



Key to Women's Health

**A Health Promotion Framework to
Prevent Stroke Among Marginalized Women**

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1. At a Glance

"Life is bigger than stroke."

"Marginalized Women, Inclusion, and Stroke" is a unique project, designed to create a new health promotion framework for preventing stroke among women. It used a methodology called Inclusion Research, which involves marginalized women in all facets of designing and implementing the research, to identify their health needs and make policies, programs and services more accessible and responsive.

The project brought together key partners in the fields of women's health, health promotion, community-based research and public health to conduct Inclusion Research in three locations in Ontario.

This new approach to research and policy development is geared to reach populations that face challenges in relation to the determinants of health, including income, employment, education, gender, culture, language, and social supports, among others. The approach creates circles of investigation, uniting researchers from the populations under study, working with professionals, to create new policy approaches to difficult problems.

Inclusion Researchers (IRs) were at the centre of this project.

After a literature search, a line of questioning was developed for the IRs to use in focus groups, with participants who represented the diverse cultures, languages, housing situations, and experiences of Ontarians.



We explored how urban, suburban and rural women (1) construct health, (2) weigh inclusion in service delivery, (3) understand the risks, symptoms and signs of stroke, and (4) prefer to learn what they need to know about preventing stroke.

The analysis of the data from the focus groups indicated that women:

- construct health in a broad and comprehensive way, with a clear understanding of the determinants of health;
- highly value inclusion;
- knew little about the risks, signs and symptoms of stroke; and
- prefer learning in an intimate group setting, especially circles of sharing and learning, with their peers.

A new health promotion framework emerged through an engaging participatory process, led by one of Canada's leading health promotion advocates. The strategy involves a targeted awareness campaign, with an emphasis on all of the elements of health; an innovative outreach strategy using lay health educators to lead circles of learning and action; and advocacy for change.

The Ontario Women's Health Network (OWHN) congratulates the focus group participants, IRs, Site Coordinators and Local Advisory Committees at the three sites, along with the Provincial Working Group for creating an atmosphere of inclusion that made this process so engaging and important for all.

For this project, we listened to the voices of women and you will hear those voices, noted in italics, throughout this report.



2. What We Were Looking For

"Every person helping each other in the community... is like having walking community centres."



According to the Heart and Stroke Foundation of Canada, almost 60% of the 50,000 strokes in Canada each year involve women. This number is even higher if you consider that stroke not only impacts women as victims, but also as caregivers of loved ones who experience stroke. However, many people, including healthcare professionals, do not know that:

- Women are at risk for stroke;
- Women's symptoms can be different than the "traditional" symptoms that are reported by men;
- There are risk factors for stroke specific to women, such as the use of oral contraceptives; increased risk of stroke during pregnancy, childbirth and menopause; and, according to the Women's Health Initiative, increased risk related to high levels of stress and depression; and
- A greater percentage of women than men die as a result of stroke.

We wanted to know whether women who face challenges - by virtue of their culture, language, poverty, living in remote areas, lack of education, lack of support, or other factors - knew about and understood the risks, signs and symptoms of stroke. And, most importantly, what is the best way to reach women with information they can understand and use in their lives?

We also established three long-term goals, which would flow from the project:

1. To increase the access to health promotion/stroke prevention services for vulnerable populations;
2. To increase the integration of stroke prevention initiatives with other work related to chronic diseases, risk conditions and relevant public policy initiatives at local, regional and provincial levels; and
3. To increase the availability, uptake and sustainability of initiatives that have proven to be effective for the prevention of stroke.



3. The Feeling and Reality of Belonging

"I have been in clinics, to the Health Bus, and I felt I belonged."



This project builds on two previous inclusion initiatives:

Count Me In! was a year-long effort of the Ontario Prevention Clearinghouse, funded by Health Canada and the Laidlaw Foundation, to build a useful, Canadian definition of inclusion and establish a way to use the definition as the key to new health promotion strategies for marginalized populations. (www.count-me-in.ca)

Count Us In! Inclusion and Homeless Women in Downtown East Toronto applied that health promotion strategy in a unique way and pioneered a method, called Inclusion Research, for investigating the health issues of marginalized populations. (www.own.on.ca)

The definition of inclusion used by both projects is:

A society where everyone belongs creates both the feeling and reality of belonging and helps each of us reach our potential.

The feeling of belonging comes through caring, cooperation, and trust. The feeling flows from attitudes, beliefs, and behaviors. We build the feeling of belonging together and for each other.

The reality of belonging comes through equity and fairness, social and economic justice, and cultural as well as spiritual respect. The reality flows from missions, mandates, policies, and programs. We build the reality of belonging by engaging our society to ensure it.

(Michael Fay, Count Me In, Ontario Prevention Clearinghouse, 2005).

4. How We Set Up the Project

"It's easier for us to come to groups like this one (even once a month) to gain health information."



The project is a collaboration of a number of project partners and working groups. The people in these groups bring a range of expertise and reflect the racial and cultural diversity of the province.

Primary Partners. OWHN managed and coordinated the project. The primary partners came together, combining their best practices and resources, to create the methodology.

- OWHN has a solid record of listening to women through innovative focus group strategies and of communicating the results through multiple channels.
- Ontario Prevention Clearinghouse (OPC), one of the premier health promotion agencies in Ontario, has focused on inclusion and health promotion strategies to reach vulnerable populations.
- The Asset Mapping Research Project (AMRP) of the Toronto Christian Resource Centre (CRC) has been an innovator in Inclusion Research strategies, involving homeless people, shelter residents and others who are marginally housed and using drop-in services, in planning, designing and implementing grassroots research projects.
- Toronto Public Health (TPH), a leader in health promotion among marginalized populations, provided guidance, support and facilities throughout the project.

Provincial Working Group. This group was set up to (1) connect with important and diverse agencies and networks working in the field of stroke and chronic disease prevention, and (2) help ensure the successful application of Inclusion Research.

The members were expected to meet at least one of the following criteria:

- Represent a provincial organization
- Have expertise in chronic disease (such as stroke and cancer) prevention
- Have experience with Inclusion Research projects
- Be willing to commit substantial time to ensure the quality and integrity of the project, and translate research to action, making a positive difference in the lives of women
- Have direct experience as a marginalized woman
- Contribute to the gender, race and class equity of the Group

Project Sites and Agencies. The Provincial Working Group selected the three sites where the Inclusion Research would be carried out. They selected the sites to represent the urban, suburban and rural settings of Ontario, as well as the cultural, linguistic and socio-economic diversity of the province. A key organization was identified in each of the locations and contracted to conduct the research in their area, under the guidance of the Provincial Working Group and with the assistance of Local Advisory Committees. The three sites and contracted agencies included:

- **Sudbury** - The Sudbury Women's Centre conducted focus groups with the diverse women from this northern city and the adjacent rural area.
- **Peel** - Region of Peel, Public Health Department and India Rainbow Community Services of Peel focused on the needs of South Asian immigrant women.
- **Downtown East Toronto** - The Asset Mapping Research Project, of the Toronto Christian Resource Centre, focused on homeless and underhoused women.

