DEVELOPING SOCIAL CAPITAL IN THE PUNJABI COMMUNITY

RESEARCH ON HIV/AIDS RELATED ISSUES IN THE PUNJABI COMMUNITY

FINAL REPORT
October 2005

Project Funded by:

Project Supervisors
Baldev Mutta
Amandeep Kaur

Project Staff
Yadevinder Mutta

In collaboration with:
Dr. Amarjit Singh

FINAL REPORT

October
2005

DEVELOPING SOCIAL CAPITAL IN THE SOUTH ASIAN COMMUNITY

HIV/AIDS Related Issues

Prepared by:
Baldev Mutta
Amandeep Kaur
Preeti Kohli

In collaboration with:
Dr. Amarjit Singh

CONTENTS

1. PREFACE AND ACKNOWLEDGEMENTS …………………………………… 4

2. REPORT ORGANIZATION ………………………………………………….. 6

3. CONTENTS: CHAPTER WISE DESCRIPTION

Chapter 1 EXECUTIVE SUMMARY ……………………………….. 7

Chapter 2 HIV/AIDS RESEARCH PROJECT …………………….. 10

Chapter 3 PCHC & RESEARCH REPORT ……………………….. 18

Chapter 4 SUMMARY OF FINDINGS …………………………….. 22

Chapter 5 SUMMARY OF RECOMMENDATIONS ……………… 33

Chapter 6 LITERATURE REVIEW ………………………………… 37

Chapter 7 FOCUS GROUP FINDINGS …………………………. 48

Chapter 8 SURVEY – HEALTHCARE PROFESSIONALS ……. 56

APPENDICES ……………………………………………………………….85
- Summary Approach to Research………………….……………………..86
- Overview of Participation Action Research………………..…………87
- HIV/AIDS Questionnaire ……………………………………………… 89
- Focus Group Questions .... .94
- Consent Form…………………………………………………..……….97
- Contact Information Form…………………………………………………98
- Confidentiality Form………………………………………………….…99

PREFACE AND ACKNOWLEDGEMENTS

The vision and work for building Social Capital in the Punjabi Community in the Region of Peel, has been greatly complemented by the relentless perseverance and persistent commitment of The Punjabi Community Health Centre (PCHC), established in the summer of 1990. The work on HIV/AIDS in the South Asian Community in the GTA has been groundbreaking in many ways: It is the first of its kind in the history of an ethnic community in Peel which makes it even more commendable in the light of the fact that it is publicly raising a forbidden issue which was seldom whispered about in the South Asian community. To have HIV/AIDS was to be stigmatized and to be condemned from the community for life. If a South Asian suffered this disease, it was seen as a result of past sins from a previous life, something to be swept under the carpet, to be hushed behind closed doors. To have drawn attention to, not only the consequences of this rampant epidemic facing the South Asian Community in general, and the Punjabi community in particular, but also to the multiple ingrained challenges affecting the appropriate redress of this problem including the consequence of denial, neglect, lack of education and treatment options, is a phenomenal break, though for this project.

The unparalleled hard work of the treasured volunteers of the PCHC, the dedicated efforts of various service providers and the imperative inputs from community members have made this project see the light of the day.

Mr. Baldev Mutta, as the project supervisor, has been indispensable in ensuring that this study was scientifically sound and useful to persons and organizations working with or within the South Asian community. He has built a foundation upon which future options can be explored and present recommendations successfully implemented.

Within our Project team, we are thankful to the following soldiers without whose battalions our war on HIV/ AIDS in the South Asian Community would remain incomplete:

The project was completed with the support of the following persons:
.

The Project Supervisors –
Baldev Mutta and Amandeep Kaur.

Project Staff –
Yadevinder Mutta

Data Entry and Analysis –
Kim Natasha Mutta and Yadevinder Mutta

Volunteers –
Kim Natasha Mutta, Harpreet Saini, Harpreet Dhaliwal and Meena Verma

Researchers
Kim Natasha Mutta and Yadevinder Mutta

This project is indebted to many service providers within the Region of Peel who participated in the HIV/AIDS questionnaire, as well as the community members who participated in the focus studies. An acclaimed note of thanks goes to the Alliance for South Asian Aids Prevention (ASAAP) for their continued qualitative inputs, supports and sharing resource material.

ASAAP is a Toronto based AIDS service organization. It was founded in 1989 as a result of the voluntary efforts of members of Khush (a social group for South Asian gays and lesbians that has since closed down), in a community response to a request for support for a South Asian couple infected with HIV/AIDS who died in isolation, unable to access services in their own language. Our catchment area is greater Toronto and all the surrounding suburbs/towns. Our services include preventative education, support to South Asians infected with and affected by HIV/AIDS, outreach, and advocacy. Services are available in Tamil, Hindi, Urdu, Punjabi, Gujarati, and Bengali.

We would also be remiss if we do not acknowledge the contributions of Dr. Amarjit Singh and Dr. Joan Oldford for reading, editing, adding and providing valuable insights towards the completion of the report. Another person who helped give shape to the research was Dr. Anubha Mehta and we thank her for assisting in this endeavour.

Lastly we hail the Ontario Trillium Foundation for funding the “Developing Social Capital in the Punjabi Community Project” and thereby recognizing the urgency of addressing the criticalness of the situation of HIV/AIDS within the South Asian community.

THE REPORT ORGANIZATION

A goal of the research team has been to present the findings and recommendations of its research on HIV/AIDS in the South Asian community to a variety of readers in an easily accessible manner. Therefore, the material in this report is organized in a well compiled format. The material may slightly over lap occasionally in different sections of the report.

The chapters in the report are organized in a way to present information in the most precise and comprehensive form.

The chapters present the following information:

Chapter	1	EXECUTIVE SUMMARY
Chapter	2	HIV/AIDS RESEARCH PROJECT
Chapter	3	PCHC & RESEARCH REPORT
Chapter	4	SUMMARY OF FINDINGS
Chapter	5	SUMMARY OF RECOMMENDATIONS
Chapter	6	LITERATURE REVIEW
Chapter	7	FOCUS GROUP FINDINGS
Chapter	8	SURVEY – HEALTHCARE PROFESSIONALS

CHAPTER 1

EXECUTIVE SUMMARY

HIV/AIDS, since its emergence on the World, has remained a difficult issue for service providers and the community at large. A great deal of effort has gone into awareness and education campaigns and the improvement of services offered to the infected and affected by HIV/AIDS. Even with the mass efforts made in main stream society, HIV/AIDS still remains an uncomfortable issue. Even with such strong efforts that have been made in mainstream society, many ethnic communities have remained in the dark, leaving a gap of much needed research and comprehensive understanding of HIV/AIDS in ethnic communities. In particular, there is a dire need for understanding the complexities surrounding HIV/AIDS in the South Asian community. India has been marked as the next Africa for the HIV/AIDS epidemic and Health Canada has identified the South Asian community in Canada as one of ethnic communities at risk. The Punjabi Community Health Centre deemed it a vital need in the South Asian community to complete a comprehensive needs assessment of HIV/AIDS within the South Asian community in the Region of Peel.

The research study titled, "Research on HIV/AIDS related Issues in the Punjabi Community", was an attempt towards the development of a comprehensive service delivery system for the Punjabi community to tackle this issue. This Participatory Research is an exploratory study taken with the objectives to determine the complex issues surrounding HIV/AIDS in the Punjabi community, to build linkages with the internal and external stakeholders to identify, acknowledge and address the complex issues of HIV/AIDS and to identify how the complex problems of HIV/AIDS can be dealt with in the Punjabi community at the individual, familial and community level.

Methodology

The research team:

- Worked in a cooperative and collaborative manner from the beginning discussions to the analysis of the data and the compiling of the report.
- Decided that the research would be based on the principles of Participatory Action Research.
- Initially formed a steering committee of mainstream and ethno specific service providers and community members who helped to give the project guidance.
- After the disbanding of the steering committee, project staff and supervisors continued building upon guidance gleamed from the steering committee, improving upon the project work plan and set into place an active project action plan.
- Reviewed existing literature on HIV/AIDS in relation to South Asian communities. There was a grave scarcity of information relevant to South Asian communities and HIV/AIDS. Given both the limited time and available resources, a significant effort was made to unearth and develop a quality literature review.

- Research was conducted specific to the administration of questionnaires to service providers and specific to the sensitivity of HIV/AIDS questionnaires. A questionnaire of both qualitative and quantitative nature was developed. The questionnaire was designed to garner what services service providers felt were available to the South Asian community and the perceptions service providers held regarding HIV/AIDS within the South Asian community.

- Developed a question set that would be administered to three community groups. Focus group questions were qualitative in nature. The three selected focus groups, represented three sub-groups within the South Asian community; Youth (male and female), Seniors (male and female) and religious leaders (all males).

Major Findings

The research study has highlighted some very important findings related to HIV/AIDS. There is little understanding of how HIV/AIDS is contracted and the myths and misconceptions are very pervasive in the community. In addition, there seems to be a wall of secrecy and denial around talking, acknowledging and dealing with HIV/AIDS issues. The general consensus seems to be that, within South Asian culture, "sex" is just not talked about. The study also highlighted a need for "sensitivity training" to be imparted to mainstream agencies and to the South Asian health care providers.

The research had to find answer to this question, "Is there a need for culturally appropriate service delivery to the South Asian community for HIV/AIDS and, if so, what services would best meet that need?"

The immediate research question was answered and that answer is "YES". There is most definitely a significant need to provide culturally appropriate service to the South Asian community around HIV/AIDS.

The findings are compiled in detail in a separate section called 'summary of findings'.

Major Recommendations

The research team successfully conducted a Participatory Action Research of HIV/AIDS within the South Asian community and was also able to ascertain what the community wanted to see done regarding the issue of HIV/AIDS. The following areas were identified:

1. Raise awareness about HIV/AIDS as an issue and particularly within the South Asian community using a variety of mechanisms
   - TV, radio and print media. Specifically, ethnic TV, radio and print media in the appropriate languages.
   - Workshops for community members and for mainstream organizations working with the South Asian community.
   - An outreach campaign that specifically targets the South Asian community and their needs around HIV/AIDS.

2. Develop inter-generational programming that allows for the lines of communication to be opened, for all age groups to share their thoughts and allows for HIV/AIDS to be an issue that can be discussed.

3. Address needs of the South Asian community around HIV/AIDS
    - Support to the infected and affected
    - Support to those dealing with HIV/AIDS related issues; drug or substance abuse, new immigrants, MSM, homosexuality and (trans-gendered)
    - Access and awareness of services
    - Cultural factors (myths and stereotypes held)

4. Develop resources
    - Videos, DVDs and print literature

Detailed recommendations are compiled in the report.

Summary

This study has presented strong evidence that HIV/AIDS is an important issue in the South Asian community that must be addressed. The Punjabi Community Health Centre has shown interest in developing future projects related to these recommendations.

The Board of the Punjabi Community Health Centre has approved the research report and will provide assistance in implementing the findings of the report.

Chapter 2

HIV/AIDS RESEARCH PROJECT

INTRODUCTION

Global Problem

The latest statistics on the world epidemic of AIDS & HIV were published by UNAIDS/WHO in December, 2004. The report gives the latest AIDS and HIV statistics for the whole world and for regions.

World estimates of the HIV & AIDS epidemics at the end of 2004

Number of people living with HIV/AIDS in 2004		**Estimate***	**Range***
	Total	39.4	35.0 – 44.3
	Adults	37.2	33.8 – 41.7
	Women	17.6	16.3 – 19.5
	Children 15	2.2	2.0 – 2.6
People newly infected with HIV in 2004		**Estimate***	**Range***
	Total	4.9	4.3 – 6.4
	Adults	4.3	3.7 – 5.7
	Children 15	0.64	0.57 – 0.75
AIDS deaths in 2004		**Estimate***	**Range***
	Total	3.1	2.8 – 3.5
	Adults	2.6	2.3 – 2.9
	Children	0.51	0.46 - 0

***Millions**

More than **20 million** people have died of AIDS since 1981.

Africa has **12 million** AIDS orphans.

By December, 2004 women accounted for **47%** of all people living with HIV worldwide, and for **57%** in sub-Saharan Africa.

Young people (15-24 years old) account for **half** of all new HIV infections worldwide - more than **6,000** become infected with HIV every day.

Of the **6.5 million** people in developing and transitional countries who need life-saving AIDS drugs, less than **1 million** are receiving them.

Regional statistics for HIV & AIDS end of 2004

Region	Adults & Children Living with HIV/AIDS*	Adults & Children Newly Infected*	Adult Infection Rate (%)	Deaths of Adults & Children*
Sub-Saharan Africa	25.4	3.1	7.4	2.3
East Asia	1.1	0.29	0.1	0.051
South and South-East Asia	7.1	0.89	0.6	0.49
Oceania	0.035	0.005	0.2	0.0007
Eastern Europe & Central Asia	1.4	0.21	0.8	0.060
Western & Central Europe	0.61	0.021	0.3	0.0065
North Africa & Middle East	0.54	0.092	0.3	0.028
North America	1.0	0.044	0.6	0.016
Caribbean	0.44	0.053	2.3	0.036
Latin America	1.7	0.24	0.6	0.095
Global Total	39.4	4.9	1.1	3.1

***** *millions***

During 2004 around five million adults and children became infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS. By the end of the year, an estimated 39.4 million people worldwide were living with HIV/AIDS. The year also saw more than three million deaths from AIDS, despite the availability of HIV antiretroviral therapy which reduced the number of deaths in high income countries.

Notes

Adults in this report are defined as men and women aged 15-49 years. This age range captures those in their most sexually active years. While the risk of HIV infection continues beyond the age of 50, the vast majority of people with substantial risk behaviour are likely to have become infected by this age. Since population structures differ greatly from one country to another, especially for children and the upper adult ages, the restriction of 'adults' to 15-49 has the advantage of making different populations more comparable.

Children orphaned by AIDS are those children under 18 who have lost one or both parents to AIDS.

All the statistics on this page need to be interpreted with caution because they are estimates.

Sources:
UNAIDS/WHO AIDS epidemic update, December 2004
UNAIDS/WHO 2004 Report on the global AIDS epidemic

HIV/AIDS in Canada

HIV statistics

At the end of 2002, there were an estimated 56,000 people in Canada living with HIV (including those living with AIDS). Of these, around 30% were unaware of their infection. The 2002 figure represents an increase of around 12% from the previous estimate of 49,800 at the end of 1999. It is estimated that between 2,800 and 5,200 new HIV infections occur in Canada each year, though many of these are not reported right away.[1]

From the start of testing in November 1985 until the end of December 2004, there have been 57,674 positive HIV tests reported to CIDPC (Centre for Infectious Disease Prevention and Control). In 2004 there were 2,529 positive test results. This figure includes persons not featured in the table below, since they were under 15 years old, their gender was not reported, or they were reported as transgender.

Positive HIV test reports in adults (15 or over) by exposure category

Exposure Category	Male		Female	
	2004	Cumulative total until end 2004	2004	Cumulative total until end 2004
Men who have sex with men (MSM)	558	16,985	-	-
MSM and injection drug use	29	680	-	-
Injection drug use	136	3,250	96	1,491
Blood/blood products	8	620	6	204
Heterosexual contact	189	2,416	190	2,049
Other	29	560	9	188
No identified risk/no reported risk	863	19,366	356	4,298
Total	1812	43,877	657	8,230

In the period 1985-98, the MSM category accounted for 66% of all HIV diagnoses for which exposure category was reported. This proportion dropped to 36% in 2001, but then rose again to 45% in 2004. MSM remains the largest single exposure category.

Women represent a growing proportion of adult HIV diagnoses, reaching 27% in 2004. Just under two-thirds of the women diagnosed in 2004 with reported exposure category were probably infected through heterosexual contact.

AIDS statistics

By the end of December, 2004, reports had been received of 19,828 AIDS diagnoses in Canada.

At least 13,400 people with AIDS have died.

AIDS cases in adults (15 or over) by exposure category

Exposure Category	Male		Female	
	2004	Cumulative total until end 2004	2004	Cumulative total until end 2004
Men who have sex with men (MSM)	68	13,090	-	-
MSM and injection drug use	11	806	-	-
Injection drug use	25	1,048	10	382
Blood/blood products	1	458	1	139
Heterosexual contact	41	1,670	30	1,084
Other/no identified risk factor	42	829	7	91
Total	188	17,901	48	1,696

Among adult AIDS cases reported with known exposure category, the proportion accounted for by MSM fell from more than three-quarters in the years prior to 1994, to 36% in 2004. Conversely, the heterosexual exposure category increased from 10% to 38% over the same period.

Sources:

- *Public Health Agency of Canada. HIV and AIDS in Canada. Surveillance report to December 31, 2004. Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Health Canada, April 2005.*

References:

- [1] *Health Canada. HIV/AIDS EPI Updates, May 2005, Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Health Canada, 2005.*

HIV/AIDS IN INDIA

India has had a sharp increase in the estimated number of HIV infections, from a few thousand in the early 1990s to around 5.1 million children and adults living with HIV/AIDS in 2003.[1] With a population of over one billion, the HIV epidemics in India will have a major impact on the overall spread of HIV in Asia and the Pacific and, indeed, worldwide.

The spread of HIV within the country is as diverse as the societal patterns between its different regions, states and metropolitan areas. In fact, India's epidemic is made up of a number of epidemics, and in some places they occur within the same state. The epidemics vary from states with mainly heterosexual transmission of HIV, to some states where injecting drug use is the main route of HIV transmission. Both tracking the epidemic and implementing effective programs pose a serious challenge to the authorities and communities in India.

The Early Years of the Response to HIV/AIDS in India

The first case of HIV infection in India was diagnosed among commercial sex workers in Chennai, Tamil Nadu, in 1986. Soon after, a number of screening centres were established throughout the country. Initially, the focus was on screening foreigners, especially foreign students. Gradually, the focus moved on to screening blood banks. By early 1987, efforts were made to set up a national network of HIV screening centres in major urban areas.[2]

Number of people affected by HIV/AIDS in India

Current Estimates & Future Projections

Globally, India is second only to South Africa in terms of the overall number of people living with the disease.[3]

- NACO estimated that the number of Indians living with HIV increased by 500,000 in 2003 to 5.1 million. Around 38 percent of these people were women.
- By the end of May, 2005, the total number of AIDS cases reported in India was 109,349 of whom 31,982 were women. These data also indicated that 37% of reported AIDS cases were diagnosed among people under 30. Many more AIDS cases go unreported.
- The UN Population Division projects that India's adult HIV prevalence will peak at 1.9% in 2019. The UN estimates there were 2.7 million AIDS deaths in India between 1980 and 2000. During 2000-15, the UN has projected 12.3 million AIDS deaths and 49.5 million deaths during 2015-50.[4]
- A 2002 report by the CIA's National Intelligence Council predicted 20 million to 25 million AIDS cases in India by 2010, more than in any other country in the world.[5]

Sources

This page has been written and edited by Jenni Fredriksson-Bass and Annabel Kanabus

The main sources include:

- *Ekstrand Maria, Garbus Lisa and Marseille Elliot (2003) 'HIV/AIDS in India', AIDS Research Institute: AIDS Policy Research Center, University of California, San Franciso, August. http://ari.ucsf.edu/ari/policy/countries.htm*
- *National AIDS Control Organization NACO (2003) 'HIV/AIDS Surveillance in India'*

References

1. *UNAIDS 2004 Report on the Global AIDS Epidemic*
2. *You and AIDS (2001)' South and North East Asia at a glance: India*
3. *National Intelligence Council (2002) 'The Next wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India and China', September, p.3*
4. *World Bank 'South Asia Region (SAR)- India', Regional Updates, www.worldbank.org/ungass/India.htm accessed 22/10/03*
5. *World bank (2002) ''Number of AIDS orphans to rise', Press review, July 11*

South Asian Culture and HIV/AIDS in the Indian sub-continent

In the Indian sub-continent, HIV/AIDS is not well known and, if it is known, then it is associated with people who are poor, sex trade workers, migrants, truck drivers, intravenous drug users (IDUs) and homosexuals. These strata face discrimination, ostracization, and stigmatization and are shunned by the general society. Individuals who are infected with HIV/AIDS receive poor health care due to societal indifference.

