

# **Learning More Today For Ourselves and Our Children**

**An Assessment of Consumer Health Information  
For Aboriginal Women In Ontario**

**Final Report**

**Prepared for the Ontario Women's Health Council**

**Oshki-Pimache-O-Win Education and Training Institute  
Ontario Native Women's Association  
Centre for Rural and Northern Health Research**

**2005**

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# Acknowledgments

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This study would not have been possible without the help of many people. The researchers acknowledge, with gratitude, the significant contributions that each person made, although it is not possible to do so by name.

We particularly wish to thank the many representatives of Aboriginal communities and organizations who assisted in the study. These individuals provided ongoing assistance during the development and data collection phases of the project. Their efforts, in publicizing the study and providing on-site support for focus groups and talking circles, were invaluable. They also provided help, in many ways, to ensure that written surveys could be distributed throughout the province.

We acknowledge the financial support provided for the study by the Ontario Women's Health Council. The opinions reported in this report are those of respondents and the interpretations are the authors' alone; no official endorsement by the Ontario Women's

Health Council is intended or should be inferred.

Central to this evaluation's success are the 457 Aboriginal women and 54 health care providers who gave freely of their time to participate. Their willingness to share personal experiences, opinions, insights and suggestions is much appreciated. Their thoughts and concerns lie at the heart of this study.

Special thanks to the young mother, a focus group participant who must remain anonymous, whose words so eloquently summed up the concerns that Aboriginal women have about the health of their communities. Her words also suggested the title of this report. Talking about the need to learn more, she said:

*Everything. We women need to learn more today for ourselves and our children. Just learning makes it a good day. It's very important to talk about everything.*



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# Executive Summary

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Reflecting on the limited health information available in her community, an Aboriginal woman said: "Everything is needed, there is not enough information here." Her words capture the central concerns which underlie the study, commissioned by the Ontario Women's Health Council. The goal of the study was to ensure that Aboriginal women, like all women in Ontario, have access to understandable and culturally-appropriate health information. Its objectives were to:

- ◆ Determine what information exists for Aboriginal women about the health issues affecting them and whether its content and format meets their needs;
- ◆ Identify how Aboriginal women access health information resources, including traditional approaches; and
- ◆ Recommend means of filling information gaps, as well as the best media and methods for widely disseminating health information to this audience of consumers.

The findings reported in this document reflect the views of 474 Aboriginal women who reside in the province's First Nations, Métis and Inuit communities, including urban, rural and isolated regions. Additional insights were obtained from 54 representatives of Aboriginal organizations.

The participatory research process which explored their views was guided by a steering committee representing key Aboriginal stakeholders. Data was collected using talking circles, focus groups, key informant interviews and written surveys, following techniques which have been identified as being appropriate for research with Aboriginal peoples.

As well as the final report, the principal deliverable from the study, a variety of dissemination activities will transfer knowledge to Aboriginal communities and the organizations that provide care to their residents. Dissemination activities will be community and organization-specific.

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## Key Findings

Results suggest that finding appropriate health information resources is a considerable challenge for Aboriginal women, which will require concerted efforts to address. Nearly all women experience serious problems accessing and understanding health information.

Consumers and providers confirmed that Aboriginal communities required enhanced information on a wide range of health concerns: serious illness, mental health, reproductive health, healthy sexuality, screening and wellness programs.

There were also serious gaps in the health information which was available. Specialized information to assist in care of people with disabilities, children, teens and elders was unavailable in most locations. There was also an absence of community-specific information on environmental health concerns.

The scan revealed several factors which limit Aboriginal women's ability to access and use available health information. Access was difficult due to problems locating resources and absence of technological supports. Barriers to understanding included difficulty comprehending material that was complex and depicted unfamiliar community contexts or unavailable services.

The lack of Aboriginal-language resources was a significant barrier to people from traditional communities. There were also few resources that reflected the diversity of First Nations, Métis and Inuit cultures. Specialized supports that would enhance the cultural competence of providers and provide culture-specific assistance were needed to address these issues.

In discussing their preferred learning methods, women wanted health information strategies that were responsive and flexible. Their primary preference was for shared learning strategies, using workshops, women's groups or health fairs as settings. They also saw a role for one-on-one health teaching to educate women about personal health issues and reach housebound individuals.

Print materials, such as pamphlets or flyers, were seen as effective ways of distributing information throughout Aboriginal communities. Audiovisual materials, such as television, radio or the Internet, along with audio and videotapes, were suitable strategies for delivering more in-depth health information, provided the necessary technology was available.

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## Recommendations

Recognizing that Aboriginal women, as mothers, grandmothers, sisters and aunts, play a primary role in maintaining the health of Aboriginal children, families, and communities, this report makes recommendations directed to the Ontario Ministry of Health and Long-Term Care, that must be addressed in collaboration with federal, provincial, regional and local First Nations, Métis and Inuit organizations that develop and deliver health information to Aboriginal women, families and communities.