Local Advisory Committees. These groups were formed at each site to (1) give advice and ensure that the project addressed the needs and interests of women who face challenges in relation to the determinants of health; (2) give feedback and guidance on the material collected in the literature review and from the focus groups; and (3) help develop recommendations for the health promotion framework, based on the research findings.

The members selected met at least one of the following criteria:

- Contribute to the cross-sectoral representation of the determinants of health of each Committee
- Have expertise in stroke and chronic disease prevention
- Contribute to the gender, race and/or class equity of the Committee
- Bring expertise and experience with influencing change

IRs play crucial and continuing roles in each of the Local Advisory Committees.

5. Our Way of Working

"We learn from experience. Sometimes we ourselves suffer and learn."



The primary partners in the project became pioneers in Inclusion Research with Count Us In!, a project funded by the Wellesley Institute in 2005. The Count Us In! Working Group enshrined a set of key objectives grounded in feminist, inclusion, equity and community development principles. Inclusion Research must:

- be community defined and driven;
- value participants as stakeholders whose experiences count;
- lead to community empowerment through meaningful engagement with the project;
- eliminate barriers and enable equitable access to resources and opportunities;
- be sustainable;
- meet challenges with creative solutions;
- build individual potential and local self-reliance; and
- provide economic opportunities for participants.

The possibility of power differences within and among the groups in the project was managed with constant care. The voice of everyone who was involved with the project, provincially and locally, was respected, honored and valued.

A by-product of our way of working is the sound of women's voices. Every process and aspect of the project - the research method, line of questioning, focus group strategy, analysis of data, and development of the health promotion framework - was collaborative, participatory and, consequently, close to the feelings and realities of women who face challenges in relation to the determinants of health in Ontario.

6. Searching the Literature

"...there is a commonality of women taking power of their health concerns, and want to take the power of their health concerns."



The primary partners in this project, keying in on notions that characterize feminist and participatory research, are developing the new field of Inclusion Research to investigate the feelings and realities of women who face challenges in relation to the determinants of health.

The literature search turned up useful information about feminist research, participatory research and the determinants of health, but very few examples of tying the three together.

The search turned up a vast array of information about the risks, signs and symptoms of stroke, but very little about how that information is transferred to women, especially women who face challenges in relation to the determinants of health. They may have significant challenges involving culture, language and literacy, combined with a lack of access to the dominant modes of information transfer, such as daily newspapers, magazines, cable and satellite television.

The search also determined that there are no statistics available on women who face challenges in relation to the determinants of health and stroke, as socio-economic status is not included in any of the information gathered on stroke or cardiovascular patients in Ontario. This presents an important gap in the reporting system.

When Barbara Miles, the Consultant conducting the literature search, interviewed stroke managers, hospital workers and program assistants who serve stroke patients, it became apparent that women who face challenges in relation to the determinants of health often do not survive a stroke. Although they are never turned away from treatment centres because of their circumstances, if they do not have the family support system to ensure their rehabilitation, they inevitably suffer from further disability and subsequent strokes.

7. Line of Questioning

*"There are many things we want to talk about.
We could have more discussions like this."*



A line of questioning was drafted by Fay & Associates, examined by the Provincial Working Group, the Site Coordinators and the IRs, and tested by small groups at the three sites. Background guides and resource materials for the IRs to use in the focus groups supplemented the final line of questioning. It is important to note that there were great challenges in finding appropriate, understandable and reliable resource materials about stroke for the IRs to hand out to the focus groups.

There were four sets of questions, representing the important elements of the investigation:

- A. How do focus group participants construct the concept of health?**
 - 1. What do you think leads to good health?
 - 2. What do you think leads to bad health?
 - 3. How did you learn about what leads to good and bad health?

- B. How do participants weigh the importance of inclusive strategies in services?**
 - 4. Have you, as an individual, ever felt welcomed - like you fit in and felt comfortable and belonged - when you used a program or service, such as a clinic, hospital or community health centre? What specifically made you feel that way? The people? The place? Anything else?
 - 5. Have you ever felt unwelcome - like you didn't fit in or didn't belong - when you used a program or service? What were some of the difficulties you experienced? The people? The place? Anything else?
 - 6. How should programs or services use your experiences of belonging or not belonging to improve what they do?

- C. What do participants know about stroke, including risks, symptoms and signs?**
7. What do you think a stroke is?
 8. What do you think increases a woman's risk for stroke?
 9. What might increase the risk of stroke for women who are isolated or on the edge?
 10. How would you know if you or someone else was having a stroke?
 11. What are the symptoms of stroke that are unique for women?
 12. What might prevent women who are isolated or on the edge from
 - (a) recognizing the signs and symptoms of stroke;
 - (b) communicating about stroke; or
 - (c) being heard about the signs and symptoms of stroke?
- D. What is the best way to reach women who experience or face challenges in relation to the determinants of health with information they can understand and act on?**
13. What programs or services give you information about the risks and symptoms of stroke that you understand and can act on? Is there anything special that women may need in programs?
 14. What is the best way to reach women with information about stroke that they will understand and act on?
 15. Is this the best way to reach women who are on the edge or isolated? Can you suggest other ways to reach women to help them understand and act on the risks and symptoms of stroke?

Because of the multilingual, multicultural and socio-economic diversity of the participants, it was challenging to find language that all of the participants would understand. A striking example was the word "marginal." After great debate, final wording was settled upon: "marginal" was replaced by "isolated or on the edge." However, this wording caused challenges at the sites. OWHN will pursue additional research to define and describe marginalization that results from language and cultural barriers.



8. The Focus Groups

"After waiting for three to four hours, the doctor sees you. They make us remove our clothes and sit for so long in that state. (teen char ghante wait karane ke baad doctor hamein dekhta hai. Voh humare kapde nikalwa dete hain aur humein usi haal mein baithna padta hai.)"



IRs conducted ten focus groups at the three sites, with a total of seventy participants.

The focus group participants were recruited by using outreach strategies among cooperating agencies identified by the site agencies and the IRs. The sites recruited a diverse group of women for the focus groups, based on their understanding of the local demographics.

Sudbury. IRs conducted three focus groups, involving 22 participants at three very different sites in Sudbury and the surrounding area.

- **Downtown.** The participants at this focus group were women who use the services of the Sudbury Women's Centre and related agencies in the centre of the city.
- **Valley East.** This focus group was held with women who live farther away from the centre of the city.
- **Lively.** This focus group was held in the town of Lively, Ontario, 22 kilometers from the city, with some representation from the surrounding rural area, including Whitefish, Naughton and Worthington. Many of the participants in this group mentioned the difficulty in attending groups of this sort because of a lack of transportation and childcare.