It is generally believed that the "stigma" forces individuals with HIV/AIDS to keep their illness a secret. Owing to little understanding of how HIV/AIDS is contracted, the myths and misconceptions continue to prevail, which leads to treating individuals infected with HIV/AIDS with disdain and disrespect. This results in the delivery of poor health cares services to those that need help the most.

Understanding HIV/AIDS

Beginnings…..

Acquired Immune Deficiency Syndrome, or AIDS, was first reported in mid-1981 in the United States; it is believed to have originated in Sub-Saharan Africa. The human immunodeficiency virus (HIV) that causes AIDS was identified in 1983, and by 1985 tests to detect the virus were available. The credit for discovering the AIDS virus is jointly shared by Dr. Robert Gallo, a researcher at the National Cancer Institute, and Luc Montagnier of the Pasteur Institute, France.

Transmission

The AIDS virus can be spread in many ways. AIDS can be transmitted by direct contact of bodily fluids from an infected male or female. The AIDS infected blood contaminates uninfected blood. The three most common methods of transmission are:

1. sexual activity such as sexual intercourse (blood to semen contact),
2. oral or anal sex;
3. blood transfusions of infected blood; and the sharing of intravenous needles which may have contaminated blood still in them.

Another common way of AIDS transmission is mother to child transmission. The virus can be transmitted to the child from the mother before or during the delivery of the baby. The other mother-to-child transmission case is through the breast milk that he/she is fed in the early stages of the child's life. At this time, there is no cure for this deadly virus, but, by using forms of prevention that are described further into the page, the chance of contracting AIDS can be lessened.

Symptoms

Stage 1: No Symptoms - In the first stages of HIV, the symptoms do not show. People can live with AIDS for years without knowing it. Blood tests at the doctor will show antibodies after they form to fight the AIDS virus, but it takes the antibodies three months to show up. That means that if you take a blood test right after you have sex, the virus, if present, will not show up for another three months.

Stage 2: Mild Illness - At this stage the virus grows within the white blood cells and destroys them. When most of the cells are destroyed, the immune system is destroyed and the body weakens. Some symptoms include tiredness and weight loss. Infected persons may develop a cough, diarrhea, fever, or sweating at night. With HIV, a cold is more threatening to them than to a person without the disease.

Stage 3: Severe Illness - By this time, the AIDS virus has nearly destroyed the body's immune system. The body has great difficulty fighting off germs. Also, patients can develop a rare type of cancer called Kaposi's sarcoma. AIDS doesn't kill anyone, but other infections and cancer do.

Treatment

Scientists are trying to develop a cure for the AIDS virus. There are three parts to finding the cure. The three parts are:

1. To devise a drug that will kill the HIV once it enters the body.
2. To create a vaccine that would prevent the disease.
3. To educate people world wide about the dangers of AIDS and how to prevent the HIV infection.

In 1986, the first step was taken in AIDS prevention. AZT is a pill that has prolonged the lives of HIV infected patients. Ninety percent of patients who have taken the AZT pill are still alive after one year of being diagnosed. This is an increase of 50% over those without the pill.

There are some side effects of AZT. Some patients have developed a resistance to the drug after prolonged use.

Other drugs have also been tested in the past few years. These drugs have different side effects, but by switching medicines, a patient may not suffer from many of the side effects.

Medicines to fight AIDS need to be developed to kill the viruses, but not the cells that the viruses live in. Doctors are trying to develop the medicines and test them quickly

enough to be available to AIDS patients. Many AIDS and HIV-infected patients are volunteering to test the medicines. These medicines are experimental and are still being tested, so they may or may not slow down the spreading of the virus.

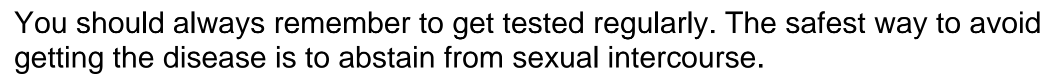
Prevention

HIV can be prevented in many ways, but they are not always followed. People die when they do not play it safe. That is why we have to spread the word on prevention.

There are three main ways the HIV can be spread:

1. sexual intercourse
2. intravenous drugs
3. blood transfusions (which are very rare now because all blood is tested)

You should always remember to get tested regularly. The safest way to avoid getting the disease is to abstain from sexual intercourse.



CHAPTER 3

PCHC AND THE RESEARCH PROJECT

History of the Punjabi Community Health Centre

The Punjabi Community Health Centre (PCHC) is a non-profit community based agency in the Region of Peel. It was incorporated as a community-based agency and a resource centre in 1995.

Developed in the spring of 1990, the Punjabi Community Health Project in Peel was an innovative Health Promotion Project based on the principles of Community Development.

Vision

The Punjabi Community Health Centre strives to create a healthy and vibrant community, which values the cultural mosaic of the Region of Peel.

Mission

The PCHC will serve the Peel community through community development, culturally appropriate service delivery, partnership with other organizations, research and asset inventories, developing resources and recruiting volunteers from within the community, and consulting and promoting diversity through community outreach.

Introduction to the Project

The Research on HIV/AIDS in the South Asian Community is a community-based research and development project. The Punjabi Community Health Centre and community partners in the Region of Peel have worked on this initiative since the fall of 2002.

Information gathered for this project was collected using three deliverable methods; an in-depth literature review, qualitative focus groups and a quantitative/qualitative questionnaire. The aim of the literature review was to unearth a depth of information regarding HIV/AIDS and the South Asian community. While the search for qualified information proved difficult, the end result was a comprehensive literature review that highlighted HIV/AIDS and South Asian communities in India, the United Kingdom, and Vancouver, Canada. Three qualitative focus groups were held with different segments of the South Asian community; Youth, Seniors and Religious Members. A questionnaire both quantitative and qualitative in methodology was created to garner service providers' perceptions of HIV/AIDS in the South Asian community, while at the same time, discerning gaps in the services provided.

Background

The South Asian community is the largest ethnic community in the Region of Peel. According to the 2001 Canada census, just one of the South Asian languages, the

Punjabi, was identified as the second most-spoken mother tongue after English in the Region of Peel[1].

Large pockets of the South Asian population can be found in Malton, Mississauga and Brampton. The community is quite closely knit with its own media, small-to-medium size businesses, its own schools, religious institutions and inroads in the hospitality, travel and tourism industry. Nonetheless, as a whole, it is not an isolated community but members within it can remain isolated not having to associate with the mainstream community.

HIV/AIDS has remained at the forefront of disease notoriety. Despite its world renowned epidemic, it is a topic that easily gets pushed into the background. In mainstream communities strong efforts have been made and continue to be made, in order to keep HIV/AIDS at the forefront. This is not to say ethnic communities are left unspoken of regarding HIV/AIDS. South Asian communities are oft spoken of regarding HIV/AIDS. However, specific research regarding the South Asian community and HIV/AIDS is limited as are resources to the South Asian community regarding HIV/AIDS and related issues.

Scope of the Study

The Punjabi Community Health Centre commissioned this study and the purpose of the study was:

- to determine the level of understanding of HIV/AIDS within the South Asian community
- to determine whether the South Asian community accepts that HIV/AIDS is an issue to be dealt with within their community
- experience the medical and social service professionals have with their South Asian clients around HIV/AIDS related issues
- experience the South Asian community has in dealing with HIV/AIDS within their own community

Objectives of the Study

The specific objectives of the study were to obtain an understanding related to HIV/AIDS within the South Asian community of:

- the nature of stigma within the South Asian community
- what cultural factors contribute to myths and stigma held
- what degree of services available to the South Asian community around HIV/AIDS related issues
- what gaps might exist in services available to the South Asian community around HIV/AIDS related issues
- what ways HIV/AIDS might be destigmatized within the South Asian community
- what modalities for intervention exist within the South Asian community

---

[1] 582350 persons identified English as their mother tongue. 58105 persons identified Punjabi as their mother tongue. Only 12350 persons identified French as their mother tongue.

Approach

The research completed was done using a 'Participatory Action Research'[2] methodology to undertake research within the South Asian community. It was strongly desired that the research conducted be used to build communities, not just to collect information from them. Therefore, the role of participants will be more than just sources of data rather they will be involved community members throughout the project.

As a requirement of the project's objectives to appreciate the communities understanding for HIV/AIDS, three focus groups were held. Each of the groups represented different segments of the South Asian community allowing for capturing of a collaborative of qualitative information.

The research team also felt that quantitative data should be gathered in order to complement the qualitative data. To obtain this form of data, a questionnaire was developed and administered to social service and medical professionals who consented.

The research team was well aware that the topic of HIV/AIDS often generates feelings of discomfort within individuals which might compromise the results of this study to some extent. However, once the data was collected and analyzed, findings of some significance had emerged.

Methodology

The work plan consisted of the following: 1) Forming a research team, 2) Developing a steering committee, 3) Undertaking review of literature, 4) Developing, focus testing, revising and finalizing a questionnaire to collect quantitative data, 5) Developing a qualitative data-gathering process by using focus groups, 6) Analyses of qualitative and quantitative information collected, and 7) writing and the compilation of the final report

1. *The research team*:

   The research team comprised three individuals who had long experience working in the field of social work with project staff taking the research lead.

2. *The steering committee*:

   The steering committee consisted of social service professionals from the mainstream HIV/AIDS related-service providers and ethno-specific service providers.

3. *Review of literature*:

   The research team read several articles, research papers, and examined several internet sites in order to review the current research on HIV/AIDS and South Asian populations. The team discovered that research on HIV/AIDS and South Asian populations proved difficult to unearth, in particular, to western South Asian

---

[2] Please see appendix for a detailed overview of Participatory Action Research methodology.

populations. Research particular to Canadian South Asian populations was limited to Vancouver. However, some studies were relevant to this project. The literature section of this report contains the review of those studies.

4. *Quantitative survey tool*:

4.1 A questionnaire was developed and the supervisory staff critiqued it. A revised draft was presented for their approval. The approved draft was then tested. The questionnaire was again revised. The final questionnaire is attached in the appendices.
4.2 Numerous social service and medical professionals were contacted for their participation in the project questionnaire.
4.3 The completed questionnaires were numbered and through the use of SPSS (Statistical Package for the Social Sciences) program was coded into the computer.

5. *Qualitative data-gathering process*:

5.1 Three focus groups were organized.
5.2 The discussion was noted by a scribe and then entered into the computer.

Analysis

Each data set was analyzed separately for findings and recommendations.

Focus groups were analyzed for themes from written notes. Since seniors were uncomfortable with recordings, tape recordings were not used. The themes formed the basis for the findings and recommendations.

The quantitative data were analyzed by using SPSS. The findings formed the basis for recommendations.

Findings

Thus, each data gathering process contains a section on the findings. There are two sections under findings – (Part I) focus group and (Part II) the questionnaire.

Recommendations

Similarly, each data-gathering process contains a section on recommendations. There are two sections under recommendations – focus groups and the questionnaire.

CHAPTER 4

SUMMARY OF FINDINGS

The findings presented in this section represent the views and the opinions of the community members and health care professionals working with the Punjabi community. The opinions expressed by the participants were frank, candid and respectful. While participants had different views and opinions on the issue of HIV/AIDS, nonetheless, they all agreed that the research project is very important and worthwhile. The research team through this study has come across experiences which will highlight the "gaps" in service delivery, the need for community development projects, the need for developing culturally appropriate service delivery, and the need to develop a variety of training workshops for health care providers.

The research elicited the following findings which have been compiled under the themes. We must note that some findings could easily fit into many themes but, in order to preserve the context of the participant's discourse, the findings have been inserted into a given theme.

The themes and findings are as follows:

Prevention

The literature review highlighted low condom use amongst the Punjabi community in India as they are using the "pull-out-method" as prevention. Decisions regarding condom use are made by males.

Awareness

The general understanding of the participants of the perceived risk for contracting HIV/AIDS is low as they have little factual knowledge of the illness. The research study also found that there seems to be a lack of HIV/AIDS awareness among South Asian professionals. The general consensus from the participants seemed to be that the Punjabi community seems to be in "denial" about the HIV/AIDS illness.

Misconceptions

The participants outlined some strong myths, misconceptions about HIV/AIDS which are as follows:

- HIV/AIDS is a "white" person's illness or
- a disease of prostitutes
- Discussion on this topic or any topic related to "sex" is taboo

Health Promotion

The participants felt that HIV/AIDS is an issue which cannot be easily addressed in the community. They felt that the new immigrants have a different priorities while establishing themselves in Canada, and they are least concerned with "sexual health education".

High Risk Groups

The literature review highlighted that MSM (men having sex with Men) are the most at-risk group of getting infected by HIV/AIDS virus. The articles also delineated that MSM are perhaps likely to not disclose their sexual identity to their wives for having a fear of not being accepted in the family. Therefore, they may be infecting their wives with this

virus. The review also pointed out that sex-trade workers and truck drivers can also be categorized in high-risk groups.

Barriers

The review also outlined that South Asians are "unlikely to seek medical assistance". The barriers identified in the survey were:

- Lack of language and culturally appropriate resources
- Lack of funding
- Lack of knowledge of community needs
- Lack of outreach to the community
- Lack of networking with mainstream organizations
- Length of time, skill required for clinical intervention

Service Provision

The review pointed out that "those getting assistance from service providers are generally couples age 30-40 years.

Training Needs

The participants outlined the need for culturally sensitive training of mainstream professionals. They felt that often the cultural nuances are not understood or taken into account when mainstream services are accessed by South Asians.

The participants also felt a need to train South Asian health care professionals who are working in the health care setting. Specific references were made regarding "violations of confidentiality".

The participants also felt a need to educate the community about the complexities surrounding HIV/AIDS issues.

South Asian Context

Many myths and misconceptions exist in the community about homosexuality and HIV/AIDS which need to be addressed. The literature review highlighted that gay lifestyles and HIV positive health status would not be accepted by the family or the community. The articles outlined that South Asian men look for casual sex outside the community as "girls inside the community are not "available". The articles also pointed out that "predominantly men bring infection into the community infecting women". This point of view was not confirmed in the perceptions of the focus group was, however, by the focus group, where the participants felt that female promiscuity was responsible for infected males with HIV/AIDS. (The participants involved in focus groups seemed to have some sympathy for those that are HIV/AIDS infected but seemed to be more concerned and expressed greater sympathy for and with the "affected".) The focus group highlighted the following issues which would be faced by the infected individual:

- Shame
- Stigma
- Isolation
- Loneliness
- Abandonment
- Disownment
- Lack of support from family, friends or the community

SUMMARY OF FINDINGS – LITERATURE REVIEW

These are the collective findings which are relevant to the project:

Prevention

- Low condom use and reuse of condoms
- Low to non-existent condom use with wives
- Use of pull out method as prevention

Awareness

- Perceived risk of HIV is low
- Little factual knowledge of HIV
- HIV is seen as affecting "other people"
- Strong misconceptions regarding HIV/AIDS, especially from new immigrant population
- AIDS happens to "other" people – i.e. gay white men and taxi drivers
- HIV/AIDS is associated with poor morality
- South Asians do not discuss sexual matters with friends, family or anyone else
- Even for second generation South Asians, AIDS is still a taboo topic
- AIDS awareness remains low even among South Asian professionals
- Citizenship and Immigration Canada on January 15th, 2002 implemented a new HIV testing policy for immigrants and refugees. The introduction of the test directly impacted upon the increase in HIV positive tests, contributing to a 30% increase; one hundred and seventy-five individuals tested positive for HIV under the new policy.

Health Promotion

- HIV is closely associated with taboo issues of sex and sexuality and, therefore, cannot be easily addressed within the community.
- Health promotion is mainstream and service providers are too unfamiliar with cultural and faith backgrounds to offer the necessary support.
- Sexual knowledge of new immigrants is limited and therefore, they need access to health promotion
- Sexual health is of low priority for new immigrant (in Canada less than five years) MSMS
- There is a need to promote more dialogue about sexual and reproductive health

High Risk Groups

- High commercial sex trade
- Some areas of India report HIV prevalence as 0%, but these same areas report HIV infection at STD clinics and amongst injecting drug users
- In India, of the 42,947 cases as of December 2002, 74% were male
- 84% of all infections were transmitted sexually
- A study of South Asian adolescents indicates they know of HIV, but have little knowledge regarding transmission.
- High rates exist amongst MSMS, who lead a heterosexual 'family man life' as a result of social expectations and parental pressure to marry
- 64% of South Asians in Queens, New York, have no health coverage
- Since 1998, chlamydia has risen in which community? 34%, the highest in all ethno-cultural groups

Barriers

- Language is a communication barrier for service providers to clients
- South Asians are unlikely to seek professional assistance
- Ethnicity data is incomplete because ethnic status does not need to be reported, individuals are asked to identify with an ethnic group, but can decline to do so. Patients not wishing to identify an ethnic background may not feel they identify with the prescribed list or may not do so simply for their own anonymity, however, this does result in an underrepresentation of some ethnic groups.
- Approximately 15% of AIDS cases and 90% of positive HIV tests did not report ethnicity.

Service Provision

- Those getting assistance from service providers are generally couples between the ages of 30-40 years. HIV was transmitted from husband to wife, who was first infected by a prostitute or through gay sex.

