96	54	73	
Total for Each Community	<b>128</b>		<b>106</b>		<b>130</b>		<b>127</b>		
Total Participants			<b>491</b>		<b>491</b>				<b>491</b>



## **APPENDIX 19**

### **EVALUATION FORM FOR FACILITATORS**



## Appendix 19

### Evaluation Form for Facilitators

#### Background

1. Which cultural group did you facilitate?  
 Chinese    Filipino    Vietnamese    Egyptian
2. In which city (cities) did you facilitate your focus groups?  
 Toronto    Ottawa    Montreal    Vancouver    Calgary
3. Were your tasks and responsibilities clear?    Yes    No

#### Focus Group Venue

4. Was the location of the meeting satisfactory?  
 Very Satisfactory    Satisfactory    Not satisfactory
5. Was the meeting room comfortable?  
 Very comfortable    Comfortable    Not comfortable
6. Were the refreshments adequate?  
 Very adequate    Adequate    Inadequate

#### Focus Group Participants

7. Was the size of the focus group appropriate?    Yes    No  
If no, why not?

- 
8. Was the time allocated for each focus group meeting sufficient?  
 Yes    No
  9. Were the focus group participants interested in the issue?  
 Very interested    Interested    Not interested
  10. Did the focus group participants provide the information required?  
 Yes    No  
If no, why not?

- 
11. Were the focus group participants satisfied with the focus group process?  
 Very satisfied    Satisfied    Not satisfied  
If they were not satisfied, please explain.

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12. Did the focus group participants actively engage in discussion?  Yes  No

If no, why not?

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**Yourself**

13. Was the facilitator's training session in Ottawa helpful to you in conducting the focus groups?

Very useful  Useful  Not useful

Comments, if any :

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14. Would other facilitation materials have been helpful to you?  Yes  No

If yes, please explain:

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15. Did you experience any problems/concerns/problems during facilitation?

Yes  No

If yes, please describe:

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16. In your opinion, can anything be done to improve the focus groups?

Yes  No

If yes, please explain:

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17. What lessons have you learned in conducting these focus groups?

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18. What similarities have you observed between groups in different cities?

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19. What differences have you observed between groups in different cities?

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20. What did you like the most in your role as a facilitator?

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21. What did you like the least in your role as a facilitator?

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22. In your opinion, what could be done next to keep the momentum going on hepatitis C?

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23. In your opinion, is the focus group meeting the best way to reach your community?

Yes       No

If not, please explain:

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24. Any further comments?

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- Thank you -

Please email the completed form to Sucey Eapen, Project Coordinator [suceyepen@yahoo.com](mailto:suceyepen@yahoo.com)  
**by November 3, 2008**





## **APPENDIX 20**

### **EVALUATION FORM FOR KEY INFORMANTS (COORDINATORS)**



## Appendix 20

### Evaluation Form for Key Informants (Coordinators)

#### Background:

1. Which cultural group did you coordinate?  
 Chinese    Filipino    Vietnamese    Egyptian
2. In which city was the focus group held?  
 Toronto    Ottawa    Montreal    Vancouver    Calgary
3. What is your role in your community?  
\_\_\_\_\_

#### Before the Focus Group Meeting:

4. Were you clear about the objectives of the focus group meeting?  
 Yes    No
5. Did you receive the background information on the project?  
 Yes    No
6. Were your tasks and responsibilities clear?  
 Yes    No
7. Did you encounter any barriers in recruiting participants for the focus group meeting?  
 Yes    No  
If yes, please describe:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8. How did you overcome the barriers?  
\_\_\_\_\_  
\_\_\_\_\_

9. Please describe the most successful way of recruiting participants for focus groups.  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. Were there any barriers in finding a satisfactory venue for the focus group meeting?

- Yes       No

If yes, please describe:

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11. How did you overcome the barriers?

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**During the Focus Group Meeting:**

12. Was the presentation by the facilitator clear?

- Very clear       Clear       Not clear

13. Was the pace of the presentation satisfactory?

- Very satisfactory       Satisfactory       Not satisfactory

14. Was there enough time allotted for each focus group meeting?

- Yes       No

If no, please explain:

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---

15. Were the materials distributed at the focus group meeting useful to the participants?

- Very useful       Useful       Not Useful

16. In your opinion, did the project reach a wide variety of community participants?

- Yes       No

If no, please explain:

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**After the Focus Group Meeting:**

17. In your opinion, how effective was the focus group meeting in gathering information on the best ways

to reach the community?

- Very effective       Effective       Not effective

18. Could the focus group meeting have been better?

- Yes       No

If yes, how?

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19. In your opinion, how satisfied were the participants with the focus group meeting?

- Very satisfied       Satisfied       Not satisfied

20. What lessons have you learned in coordinating the focus groups?

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21. What is the one thing you enjoyed most?

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22. What is the one thing you enjoyed least?

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23. What are the similarities you have seen between focus group meetings?

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24. What are the differences you have seen between focus group meetings?

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25. Is there any action planned as follow-up of the focus group meeting?

- Yes       No

If yes, please describe.

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26. Were there any new contacts that were developed as a result of the focus group meeting?

- Yes       No

If yes, please list:

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27. Do you have any recommendations for future work?

- Yes       No

If yes, please describe:

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28. In your opinion, is the focus group meeting the best way to reach your community?

- Yes       No

If not, please explain:

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29. Other comments.

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- Thank you -

Please email the completed form to Sucy Eapen, Project Coordinator [sucyeapen@yahoo.com](mailto:sucyeapen@yahoo.com)  
**by November 3, 2008**