Peel. IRs conducted three focus groups, with a total of 25 participants. The participants included recent immigrants and refugees from South Asia, including Pakistan, India, Bangladesh and Sri Lanka. The sessions were conducted in English, Hindi, Punjabi, Urdu and Tamil, with simultaneous translation of questions and answers and multi-lingual recording. The sessions were held in the Board Room of India Rainbow Community Services of Peel.

- English, Hindi and Punjabi (one session)
- English, Hindi and Urdu (one session)
- English and Tamil (one session)

Downtown East Toronto. IRs conducted four focus groups, involving 23 participants who are homeless or underhoused. The IRs at this site had experience conducting Inclusion Research, as they had led the research for the Count Us In! project and were intensely involved in selecting locations and doing outreach. Agencies that serve marginally housed women in Downtown East Toronto, including the Fred Victor Centre, Toronto Christian Resource Centre, Council Fire and Toronto Community Housing, recruited the participants and hosted the focus groups.

9. The Voices

"We can involve the government to find ways to change things when we voice our opinions."



The data were rich, the voices strong. And there were some surprises.

It was not a shock that the women who participated in the focus groups faced challenges, based on lack of access to the determinants of health, specifically health services, education, employment, income and social support, compounded by language, cultural, socio-economic and geographical barriers. The participants knew little about the risks, signs and symptoms of stroke. In fact, participants clearly stated that some of the ways information about stroke is presented creates additional stress, compounded by an inability to discuss the issue in their family and cultural context.

The surprises revolved around the way the focus groups constructed health: a broad and comprehensive view that clearly valued emotional, spiritual, family, community and social factors as being essential to health. Participants expressed a strong preference for learning about the risks, signs and symptoms of stroke in intimate settings, small circles of sharing, learning and taking action on health issues, like stroke.



10. What Do the Voices Tell Us?

"Women need to come together to spread the message to prevent stroke."

Dr. Suzanne Jackson, Director of the Centre for Health Promotion at the University of Toronto, led a project team through a two-day process of analyzing the data. The team of thirty people included IRs and Site Coordinators from the three sites, members of the Provincial Working Group and Toronto Local Advisory Committee, OWHN staff, project consultants, and students working on the project. The group worked as a large team and in smaller teams in a disciplined process designed by Dr. Jackson.

Dr. Jackson led the group through the process: (a) discussing the feelings experienced by the IRs at each of the sites and highlights from the focus groups, (b) examining the data to discover and articulate themes, within the four larger clusters in the line of questioning, (c) finding specific quotes to illustrate the themes, (d) building the health promotion framework from the data and themes, and (e) developing recommendations for action. The process was supported by the quick turnaround of resource materials provided by OWHN, with the assistance of staff from the Ontario Chronic Disease Prevention Alliance.

Highlights from the Focus Groups

The results fell into five categories:

- Barriers and lack of access to healthcare, including:
 - › Lack of physicians, especially female physicians and physicians from diverse cultural backgrounds
 - › Long distances from facilities
 - › Challenges with emergency services, particularly when there is no access to a phone for help, and a \$60.00 fee for the service
 - › Absence of cultural and linguistic interpretation services
 - › Negative attitudes among healthcare providers based on stereotyping
 - › No health coverage for recent immigrants and refugees
 - › No child care or child minding

- Lack of access to the determinants of health, such as employment, income, education and social supports
- A strong sense of being "heard" for the first time, with the related need to bring the voices of women to the table
- A strong statement on the destructive role of stress in the lives of women, constantly challenged by economic and cultural barriers, as well as being confined, because of culture, within the family
- A clear belief that women with challenges would find the safety and security of peer-led groups an ideal place to learn and share about health issues in the very broad way they understand them.

Themes and Quotes from the Focus Groups

The small teams conducted a thematic analysis of the data from the focus groups, based on the four clusters of the line of questioning.

As a first step, the small teams reviewed the data for each question and developed a set of themes to encompass the data.

As a second step, the small teams identified quotes from the data to illustrate the themes, and organized those quotes according to the construct of health that emerged from the data.

In the following sections, the themes will be presented, with quotes from the focus groups to illustrate them.

11. What Is Health?



"Body, mind and spirit."

How do focus group participants construct the concept of health?

Themes:

The analysis team found a comprehensive and holistic concept of health in the data, involving the following eight elements that, according to the responses from the participants, make up health:

- Family health
- Physical health
- Emotional health
- Community health and education
- The health system
- Spiritual health
- Environmental health
- Financial health

The elements are distinct yet also interact with one another. The team saw these elements forming a circle around the individual, which took the form of a wheel with eight spokes. If any of the spokes were out of balance, the health of the person would be affected. The Key to Women's Health was to keep all eight elements in balance. This formulation became useful in analyzing all of the questions, with responses falling in one or another of the eight elements.

This formulation resembles the "wellness wheel" illustrated here by a graphic used by the University of South Africa for student counseling (with Family Health and the Health System in our analysis, occupied by Occupational Health and Intellectual Health in theirs):



The image of the wheel with eight spokes became important as the analysis progressed and also emerged in the discussion on the health promotion framework.

Quotes from the Focus Groups:

Q1. What do you think leads to good health?

The responses from the participants to this question were almost evenly balanced around the eight elements. Family Health and Financial Health were only mentioned in relation to "bad" health.

- Physical Health

"Prevention is better than cure."

"Sleep causes a lot of problems... need your sleep."

"Nutrition, exercise, walking, no smoking, sleeping, no drugs, healthy sleep habits, stress management."

- Emotional Health

"Be happy, take no tensions."

"A balance of downtime and worktime."

"Being in contact with people who don't corrupt your mind."

- Community and Social Health

"We need knowledge to access information."

"Modeling peers, parents, etc."

- Health System

"Yearly regular check-up."

"Family doctor."

"Proper medical attention."

- Spiritual Health

"Need to treat mind, body, soul."

"Spiritual."

"Going to church on Sunday, being active, volunteer with the community."

- Environmental Health

"Happy and clean environment."

"Healthy environment."

Q2. What do you think leads to bad health?

The responses to this question referred to all eight elements, except there was a disproportionately high number of responses related to Financial Health.

- Family Health

"We have parents and supporters in our country, but lack of moral support here. (humare desh mein maa baap aur support karne vale hote hain, yahan hume koi support nahin hai.)"

"Abusive home."

"More family time."

- Physical Health

"Junk food, we are taking the Canadian habit."

"Smoking, over-eating, substance abuse, drinking, not enough health, not enough sleep, worrying too much, abusing drugs, alcohol, bad drugs and needles, illegal drugs."

"Increased TV, computers, games."

- Emotional Health

"Immigrant stress, since coming to this country, immigrant stress that causes bad health."

"Too fast-paced society."

- Community Health and Education

"Huge factor is lack of education."

"Having abilities and not being able to use it, not only in Canada, but all over the world."

"I'm disabled. I use a scooter. I can't do much for myself. My husband helps but he is tired of doing it. The nurse comes twice a month, and I've asked for the nurse to come more frequently, but they only allow twice a month and this is no good for me."