South Asian context

- Western values taught to youth in Canada are in conflict with ‘the good’ of the family.
- South Asian women are defined by the community and their roles as wives, mothers, and daughters.
- Female virginity is of high priority prior to marriage, i.e., “family honour”
- Many myths and misconceptions exist in the community regarding homosexuality and bisexuality.
- Gay, bisexual or MSM relationships are kept hidden and individuals go through with marriage to avoid conflict within the family – this is even greater amongst new immigrants. There is a concept of “private shame” and a public heterosexual lifestyle.
- There is a non-acceptance of gay lifestyle or HIV positive health status by family and community.
- Many taboos exist within the South Asian community, e.g., sex before marriage (especially for women), sex during menstruation, masturbation is seen as “dirty and impure” and a waste of semen.
- Sexual discussion is also taboo. This results in knowledge coming mainly from peers.
- Women are not to have sexual knowledge; they are expected to learn from their husbands.
- If caught dating a South Asian girl, the male may be forced into marriage to preserve her purity. This results in many South Asian males looking outside of the community for casual sex
- Prescribed sex roles exist for men and women after marriage
- Women are not to be sexually aggressive or aware. If they are, this may be perceived as “having slept around or with someone else.”
- MSM must be the aggressor; this to them means they are not gay.
- Married men “tend to roam around”, covertly they have unprotected sex with other men or women, but these behaviours are not discussed.
- Predominantly men bring infection into the community and infect women

- Prior to and during marriage, many men go to prostitutes, “always present, always hidden” or deemed “private business”
- Many young men are encouraged to lose their virginity to prostitutes; this behaviour is more prevalent with new immigrants
- Young women concerned with protecting their virginity may have anal sex but are unaware of the risk of HIV infection.
- In traditional households little to no permission is allowed for wives to question the behaviours of their husbands.
- Decisions regarding condom use is made by the male
- Men perceive that they can’t get HIV because they don’t do drugs and are not gay.
- There is a limited knowledge of HIV/AIDS, and of prevention/safer sex
- There is a perception that HIV is a gay or “white” disease
- There is a strong lack of AIDS prevention/education programs within South Asian communities
- There is a lack of culturally appropriate resources
- The community has a history of “shunning” or ostracizing others so those infected keep their status hidden
- The community denies the existence of risk behaviours so this contributes to the denial of HIV/AIDS in the community.

SUMMARY OF FINDINGS - FOCUS GROUPS

Finding number one

While youth had some general information regarding HIV/AIDS, the other two focus groups had limited knowledge of HIV/AIDS. The seniors and religious members did not have a clear understanding about the contraction of the disease and/or who it affects.

Finding number two

The focus groups did not identify HIV/AIDS as affecting the South Asian Community. While HIV/AIDS was recognized as a problem in India, many participants were unaware of the issue or felt that it was not an issue in Canada. Prolonged discussion indicated that many were in denial regarding HIV/AIDS and the South Asian community and that many chose to hold on to myths and stereotypes regarding the disease.

Finding number three

All three focus groups held common myths and stereotypes associated with HIV/AIDS. It should be noted that while the myths and stereotypes may be common, these perceptions have been continuously addressed in mainstream HIV/AIDS awareness campaigns. All three groups associated HIV/AIDS with being a 'gay' disease or a 'white' disease. Many views held by the focus groups centered on gays; being gay will cause HIV/AIDS, having gay sex will cause HIV/AIDS or that gays are to be blamed for the disease and people should stay away from them. Another stereotyped held is that promiscuity leads to HIV/AIDS. However, only the seniors and religious members' focus groups, blamed promiscuity on females. In fact, two of the focus groups placed a great deal of blame for HIV/AIDS entering the community on the behaviours of females.

Finding number four

Many participants involved in the focus groups seemed to have some sympathy for those who are HIV/AIDS infected. However, in all of the focus groups, participants were better able to identify with, and expressed greater sympathy for, the affected. Further discussion led to exposing the fears that participants held; how would the rest of the community view them, "family shame" and "financial stress".

Finding number five

When asked what sufferers of HIV/AIDS in the South Asian Community would face, the focus groups highlighted much of the stigma that can be faced in the South Asian community. HIV/AIDS infected would suffer isolation, abandonment, disownment and the lack of support from family, friends or the community. The focus groups readily admitted to the stigma that is faced. Some participants even encouraged the stigmatic behaviours.

Finding number six

One of the most enlightened findings was the strong desire of all of the focus groups to be involved in more groups, to have workshops for the community, to be provided with language and culturally appropriate services and resources, to be provided with more literature and simply to be more informed and aware of HIV/AIDS. Some of the suggestions the focus groups gave were; to hold half-day workshops for educating the community about the issues and complexities surrounding HIV/AIDS.

Finding number seven

The participants talked about the insensitivity of the healthcare providers. In addition, breech of confidentiality by South Asian professionals was also raised as an issue.

SUMMARY FINDINGS – HEALTHCARE PROVIDERS' SURVEY

1. 44.4% of services provided are medical, 22.2% of services are provided to youth. With 11.1% of services being provided to men, women, parenting, prevention education and confidential support.

2. 88.9% of service providers provide service within the Region of Peel with 27.8% of services also being provided to Toronto and the GTA.

3. 44.5% of service providers' roles are medical, 33.5% of the roles are frontline and 27.9% hold supervisory roles.

4. 38.9% of services delivered are medical, 33.6% of services provided are community awareness, education and outreach. 33.4% of services delivered are to youth.

5. 77.7% of service providers said "yes" they provide support of information about HIV/AIDS while 26.3% said "no".

6. 27.8.% of services providers provide both HIV prevention and awareness, 22.2% provide only HIV awareness, 16.7% of services provided are HIV prevention/awareness/ care or no response, 11.1% provide only HIV prevention or an issue other than a HIV/AIDS topic is their focus.

7. 68.4% said "yes" they have personally provided support or information. 31.6% said "no".

8. An overwhelming 62.5% of services provide awareness/advocacy/outreach/ prevention educational support. 43.8% offer information/referral services, 37.5% offer counseling support, 31.3% offer testing/diagnosis, 18.8% offer medical care and 6.3% offer immigration/housing support or offer something other than the stated choices.

9. 44.4% of service providers deemed that they offer HIV services around testing/diagnosis, 27.8% offer HIV related services around substance abuse and treatment education and 50% of service providers offer HIV related services around prevention education.

10. 42.1% of service providers estimated that 76%-100% of clients accessing services were South Asian. 36.8% estimated this number at 0%-25%. 21.1% estimated that South Asians made up 26%-50% of their clients.

11. 36.8% identified that, of the South Asian clients accessing services, it is mostly females. 31.6% said there is an equal gender distribution. 15.8% stated that they saw mostly male South Asian clients. 10.5% stated they saw only slightly more men than women and 5.3% have slightly more female clients than men accessing their services.

12. Service providers identified their South Asian clients' language skills as 57.9% having a greater fluency in their mother tongue than English, while they identified 21.1% as having a greater fluency in English than in their mother tongue. According to the service provider 10.5% are fluent in mother tongue, 5.3% are equally fluent in mother tongue and English. The 5.3% of the service providers had no response to this question.

13. When asked to describe the education level of their South Asian clients, 31.6% identified their clients as having some high school education while 31.6% identified that their clients had completed high school. 15.8% did not respond to this question. 10.5% stated their clients had some post-secondary education and 10.5% stated that their clients' education had ended prior to high school.

14. 76.5 % of respondents identified providing services to South Asian clients that are new immigrants (in Canada 0-5yrs). 58.8% identified providing service to South Asian clients who have resided in Canada 6-10yrs. 29.4% identified clients that were born in Canada and 17.6% were identified as having been in Canada 10-20+yrs.

15. 94.7% of service providers provide services to South Asian clients who are Punjabi speaking, 89.5% to Hindi speaking, 78.9% to an Urdu speaking, 57.9% to Gujarati speaking, 47.4% to both Tamil and Arabic and 31.6% of service is provided to other South Asian-speaking populations.

16. 84.2% of those surveyed provide services to South Asians belonging to the Hindu religious faith. 78.9% of service providers provide service to South Asian that are of the Sikh and Muslim religious faiths. 73.7% provide service to South Asian who are Christian and 15.8% of service is provided to those who belong to other religious faiths.

17. When estimating the percentage of their South Asian clients whom they had provided HIV/AIDS support or information to, 44% of services providers identified they had provided service to 0% of their South Asian clients. 11% identified only 1%, 11% identified 5% and 11% identified having provided HIV/AIDS support of information to 15% of their South Asian clients. 6% said this information was not known, 6% had no response, 6% had only 2 cases, 6% identified 10% and another 6% identified 40% of their clients had been provided with HIV/AIDS support or information.

18. With regards to the sexuality of their South Asian clients, service providers deemed 52.6% to be heterosexual, 26.3% declared this information was not known about the clients they see or that they see South Asian clients of all sexual orientations. 5.3% deemed that they see bisexual clients.

19. When describing the serostatus of their South Asian clients, 36.8% said that information was not known, 31.6% had no clients living with HIV/AIDS, 15.8% said most were not living with HIV/AIDS, 10.5% gave no response and 5.3% said most were living with HIV/AIDS.

20. 84.2% of those surveyed had no response as to modes of HIV transmission for their South Asian clients. Of those who were aware of their clients' mode of transmission, 10.5% indicated transmission mode as one of the following; male to female, male to male and mother to child (utero/birthing). 5.3% identified known modes of transmission as female to male and mother to child (breastfeeding).

21. Services providers identified the following as barriers to their effective delivery of HIV/AIDS to the South Asian community; 56.3% identified the lack of language and culturally appropriate resources, 50% identified the lack of funding, 35.7% identified the lack of knowledge of community needs, 31.3% identified the lack of outreach to the community, 18.8% had no response, 6.3% identified length of time and skills required for clinical intervention and networking with mainstream organizations.

22. Service providers ranked the level of support available to the South Asian community as follows; 31.6% deemed it to be fair, 26.3% deemed it to be poor, 21.1% deemed it to be good, 15.8% deemed it substandard and 5.3% deemed services available as excellent.

23. Service providers identified their South Asian clients who access services around HIV/AIDS as 46.2% sexually active heterosexuals and new immigrants, 38.5% were identified as providing services to youth under 18 years of age, 23.1% of service delivery goes to men who have sex with men, 15.4% of services being delivered to substance users and substance addicts. 7.7% of identified service delivery goes to injection drug users and commercial sex workers.

24. 94.7% of respondents said "yes, individuals who have or are suspected of having HIV/AIDS within the South Asian community are stigmatized." 5.3% had no response to this question.

25. Respondents identified peoples within the South Asian community who would suffer more stigma as the following; 77.8% identified homosexuals or gays, 72.2% identified females, 66.7% identified trans-gendered, 22.2% identified married individuals, 16.7% identified children, 11.1% identified singles and that, overall, it is not accepted by the culture; the perception is that those infected deserve it, 5.6% identified seniors, males, and that all people are stigmatized equally since anyone infected with HIV/AIDS is not seen as normal.

26. Services providers perceived the following as common types of stigma suffered within the South Asian community; 58.8% identified no support from community, family or friends and isolation, 23.5% identified that a common stigma held was that it is an individual's fault as a female or for being gay, 17.6% identified that the community would deem it against religious values, 11.8% identified gossip and being ostracized (made a spectacle of), 5.9% identified exclusion; people are not knowledgeable. Therefore, shame, substance abuse, lack of education and community blame for females having premarital sex are contributing factors.

27. Service providers identified methods of intervention to stop stigmatization of HIV/AIDS with the South Asian community as follows; 81.3% identified education, 68.8% identified awareness, 18.8% identified prevention, 12.5% identified knowing the facts about transmission and outreach, 6.3% identified, developing resources, greater recognition by community of change, personal health, open dialogue, and truth, an increase of community comfort level by providing support groups and elimination of" it's your fault if you have it" thought process.

28. Service providers identified important factors around HIV/AIDS that the South Asian Community is in need of as follows; 94.7% identified prevention, 78.9% identified language and culturally appropriate services and resources, 68.4% identified drug and substance use education and counseling support, 63.2% identified peer support, 57.9% identified testing and diagnosis, 5.3% identified sex education, development of resources and other factors.

CHAPTER 5

SUMMARY OF RECOMMENDATIONS

The research study brought into light the fact that HIV/AIDS is prevalent in the Punjabi community. Although, the infected and affected individuals face extreme isolation, and ostracization, the problem does exist in the community. The research also highlighted that individuals may have difficulty accessing services for a variety of reasons. The following recommendations are suggested which would address the needs of the Punjabi community in the areas of HIV/AIDS.

Recommendation One

Develop multi-dimensional projects which address the needs of high risk groups: youth, women and Men having Sex with Men (MSM).

Recommendation Two

Develop culturally appropriate resources for the community.

Recommendation Three

In order to deal with the aftermath of HIV/AIDS, PCHC should develop culturally appropriate:

- Support groups for the infected and the affected
- A therapeutic group program for the infected

Recommendation Four

Develop culturally appropriate comprehensive programs aiming at prevention, curative and rehabilitative aspects of HIV/AIDS.

Recommendation Five

In order to educate the Punjabi community, the preventative programs should be comprised of:

- Awareness campaigns
- Educational workshops
- Use of electronic mass media (internet, radio, television)
- Plays and dramas (the arts community)
- Resources (videos, handbooks, brochures)

Recommendation Six

Develop culturally sensitive workshops for the mainstream and multicultural healthcare providers.

Recommendation Seven

Develop research projects to explore the specific needs of HIV/AIDS in the South Asian community.

SUMMARY OF RECOMMENDATIONS – LITERATURE REVIEW

Health Promotion

1. Normalize HIV as a part of health promotion
2. Generate support from community leaders
3. Use community leaders to promote messages
4. Avoid HIV/AIDS education in religious institutions because of religious barriers and taboos
5. Have multiple streams of promotion material to reinforce the message
6. Identify and ease the fear of AIDS and its denial in the South Asian community – link fear to the risk of HIV infection
7. Promote the discussion of sexual health within the community
8. Provide information resources in plain non-jargon language
9. Obtain recent statistics on the relevance of HIV/AIDS in the community
10. Re-focus HIV as a public health issue and separate it from homosexuality
11. Address HIV as a priority to the community
12. Provide information to youth in schools
13. Approach individuals in the community directly for their input
14. Use pictures to make the material easier to identify
15. Distribute pamphlets with information on community groups and counseling
16. Use community television, print and radio
17. Provide testimonials from respected professionals
18. Promote condom use
19. Give youth an opportunity to discuss sexual health issues

High Risk Groups

20. High risk groups are: youth, women and MSM

Service Provision

21. Increase the availability of culturally appropriate literature
22. Conduct research related to sexual health behaviour
23. Improve health system effectiveness
24. Provide resources that are written in the language of the community
25. Increase AIDS awareness among South Asian professionals
26. Increase cultural sensitivity among mainstream and service providers who unfamiliar with the cultural and faith backgrounds of the community.

South Asian context

27. Addressing HIV/AIDS in the South Asian community would require a culturally appropriate and holistic approach.

SUMMARY OF RECOMMENDATIONS – FOCUS GROUPS

1. Organize community development projects which would raise the awareness about the issues pertaining to HIV/AIDS in the Punjabi community in a culturally appropriate manner.

2. Organize community development projects which would educate the community about the issues pertaining to HIV/AIDS in the Punjabi community in the following areas:

    - Myths and stereotypes about how disease is contracted
    - How we can protect ourselves
    - What is involved in testing
    - Where one can go for testing
    - What is confidentiality and the responsibilities of the health care providers
    - Compassion and kindness towards the "ill"
    - The cultural norms and traditions related to stigma, isolation, abandonment, un-acceptance, disownment, and ostracization
        a. For the infected

3. Specific community development projects related to addressing discrimination and stigmatization against "Females and Gays" for being responsible for more contraction for the disease.

4. Develop culturally appropriate services. In particular, support groups for the infected and the affected.

5. Develop culturally appropriate resources (print, video and audio) for the community.

6. Develop culturally sensitive workshops for the mainstream and multicultural service providers.

RECOMMENDATIONS – HEALTHCARE PROVIDERS SURVEY

1. Undertake research to explore the specific needs of HIV/AIDS within the South Asian community.

2. Develop specific educational programs related to understanding HIV/AIDS and HIV/AIDS within the South Asian community for the South Asian community.

3. Develop community-wide awareness programs on HIV/AIDS and HIV/AIDS related concerns.

4. Develop language and culturally appropriate resources to be used for both awareness and outreach to the South Asian community.

5. Develop outreach campaigns for the South Asian community related to HIV/AIDS that address cultural factors and commonly held myths and stigmas.

6. Develop culturally sensitivity workshops for service providers of HIV/AIDS both for specific and related services.

CHAPTER 6

REVIEW OF LITERATURE
Developing Social Capital
Sensitive Issues: HIV/AIDS Component
Literature Review

Introduction

Seven relevant articles were reviewed and analyzed. This section contains relevant findings which are meaningful for the research study.

Review

1. Bryon, Angela D. Fisher, Jeffrey. "Determinants of HIV Risk among Indian Truck Drivers." Social Science & Medicine 2001: V53. Pp1413-1426

The article details concern over the HIV epidemic in India reaching similar status as in Africa. The study addresses the fact that not much research has been done concerning high-risk sexual behavior. The article states that the primary barrier to in-depth research is cultural barriers that create a taboo again discussing sexual matters. The study was focused on truck drivers because, while unprotected heterosexual intercourse is the number one means of transmission, secondly is the truck drivers and commercial sex workers. High-risk sexual behaviours lead to the spread of HIV from primary partners to secondary partners placing the general population at risk.

Relevant Findings:

- Low condom use
- Reuse of condoms
- High commercial sex trade
- Low to non-existent condom use with wives
- Use of pull out method as prevention
- Perceived risk of HIV is low
- Little factual knowledge of HIV

2. “Muslims, Sexual Health & HIV: Report of a NAZ Project”. London Expert Forum. London Central Mosque in Partnership with the Islamic Cultural Centre. June 27th & 28th, 2002. pp5-12.

The report identifies perceptions, challenges and recommendations as determined by the members of the Muslim community who attended the forum.

Relevant Findings:
Challenges Identified

- HIV is seen as affecting “other people”
- HIV is closely associated with taboo issues of sex and sexuality and, therefore, cannot be easily addressed within the community.
- Health promotion is mainstream and service providers are too unfamiliar with cultural and faith backgrounds to offer the necessary support.
- Sexual knowledge of new immigrants is very limited and they need access to health promotion

Recommendations

- Promote the discussion of sexual health within the community
- Normalize HIV as a part of health promotion
- Use community leaders to promote messages
- Give youth an opportunity to discuss sexual health issues
- Have multiple streams of promotion material to reinforce the message
- Re-focus HIV as a public health issue and separate it from homosexuality
- Increase the availability of culturally appropriate literature
- Address HIV as a priority to the community
- Conduct research related to sexual health behaviour
- Improve health system effectiveness

3. An HIV Research Needs Assessment of MSM in Ethno-Cultural Communities: Perspectives of Volunteers and Service Providers

The study is specific to the behaviour and risk factors of various identified ethno-cultural groups as seen from the perspective of volunteers and service providers. The report dedicates findings to each of the identified ethno-cultural groups separately. This includes South Asian men who have sex with men.

Relevant Findings:

- Language is a communication barrier for service providers to clients
- Sexual Health is of low priority for new immigrant (in Canada less than five years) MSM
- Strong misconceptions regarding HIV/AIDS, especially from new immigrant population

4. Indian HIV & Aids Statistics. www.avert.org

HIV infection is reported in all states and union territories for India. The concentration of the HIV epidemic is primarily in the South of India having 96% of all reported cases. Infection is deemed mostly as a result of heterosexual contact amongst injecting drug users and their partners. It is strongly speculated that the epidemic is underestimated as a result of patients dying prior to being diagnosed.

Relevant Findings:

- Of the 42,947 cases as of December 2002, 74% were male
- 84% of all infections were transmitted sexually
- Some areas of India report HIV prevalence as 0% but these same areas report HIV infection at STD clinics and amongst injecting drug users.

5. Upadhyay, Akhilesh. HEALTH- U.S: Denial Marks South Asians' HIV/AIDS Experience. Inter Press Service – May 9th, 2003

   The article discusses the prevalence of HIV in the South Asian community in New York. Service providers and community advocates detail their perceptions to barriers within that community.

   Relevant Findings:
   - AIDS happens to "other" people – 'white gay men' and taxi drivers
   - HIV/AIDS is associated with poor morality
   - South Asians do not discuss sexual matters with friends, family or anyone else
   - South Asians are unlikely to seek professional assistance
   - A study of South Asian adolescents indicates they know of HIV but have little knowledge regarding transmission.
   - Even for second generation South Asians, AIDS is still a taboo topic
   - Those getting assistance from service providers are generally couples age 30-40yrs. HIV was transmitted from husband to wife, who first was infected by a prostitute or through gay sex.
   - Need to promote more dialogue about sexual and reproductive health
   - 64% of South Asians in Queens, New York have no health coverage
   - Since 1998 Chlamydia has risen 34%, the highest in all ethno-cultural groups
   - AIDS awareness remains low even among South Asian professionals
   - High rates of MSM who lead a heterosexual 'family man' life as a result of social expectations and parental pressure to marry

6. HIV/AIDS in the Context of Culture: Report for the South Asian Communities. Ethnocultural Communities Facing AIDS: A National Study. 1993. National AIDS Clearing House.

The report was done to gain a better understanding of social, cultural and personal factors related to HIV transmission in the South Asian community, specifically the South Asian community in Vancouver. The report is from the perspective of community leaders, health care professionals, educators, people working in the AIDS field and other members of the community. South Asian Community identifies itself by the religion, linguistic background and geographic region where they or their family came from. In the case of Vancouver, 70% of the South Asian population was identified as Punjabi.

Relevant Findings:

- Western values taught to youth in Canada are in conflict with the good of the family.
- South Asian women are defined by the community and their role as wives, mother, and daughters.
- Female virginity is of high priority prior to marriage, i.e., "family honour"
- Many myths and misconceptions exist in the community regarding homosexuality and bisexuality.
- Gay, bisexual or MSM are kept hidden and men go through with marriage to avoid conflict within the family – this is even greater amongst new immigrants. Concept of "private shame" and a public heterosexual lifestyle.
- Gay lifestyle or HIV positive health status are unacceptable by family and community.
- There are many taboos within the South Asian community: sex before marriage (especially for women), sex during menstruation, masturbation is seen as "dirty and impure" and a waste of semen.
- Sexual discussion is also taboo. This results in knowledge coming from peers.
- Women are not to have sexual knowledge; they are expected to learn from their husbands.
- If caught dating a South Asian girl, the male may be forced into marriage to preserve her purity. This results in many South Asian males looking outside of the community for casual sex
- There are prescribed sex roles for men and women after marriage
- Women are not to be sexually aggressive or aware. If so, this may be perceived as their having slept around or with someone else.
- MSM must be the aggressor; this to them, means they are not gay.
- Married men "tend to roam around", covertly, they have unprotected sex with other men or women, but these behaviours are not discussed.
- Predominantly men are bringing infection into the community and infecting women
- Prior to and during marriage, many men go to prostitutes, "always present, always hidden" or deemed "private business"
- Many young men are encouraged to lose their virginity to prostitutes – this behaviour is greater with new immigrants
- Young women concerned with protecting their virginity may have anal sex, but are unaware of the risk of HIV infection.

- In traditional households, little to no permission is allowed to wives to question the behaviours of her husband.
- Decisions regarding condom use are made by the male
- There is a perception that they can't get HIV because they don't do drugs and are not gay.
- There is very limited knowledge of HIV/AIDS, and prevention/safer sex
- There is a perception that HIV is a gay or "white" disease
- There is a strong lack of AIDS prevention/education programs within South Asian communities
- There is lack of culturally appropriate resources
- The community has a history of "shunning" or ostracizing others – those infected keep their status hidden
- The community denies the existence of risk behaviours; this contributes to the denial of HIV/AIDS in the community.

Recommendations

- Prepare informational resources in plain non-jargon language, the language of the community and use pictures to make the material easier to identify.
- Obtain recent statistics on the relevance of HIV/AIDS in the community.
- Identify and ease the fear of AIDS and its denial in the South Asian community – link fear to the risk of HIV infection
- Avoid HIV/AIDS education in religious institutions because of religious barriers and taboos
- Generate support from community leaders
- Provide testimonials from respected professionals
- Approach individuals in the community directly for their input
- Provide information to youth in schools
- Distribute pamphlets with information on community groups and counseling
- Use community television, print and radio to promote awareness

7. Surveillance Report to December 31,2002: HIV and AIDS in Canada. Health Canada. April 2003,
The report is an overall state of the nation report concerning HIV/AIDS within Canada.

Relevant Findings:

- Citizenship and Immigration Canada on January 15th, 2002, implemented a new HIV testing policy for immigrants and refugees. The introduction of the test directly impacted upon the increase in HIV positive tests, contributing to the 30% increase. One hundred and seventy-five individuals tested positive for HIV under the new policy.
- Ethnicity data is incomplete because ethnic status does not need to be reported, individuals are asked to identify with an ethnic group but can decline to do so. Patients not wishing to identify an ethnic background may not feel they identify with the prescribed list or simply for their own anonymity. However, this does result in an underrepresentation on some ethnic groups.
- Approximately 15% of AIDS cases and 90% of positive HIV tests did not report ethnicity.

General Terms

AIDS: Acquired Immunodeficiency Syndrome
HIV: Human Immunodeficiency Virus
Incidence: The number of new occurrences or a disease in a specified time period
Prevalence: The number of people with the disease who are living during a specified time period
Exposure Categories
MSM: Men who have sex with men; this includes men who report either homosexual or bisexual contact
MSM/IDU: Men who have had sex with men and have injected drugs.
IDU: Injecting drug users
Blood/blood Products

SUMMARY OF FINDINGS – LITERATURE REVIEW

These are the collective findings which are relevant to the project:

Prevention

- Low condom use and reuse of condoms
- Low to non-existent condom use with wives
- Use of pull-out method as prevention

Awareness

- Perceived risk of HIV is low
- Little factual knowledge of HIV
- HIV is seen as affecting "other people"
- Strong misconceptions regarding HIV/AIDS, especially from new immigrant population
- AIDS happens to "other" people – white gay men and taxi drivers
- HIV/AIDS is associated with poor morality
- South Asians do not discuss sexual matters with friends, family or anyone else
- Even for second generation South Asians, AIDS is still a taboo topic
- AIDS awareness remains low even among South Asian professionals
- Citizenship and Immigration Canada on January 15th, 2002 implemented a new HIV testing policy for immigrants and refugees. The introduction of the test directly impacted upon the increase in HIV positive tests, contributing to the 30% increase. One hundred and seventy-five individuals tested positive for HIV under the new policy.

Health Promotion

- HIV is closely associated with taboo issues of sex and sexuality and, therefore, cannot be easily addressed within the community.
- Health promotion is mainstream and service providers are too unfamiliar with cultural and faith backgrounds to offer the necessary support.
- Sexual knowledge of new immigrants is very limited and they need access to health promotion
- Sexual health is of low priority for new immigrant (in Canada less than five years) MSM
- There is a need to promote more dialogue about sexual and reproductive health

High Risk Groups

- High commercial sex trade
- Some areas of India report HIV prevalence as 0%, but these same areas report HIV infection at STD clinics and amongst injecting drug users
- In India, of the 42,947 cases as of December 2002, 74% were male
- 84% of all infections were transmitted sexually
- A study of South Asian adolescents indicates they know of HIV, but have little knowledge regarding transmission.
- High rates amongst MSM who lead a heterosexual family man life as a result of social expectations and parental pressure to marry
- 64% of South Asians in Queens, New York, have no health coverage
- Since 1998 chlamydia has risen 34%, the highest in all ethno-cultural groups

Barriers

- Language is a communication barrier between service providers and clients
- South Asians are unlikely to seek professional assistance
- Ethnicity data is incomplete because ethnic status does not need to be reported; individuals are asked to identify with an ethnic group but can decline to do so. Patients not wishing to identify an ethnic background may not feel they identify with the prescribed list or do not do so simply for their own anonymity. However, this does result in an underrepresentation on some ethnic groups.
- Approximately 15% of AIDS cases and 90% of positive HIV tests did not report ethnicity.

Service Provision

- Those getting assistance from service providers are generally couples age 30-40yrs. HIV was transmitted from husband to wife, who first was infected by a prostitute or through gay sex.

South Asian context

- Western values taught to youth in Canada are in conflict with the good of the family.
- South Asian women are defined by the community and their role as wives, mother, and daughters.
- Female virginity is of high priority prior to marriage, “family honour”
- Many myths and misconceptions exist in the community regarding homosexuality and bisexuality.
- Gay, bisexual or MSM are kept hidden and men go through with marriage to avoid conflict within the family – this is even greater amongst new immigrants. Concept of “private shame” and a public heterosexual lifestyle.
- There is a non-acceptance of gay lifestyle or HIV positive health status by family and community.
- Many taboos exist within the South Asian community: sex before marriage (especially for women), sex during menstruation, masturbation is seen as “dirty and impure” and a waste of semen.
- Sexual discussion is also taboo. This results in knowledge coming from peers.
- Women are not to have sexual knowledge; they are expected to learn from their husbands.
- If caught dating South Asian girls, males may be forced into marriage to preserve his purity. This results in many South Asian males looking outside of the community for casual sex
- There are prescribed sex roles for men and women after marriage
- Women are not to be sexually aggressive or aware; this may be perceived as having ‘slept around’ or ‘with someone else’.
- MSM must be the aggressor; this to them means they are not gay.
- Married men “tend to roam around” and covertly may have unprotected sex with other men or women, but these behaviours are not discussed.
- Predominantly men are bringing infection into the community and infecting women
- Prior to and during marriage, many men go to prostitutes, “always present, always hidden” or deemed “private business”

- Many young men are encouraged to lose their virginity to prostitutes – this behaviour is greater with new immigrants
- Young women, concerned with protecting their virginity, may have anal sex but are unaware of the risk of HIV infection.
- In traditional households little to no permission is allowed for wives to question the behaviours of her husband.
- Decisions regarding condom use are made by the male
- There is a perception that men can't get HIV because they don't do drugs and are not gay.
- There is a very limited knowledge of HIV/AIDS, and prevention/safer sex
- There is a perception that HIV is a gay or "white" disease
- There is a strong lack of AIDS prevention/education programs within South Asian communities and a lack of culturally appropriate resources
- The community has a history of "shunning" or ostracizing others – those infected keep their status hidden
- The community denies the existence of risk behaviours; this contributes to the denial of HIV/AIDS in the community.

SUMMARY OF RECOMMENDATIONS – LITERATURE REVIEW

Health Promotion

27. Normalize HIV as a part of health promotion
28. Generate support from community leaders
29. Use Community leaders to promote messages
30. Avoid HIV/AIDS education in religious institutions because of religious barriers and taboos
31. Have multiple streams of promotion material to reinforce the message
32. Identify and ease the fear of AIDS and its denial in the South Asian community – link fear to the risk of HIV infection
33. Promote the discussion of sexual health within the community
34. Wrote informational resources in plain non-jargon language
35. Obtain recent statistics on the relevance of HIV/AIDS in the community
36. Re-focus HIV as a public health issue and separate it from homosexuality
37. Address HIV as a priority to the community
38. Provide information to youth in schools
39. Approach individuals in the community directly for their input
40. Use pictures to make the material easier to identify
41. Distribute pamphlets with information on community groups and counseling
42. Use community television, print and radio
43. Provide testimonials from respected professionals
44. Increase condom use

High Risk Groups

45. Give youth an opportunity to discuss sexual health issues
46. Target high-risk groups: youth, women and MSM

Service Provision

47. Increase the availability of culturally appropriate literature
48. Conduct research related to sexual health behaviour
49. Improve health system effectiveness
50. Prepare resources in the language of the community
51. Increase AIDS awareness among South Asian professionals
52. Increase cultural sensitivity among mainstream and service providers who unfamiliar with cultural and faith backgrounds.

South Asian context

53. Addressing HIV/AIDS in the South Asian community would require a culturally appropriate and holistic approach.

CHAPTER 7

FOCUS GROUP - FINDINGS

The findings presented in this section represent the views and opinions of youth, seniors and religious members from the South Asian community. The youth, seniors and religious members all participated with great enthusiasm in this study.

In total *three focus groups* were organized. The attendance varied, with the youth having eight members, seniors with ten, and eight religious leaders attending the focus groups. The discussion was transcribed by two note takers and no tape recorder was used.

Almost all the participants informed us of their gratefulness in being able to share their thoughts and opinions, and have expressed the strong desire to participate in like projects in the future. The research team has tried to capture the experiences, thoughts, sentiments and opinions shared by the community members.

The findings from all three focus groups are "collapsed" together. The words and phrases with quotation marks are direct quotes from the participants. All other information has been synthesized by the research team and collapsed into themes, findings and recommendations.

Findings - Focus Groups

1. When you hear HIV/AIDS, what comes to your mind?

   - Truck drivers, hookers, gays
   - "this is a white problem"
   - "it is a Gay disease"
   - thoughts of death and sickness and pity for the infected
   - "It is a deadly disease and having cancer is better than having AIDS"
   - The disease is more common in the Gay community
   - Only the youth commented on needles, Africa, and celebrities that came to mind; Bono for his AIDS concert advocacy, Kid Rock and Pamela Anderson for Hep C and Majic Johnson, but the youth thought he could afford to have it.

2. Is this a problem within the South Asian Community in Canada?

   - Never thought of it
   - Don't know
   - It is not a problem here in Canada but it is a problem in India
   - It is a problem for the community but on a low or limited scale
   - The problem is hidden
   - "Yes, it is a problem because parents don't believe in sex before marriage, so a lack of knowledge leads to the problem."

3. Is this a problem for the community in India?

   - Not Sure or just did not know
   - It is a problem in India because of the population and the prostitutes (youth stated they had acquired this information from the reality television show 'The Amazing Race').

- It is a problem in all areas of India; special mention was made of Mumbai and Gurdaspur (in Punjab)
- 42% of the population is infected in India
- Those who get infected in India are people who stay away from home.
- The problem is not that serious and only concerns a small group of the population
- “there is no cure”

4. Who gets affected by HIV/AIDS?

- Everyone and everybody – men, women, children and drug users
- People who live in Africa and India
- Kids get it from their parents
- The homeless get it from sharing needles. Or rather the ‘not wealthy’ get it from sharing needles
- The homosexual population
- Prostitutes/hookers and those involved with prostitutes.
- “Women whose husbands see hookers”.
- “Gays are affected and kids born with HIV”
- Families of people with AIDS are affected by the bills
- Poor people and truck drivers

5. How do people get infected with HIV/AIDS?

- From blood transfusions, sleeping with prostitutes, being born with HIV/AIDS, via sexual transmission and drug use or sharing needles
- “Gay sex or by just being Gay”
- From cuts in the mouth and from seeing a dentist
- Not wearing a condom or having unprotected sex.
- Being exposed to infected blood

6. How do people protect themselves against getting HIV/AIDS?

- Use a condom
- Abstinence; don’t have many partners or be monogamous
- Don’t share needles – Use the needle exchange programs (added answer by youth)
- Birth control – “this does not protect you” (the answer came out in the youth focus group)
- Reading, research, asking questions and getting tested
- “Don’t be stupid, if anything is questionable don’t do it. You can’t look at a person and know if they have AIDS, ask them” (youth focus group)
- Limiting contact with Gays and those with HIV/AIDS
- Join a church group
- Regular check up with one’s doctor
- Cleaning needles
- Kissing (no elaboration given)

7. Do you feel that you are able to talk to a health care provider (doctor, social workers etc.) about HIV/AIDS?

- They would not talk to their doctor; they would talk to someone they knew
- "Doctors are not good for emotional support"
- Maybe if they had questions they would talk to a doctor but, if they had AIDS, they would not talk to a doctor vs. they would talk to a doctor if they had AIDS, but not if they had questions
- Find another doctor because their family doctor would tell their parents (youth focus group)
- They would not see a South Asian doctor because they would definitely tell others
- They would get tested at a clinic in the area where they lived
- One individual told the group about their experience of getting an HIV test for work: she was not concerned going for the test but the nurse became very cautious about her actions. There was an immediate change in the nurse's behaviour loudly declaring what test was being done. The individual stated, if she had been there for personal reasons, she would have cried or left (youth focus group)
- They would talk to health care provider but not without a relative present (seniors & religious members focus groups)
- Only if the health care provider spoke their language (seniors & religious members focus groups)
- No, because there is no literature available for them to read (seniors & religious members focus groups)
- "No because no one listens to me" (seniors' focus group)
- "If you don't have it, why bother talking to a doctor"

8. What problems would a person face if he/she suffered from HIV/AIDS?

- Others around you would act differently
- It's an illness that never goes away and can only get much worse
- Isolation
- The infected person would be confused, scared, depressed, suffer pain from the illness and then probably get suicidal
- They would be alone
- They would be seen as bringing their shame to the family
- People in the community would talk about them
- They would be disowned and abandoned
- The person would suffer death, disease and health problems
- The person would face ridicule and embarrassment from family and the community
- The person would face prejudice at work and by society
- Society would discard and boycott them
- The infected person would get fevers, be sick a lot and be lazy
- The person would face human weakness
- "Children in India are isolated" (seniors' focus group)

9. What can be done to assist/provide treatment to that person?

- "Prevention is better than a cure"
- Provide for treatment
- Visit a doctor and see a specialist
- "One should be their own doctor"
- The government should cover the cost of treatment
- Create support groups
- Create community awareness
- Offer financial assistance for buying drugs and for treatment
- "Tolerance" – "Can you teach tolerance?" – "You can try" (youth focus group)
- Overall support is necessary from family, friends and strangers too
- Research is needed to find a cure
- Hospitals and clinics should be built strictly for HIV/AIDS patients
- "Nothing should be done, because people with HIV/AIDS deserve it" (religious members' focus group)

10. This is a deadly disease, in your opinion, what would be effective ways to do outreach?

- Flyers, brochures and videos
- Speeches at churches
- Doctors informing patients
- Information about HIV/AIDS shared with family and relatives; they should be educated
- Workshops
- Use of print materials
- Education about condoms and protection
- HIV/AIDS testing should be made mandatory; part of one's yearly check up. This would make it more normal
- Testing should be a standard part of every blood test (Youth Focus group)
- Outreach should be done to health service providers so that they are not so insensitive and uncomfortable
- Programs should be developed and incorporated into existing cultural groups
- Websites and newsletters should be developed
- Community groups and schools should be used to do outreach, Religious institutions are perceived to be inappropriate because they would never allow anything that could be seen as promoting sex (youth focus group)
- Groups should remain separate, one for youth, parents, etc. There is no point in doing a group for seniors because they're not going to talk about HIV/AIDS and they're not going to change (youth focus group)

11. What would you like to see PCHC do to address this issue?

- More discussions, similar to the focus group that they participated in
- Available resources should be translated into the necessary languages
- Use of media campaigns using ethnic television stations or OMNI 1 or 2 d ethnic radio stations
- Call-in radio shows aimed at specific target audiences (youth, parents etc.) - “pointless to do shows aimed at seniors because they’re not going to listen to stuff on HIV/AIDS” (comment added by youth focus group)
- Flyers, videos, and brochures in their own language
- Speeches at church
- Doctors should be informing patients
- Newspapers should put the information in the paper
- Local ethnic media should attend a half-day workshop on HIV/AIDS

12. Would you like to share any other suggestion related to the HIV/AIDS topic?

- “This is our fate we must accept it” (religious members’ focus group)
- “Prevention is better than a cure”
- The cost of health care should be covered
- Inform youth not to be promiscuous (seniors’ group)

THEMES THAT EMERGED OUT OF FOCUS GROUPS

Initial reaction to HIV/AIDS

- Youth showed a greater depth of knowledge and had more connections with the disease
- All groups share the position that the disease predominantly affects the Gay community
- South Asians do not see HIV/AIDS as a problem that affects them it does affect others; Gays, Whites, people from Africa, hookers, truck drivers etc
- Very aware of the deadly nature of the disease
- Is it a recognized problem in the South Asian Community in Canada or India?
- Uncertainty regarding the issue in Canada
- Denial of any problem within Canada in the South Asian community
- Strong awareness of HIV/AIDS as a problem in India

Understanding of HIV/AIDS

- Youth are more aware of methods of transmission and protection
- Seniors and religious group have limited knowledge of transmission and protection and still hold many myths regarding the disease.
- Many responses still centered on being Gay or participating in gay sexual behaviour
- All groups named the poor as being more susceptible to the disease
- Those who get affected by the disease are homosexuals, prostitutes, those who are involved with prostitutes, homeless, poor, drug users and families of the infected.
- Females carried some blame for husbands' indiscretions with prostitutes
- Families affected are also cited as burdened financially; no real sympathy for the infected individual

Thoughts on Health Service providers

- No group was comfortable talking to their doctors; some said they would need someone else present, only after diagnosis, not before, and not for emotional support
- Doctors viewed as last resort
- Health service providers seen as being insensitive
- Going to a South Asian health service provider not an option because confidentiality is in question by patient
- Many would prefer to have literature provided before talking to anyone

What happens to a person when have HIV/AIDS?