- The Health System

"My high blood pressure was caused by stress but my doctor kept saying, "you are a drug addict," but this is a wrong diagnosis.

"They cut the money for special diet because the doctor didn't consider me as obese anymore."

"Male doctors don't take you seriously."

- Spiritual Health

"Future dreams - if not fulfilled."

"Love, lack of love."

- Environmental Health

"Pollution, drinking too much, too much junk food, bad diet, fast food can cause diabetes."

- Financial Health

"Lack of money and sometimes lack of information on what is good; we don't get enough money to live on. They cut the money."

"Not enough money. If you don't have the resources - money - you don't get enough to live on from social assistance. They cancelled the extra money for food [Special Diet Allowance]."

"They give medication if you pay first, so I can't get my prescriptions filled."

"High rent leads to stress and diseases."

Q3. How did you learn about what leads to good and bad health?

The responses for this question are presented according to the themes that were identified, rather than the eight elements of health, because the question was more specific to learning about good and bad health:

- Media

"Newspapers, internet, radio, TV."

"TV." (Mentioned frequently)

"Posters from advertising by Public Health."

- Family/friends

***"Parents are the ones who taught me about healthy habits."
(Mentioned frequently)***

"Modeling peer, family, friend, etc."

"Which I learned from my grandfather."

- Health System

"Doctor." (Mentioned frequently)

"The government has a lot to do with health because they regulate what drugs come into the country and which ones don't."

"Hospitals. _____ Hospital is a good place to get information."

- Community Health and Education

"Programs in the drop-ins like this one."

"Health sessions like this one - these kind of sessions."

"In my schooling I learned a lot about herbal medicine."

- Personal experience

"I forgot how fresh strawberry tasted until I had one and thought what a difference it was to a store bought one."

"It's hard when you don't have the money, to eat right and buy the right food to eat."

12. What Is the Importance of Inclusion?



"When they phone you to remind you of your appointments, it shows they care."

How did the participants weigh the importance of inclusive strategies in services?

Themes

When analyzing the participants' responses, the analysis team found that there were fewer responses about inclusion and far more about exclusion. The team created the following thematic clusters:

On inclusion:

- Women felt welcomed by hospitals, doctors, clinics and community services when they were greeted, recognized, got quick results and help with costs.
- There was some difficulty in finding examples of inclusive services.

On exclusion:

- Women felt excluded and/or unwelcome - like they didn't fit in or didn't belong - as a result of
 - › racial discrimination and racialism;
 - › language barriers;
 - › long wait times;
 - › healthcare providers making unfair assumptions about them; and
 - › lack of coverage for required health services, including ambulance, drugs and dental care.

On changes needed to increase inclusion:

- Doctors recommend and provide yearly check-up and check list.
- Transportation to travel to and from healthcare services is made available to all.
- Need access to nutritious food.
- Adequate funding for healthcare system (stop waste).
- Healthcare should be provided to people without ID.
- Need for more information.
- Need for more diverse doctors.
- Need to include patients in decision-making.
- Need to eliminate fees for healthcare services and prescriptions.

Quotes from the Focus Groups

Q4. Have you, as an individual, ever felt welcome and a sense of belonging when you used a program or service, at a clinic, hospital or community health centre? What specifically made you feel this way? The people? The place? Anything else?

The responses to this question focused on Community Health, as well as the Health System:

- Community Health and Education

"If we are interested to learn, they are happy about that and helping."

"The Community Care Access Centre helped me pay for medical equipment, [so the] cost was covered."

- The Health System

"I have been in clinics, to the Health Bus, and I felt I belonged."

"Non-profit organizations - Cancer Centre - pre-admit at the hospital gives you all the information, nurses treat you well, and there all the time. Crisis centre at hospital is very good."

"At my doctor's office, the doctor or nurse's attention, or someone else, makes you feel welcomed."

Q5. Have you ever felt unwelcome - like you didn't fit in or didn't belong - when you used a program or service? What were some of the difficulties you experienced? The people? The place? Anything else?

There were far more responses to this question, indicating that participants had more to say about exclusion than inclusion. The responses were imbalanced, with a heavy weighting on Emotional Health and the Health System, with the distinct themes in those elements:

- Emotional Health

Didn't feel welcome as patients

"I don't feel like I belong anywhere."

"Doctor's time is important but not patient's."

"Doctor gives you less than ten minutes of time, they don't listen, even before my mouth is open the pen is in his hand. (doctor hume das minute bhi nahin deta, vo suntan he nahin hai, humara muh khulta nahin hai ki haat mein pen taiyar raheta hai.)"

"Doctors pushing anti-depressants and sleeping pills, which becomes an addiction...especially for women."

"Things are better there now, but at _____, it used to be that I used to be sent all over the institution because they didn't know what department should deal with me, and I ended up having to research information about my own health to struggle to get myself well, which is hard and frustrating."

"I hate to go to a new doctor because I'm treated like a hypochondriac."

"Trust issues, don't know if your information will be held against you."

Unfair assumptions

"Doctor's attitude because of source of incomes."

"People feel out of place when they walk into a room full of people dressed well if they are not dressed well."

"They ask for your address and when you give it, they say: 'Oh that place?' Then you feel like you don't belong."

"Sometimes people living here ask, 'why did you come here?' We find it very difficult to find a job and survive. When they ask, we feel more depressed."

"Doctors think I only come to them to get drugs. I look fine on the outside but I'm falling apart on the inside."

"I don't feel comfortable within myself because I don't fit in."

"People put you in category, they judge you."

Racial discrimination

"Some teenager said to my mother-in-law when she was walking outside 'Why are you dressed like that? This is my country and you shouldn't dress like that in my country.'"

"They cannot accept that I have passed that stage because I was in jail and because I am Black, and they judge me and they don't give me a chance."

- The Health System

"Going in before surgery, I was treated like @\$%."

- Difficulties accessing emergency services

"I have panic attacks. [When] I go to the hospital, they don't take me in emergency. Finally when you get in, the Doctor is not there. They check me and only give me a sleeping pill."

"I was misdiagnosed three times before they found out what was wrong with me."

"I have gone through two doctors in a year. Both of them went down south where the money is."

"People know their body best and the doctor tells you it is nothing or that it is all in your head."

Poor accessibility of services

"They penalize for cancelled appointments."

"I went to the hospital, and wasn't served in French."

Long wait times

"After waiting for three to four hours, the doctor sees you. They make us remove our clothes and sit for so long in that state."

"We have to wait for 3 months for health card, for any health problem then it is very difficult."

- Financial Health

"Medically free, but what about prescriptions?"

Q6. How should programs or services use your experiences of belonging or not belonging to improve what they do?

The responses were imbalanced, with an emphasis on Emotional Health, Community & Social Health, the Health System and Financial Health:

- Emotional Health

"Treat individuals as a person not a number."