- There was a general understanding of the gravity of the disease and that it leads to death
- There was a general isolation ostracized, disownment and abandonment from society, family and friends

What can be done to help those with HIV/AIDS?

- Financial assistance
- Support groups
- Community awareness to create tolerance and understanding
- More research and medical facilities for those with HIV/AIDS

What can be done by/for the community?

- Media campaigns using television, newspapers, radio, flyers and videos
- Ethnic media campaigns so that information is understood
- More groups/ workshops involving the community

- Information groups at religious institutions
- More information provided by doctors

SUMMARY OF FINDINGS - FOCUS GROUPS

Finding number one
While youth had some general information regarding HIV/AIDS, the other two focus groups had limited knowledge of HIV/AIDS. The seniors and religious members did not have a clear understanding about the contraction of the disease; e.g., who it affects.

Finding number two
The focus groups did not identify HIV/AIDS as affecting the South Asian Community. While HIV/AIDS was recognized as a problem in India, many participants were felt that it was not an issue in Canada. Prolonged discussion indicated that many were in denial regarding HIV/AIDS and the South Asian community and that many choose to hold on to myths and stereotypes regarding the disease.

Finding number three
All three focus groups held common myths and stereotypes associated with HIV/AIDS. It should be noted that while the myths and stereo types may be common, these perceptions have been continuously addressed in mainstream HIV/AIDS awareness campaigns. All three groups associated HIV/AIDS with being a 'Gay' disease or a 'White' disease. Many views held by the focus groups centered on Gays; being Gay will cause HIV/AIDS, having Gay sex will cause HIV/AIDS or that Gays are to be blamed for the disease and people should stay away from them. Another stereotype held is that promiscuity leads to HIV/AIDS. However, only the seniors and religious members' focus groups, blamed promiscuity on females. In fact, two of the focus groups placed a great deal of blame for HIV/AIDS entering the community on the shoulders of the behaviours of females.

Finding number four
Many participants involved in the focus groups seemed to have some sympathy for those who are HIV/AIDS infected. However, in all of the focus groups, participants were better able to identify with and expressed greater sympathy for the affected. Further discussion led to the fears that participants held; how would the rest of the community view them, family shame and financial stress.

Finding number five
When asked what sufferers of HIV/AIDS in the South Asian Community would face, the focus groups highlighted much of the stigma that can be faced in the South Asian community. HIV/AIDS infected would suffer isolation, abandonment, disownment and no support from family, friends or the community. The focus groups readily admitted to the stigma that is faced. Some participants even encouraged the stigmatic behaviours.

Finding number six
One of the most enlightened findings was the strong desire of all of the focus groups to be involved in more groups, to have workshops for the community, to be provided with language and culturally appropriate services and resources, to be provided with more literature and simply to be more informed and aware of HIV/AIDS, especially with respect to HIV/AIDS. Some of the suggestions the focus groups gave were; to hold half-day workshops for educating the community about the issues and complexities surrounding HIV/AIDS.

Finding number seven
The participants talked about the insensitivity of the healthcare providers. In addition, breech of confidentiality by South Asian professionals was also raised as an issue.

SUMMARY OF RECOMMENDATIONS – FOCUS GROUPS

7. Organize a community development project, which would raise awareness here about issues pertaining to HIV/AIDS in the Punjabi community in a culturally appropriate manner.

8. Organize a community development project which would educate the community about the issues pertaining to HIV/AIDS in the Punjabi community in the following areas:

   - Address myths and stereotypes about how disease is contracted
   - How we can protect ourselves
   - What is involved in testing
   - Where one can go for testing
   - What confidentiality is and the responsibilities of the health care providers
   - Compassion and kindness towards the “ill”
   - Address some of the cultural norms and traditions related to stigma, isolation, abandonment, lack of acceptance, disownment, and ostracization for the infected

9. Create a specific community development project related to addressing discrimination and stigmatization against “Females and Gays” for being perceived as more responsible for contraction of the disease.

10. Develop culturally appropriate services. In particular, support groups for the infected and the affected.

11. Develop culturally appropriate resources (print, video and audio) for the community.

12. Develop culturally sensitive workshops for the mainstream and multicultural service providers.

CHAPTER 8

THE SURYEY – HEALTHCARE PROFESSIONALS

Introduction

Prior to the construction of the questionnaire, a great deal of research was done regarding HIV/AIDS questionnaires and their administration and regarding the questionnaires aimed at service providers. The questionnaire was then developed and critiqued. Revisions were made to reflect input from supervisory staff persons. The approved draft was tested for question sequencing, duration of questionnaire and overall, information gathering.

Project staff and volunteers were trained to administer the questionnaires to service providers. Project staff conducted the arduous task of contacting service providers. The questionnaire delivered to service providers was divided into two categories, social service providers and doctors. Social service providers within the Region of Peel who provided direct services for HIV/AIDS to South Asians or South Asian populations were contacted and some within the GTA who delivered services specific to HIV/AIDS. Doctors whose practices were within the Region of Peel were contacted. (A total of 10 social service providers and 9 doctors were surveyed.)

The completed questionnaires were numbered and through the use of SPSS program coded into the computer. The initial work plan outlined administering the questionnaire to a total of 15 service providers; 10 medical professionals and 5 social service professionals. It was decided by project staff and supervisors to attempt to complete an equal number of questionnaires from medical and social service professionals.

The Survey In Detail

1. What service does your organization provide to the community?

Category label	Code	Count	Pct of Responses	Pct of Cases
services people who are infected and affected	1	1	2.7	5.6
direct suppport to HIV/AIDS infected	2	1	2.7	5.6
men's group	3	2	5.4	11.1
women group	4	2	5.4	11.1
healthy babies	5	1	2.7	5.6
drop-in centre for youth (youth based pr	6	4	10.8	22.2
medical (treatment, health clinic, denta	7	8	21.6	44.4
refugee reception and info referral	8	2	5.4	11.1
normal growth development	9	1	2.7	5.6
parenting	10	2	5.4	11.1
prevention education	11	2	5.4	11.1
education and outreach	12	1	2.7	5.6
home visits - families & pregnant mothers	13	1	2.7	5.6
counselling	14	1	2.7	5.6
culturally sensitive research projects	15	1	2.7	5.6
South Asian ethnic space	16	1	2.7	5.6
HIV/AIDS workshops	17	1	2.7	5.6
dealing with msm	18	1	2.7	5.6
confidential support	19	1	2.7	5.6
referral	20	2	5.4	11.1
resource centre	21	1	2.7	5.6
	Total responses	37	100.0	205.6

1 missing cases; 18 valid cases

81.1% of organizations initial service delivery is not HIV/AIDS related. Only 18.9% of service delivery is direct HIV/AIDS related service delivery. This question was asked really to see the variety of service providers selected as well as other possible avenues for HIV/AIDS related service provision.

2. What area(s) does your organization provide service to?

Category label	Code	Count	Pct of Responses	Pct of Cases
Peel	1	16	61.5	88.9
Toronto	2	5	19.2	27.8
GTA	3	5	19.2	27.8
	Total responses	26	100.0	144.4

1 missing cases; 18 valid cases

61.5% of total responses indicated service provision to the Region of Peel. 19.3% administer services to Toronto and another 19.2% to the rest of the GTA. It was important to ascertain where services were delivered in order to gauge the relevance to the South Asian community. The question was also asked to have an understanding for the geographical scope of service delivery.

3. What is your role at this organization?

Category label	Code	Count	Pct of Responses	Pct of Cases
community (development) worker	1	2	10.5	11.1
dentist	2	1	5.3	5.6
executive director	3	1	5.3	5.6
family physician	4	6	31.6	33.3
interm executive director	6	1	5.3	5.6
program support worker	7	1	5.3	5.6
psychiatrist	8	1	5.3	5.6
settlement worker	9	1	5.3	5.6
supervisor	10	2	10.5	11.1
volunteer coordinator/youth worker	11	1	5.3	5.6
volunteer	12	1	5.3	5.6
prevention education coordinator	13	1	5.3	5.6
	Total responses	19	100.0	105.6

1 missing cases; 18 valid cases

42% of respondents were medical service professionals. This is in keeping with the questionnaire administration goal of attempting to have half of the responses from services providers who are medical professionals.

4. In this role what are your key responsibilities?

Category label	Code	Count	Pct of Responses	Pct of Cases
assisting newcomers	1	1	2.4	5.6
budget	2	1	2.4	5.6
dental care	3	1	2.4	5.6
educate same pop through workshops, outreach	4	1	2.4	5.6
managing and supervision of programs and	5	2	4.9	11.1
managing/recruiting/supervising volunteers	6	3	7.3	16.7
medical treatment and support	7	7	17.1	38.9
networking	8	1	2.4	5.6
raising community and service providers	9	1	2.4	5.6
research and awareness within same community	10	1	2.4	5.6
seeking funding (working with funders)	11	2	4.9	11.1
staffing (hr issues)	12	4	9.8	22.2
addressing diversity	13	1	2.4	5.6
website for youth & msm	14	1	2.4	5.6
interaction with youth	15	2	4.9	11.1
monthly stats and reports	16	1	2.4	5.6
relationship with board	17	1	2.4	5.6
same youth event	18	1	2.4	5.6
counselling (youth, informal)	19	3	7.3	16.7
project management	20	1	2.4	5.6
build partnerships	21	1	2.4	5.6
educating both about pregnancy	22	1	2.4	5.6
focus groups	23	1	2.4	5.6
program facilitation	24	1	2.4	5.6
provide referrals	25	1	2.4	5.6
		-------	-----	-----
	Total responses	41	100.0	227.8

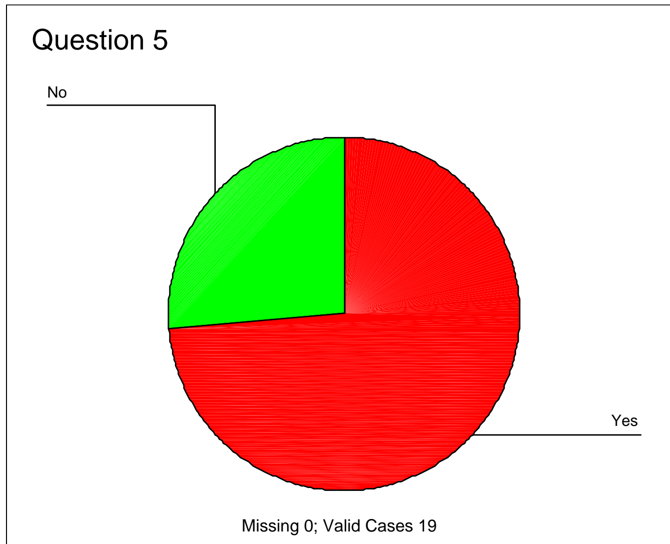
1 missing cases; 18 valid cases

This question was asked in order to ascertain what role the service providers held with respect to the delivery of services that their organization provides. This was really to gain attribute knowledge of the service providers surveyed.

5. Does your organization provide support/information about HIV/AIDS?

Question 5. Does your organization provide support/information about HIV/AIDS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	14	73.7	73.7	73.7
	No	5	26.3	26.3	100.0
	Total	19	100.0	100.0	



Statistics

Does your organization provide support/information about HIV/AIDS?

N	Valid	19
	Missing	0

Despite many of the service providers not being involved in direct HIV/AIDS service delivery, this was an expected result. However question 5 was asked to determine how many service providers in some capacity provide HIV/AIDS support or information within their regular service delivery. 73.7% of respondents state that their organizations do provide HIV/AIDS related support or information.

6. Which of the following would best describe the primary focus of your HIV/AIDS related organization?

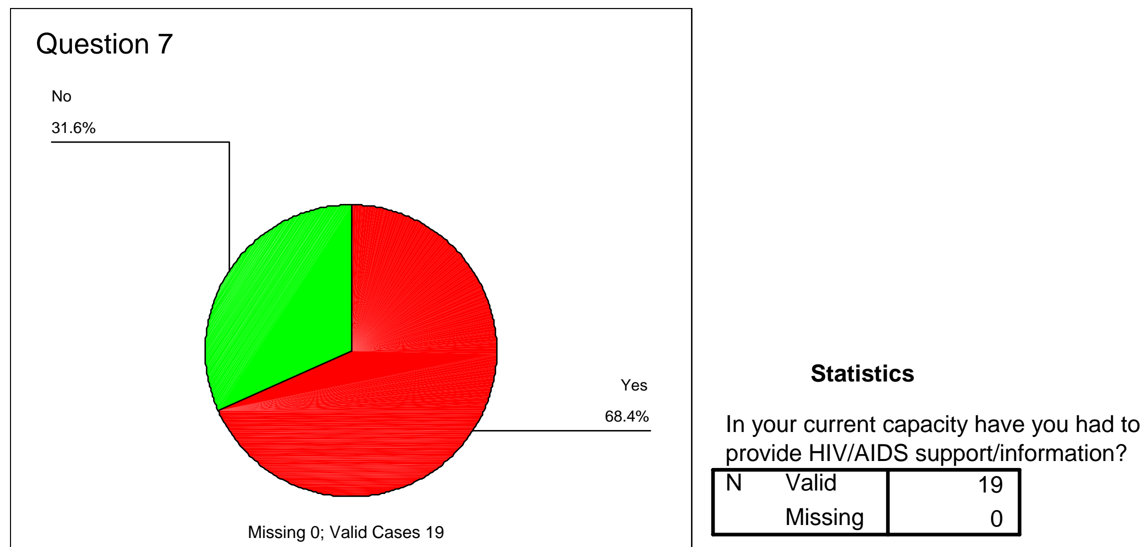
Category label	Code	Count	Pct of Responses	Pct of Cases
HIV Prevention	1	2	10.0	11.1
HIV Awareness	2	4	20.0	22.2
HIV Care	3	1	5.0	5.6
Both Prevention & Awareness	4	5	25.0	27.8
All Three	5	3	15.0	16.7
An issue other than HIV/AIDS is our primary	6	2	10.0	11.1
No Response	7	3	15.0	16.7
Total responses		20	100.0	111.1

1 missing cases; 18 valid cases

This question was asked to determine what type of HIV/AIDS related service, service providers offer. 27.8% offer both prevention and awareness and 22.2% provide only awareness. 16.7% offer HIV prevention/awareness and care. However another 16.7% had no response to this question. The importance of this question is also for comparative purposes. What service provides claim are their HIV/AIDS related services and what measures of interventions and needs that service providers feel are necessary for the South Asian community.

7. In your current capacity have you had to provide HIV/AIDS?

.



Statistics

In your current capacity have you had to provide HIV/AIDS support/information?

N	Valid	19
	Missing	0

68.4% of service providers said yes they had personally provided support or information. This question was asked to see just how many of the respondents had needed to provide HIV/AIDS support or information to their clients.

8. If yes, what kind of support/information have you provided?

Category label	Code	Count	Pct of Responses	Pct of Cases
Awareness/advocacy/outreach/prevention	1	10	30.3	62.5
Counselling/Support	2	6	18.2	37.5
Information/Referral	3	7	21.2	43.8
Testing/Diagnosis	4	5	15.2	31.3
Medical Care	5	3	9.1	18.8
Other	8	1	3.0	6.3
Immigration/housing etc	9	1	3.0	6.3
Total responses		33	100.0	206.3

3 missing cases; 16 valid cases

For the 68.4% of respondents that answered yes to question#7, it was important to determine the nature of support or information they had provided. An overwhelming 62.5% of service providers had provided Awareness/Outreach/Advocacy/Prevention Education. This is of particular note when comparing answers regarding the number of South Asian clients that they have provided HIV/AIDS related support or information to. The number of service providers having provided Awareness/Outreach/Advocacy/Prevention is also notable when reviewing answers from the focus groups as well as the questions pertaining to what needs around HIV/AIDS the South Asian community has.