"Not leaving all the decisions of a person's well-being up to big-wigs. We should have a say in the decision process."

- Community Health and Education

"There are children's programs here (at this community centre), but people in agencies don't know about it, but I do. So now I tell more people about this, they need to tell us these things at the airport(when we immigrate)..."

- The Health System

"Hire more doctors or allow foreign trained doctors to practice."

"Proper funding and usage - better doctor training - nurse presence when doctor examines - public housing improvements."

"People don't have proof of ID like OHIP cards; some people lose their wallet when they are on the street."

- Spiritual Health

"Considering different types of religions."

- Financial Health

"Bus tickets are costly, for only one stop we have to pay \$2.50 (up to \$2.75 now)."

"Government can eat hundred dollar plates of food and eat out often with caviar and travel all over the world while we eat spaghetti and beans and outdated canned goods."

"Fruits and vegetables are not provided in food banks. Only canned foods, which have high sodium level, which is bad for the heart."

"Food banks should not give bad stuff to poor people which are not wanted by other people and is not good for health. One is forced to ask what is the motive behind donating that kind of food. Need to donate good food."

"Why is there taxes on medicine? It is a daily use thing. If you are in pain, you don't need food, you need medicine."

13. What Do We Know About the Risks, Symptoms and Signs of Stroke?



"I want to know if heart attack is the same as a stroke."

What do the participants know about stroke, including risks, symptoms, and signs, especially for women who experience or face challenges in relation to the determinants of health?

Themes

The analysis team decided that the responses to questions about the definition, risks, symptoms and signs of stroke revealed four levels of knowledge among the women: (a) some women knew about stroke, (b) some women knew about women and stroke, (c) some women knew nothing about stroke, and (d) some women had been misinformed. As most participants knew little about stroke or had been misinformed, the majority of the data fell into categories (c) and (d).

When looking at participants' responses to the question "What do you think a stroke is?," the team identified the following themes, listed in the order of the number of responses:

- Symptoms (some correct, some were not)
- Medical definitions
- Causes of stroke
- Reflections of absence of knowledge

The team identified the following themes when analyzing the participants' knowledge about risks for stroke for women, listed in the order of the number of responses.

- Family and home life stresses
- Social issues
- Improper diet, lack of exercise and weight gain
- Mental health issues
- Poor physical health

- Smoking, drugs, birth control and alcohol
- Fixed factors (demographics)
- Financial problems
- Clinical services
- Environment
- Illiteracy
- Lack of knowledge

The team identified these additional themes about the risks for stroke for women who face challenges in relation to the determinants of health, listed in the order of the number of responses:

- Isolation
- Lack of income
- Exclusion
- Language barriers
- Trauma
- Lack of jobs
- Fears
- Other problems

The team identified these themes that may prevent women from recognizing, communicating and being heard about the signs and symptoms of stroke, listed in order of the number of responses:

- Lack of knowledge
- Women's role in family
- Impact of women's role in family
- Impact of isolation
- No access to information or means to access it
- Impact of culture
- Language barrier
- Difficulty with question
- Fear
- Drugs and alcohol
- Lack of income
- Embarrassment
- Illiteracy

Quotes from the Focus Groups

Q7. What do you think a stroke is?

When responding to this question, women emphasized Physical Health, but also spoke about how one's Emotional Health is connected to stroke:

- Physical Health

"An interruption in the electrical activity in the brain caused by a lack of oxygen."

"Two kinds of stroke: heart stroke and brain stroke, because of blood circulation."

"When the brain is lacking oxygen and part of it dies."

"If you don't pick up your socks, you can have a stroke."

- Emotional Health

"Being isolated - you can't express your feelings or even know where to get help and information."

- Financial Health

"Husband don't have job, and he sits at home, the whole family can get a stroke (laughter)."

Q8. What do you think increases a woman's risk for stroke?

The participants' responses emphasized Family Health, Emotional Health and Financial Health, indicating that from their point of view, risks for stroke involve far more than just a person's Physical Health.

- Family Health

"Women are ignored in childhood...and when we do for our self we feel guilty."

"Women don't have time because they take care of others - kids, parents, spouse, pets, etc."

"Kids demand more from parents, this causes stress."

"Too much work, they [women] do more work than men. Men go to work, come home and put their feet up, but women work around the clock. Woman's work is never done. (Bahut zayda kaam, mardon se zayda kaam karti hain. Aadmi kaam par jata hai, ghar aata hai aur pair upar karke baith jaata hai, par aurat saara din kaam karti hai, aurat ka kaam kabhi khatam nahin hota.)"

- Physical Health

"Birth control, smoking - if both, the risk of stroke is higher; high blood pressure; if have diabetes, excessive weight."

- Emotional Health

"Culture problems, your sound environment is broken, no family supports, no job..."

"There should be something to help you when you are alone and have a stroke."

"Women are known to put themselves last."

"We sit outside at nights until very late so as not to be alone in the apartment."

"Stress, smoking, drinking, husband, stressful situations within the family."

"Anxiety, loneliness, depression, isolation, no friends, no supports, self talk."

"Lack of sharing, discussion with husband, handling the problems alone looks like end of the road and life."

"As women we often self-diagnose our pain and brush it off as nothing...oh its just a headache!"

"What's the use of seeing a doctor? He'll just tell me it's all in my head."

- Financial Health

"Lack of money."

"Not taking proper diet, irregular unbalanced diet."

"Lack of medication and proper care. Sometimes they can't afford to buy the necessities because they have no money."

Q9. What might increase the risk of stroke for women who are isolated or on the edge?

Most of the responses emphasized Financial Health and Emotional Health, indicating the destructive effect of stress in the lives of the participants.

The analysis team thought it was important to raise the issue of power and control on this question. For example, for many women, a lack of childcare is a large reason why they can't access employment/jobs, which leads to poor health and higher risk of stroke. It was noted that both the IRs and focus group participants could participate in the project because childcare was provided at the sites.

- Emotional Health

"Language problem - no one to share; keep themselves isolated."

"Fragmented communities result in women being isolated in remote areas without access to services."

"Isolation leads to no confidence - leads to depression."

"You can be in a crowd of people and still feel lonely and isolated, and this is stressful."

- Community Health and Education

"Treated like educated slave."

"Education is not recognized, you can't support yourself."

"Having mental issues...Lack of access to care when it is needed and understanding."

"School 15 minutes walk, no transport, has to carry infants and walk..."

- The Health System

"Women in outlying communities have to book handi-transit two weeks in advance, but should a doctor cancel the appointment, he does it the day before and I still have to pay."

"We can involve the government to find ways to change things when we voice our opinions."

- Financial Health

"Can't make emergency calls due to communications barriers like not having a phone."

"Money problem, men spend the money...and not giving money for family expenses."

"Living in fear due to lack of money and support. We live in fear...(Dar mein jeete hain paise aur support ke bina...)"

"Hand to mouth."

"Lack of income causes the most stress."

"Lack of income because you are under a lot of stress."

"I am afraid to call an ambulance because if isn't an overnight, I will get a bill and no way home."

"Little or no opportunities for women to gain meaningful employment in a one-industry town."

"Being a woman, we are weak, no money, no job; if work, it is minimum wages."

"Lack of job equals lack of respect..."

Q 10. How would you know if you or someone else was having a stroke?

The participants had some knowledge of the physical signs of stroke, and a desire to learn more about those signs.

- Physical Health

"We didn't know what was wrong. He was talking confused, he was being odd, went to sleep and in the morning he was paralyzed."

"Screaming, attention seeking."

"I haven't had that experience but I think they may hold their chest."

"Then there's the silent stroke. You can't see it coming, it creeps upon you. It just happens. Your eyes become blurry, everything gets dim."

- Emotional Health

"Keep things in the heart."

- Community Health and Education

"Educate your family about the signs, when you have someone closer to you, you want to know more."

"We need more education on this...Doctors don't take you seriously."

- Spiritual Health

"Women has less strength because born out of left rib of man."

Q 11. What might prevent women who are isolated or on the edge from (a) recognizing the signs and symptoms of stroke; (b) communicating about stroke; or (c) being heard about the signs and symptoms of stroke?

The participants' responses indicated that family pressures and social barriers, such as illiteracy and a lack of information in multiple languages, can prevent women from communicating, and may limit what women know about the signs and symptoms of stroke.

- Family Health

"No time for self or to get knowledge, taking care of children all the time."

"Husband and family members will not let women go out... don't want [us] to become smart. They are scared. If we become smart, we will leave them, so they don't let us go out. (Husband aur ghar wale aurat ko bahar nahin jaane dete, chate nahin hai ke smart bane, darte hain, agar hum smart ban gaye toh uneh chod denge, is liye bahar nahin jaane dete.)"

- Physical Health

"It may be because of heavy drugs or alcohol."

- Emotional Health

"Always have someone close to you call daily (if you live alone) to check on you."

- Community Health and Education

"Illiteracy, don't know what to do or who to talk to."

"Lack of information - communication - lack of multi-language information."

14. What is the Best Way to Reach Women?



"Outreach workers - a way of educating, they helped."

What is the best way to reach women who experience or face challenges in relation to the determinants of health with information they can understand and act on?

Themes

The analysis team had a rich array of data on how women receive information now, and how they would prefer to receive it, which formed the building blocks for the new health promotion framework.

Q 12. What programs or services give you information about the risks and symptoms of stroke that you understand and can act on? Is there anything special that women may need in programs?

- Advertisements

"Malls and beauty parlour."

"You can go to the library."

"Information on billboards, subways, bus shelters, transit vehicles."

- Community Outreach

"No one knows about services. In _____ they had a program about T.B. that day and I thought, why don't they have regular programs to reach people, like monthly. These would be good in community centres. If you only sit at home, you will not get any information."

"Community event involvement."

- Medical Information

"Doctors." (Noted frequently)

"Clinics, community health centres."

- Information from Peers

"Knowledge about the old remedies ancestors used, rather than going to the doctor."

- Media

"TV, Internet." (Noted frequently)

Q 13. What is the best way to reach women, with information about stroke that they will understand and act on?

- Advertisements

See responses to Question 15.

- Community Outreach

"Settlement counselors who come to the door (especially for new immigrants) or at least call at home to set up an appointment."

"AIDS day like special day for stroke to tell more about."

"Settlement counseling should help newcomers by giving them information."

"Like this program - focus group should be conducted very often."

"Work-related training."

"Outreach workers should go out to homeless people and speak to them one to one, keeping in mind that some people can't read. It's easier for us to come to groups like this one (even once a month) to gain health information."

- Medical Information

"Government must accept naturopaths, homeopaths, and other alternative medicine as valid treatments to be regulated and covered as part of healthcare."

"Emotional support from nurses at community centres, Health Unit, Diabetes Centre, Native Centre, libraries, _____House (women's shelter), doctors, Telehealth, public computers with net access, magazines, religion, pharmacy, videos."

"There are nurses who come here and give us information about heart and stroke and check our blood pressure."

"Nurses better where women can share longer time."

"Doctor should give care, extra time, information because they know a lot of your case."

"Accepting naturopathy and homeopathy, and don't cut back on anything."

"The best way to reach women with this information to act on is through the family doctor, drugstore, hospitals."

- Information in Multiple Languages

See responses to Question 15.

- Information from Peers

See responses to Question 15.

- Media

"Telephone number should be provided where they can call any time for help."

- Others

"Medicine should be subsidized."

"Babysitting programs."

"School teach kids = parents learn."

"Free gym."

"Talk to people who survived strokes."

"Go to the government and tell them."

"I did a lot of traveling checking on people with stroke. You don't know when to expect it, but if you get it and go to hospital on time, you can get treatment and stop paralysis."

Q 14. Is this the best way to reach women who are on the edge or isolated? Can you suggest other ways to reach women to help them understand and act on the risks and symptoms of stroke?

- Advertisements

"When you print information, don't use the \$10 dollar words when a \$2 dollar word can get the point across more easily."

"We have to look and have time to look in newspapers, I don't have the time."

"Flyers and short points are the way to go."

"T.V. All have it, 80% watch TV. Even if we can't read, easier to learn and remember, especially for women who are isolated."

"Have a booklet, give at airport, tell us where to go for doctors and related things."

"Flyers tell me about sales in all the shops, but why not about stroke or programs in community centres or medical information."

"If I get flyers at home for shopping like Wal-Mart and Zellers, should get flyers with hospital."

"1-800 number, posters on the TTC, more focus groups like this one, women's group to prevent stroke."

"Information mailed to every home, shelter, drop-in etc."

"Health tips on T.V. on Saturday and Sunday, on different cultural programs, like OMNI 2."

"Telephone service that speaks our language or simple English."

"Mail home flyers and special headlines stating it is IMPORTANT FOR WOMEN."

"Instead of commercial break, give this information during the break - between Hindi and Tamil pictures - everyone sees movies."

"Make big signs along the subways and bus stops and on billboards. Translate information..."

- Community Outreach

"Flyers - translate English info to their own language. Public education (community, mobile unit) organization take info to the isolated people. Doctors should do more prevention awareness. Children at schools (information will be passed to parents), healing circles, radio, newspaper, TV, [learning from other women's] past experience - group sharing."

"There are many things we want to talk about. We could have more discussions like this."

"There should be Stroke Anonymous for women, just as there are Alcohol[ics] Anonymous, Smoking Anonymous...Women need to come together to spread the message to prevent stroke."

"People can come and visit you and talk to you and have a cup of tea with you."

- Multi-Lingual Information

"Translate English information to each culture's language to reach elders who might not know English."

"More publications in other languages, and maybe some women's group for those with the same problems."

"More multicultural information and translations."

- Other Suggestions

"Nature walks."