9. In your current capacity which of the following areas best describes your particular HIV/AIDS related specialty?

Category label	Code	Count	Pct of Responses	Pct of Cases
Substance Abuse	1	5	10.2	27.8
Treatment Education	2	5	10.2	27.8
Case Management	3	2	4.1	11.1
Peer Counselling	4	4	8.2	22.2
Prevention Education	5	9	18.4	50.0
Testing/Diagnosis	6	8	16.3	44.4
Advocacy	7	3	6.1	16.7
Nutrition	8	1	2.0	5.6
Support Counselling	9	4	8.2	22.2
Research	10	1	2.0	5.6
Medical Care	12	1	2.0	5.6
Other	13	2	4.1	11.1
No Response	14	2	4.1	11.1
cultural understanding	15	2	4.1	11.1
	Total responses	49	100.0	272.2

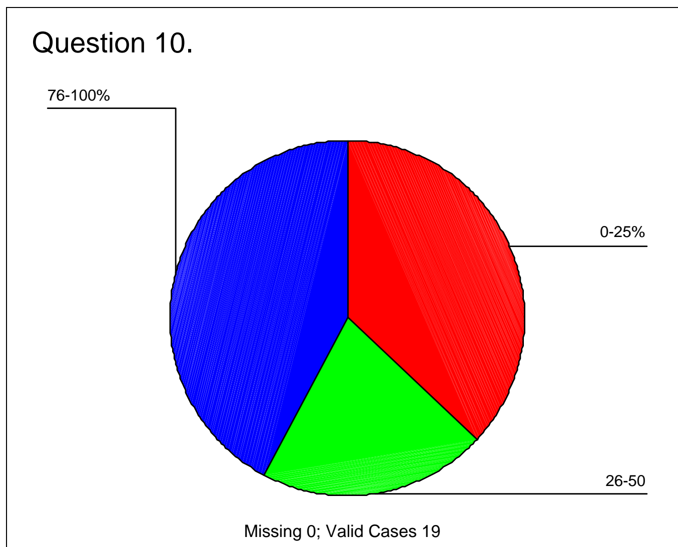
1 missing cases; 18 valid cases

This question was asked to gain knowledge of what areas service providers provide their HIV/AIDS related service. 44.4% stated their specialty was testing and diagnosis. This corresponds with the number of medical professional surveyed as well as the service providers involved with direst HIV/AIDS related services. An overwhelming 50% specialize in prevention education. This is a significant finding given service providers perceived needs of the South Asian community. 27.8% offer HIV related services around substance abuse and treatment education and 22.2% offer support counseling.

10. Estimate the percentage of South Asian clients that are accessing services from your organization?

Question 10. Estimate the percentage of South Asian clients that are accessing services from your organization?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0-25%	7	36.8	36.8	36.8
	26-50	4	21.1	21.1	57.9
	76-100%	8	42.1	42.1	100.0
	Total	19	100.0	100.0	



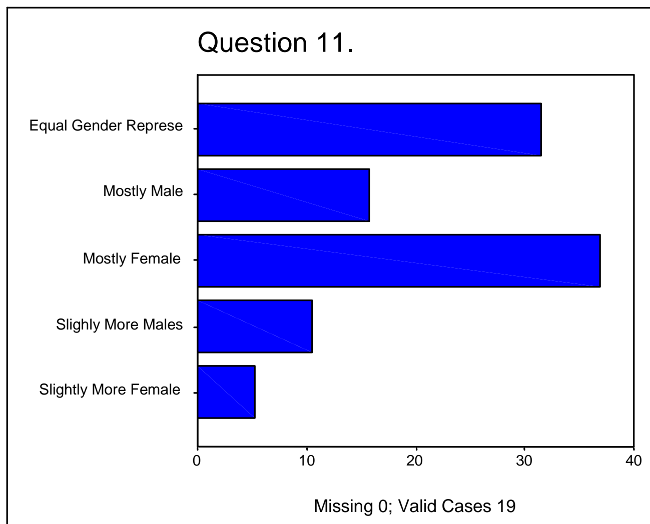
Question 10

Question 10 was asked in order to ascertain the number of South Asian clients that service providers have contact with. Given the nature of the study the importance of this question is self evident. 42.1% of service providers estimated that 76%-100% of clients accessing services were South Asian. 36.8% estimated this number at 0%-25%. 21.1% estimated that South Asians made up 26%-50% of their clients. The significance of this question is that more that 50% of service providers clients base is at least 50% South Asian. Making effective service provision to the South Asian community, a mandatory measure of the efficiency of their overall efficacy.

11. With respect to gender of your South Asian clients which of the following best describes those who access service from your organization?

Question 11. With respect to gender of your South Asian, clients which of the following best describes those who access services from your organization?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Equal Gender Representation	6	31.6	31.6	31.6
	Mostly Male	3	15.8	15.8	47.4
	Mostly Female	7	36.8	36.8	84.2
	Slighly More Males	2	10.5	10.5	94.7
	Slightly More Females	1	5.3	5.3	100.0
	Total	19	100.0	100.0	



Statistics

Of the South Asian clients who access your service, which best describes their language skills?

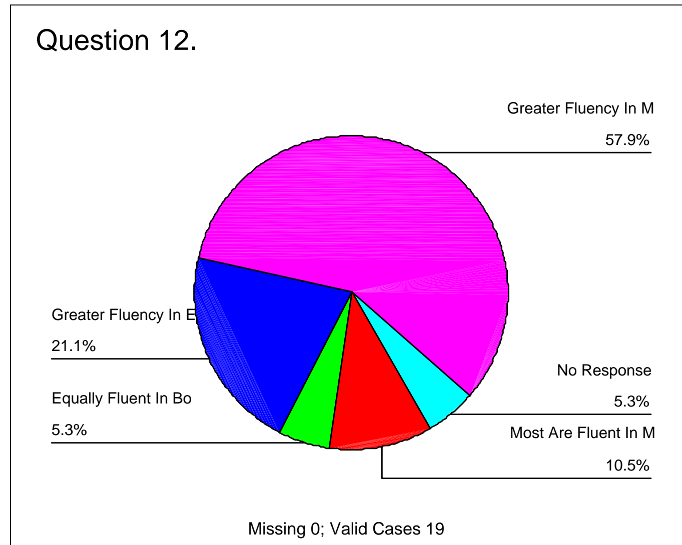
N	Valid	19
	Missing	0

This question was asked as a means of gaining attribute knowledge of South Asian clients accessing services. 36.8% identified that, of the South Asian clients accessing services, it is mostly female. 31.6% said there is an equal gender distribution. 15.8% stated that they saw mostly male South Asian clients. 10.5% stated they saw only slightly more men than women and 5.3% have slightly more female clients than men accessing their services.

12. Of the South Asian clients that access your service which best describes their language skills?

Question 12. Of the South Asian clients who access your service, which best describes their language skills?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Most Are Fluent In Mother Tongue Other Than English	2	10.5	10.5	10.5
	Equally Fluent In Both English And Mother Tongue	1	5.3	5.3	15.8
	Greater Fluency In English Than Mother Tongue	4	21.1	21.1	36.8
	Greater Fluency In Mother Tongue Than English	11	57.9	57.9	94.7
	No Response	1	5.3	5.3	100.0
	Total	19	100.0	100.0	



Statistics

Of the South Asian clients that access your service which best describes their level of education?

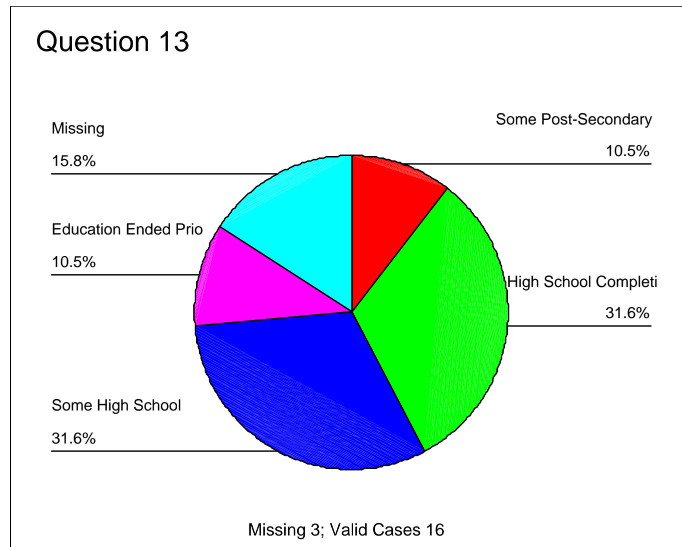
N	Valid	16
	Missing	3

Determining the language skills of the South Asian clients accessing service was an extremely important attribute to gain knowledge of. 57.9% identified that their clients have greater fluency in their mother tongue than in English. The significance is that given that more than 50% of service providers have a South Asian clients base of greater than 50%, language appropriate services is a must.

13. Of the South Asian clients that access your service which best describes their level of education?

Question 13. Of the South Asian clients who access your service, which best describes their level of education?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Some Post-Secondary or Completion	2	10.5	12.5	12.5
	High School Completion	6	31.6	37.5	50.0
	Some High School	6	31.6	37.5	87.5
	Education Ended Prior To High School	2	10.5	12.5	100.0
	Total	16	84.2	100.0	
Missing	System	3	15.8		
Total		19	100.0		



Statistics

Please estrimate the percentage of South Asian clients whom you have provided HIV/AIDS support/information to?

N	Valid	18
	Missing	1

Determining

An important attribute to be knowledgeable of is the level of education of the clients accessing service. This helps gauge their comprehension level and the level of comprehension of needed services and resources. 31.6% identified their clients as having some high school education, and 31.6% identified that their clients had completed high school. 15.8% did not respond to this question. 10.5% stated their clients had some post-secondary education and 10.5% stated that their client’s educations had ended prior to high school. This indicates that more than 60% of South Asian clients have a high school education or less. It should also be noted that many of the clients probably completed their education in their home country. This level of comprehension coupled with language skills demands language and culturally appropriate services and resources be provided to the South Asian community.

14. Of the South Asian clients who access your service, which best describes their length of Canadian residency?

Category label	Code	Count	Pct of Responses	Pct of Cases
New Immigrants (0-5 yrs.)	1	13	41.9	76.5
Resided In Canada (6-10 yrs.)	2	10	32.3	58.8
Resided In Canada (10-20+ yrs.)	3	3	9.7	17.6
Born In Canada	4	5	16.1	29.4
	Total responses	31	100.0	182.4

2 missing cases; 17 valid cases

This question was asked to determine the length of Canadian residency of South Asian clients. 76.5% of responses indicated clients who are new immigrants and 58.8% of responses also indicated clients have resided in Canada 6-10yrs. (Given that many of the clients are new to the country having come from a country such as India which faces and AIDS empidemic similar to Africa's.)

15. Please identify the South Asian communities that your organization has provided service to?

Category label	Code	Count	Pct of Responses	Pct of Cases
Punjabi	1	18	21.2	94.7
Hindi	2	17	20.0	89.5
Urdu	3	15	17.6	78.9
Tamil	4	9	10.6	47.4
Gujarati	5	11	12.9	57.9
Arabic	6	9	10.6	47.4
Other	7	6	7.1	31.6
	Total responses	85	100.0	447.4

0 missing cases; 19 valid cases

This question was asked to see which specific South Asian communities were accessing services. 94.7% of services are provided to South Asian clients who are Punjabi speaking, 89.5% to Hindi speaking, 78.9% to an Urdu speaking, 57.9% to Gujarati speaking, 47.4% to both Tamil and Arabic and 31.6% of services are provided to other South Asian speaking populations. This question easily indicates which languages would be best to provide resources in to be most effective within the South Asian population.

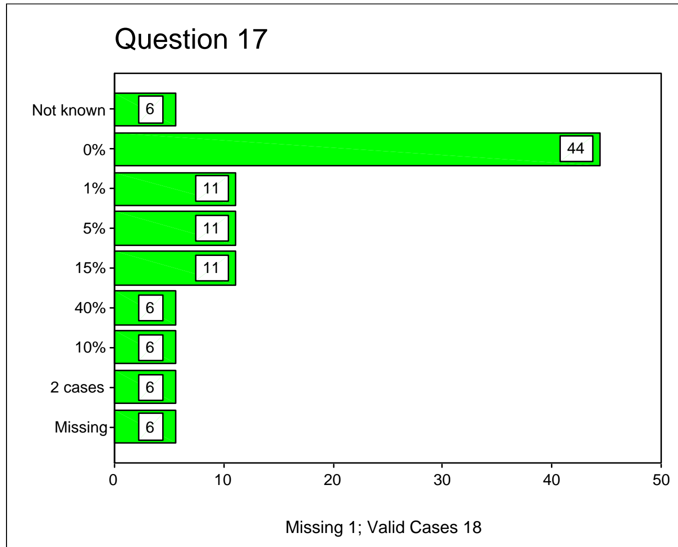
16. Please identify the South Asian religious communities your organization has provided service to?

Category label	Code	Count	Pct of Responses	Pct of Cases
Hindu	1	16	25.4	84.2
Sikh	2	15	23.8	78.9
Muslim	3	15	23.8	78.9
Christian	4	14	22.2	73.7
Other	5	3	4.8	15.8
	Total responses	63	100.0	331.6

0 missing cases; 19 valid cases

This question was asked in order to know which religious groups were accessing services. 84.2% of those surveyed provide services to South Asians belonging to the Hindu religious faith. 78.9% of service providers provide service to South Asian who are of the Sikh and Muslim religious faiths. While 73.7% provide service to South Asians who are Christian and 15.8% of service is provided to those who belong to other religious faiths. What is interesting to note is that in the previous question 94.7% of responses indicated having Punjabi speaking clients. Within South Asian communities, religion and language are closely connected. Responses to this question should have shown the Sikh religious group at a similar percentage. This question highlights a lack of understanding of the South Asian community on the part of service providers.

17. Please estimate the percentage of South Asian clients whom you have provided HIV/AIDS support/information to?



This question was asked to determine the number of South Asian clients service providers had given HIV/AIDS support or information directly to. 44% of respondents had not provided any such service to any of their South Asian clients. 11% identified they had provided support or information to 1% of their South Asian clients.

Another 11% of respondents indicated providing service to 5% of their clients. Another 11% of respondents had provided service to 15% of their South Asian clients. 6% said that information was not known, 6% identified providing service to 10% and another 6% had only had two cases where they had provided service to South Asian clients. For such a sensitive issue as HIV/AIDS, any number of accessed services is significant especially when compared to the high number of overall South Asian clients whom service providers deliver services to.

Please estrimate the percentage of South Asian clients whom you have provided HIV/AIDS support/information to?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not known	1	5.3	5.6	5.6
	0%	8	42.1	44.4	50.0
	1%	2	10.5	11.1	61.1
	5%	2	10.5	11.1	72.2
	15%	2	10.5	11.1	83.3
	40%	1	5.3	5.6	88.9
	10%	1	5.3	5.6	94.4
	2 cases	1	5.3	5.6	100.0
	Total	18	94.7	100.0	
Missing	System	1	5.3		
Total		19	100.0		

Statistics

Which best describes the HIV serostatus of your South Asian clients?

N	Valid	17
	Missing	2

18. Which best describes the sexual orientation of the South Asian clients whom your organization provides service to?

Category label	Code	Count	Pct of Responses	Pct of Cases
Heterosexual	1	10	47.6	52.6
Bisexual	3	1	4.8	5.3
All sexual orientations	4	5	23.8	26.3
Information is not known about the individual	5	5	23.8	26.3
Total responses		21	100.0	110.5

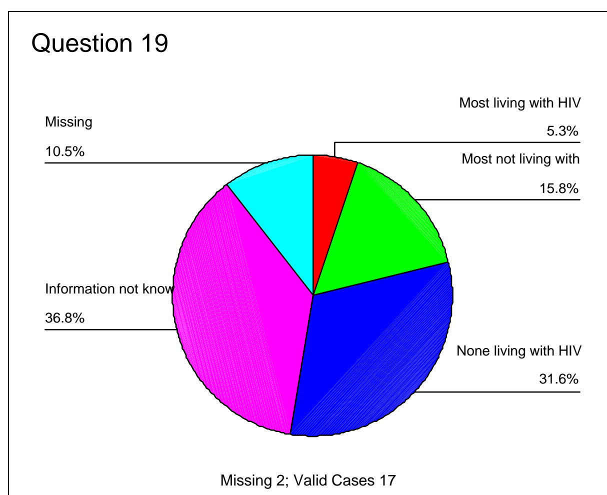
0 missing cases; 19 valid cases

Knowing the sexual orientation of clients accessing services was important, with respect to what segments of the population are accessing service. 52.6% of responses indicate service provision to heterosexual clients, 26.3% to all sexual orientations or the information is not known about the clients service is provided to. Lastly, 5.3% provided services to South Asian clients who are bisexual.

19. Which best describes the HIV serostatus of your South Asian clients?

Question 19. Which best describes the HIV serostatus of your South Asian clients?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Most living with HIV	1	5.3	5.9	5.9
	Most not living with HIV	3	15.8	17.6	23.5
	None living with HIV	6	31.6	35.3	58.8
	Information not known	7	36.8	41.2	100.0
	Total	17	89.5	100.0	
Missing	System	2	10.5		
Total		19	100.0		



The serostatus refers to the viral load status or lack there of, of an individual. 31.6% of respondents had no clients living with HIV/AIDS (having 0% viral load). 15.8% said most of their South Asian clients were not living with HIV/AIDS, suggesting that a small portion of their clients are infected or suspected of infection. 10.5% of respondents had no response and 5.3% said most were living with HIV/AIDS. The last response clearly comes from the service providers providing direct HIV/AIDS services.

20. Of your South Asian clients with HIV/AIDS what was their mode of transmission?

Category label	Code	Count	Pct of Responses	Pct of Cases
Male to female	1	2	8.3	10.5
Female to male	2	1	4.2	5.3
Male to male	3	2	8.3	10.5
Mother to child (utero/birthing)	8	2	8.3	10.5
Mother to child (breastfeeding)	9	1	4.2	5.3
No response	12	16	66.7	84.2
	Total responses	24	100.0	126.3

0 missing cases; 19 valid cases

While many of the respondents had not had South Asian clients who were HIV/AIDS infected as indicated by the 84.2% who gave no response, it was important to note the modes of transmission for those with infected clients. 10.5% gave responses of male-to-female transmission, male-to-male transmission, mother-to-child (utero/birthing), and 5.3% gave responses of female-to-male and mother-to-child (breastfeeding). While the case numbers were low, many of the transmission modes indicate a responsibility for the male partner. Another significant note is the transmission of HIV/AIDS from mother-to-child. This could still be linked to the actions of the male partner. But mother-to-child transmission is of significance because of the ability to request HIV/AIDS testing during pregnancy. This could indicate a lack of awareness on the mother's part of medical professionals making pregnant clients aware of the availability of testing during pregnancy.

21. What are the most significant barriers to your organization delivering effective service in its HIV/AIDS related capacity to its South Asian clients?

Category label	Code	Count	Pct of Responses	Pct of Cases
Funding	1	8	23.5	50.0
Knowledge and awareness of community need	2	6	17.6	37.5
Outreach to the community	3	5	14.7	31.3
Language and culturally appropriate resources	4	9	26.5	56.3
No response	6	3	8.8	18.8
Length of time	7	1	2.9	6.3
Skills required for clinical intervention	8	1	2.9	6.3
networking with applied skilled mainstream	9	1	2.9	6.3
	Total responses	34	100.0	212.5

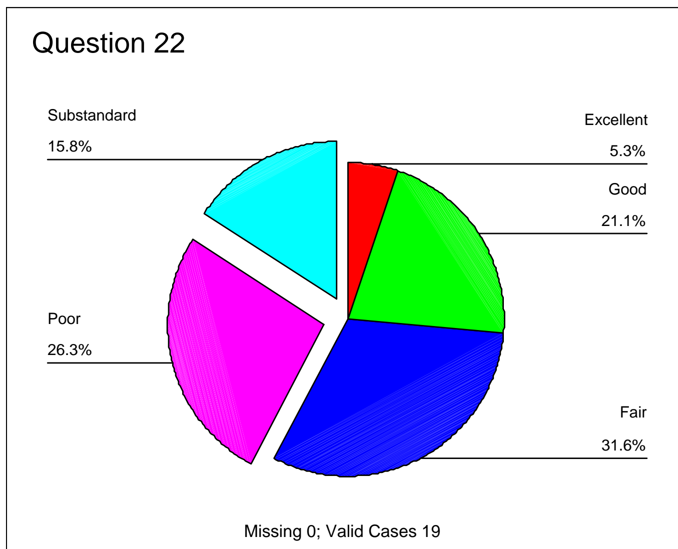
3 missing cases; 16 valid cases

This question was asked both to determine the needs of service providers in providing effective service delivery to the South Asian community. Answers are significant because they suggest gaps in services available to the South Asian community around HIV/AIDS. 56.3% of the responses noted a need for language and culturally appropriate resources, 50% indicated a need for funding, 37.5% noted knowledge and awareness of community needs as a barrier, 31.3% indicated outreach to the community as a barrier, 18.8% had no response, and 6.3% require greater time with clients, and increased skills for clinical intervention and networking with mainstream organizations. Many of the barriers to services that were noted indicated difficulties in mainstream service providers' connection and understanding of the South Asian community.

22. Please estimate the level of support you feel is available to the South Asian community around HIV/AIDS?

Question 22. Please estimate the level of support you feel is available to the South Asian community around HIV/AIDS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Excellent	1	5.3	5.3	5.3
	Good	4	21.1	21.1	26.3
	Fair	6	31.6	31.6	57.9
	Poor	5	26.3	26.3	84.2
	Substandard	3	15.8	15.8	100.0
	Total	19	100.0	100.0	



Statistics

Please estimate the level of support you feel is available to the South Asian community around HIV/AIDS?

N	Valid	19
	Missing	0

This question was asked of service providers to ascertain the level of support that they feel is available to the South Asian community around HIV/AIDS. 31.6% stated support was fair, 26.3% deemed support to be poor, 21.1% stated support was good, 15.8% deemed support available as substandard and 5.3% deemed services as excellent. However, while the most respondents indicated support to be poor, when grouped together, more than half of the respondents deemed services to be fair or better. This response does not seem in keeping with future questions highlighting significant needs of the South Asian community with respect to HIV/AIDS. The previous question gave significant note to the many barriers service providers face in delivering service to the South Asian community, specifically, in their abilities to connect or understand the South Asian community.

23. HIV prevention and care services are often aimed at specifically identified groups. Which best describes the South Asian clients whom your organization provides these services to?

Category label	Code	Count	Pct of Responses	Pct of Cases
Substance users (not addicts or abusers)	1	2	7.7	15.4
Substance abusers and addicts	2	2	7.7	15.4
Men who have sex with men	3	3	11.5	23.1
Sexually active heterosexuals	4	6	23.1	46.2
Youth under 18 yrs	5	5	19.2	38.5
Commercial sex workers	7	1	3.8	7.7
Injection drug users	8	1	3.8	7.7
New immigrants	9	6	23.1	46.2
	Total responses	26	100.0	200.0

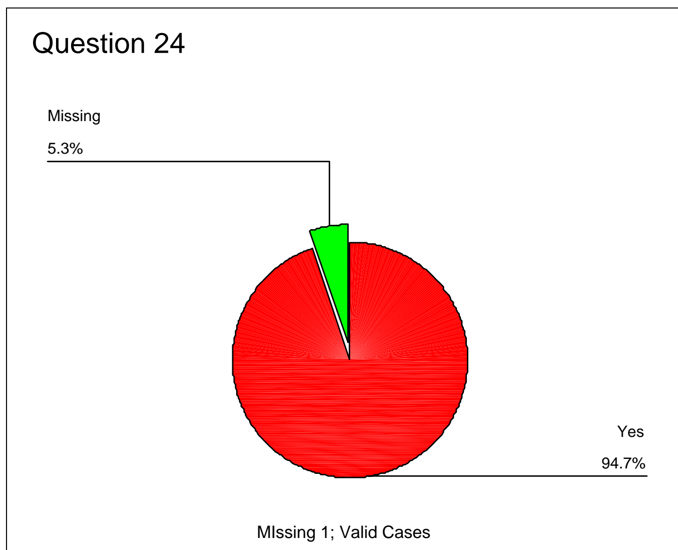
6 missing cases; 13 valid cases

This question was asked in order to determine who in the South Asian community services are being aimed at and, to some extent, which groups within the South Asian population are accessing services around HIV/AIDS. 46.2% identified aiming service to sexually active heterosexuals, 38.5% identified youth under the age of 18 years, 23.1% of services are aimed at men who have sex with men, 15.4% to substance users and abusers and 7.7% identified services aimed at injection drug users and commercial sex workers.

24. Do you think that people who have or are suspected of having HIV or AIDS within the South Asian community are stigmatized?

Question 24. Do you think that people who have or are suspected of having HIV or AIDS within the South Asian community are stigmatized?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	18	94.7	100.0	100.0
Missing	System	1	5.3		
Total		19	100.0		



Statistics

Do you think that people who have or are suspected oh having HIV or AIDS within the South Asian community are stigmatized?

N	Valid	18
	Missing	1

An outstanding 94.7% of respondents answered yes, that persons infected or suspected of having HIV/AIDS are subject to stigmatization within the South Asian community. While this answer was anticipated, it is significant due to the overall implications it has leaves for stigmatization within the South Asian community, suggesting that, despite the majority of the service providers delivering services related to HIV/AIDS awareness and prevention, their services are not being accessed or are ineffective.

25. Are there persons within the South Asian community who are likely to suffer stigma more? And why?

Category label	Code	Count	Pct of Responses	Pct of Cases
Males	1	1	1.9	5.6
Females	2	13	24.1	72.2
Children	3	3	5.6	16.7
Seniors	4	1	1.9	5.6
Singles	5	2	3.7	11.1
Married	6	4	7.4	22.2
Homosexuals or gay	7	14	25.9	77.8
Trans-gendered	8	12	22.2	66.7
All equal	9	1	1.9	5.6
Not accepted by culture - they deserve it	11	2	3.7	11.1
Not seen as normal	12	1	1.9	5.6
	Total responses	54	100.0	300.0

This question was asked to ascertain whether some populations within the South Asian community may suffer more stigma than another to gain any insights as to why it is believed that those groups would suffer more stigma. 77.8% of response indicated that homosexuals and Gay populations would suffer more stigma, 72.2% responses indicated that females would be subjected to greater stigma, 66.7% indicated that trans-gendered, 22.2% identified married individuals, 16.7% identified children, 11.1% indicated singles and that overall it is not accepted by the culture and those infected deserve it. 5.6% identified seniors, males, that all people are stigmatized equally and that anyone infected with HIV/AIDS is not seen as normal.

1 missing cases; 18 valid cases

26. What are common examples of stigma in the South Asian community?

Category label	Code	Count	Pct of Responses	Pct of Cases
Isolation	1	10	27.0	58.8
No support from family, friends or community	2	10	27.0	58.8
outsider exclusion	3	1	2.7	5.9
people are not knowledgeable	4	1	2.7	5.9
shame	5	1	2.7	5.9
substance abuse	6	1	2.7	5.9
women are the ones having premarital sex	7	1	2.7	5.9
fault of being female or gay	8	4	10.8	23.5
against religious values and religious values	9	3	8.1	17.6
gossip	10	2	5.4	11.8
lack of education	11	1	2.7	5.9
ostrasized - made a spectacle of	13	2	5.4	11.8
Total responses		37	100.0	217.6

Asking service providers to identify examples of stigma within the South Asian community was a necessary question as a follow-up to previous questions and to gain better insight about HIV/AIDS within the South Asian community. In their professional roles respondents are able to observe the community of their clients and be able to offer informed observations. This question also acts as a comparative tool to one asked in the community focus groups. 58.8% of the responses identified isolation and no support from family, friends or community. 23.5% of respondents perceived that a commonly held stigma in the community was that "it is the individuals fault for being Gay". 17.6% of respondents identified that the community would deem it to be against religious values. Other examples of stigma noted were; 11.8% stated gossip and being ostracized (or made a spectacle of), 5.9% identified exclusion, people are not knowledgeable, unclear, shame, substance abuse, stigma as a result of lack of education and that some in the community place the blame on females for having premarital sex. Many of the examples of stigma indicated show a strong need within the community. Some examples of stigma are issues that have long since been tackled within the mainstream, yet remain pervasive in the South Asian community due to unsuccessful measures or no initiatives having been attempted.

2 missing cases; 17 valid cases

27. What are possible activities or interventions useful in stopping the stigmatization of people with HIV/AIDS in the South Asian community?

Category label	Code	Count	Pct of Responses	Pct of Cases
Awareness	1	11	28.2	68.8
Education	2	13	33.3	81.3
Prevention	3	3	7.7	18.8
Developing resources	4	1	2.6	6.3
know the facts - transmission	5	2	5.1	12.5
Greater recognition by community of chan??	6	1	2.6	6.3
Personal health	7	1	2.6	6.3
Open dialogue	8	1	2.6	6.3
Outreach	9	2	5.1	12.5
Truth	10	1	2.6	6.3
It's your fault if you have it	11	1	2.6	6.3
Increase community comfort level	12	1	2.6	6.3
Support groups	13	1	2.6	6.3
Total responses		39	100.0	243.8

3 missing cases; 16 valid cases

This was a vital question to ask service providers as all of them have valued skill in the area of activities and interventions useful in gainful measures for communities. Several methods were recommended. 81.3% of responses were in favour of education, 68.8% identified awareness, 18.8% of responses were in favour of prevention, 12.5% identified knowing the facts about transmission and outreach. 6.3% of responses identified the following; developing resources, greater recognition by community of change, personal health, open dialogue, truth, increased community comfort level with support groups and eliminating "its your fault if you have it" thought processes.

28. What do you feel are the most important factors around HIV/AIDS that the South Asian community is in need of?

Category label	Code	Count	Pct of Responses	Pct of Cases
Prevention/Awareness education	1	18	19.4	94.7
Testing/diagnosis	2	11	11.8	57.9
Language/culturally appropriate services	3	15	16.1	78.9
Drug and substance use education	4	13	14.0	68.4
Counselling support	5	13	14.0	68.4
Information referral	6	8	8.6	42.1
Peer support	7	12	12.9	63.2
Other	8	1	1.1	5.3
Sex education	9	1	1.1	5.3
Develop resources	10	1	1.1	5.3
	Total responses	93	100.0	489.5

0 missing cases; 19 valid cases

This question was asked in order to gather from service providers a prioritization or list of important factors around HIV/AIDS that the South Asian community is in need of. The answers hold a great deal of significance, given that respondents are already in the business of providing service delivery to the South Asian community and can clearly identify perceived gaps. Respondents identified multiple factors; 94.7% identified a need for prevention, 78.9% identified a need for language and culturally appropriate services and resources, 68.4% identified drug and substance use, 63.2% identified peer support, 57.9% identified testing and diagnosis and 5.3% identified sex education, the development of resources and other factors. The identified needs by service providers rank current service provision as being anything more than sub standard.

SUMMARY FINDINGS – HEALTHCARE PROVIDERS SURVEY

29. 44.4% of services provided are medical, 22.2% of services are provided to youth, with 11.1% of services being provided to men, women, parenting, prevention education and confidential support.

30. 88.9% of service providers provide service within the Region of Peel with 27.8% of services also being provided to Toronto and the GTA.

31. 44.5% of service providers of service providers roles are medical, 33.5% of the roles are frontline and 27.9% hold supervisory roles.

32. 38.9% of services delivered are medical, 33.6% of services provided are community awareness, education and outreach. 33.4% of services delivered are to youth.

33. 77.7% of service providers said, “yes”, they provide support of information about HIV/AIDS. 26.3% said “no”.

34. 27.8.% of services providers provide both HIV prevention and awareness, 22.2% provide only HIV awareness, 16.7% of services provided are HIV prevention/awareness/ care or no response, 11.1% provide only HIV prevention or an issue other than a HIV/AIDS topic is their focus.

35. 68.4% said, “yes”, they have personally provided support or information. 31.6% said “no”.

36. An overwhelming 62.5% of service providers are involved in awareness/ advocacy/outreach/prevention and educational support. 43.8% offer information/referral services, 37.5% offer counseling support, 31.3% offer testing/diagnosis, 18.8% offer medical care and 6.3% offer immigration/housing support or offer something other than the stated choices.

37. 44.4% of service providers deemed that they offer HIV services around testing/diagnosis, 27.8% offer HIV-related services around substance abuse and treatment education and 50% of service providers offer HIV-related services around prevention education

38. 42.1% of service providers estimated that 76%-100% of clients accessing services were South Asian. 36.8% estimated this number at 0%-25%. 21.1% estimated that South Asians made up 26%-50% of their clients

39. 36.8% identified that, of the South Asian clients accessing services, it is mostly females. 31.6% said there is an equal gender distribution. 15.8% stated that they saw mostly male South Asian clients. 10.5% stated they saw only slightly more men than women and 5.3% stated they have slightly more female clients than men accessing their services.

40. Service providers perceived that 57.9% of their South Asian clients have greater fluency in mother tongue than English; 21.1% have a greater fluency in English than in their mother tongue; 10.5% are fluent in mother tongue, 5.3% are equally fluent in mother tongue and English, and 5.3% had no response to this question.

41. When asked to describe the educational level of their South Asian clients, 31.6% identified their clients as having some high school education and 31.6% identified that their clients had completed high school. 15.8% did not respond to this question. 10.5% stated their clients had some post secondary education and 10.5% stated that their clients' educations had ended prior to high school.

42. 76.5 % of respondents identified providing services to South Asian clients who are new immigrants (in Canada 0-5yrs). 58.8% identified providing service to South Asian clients who have resided in Canada 6-10yrs. 29.4% identified clients that were born in Canada and 17.6% were identified as having been in Canada 10-20+yrs.

43. 94.7% of service providers provide services to South Asian clients who are Punjabi speaking, 89.5% to Hindi speaking, 78.9% to an Urdu speaking, 57.9% to Gujarati speaking, 47.4% to both Tamil and Arabic and 31.6% of service is provided to other South Asian speaking populations.

44. 84.2% of those surveyed provide services to South Asians belonging to the Hindu religious faith. 78.9% of service providers provide service to South Asian who are of the Sikh and Muslim religious faiths. While 73.7% provide service to South Asians who are Christian and 15.8% of service is provided to those who belong to other religious faiths.

45. When estimating the percentage of their South Asian clients for whom they had provided HIV/AIDS support or information, 44% of services providers identified they had provided service to 0% of their South Asian clients. 11% identified only 1%, 11% identified 5% and 11% identified having provided HIV/AIDS support of information to 15% of their South Asian clients. 6% said this information was not known, 6% had no response, 6% had only 2 cases, 6% identified 10% and another 6% identified 40% of their clients had been provided with HIV/AIDS support or information.

46. With regards to the sexuality of their South Asian clients, service providers deemed 52.6% to be heterosexual, 26.3% declared this information was not known about the clients they see or that they see South Asian clients of all sexual orientations. 5.3% deemed that they see bisexual clients.

47. When describing the serostatus of their South Asian clients, 36.8% said that information was not known, 31.6% had no clients living with HIV/AIDS, 15.8% said most were not living with HIV/AIDS, 10.5% gave nor response and 5.3% said most were living with HIV/AIDS.

48. 84.2% of those surveyed had no response as to modes of HIV transmission for their South Asian clients. Of those who were aware of their clients' mode of transmission, 10.5% indicated transmission mode as one of the following; male to female, male to male and mother to child (utero/birthing). 5.3% identified known modes of transmission as female-to-male and mother-to-child (breastfeeding).

49. Services providers identified the following as barriers to their effective delivery of HIV/AIDS to the South Asian community; 56.3% identified the lack of language and culturally appropriate resources, 50% identified the lack of funding, 35.7% identified the lack of knowledge of community needs, 31.3% identified the lack of outreach to the community, 18.8% had no response, 6.3% identified length of time and skills required for clinical intervention and networking with mainstream organizations.

50. Service providers ranked the level of support available to the South Asian community as follows; 31.6% deemed it to be fair, 26.3% deemed it to be poor, 21.1% deemed it to be good, 15.8% deemed it substandard and 5.3% deemed services available as excellent.

51. Service providers identified their South Asian clients that access services around HIV/AIDS as 46.2% sexually active heterosexuals and new immigrants, 38.5% were identified as providing services to youth under 18 years of age, 23.1% of service delivery goes to men who have sex with men, 15.4% of services being delivered to substance users and substance addicts. 7.7% of identified service delivery goes to injection drug users and commercial sex workers.

52. 94.7% of respondents said that individuals who have or are suspected of having HIV/AIDS within the South Asian community are stigmatized. 5.3% had no response to this question.

53. Respondents identified persons within the South Asian community who would suffer more stigma as the following; 77.8% identified homosexuals or Gays, 72.2% identified females, 66.7% identified trans-gendered, 22.2% identified married individuals, 16.7% identified children, 11.1% identified singles and that overall, it is not accepted by the culture. The perception is that those infected deserve it, 5.6% identified seniors, males, that all people are stigmatized equally and that anyone infected with HIV/AIDS is not seen as normal.

54. Services providers perceived the following as common types of stigma suffered within the South Asian community; 58.8% identified no support from community, family or friends and isolation, 23.5% identified that a common stigma held was that it is the individual's fault as a female, or for being gay, 17.6% identified that the community would deem it against religious values, 11.8% identified gossip and being ostracized (made a spectacle of), 5.9% identified exclusion, people are not knowledgeable, shame , substance abuse, lack of education and that some in the community blame females for having premarital sex.

55. Service providers identified methods of intervention to stop stigmatization of HIV/AIDS with the South Asian community as follows; 81.3% identified education, 68.8% identified awareness, 18.8% identified prevention, 12.5% identified knowing the facts about transmission and outreach, 6.3% identified, developing resources, greater recognition by community of change, personal health, open dialogue, truth, increasing community comfort level through support groups and eliminate " its your fault if you have it" thought processes.

56. Service providers identified important factors around HIV/AIDS that the South Asian Community is in need of as follows; 94.7% identified prevention, 78.9% identified language and culturally appropriate services and resources, 68.4% identified drug and substance use education and counseling support, 63.2% identified peer support, 57.9% identified testing and diagnosis, 5.3% identified sex education, development of resources and other factors.

RECOMMENDATIONS – HEALTHCARE PROVIDERS' SURVEY

1. Undertake research to explore the specific needs of HIV/AIDS within the South Asian community.

2. Develop specific educational programs related to understanding HIV/AIDS and HIV/AIDS within the South Asian community for the South Asian community.

3. Develop community-wide awareness programs on HIV/AIDS and HIV/AIDS-related concerns.

4. Develop language and culturally-appropriate resources to be used for both awareness and outreach to the South Asian community.

5. Develop outreach campaigns for the South Asian community related to HIV/AIDS that address cultural factors and commonly held myths and stigmas.