15. Health Promotion Framework

"By women, for women, about women."

The Health Promotion Framework emerged through the intense dialogue between Dr. Jackson and the large and small teams over a two-day period. The Framework began to take shape based on:

1. The understanding that the participants in the focus groups constructed health in a comprehensive, holistic manner, with an emphasis on the Emotional, Community & Social, and Family elements;
2. The insight that current modes of transferring knowledge about stroke to women are not resulting in accurate, usable information that women act on;
3. Women's clear and consistent preference to receive information in simple, plain language formats, and in the intimate, sharing environment of small peer-led groups; and
4. The need to accommodate women's geographic, cultural, socio-economic and linguistic differences.

A compelling image began to emerge. The large and small teams were beginning to see small groups of women in the centre of circles of learning and action, focused on the eight elements of health.

The team came up with the idea of combining the Count Us In! logo and women's symbol, which represent different aspects of the project, in the form of a symbolic key to women's health. The image was captured and fashioned electronically by Ramin Shokat Pourtorab, Site Coordinator and IT Specialist, AMRP, as the project logo:



Key to Women's Health

A statement from one of the participants helped guide the recommendations about how the health system can better serve marginalized women. The analysis team felt it was important to include the statement, as it was recorded:

"Presence when the doctor examines; public housing improvements; a complaint line; a suggestion box that is held in trust to have security and ability to have comments without punishment; accountability [of] health professionals."

When speaking about what they require from health promotion activities and health service providers, women expressed the following fundamental needs:

- We must be able to make comments without fear.
- We must have security and trust.
- The systems must be accountable to the people they serve.
- The presence of a known and trusted person in the room allows us to feel safe.

With all this in mind, the large and small groups constructed the framework. Like much of the theory and practice of the focus group process and the analysis, the framework can be represented as a circle.

The Key to Women's Health campaign begins with increasing people's awareness about stroke among women, with a focus on the eight elements of health; it advances through an innovative form of outreach, sharing and learning; and it follows through with advocacy to improve women's access to the determinants of health and the health system.

Key to Women's Health Campaign



Awareness Campaign

- Use images of women, ordinary survivors of stroke and cultural icons, from the diverse communities of Ontario, to become the public face of stroke prevention for women.
- Create flyers, posters and billboards, which feature the images of women, and use plain language and positive messages about stroke prevention. These should be available in multiple languages, in areas where women meet, share and interact with one another.
- Create spots to use (a) between films on channels such as OMNI, Channel 33, City TV or Channel 10, and (b) before and after films shown at drop-in shelters, community centres and other locations.
- Set up a 1-800 number that women can call to get information and referrals in different languages, similar to the Centre for Addiction and Mental Health hotlines.
- Introduce a "Stroke Awareness Day" and link with other events in the community, especially in isolated areas, to bring information to women.
- Use web-based strategies.
- The Awareness Campaign should take into account how the women in the focus groups constructed health, based on the eight elements, with stronger weighting of the non-physical elements involved.

Outreach Campaign

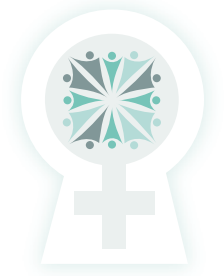
- Train Inclusion Researchers as peer health educators to do outreach in communities and to facilitate "Key to Women's Health Circles" - sharing/learning/action groups for women.
- Key to Women's Health Circles would meet frequently in diverse places, such as shelters and community centres, and include women from diverse cultures, with appropriate language and cultural supports.
- Circles would consider issues based on women's needs, as identified by the women in the Circles. Topics may include legal issues, medical issues, the experiences of stroke survivors, advocacy for people on welfare and housing.
- Circles could become support groups/seminars on coping and problem-solving skills, stress management, yogic exercise, life skills in Canada, personal growth and parenting skills. Childcare and bus fares would be provided.
- In addition, new focus groups should explore issues such as abuse, isolation, finances, employment and education, using the same strategies as those used for this project.
- Invite people to make presentations to the Key to Women's Health Circles on various stroke-related issues.
- Keep in touch with focus group participants and, where possible, provide support by connecting them to services.
- Co-ordinate with schools to help educate children and families about health issues, such as stroke.
- Provide one-on-one support to newcomers, such as assistance in getting health cards and interim healthcare.

Advocacy for Health

- Advocate to increase welfare rates, build more affordable housing and promote the other elements of health.
- Advocacy should include improving access to all parts of the health system, including health cards for newcomers.
- Advocacy work should aim to improve both alternative and traditional approaches to health promotion and healthcare.

16. Immediate Actions

"Treat an individual as a person, not a number."



The process was complete when the participants considered immediate actions to begin to bring the ideas in this project alive. The actions fell into three categories, with IRs being central:

Actions Related to Local Partners

- Create partnerships with local and provincial organizations.
- Share findings and recommendations with Local Health Integration Networks.
- Influence Ontario Public Health Association.
- Strengthen existing partnerships.
- Share resources with the public and with agencies (cultural and non-cultural).
- Act as a link between Inclusion Researchers and community agencies that wish to conduct surveys and focus groups on a fee basis.
- Discuss mental health issues in the focus group format, including the relationship between mental health and stroke.

Actions Related to Funders

- Secure funding for provincial, municipal and local projects.
- Subsidize dental and eye care.
- Subsidize medicines and reduce pharmacy fees.

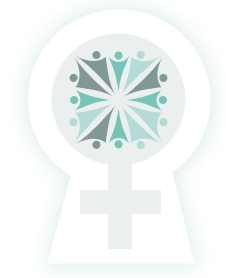
Urgent Actions

Access and Transportation

- Provide free day passes for public transit so that low-income people can travel to doctors' offices and health centres.

Immigration Experiences and Policies

- Eliminate the three-month period that newcomers must wait before being eligible for public healthcare benefits.
- Simplify the process of applying for a health card.
- Recognize the credentials of foreign-trained healthcare professionals.
- Provide people who are about to immigrate to Canada with information about the healthcare system at the time that their Visa is issued.



17. A Feeling of Belonging

"The project must rise to the challenge of building the capacity of Inclusion Researchers."

After analyzing the data, the people who participated in this process were asked an important question. Their answers spoke eloquently about the importance of inclusion:

How are you feeling at the end of the day?

"Hopeful."

"Feel part of the system."

"Able to express our needs."

"Brainstorming session - everyone had a good pool of suggestions, gave lot of recognition when put into action."

"Feel excited, just the beginning."

"Very curious to see what will happen next."

"Came through very clear to me: marginalized women have a lot of information that they seek and want to share with us, which allows us the opportunity to work to strive forward to improve our health system."

"Dual possibility exciting... re: potential can collapse in on itself and go nowhere. Not absolutely clear it will move forward in a positive direction."

"Speaks to the challenge of marginalized women's perspective on stroke and other areas."

"No matter where the women are from, we seem to have the same ideas and problems and hopefully the same solutions we can all share."