6. Develop culturally sensitivity workshops for service providers of HIV/AIDS specifically and other related services.

APPENDICES

1. SUMMARY OF APPROACH TO HIV/AIDS RESEARCH PROJECT

1. Social Policy Context of Project		**2. Purpose of Project**
• Healthy Communities • Building Community Capacity • Building Social Capital • Valuing Diversity (Equity, access, etc.)		• To develop individual, family and community's capacity to understand, acknowledge and address the challenges associated with HIV/AIDS Issues in the Punjabi community.

3. Project objectives

- To identify the challenges associated with HIV/AIDS in the Punjabi community.
- To build linkages with internal and external stakeholders to identify, acknowledge and address the issues of HIV/AIDS.
- To identify how the complex problems of HIV/AIDS can be dealt within the Punjabi community at the individual, familial and community level.

4. Approaches to developing asset inventory	**5. Research questions**	**6. Research Methodology**
• Link the collection of data on HIV/AIDS issues and Aspirations identified by the respondents. (This gives the Research personal and social meaning for the community). • Do an analysis of the implications of the research for program planning, activities etc. • Identify how the community can participate in the program planning and delivery of services.	a. How is HIV/AIDS defined in the Punjabi community? b. What are the challenges and complexities of HIV/AIDS in the community? c. How do respondents think these concerns should be addressed? d. How would respondents like to contribute to addressing these concerns? e. Which health promotion strategies will be effective in the Punjabi community?	**A. Data Collection*** (i) Quantitative research • 45 questionnaires to be filled (ii) Qualitative research • Focus groups (iii) Literature review • From previous survey/reports internet **B. Data Analysis** **C. Report Writing (**Formal) • Report for the Punjabi Community Health Centre • Presentation package on findings & recommendations • Summary of findings & recommendations for distribution to the community • Community forum to release findings • Publish findings in academic journals

* Data collection methods will be discussed in detail at the meeting.

Note: Definition (Elder Abuse):
"The product of the interplay among the social, health, economic and environmental conditions which affect human and social development." (Source: The Quality of Life in Ontario - Spring 1999, Ontario)

Participatory Action Research (PAR)

Participatory Action Research[3] engages practitioners, researchers and citizens in a collaborative process to meet the specific needs of the community (Israel *et al.*, 1994). Participatory research[4] originated from community development and determines the process whereby people are engaged in creating knowledge for themselves and they, in turn, take actions on the findings (The Royal Society of Canada, 1995).

In less developed countries, PAR was as a method to engage the masses in community development work (Brown and tendon, 1983). The following characteristics form the basis of PAR (adapted from Israel et al., 1994 & The Royal Society of Canada, 1995):

- The issues are identified by the citizens and not by the health care professionals.
- The collaborative process forces cooperation and collaboration between practitioners (community developers), researchers and citizens.
- Citizens have wisdom[5] (A Community Development Strategy for the Health Department, Region of Peel, 1989) to understand and assess their needs which can be incorporated by researchers in order to obtain valid and reliable results.
- This process ensures that citizens have control over the final outcome of the study. The decisions regarding research are made collectively by the research team which has representation from the citizens. Through this process the citizens get empowered and develop leadership in order to take actions on identified needs.

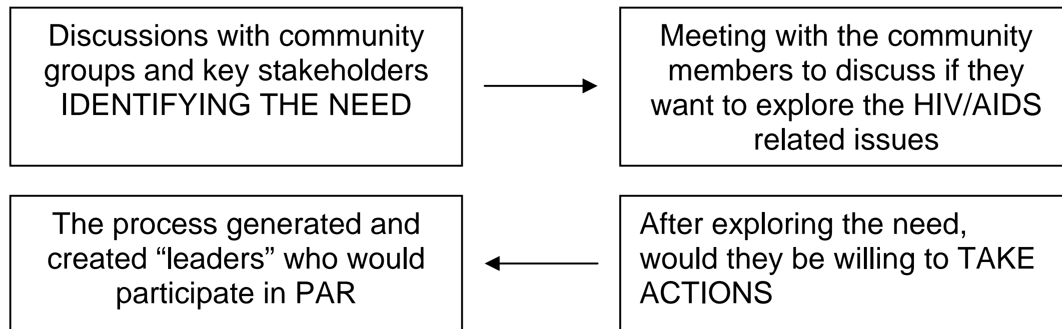
The process used in this research report has already generated interest amongst seniors to address their identified needs. They have organized themselves into a seniors' group. They have named their group as the SAHARA[6] Seniors Group. They are meeting on a weekly basis and are working on a wall hanging[7] that would depict various forms of senior abuse.

---

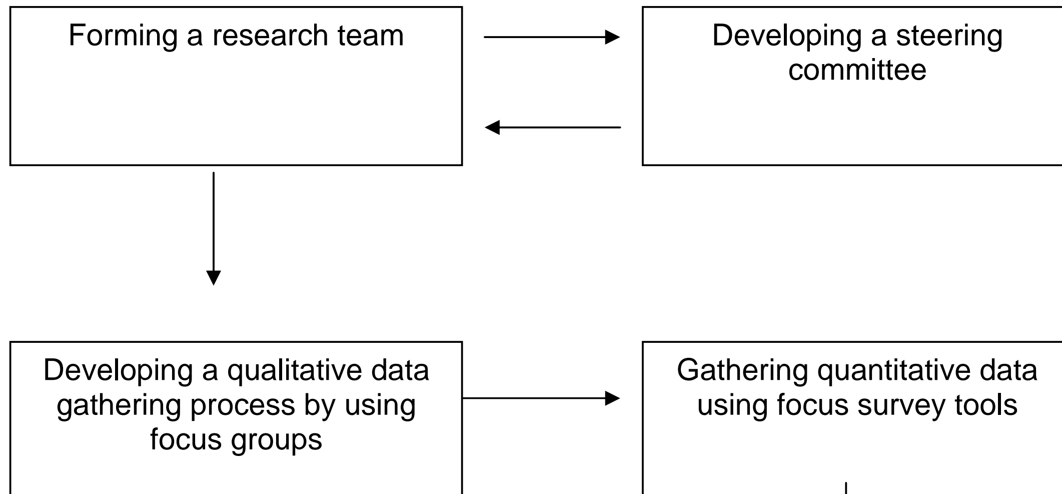
[3] Israel, B.A., Checkoway, B., Schulz, A. & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. Health Education Quarterly, 21(2), 149-170.
[4] The Royal Society of Canada (1995). Study of Participatory research in Health Promotion, University of British Columbia, Institute of Health Promotion Research.
[5] Commissioner and Medical Officer of Health, A Community Development Strategy for the Health Department, Region of Peel, January 1989
[6] SAHARA in Punjabi language means " to support".
[7] Wall Hanging is an arts and crafts activity that the SAHARA Senior's Group is undertaking which will be displayed at the PCHC's office to raise awareness of senior abuse within the community.

The process could be summarized as follows:

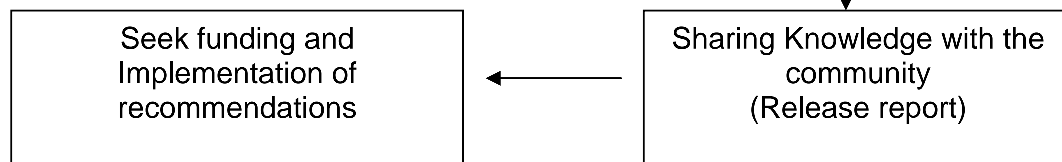
Pre-Research Work:



Research Work:



Post Research Work:



HIV/AIDS Questionnaire

1. What service does your organization provide to the community?

2. What areas does your organization provide service to?
   Peel |__| Toronto |__| GTA |__| Other |__|

3. What is your role at this organization?

4. In this role, what are your key responsibilities?

5. Does your organization provide support/information about HIV/AIDS?
   Yes |__| No |__|

6. Which of the following would best describe the primary focus of your HIV/AIDS related organization?
   |__| HIV Prevention
   |__| HIV Awareness
   |__| HIV Care
   |__| Both Prevention & Awareness
   |__| All Three
   |__| An Issue Other than HIV/AIDS Is Our Primary Focus
   |__| No Response

7. In your current capacity have you had to provide HIV/AIDS support/information?
   Yes |__| No |__|

8. If Yes, what kind of support/information have your provided?
   |__| Awareness/Advocacy/Outreach/Prevention Education
   |__| Counseling/Support
   |__| Information/Referral
   |__| Testing/Diagnosis
   |__| Medical Care
   |__| Home/Hospital Care
   |__| Peer Support
   |__| Other

9. In your current capacity which of the following areas best describes your particular HIV/AIDS related specialty?

|__| Substance Abuse
|__| Treatment Education
|__| Case Management
|__| Peer Counseling
|__| Prevention Education
|__| Testing/Diagnosis
|__| Advocacy
|__| Nutrition
|__| Support Counseling
|__| Research
|__| Clinical Trials
|__| Medical Care
|__| Other
|__| No Response

10. Estimate the percentage of South Asian clients that are accessing services from your organization?

11. With respect to gender of your South Asian clients, which of the following best describes those who access service from your organization?

|__| Equal Gender Representation
|__| Mostly Male
|__| Mostly Female
|__| Mostly Trans-gendered
|__| Slightly More Males
|__| Slightly More Females
|__| No Response

12. Of the South Asian clients that access your service, which best describes their language skills?

|__| Most Are Fluent In English
|__| Most Are Fluent In Mother Tongue (other than English)
|__| Equally Fluent In Both English and Mother Tongue
|__| Greater Fluency In English than Mother Tongue
|__| Greater Fluency In Mother Tongue than English
|__| No Response

13. Of the South Asian clients that access your service which best describes their level of education?

|__| Some Post Secondary or Completion
|__| High School Completion
|__| Some High School
|__| Education Ended Prior to High School

14. Of the South Asian Clients that access your service which best describes their length of Canadian residency?

|__| New Immigrants (0-5yrs)
|__| Resided In Canada(6-10yrs)
|__| Resided In Canada (10-20+yrs)
|__| Born In Canada

15. Please Identify the South Asian communities that your organization has provided service to?

|__| Punjabi
|__| Hindi
|__| Urdu
|__| Tamil
|__| Gujarati
|__| Arabic
|__| Other

16. Please Identify the South Asian religious communities your organization has provided service to?

|__| Hindu
|__| Sikh
|__| Muslim
|__| Christian
|__| Other

17. Please estimate the percentage of South Asian clients whom you have provided HIV/AIDS support/information to?

18. Which best describes the sexual orientation of the South Asian clients that your organization provides service to?

|__| Heterosexual
|__| Homosexual or Gay
|__| Bisexual
|__| All Sexual Orientations
|__| Information Is Not Known About the Individuals I Work With

19. Which best describes the HIV serostatus of your South Asian clients?

|__| Most Living With HIV
|__| Most Not Living With HIV
|__| None Living With HIV
|__| Information Not known

20. Of your South Asian clients with HIV/AIDS what was their mode of transmission?

|__| Male To Female
|__| Female To Male
|__| Male To Male
|__| Female To Female
|__| Injection Drug Use
|__| Needle Use
|__| Blood Transfusion
|__| Mother to Child (utero/birthing)
|__| Mother To Child (breastfeeding)
|__| Other
|__| Information Not Known
|__| No Response

21. What are the most significant barriers to your organization delivering effective service in its HIV/AIDS-related capacity to its South Asian clients?

|__| Funding
|__| Knowledge And Awareness Of Community Needs And Issues
|__| Outreach To The Community
|__| Language And Culturally Appropriate Resources
|__| Other
|__| No Response

22. Please estimate the level of support you feel is available to the South Asian community around HIV/AIDS?

Excellent Good Fair Poor Substandard

23. HIV prevention and care services are often aimed to specifically identified groups. Which best describes the South Asian clients whom your organization provides these services to?

|__| Substance Users(not addicts or abusers)
|__| Substance Abusers or Addicts
|__| Men Who Have Sex With Men
|__| Sexually Active Heterosexuals
|__| Youth Under 18yrs
|__| Homeless or At Risk For homelessness
|__| Commercial Sex Workers
|__| Injection Drug Users
|__| New immigrants

24. Do you think that people who have or are suspected of having HIV or AIDS within the South Asian community are stigmatized?

Yes |__| No |__|

25. Are there persons within the South Asian community who are likely to suffer stigma more? And Why?

|__| Males
|__| Females
|__| Children
|__| Seniors
|__| Singles
|__| Married
|__| Homosexual Or Gay
|__| Trans-gendered

26. What are common examples of stigma in the South Asian Community?

27. What are possible activities or interventions that would be useful in stopping the stigmatization of people with HIV/AIDS in the South Asian Community?

28. What do you feel are the most important factors around HIV/AIDS that the South Asian community is in need of?

|__| Prevention /Awareness Education
|__| Testing/Diagnosis
|__| Language/Culturally Appropriate Services and Resources
|__| Drug And Substance Use Education
|__| Counseling Support
|__| Information Referral
|__| Peer Support
|__| Other

Focus Group Questions

1. When you hear HIV/AIDS, what comes to your mind?

Probes: Use silence to extract information -
Disease that affects specific communities
Deadly Disease
Celebrities that have died from the disease

2. Is this a problem within the South Asian Community in Canada?

Probes: Use silence to extract information -
How many people do you think are infected by it?
Any person that you know is affected or infected by it…

3. Is this a problem for community in India?

Probes: Use silence to extract information -
Have you read or heard about it?
Mumbai
Kerala
Punjab
Truck drivers
prostitutes

4. Who gets affected by HIV/AIDS?

Probes: Use silence to extract information – Let the focus group participants give you an answer.

5. How do people get infected with HIV/AIDS?

Probes: Use silence to extract information -
Exchange of needles
Blood transfusion
Unprotected sex
Mother to Child

6. **How do people protect themselves from getting HIV/AIDS?**

Probes: Use silence to extract information – Let the focus group participants give you an answer.

7. **Do you feel that you are able to talk to a health care provider (doctor, social workers etc.) about HIV/AIDS?**

Probes: Use silence to extract information –

7. **What problems would a person face if he/she suffered from HIV/AIDS?**

Probes: Use silence to extract information -

8. **What can be done to assist/provide treatment to that person?**

Probes: Use silence to extract information -

9. **This is a deadly disease, in your opinion, what would be effective ways to do outreach?**

Probes: Use silence to extract information -

10. **What would you like to see PCHC do to address this issue?**

Probes: Use silence to extract information –

Flyers
Videos
Brochures
TV messages

11. Would you like to share any other suggestion related to the HIV/AIDS topic?

Probes: Use silence to extract information –

Building Social Capital in the Punjabi Community
HIV/AIDS Research Project

CONSENT FORM

Greetings and Welcome!

The Punjabi community Health Centre is a non-profit community based social service organization whose main mission is to deliver culturally appropriate social work intervention in the Punjabi community. PCHC strongly believes in partnerships with other mainstream and ethno-specific organizations. PCHC has partnerships with Victim Services of Peel, Coalition of Agencies Serving South Asians, COSTI, Women Abuse Council of Metro Toronto, William Osler Hospital, Can-Sikh Cultural Centre, and Sikh Heritage Centre.

Punjabi Community Health Centre also runs the following Core Programs:

- SAHARA Men's group is operated from two locations (Brampton and Mississauga). This is a culturally appropriate group program designed to meet the needs of Punjabi men in the areas of addiction and anger management.
- SAHARA Women's group is operated from Brampton. This is a culturally appropriate group program designed to meet the needs of Punjabi women. The group program deals with the after care needs of abused women and children.
- SAHARA Senior's group addresses the needs of the seniors and currently operates on one day per week basis.
- Parenting sessions are organized in collaboration with the Mississauga Gurdwara, Peel District School Board and other religious institutions.
- PCHC provides individual, family, couples, and group counselling programs.
- PCHC provides a food bank which addresses the needs of the abused women. Our volunteers drop off the food to the abused women.

Punjabi Community Health Centre has received four years funding from the Ontario Trillium Foundation to Build Social Capital in the Punjabi Community. One of the objectives of this four-year project is to undertake research in the Punjabi community to explore the challenges associated with the HIV/AIDS. After the conclusion of the research phase, the project will continue to work with the community to address the identified challenges.

The research team is seeking your cooperation to participate in the focus groups and to complete individual questionnaires. Your knowledge, expertise, and beliefs will help us in identifying the challenges associated with HIV/AIDS related issues within the Punjabi community. Your participation in the focus groups will require a commitment of two hours. However, the individual questionnaires could be filled within one hour. If you need more information on any of the questions, please do not hesitate to ask me.

YOUR NAME WILL NOT APPEAR IN THE FINAL REPORT. INFORMATION PROVIDED BY YOU WILL BE KEPT CONFIDENTIAL. YOU DO NOT HAVE TO PROVIDE AN ANSWER TO ANY QUESTION YOU ARE UNCOMFORATBLE ANSWERING.

Thank you for completing this questionnaire. The Punjabi Community Health Centre will release its findings to the community by organizing a public forum. All participants are welcome to attend the community forum. Thank you!

Building Social Capital in the Punjabi Community

HIV/AIDS Research Project

CONTACT INFORMATION

Please contact any of the following persons if you have any questions about the project, the survey questionnaire, the interviews conducted, etc.

Amandeep Kaur
Program Manager
P.O. Box 38670,
Brampton West Postal Outlet,
Brampton, ON, L6Y 4W5
Phone: (905) 301-2978 Fax: (905) 457-3902
Email: aman13@rogers.com
WWW.pchealthcentre.com

Yadevinder Mutta
Project Coordinator
P.O. Box 38670,
Brampton West Postal Outlet,
Brampton, ON, L6Y 4W5
Phone: (905) 301-2978 Fax: (905) 457-3902
Email: bmutta@rogers.com
WWW.pchealthcentre.com

BUILDING SOCIAL CAPITAL IN THE PUNJABI COMMUNITY

HIV/AIDS RESEARCH PROJECT

STATEMENT TO TREAT INFORMATION COLLECTED FROM PARTICIPANTS

AS CONFIDENTIAL INFORMATION

Name of Interviewer: ______________________________________

The interviewer understands and promises to abide by the following terms and conditions:

1. The interviewer will not personally use or disclose the information collected from the persons interviewed to anyone.

2. The interviewer will keep the questionnaires completed in a physically secure location and give them to the Coordinator of the Punjabi Community Health Centre as directed during the training session for interviewers.

2. The interviewer will return all completed and non-completed survey questionnaires to the Coordinator of the Punjabi Community Health Centre at the end of the interviewing period.

3. The interviewer will not contact any individual to whom the personal information collected, relates, directly or indirectly, without the prior written consent of the person who provided the information and the Coordinator of the Punjabi Community Health Centre.

4. The Coordinator of the Punjabi Community Health Centre will ensure that no personal information provided by the persons interviewed will be used or disclosed in a form in which the individual to whom it relates can be identified, without the prior written consent of the said individual and the Coordinator of the Punjabi Community Health Centre.

Signature of Interviewer: _________________________________ **Date:**

Signature of the Coordinator :_____________________________ **Date:**

Punjabi Community Health Centre