18. A Final Word

"A sense of belonging."

OWHN is proud to be involved with so many creative and dedicated women from across Ontario.

The process of looking into the knowledge and needs of marginalized women in the area of stroke prevention is essential to saving the lives of and providing treatment for people who are sometimes forgotten in the creation of great plans.

OWHN congratulates the Ontario Ministry of Health Promotion and the Ministry of Health and Long-Term Care* for remembering them. We hope to continue working with the Ministries to shape a health promotion approach from this framework that will engage women, ease some of their stresses, and help them to achieve healthier lives for themselves and for their families.

We thank all of the women who gave so much to this project and promise to stay by your side.

**The views expressed in this report are the views of the project participants and do not necessarily reflect the views of the Ontario Ministry of Health Promotion or the Ministry of Health and Long-Term Care.*



Appendix A: Inclusion Researchers and Site Coordinators

Peel Site

Inclusion Researchers

Chandana Basu

Sadaf Dhiloon

Anita R. D'Souza

Miriam Fernandez

Prabavathi Jeganathan

Angeline Janet Nithya

Karuna Saini

Site Coordinators

Urvashi Sirohi Joseph

Sabrina Merali

Parminder Kaur Singh

Sudbury Site

Inclusion Researchers

Sue Leblanc

Tina-Louise Leblond

Tammy Romain

Hilda Toulouse

Natasha White

Pilot Site Administrators

Barb Garon

Rose Menard

Toronto Site

Inclusion Researchers

Farida Athumani

Marcia Jarman

Kathy Kunsmann

Site Coordinators

Adonica Huggins

Ramin Shokat Pourtorab

(& IT Specialist)

Appendix B: Provincial Working Group

The following members served with great dedication:

Catherine Turl, Toronto Public Health, Chair

Farida Athumani, Asset Mapping Research Project, IR

Krissa Fay, Ontario Prevention Clearinghouse

Michael Fay, Fay & Associates, Consultant, Writer

Barb Garon, Sudbury Women's Centre, Site Coordinator

Lori Greco, Region of Peel, Public Health Department

Tekla Hendrickson, Ontario Women's Health Network, Project Coordinator

Adonica Huggins, Asset Mapping Research Project, Site Coordinator

Marcia Jarman, Asset Mapping Research Project, IR

Prabavathi Jeganathan, Peel, IR

Urvashi Sirohi Joseph, India Rainbow Community Services of Peel, Site Coordinator

Anne-Marie Kungl, Ontario Chronic Disease Prevention Alliance

Rose Menard, Sudbury Women's Centre, Site Coordinator

Sabrina Merali, Region of Peel, Public Health Department, Site Coordinator

Barbara Miles, Consultant, Literature Search

Victoria Nadalin, Cancer Care Ontario

Suzanne Schwenger, Ontario Prevention Clearinghouse, Stroke Prevention Initiative

Ramin Shokat Pourtorab, Asset Mapping Research Project, Site Coordinator
and IT Specialist

Appendix C: Local Advisory Committee

Peel Site

Chandana Basu, Inclusion Researcher

Eva Beaulieu, Credit Valley Hospital

Kitty Chadda, India Rainbow Community Services of Peel

Christina Fung, Chinese Association of Mississauga

Mina Fung, Chinese Association of Mississauga

Lori Greco, Region of Peel, Public Health

Susan Himel, Trillium Health Center, Health Information and Wellness

Amanda Jones, Caledon Meals on Wheels

Urvashi Joseph, India Rainbow Community Services of Peel

Parminder Kaur, India Rainbow Community Services of Peel

Rina Lad, Diabetes Association

Michelle Langham, Ontario Works

Sabrina Merali, Region of Peel, Public Health

Neelam Rampal, Brampton Neighbourhood Resource Centre

Kaurna Saini, Inclusion Researcher

Audra Singh, Heart and Stroke Foundation

Sharon Trottman, West GTA Stroke Network

Vanita Varma, Telecare Distress Centre

Appendix C: Local Advisory Committee

Toronto Site

Farida Athumani, Inclusion Researcher

Heather Brien, Toronto Community Care Access Centre

Robert Butler, Central Neighbourhood House

Donna Cheung, Regional Stroke Network, St. Michael's Hospital

Erika Coleman, 416 Drop-in Centre

Katherina Colwell, South East Toronto Stroke Network, St. Michael's Hospital

Alice Gorman, Toronto Public Health

Laura Hanson, Street Health

Adonica Huggins, Toronto Christian Resource Centre

Stephen Hwang, St. Michael's Hospital

Deanne Kukulewich, Ontario March of Dimes

Kathy Kunsmann, Inclusion Researcher

Ramin Shokat Pourtorab, Toronto Christian Resource Centre

Tracy Warne, Sherbourne Health Centre

Gail Yardy, St. Michael's Hospital

Shelley Young, Toronto Public Health

Appendix D: Demographics of Participants

Stroke

Have you had a stroke?	Peel	Sudbury	Toronto	# of Participants
no	17	20	15	52
not sure	5	1	4	10
yes	3	1	3	7

Age

Age	Peel	Sudbury	Toronto	# of Participants
18-29	4	4	3	11
30-35	6	3	1	11
36-40	6	1		7
41-45	1		4	5
46-50		5	4	9
51-55	2	6	3	11
56-60	2	2	6	10
61-65	4			4
65+		1	2	3
Total	25	22	23	71

Appendix D: Demographics of Participants

Citizenship Status

Citizenship Status	Peel	Sudbury	Toronto	# of Participants
Canadian citizen	9	22	18	49
Permanent resident	11		4	15
Newcomer to Canada (less than 5 years)	9			9
Immigrant/Refugee	6		1	7
Total	35	22	23	80

Disabilities and Addictions

Site	Physical Disability	Mental Disability	Developmental Disability	Learning Disability	Addiction	# of Participants
Peel	2	4	2	2		8
Sudbury	2	4	2	2	1	9
Toronto	4	8	4	5	2	19
Total	8	16	8	9	3	36

Education

Highest Level of Education	Peel	Sudbury	Toronto	# of Participants
some post-secondary	11	11	10	32
some high school	11	9	9	29
not specified		2	2	4
some elementary school	2		2	4
no formal education	1			1

Appendix D: Demographics of Participants

Ethno-Racial Identity

Ethno-Racial Identity	Peel	Sudbury	Toronto	# of Participants
Caucasian	1	19	11	31
Person of Colour/Visible Minority	21		7	28
Aboriginal, Non-Status, Métis or Inuit		2	4	6
member of an ethnic group	2			2
other	1	1		2
Total	25	22	22	69

Housing

Housing	Peel	Sudbury	Toronto	# of Participants
live in subsidized housing	6	6	11	23
live in a room, apartment or house that I rent	11	4	3	19
live in housing that I own	2	9	1	12
live with family	6	1		7
live in a shelter			5	5
live in the home of friends			3	3
live on the street		2		2
Total	25	22	23	71