To ensure that Aboriginal women have the health resources that they need, it is recommended that these organizations:

### **Target funds to**

- 1) Ensure that Aboriginal women have access to timely, appropriate information on all health issues.
- 2) Augment Aboriginal-specific resources to address the most pressing needs for information about diabetes, cancer, family violence, and nutrition.
- 3) Improve Aboriginal communities' access to information on other serious illnesses, including heart disease, arthritis, lung conditions and digestive disorders.

- 4) Make sure that Aboriginal women have access to resources on mental health issues, including substance abuse, stress and depression, with emphasis on women's perspectives.
- 5) Ensure that Aboriginal women have access to up-to-date material on reproductive health issues, pregnancy, childbirth, menstruation, birth control, and hormone replacement therapy.
- 6) Provide Aboriginal communities with resources promoting healthy sexuality, prevention of HIV/AIDS and other sexually transmitted diseases.
- 7) Deliver "hands on" cultural sensitivity training to enhance health providers' ability to understand the concerns of Aboriginal women.
- 8) Support nurse practitioners as an acceptable alternative for delivering wellness information to Aboriginal women who lack full time physician care.
- 9) Train and employ Aboriginal women's health support workers to assist in the dissemination of information to Aboriginal women in home, community, and hospital settings.
- 10) Support development and utilization of technology-based Aboriginal health resources, by providing public-access computers and training Aboriginal women in their use.

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***Work collaboratively with Aboriginal women's groups to***

- 1) Identify community-specific needs for specialized health information programming for Aboriginal women with disabilities, children, teens, young adults and elders.
- 2) Develop strategies to ensure that Aboriginal women with disabilities have access to information on home supports, assistive devices, transportation and rehabilitative care.
- 3) Develop Aboriginal-specific resources to address children's nutritional needs, food availability, traditional foods, and special diets for diabetes or lactose intolerance.
- 4) Develop Aboriginal-specific resources to assist caregivers of children with special needs, including FAS/FAE, learning disabilities, speech and language difficulties.
- 5) Develop specialized information to assist Aboriginal women caring for children who are born drug addicted or developmentally delayed.
- 6) Develop health resources to inform Aboriginal women about screening programs, including what to expect when they go to a physician.
- 7) Explore community-specific needs for information on environmental health issues.
- 8) Develop health materials to assist communities in identifying and addressing environmental health problems, including water and food-borne illness, chemical toxins and

environmentally-induced allergies, asthma and infections.

9) Sponsor specialized sessions to help Aboriginal women address issues of shyness and improve confidence in locating information, accessing services and asking questions.

10) Encourage Aboriginal women to take an active role in locating health information and sharing it with their communities.

***Enhance Aboriginal women's understanding of health information by***

- 1) Modifying health materials so they contain clear language, appropriate pictures and simple diagrams.
- 2) Explaining medical terms in plain language to ensure that women with limited English-language reading skills can understand.
- 3) Including translations, in written or oral formats, to assist women who are most comfortable communicating in an Aboriginal language.
- 4) Producing health materials that accurately reflect the range of resources and services in Aboriginal communities.
- 5) Including directions for initiating referrals at a distance, with step-by-step instructions that are clear and concise.

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6) Explaining differences between services available in smaller and larger communities for women who move from one to the other.

***Acknowledge Aboriginal women's appreciation of health materials which respect traditions by***

- 1) Using traditional approaches to enhance understanding.
- 2) Including Aboriginal content in pamphlets or videos, featuring Aboriginal designs.
- 3) Using examples and illustrations featuring Aboriginal women, their families and community settings.
- 4) Developing culture-specific materials that reflect the diversity of traditions, beliefs and values of Aboriginal peoples.
- 5) Recognizing Aboriginal women's widespread preferences for holistic approaches, encompassing physical, social, mental and spiritual aspects of wellness.
- 6) Resources permitting, sponsor separate health information programming for First Nations, Métis and Inuit communities.
- 7) Making sure that Aboriginal programming on television, radio, video, audio or the Internet is well-publicized.
- 8) Publicizing the Aboriginal-language translations and supports that are available.

***Work collaboratively with Aboriginal organizations to***

- 1) Encourage widespread dissemination of health information within Aboriginal communities.
- 2) Use front-line health and social service workers to disseminate health information to clients.
- 3) Use pamphlets, flyers and newsletters and organizational mailing lists to publicize community health initiatives and new information.
- 4) Place information in community settings where women gather, such as cultural centres, recreational facilities and shopping areas.
- 5) Accommodate Aboriginal women's preferences for shared learning by offering group education sessions.
- 6) Support one-on-one teaching as an alternative when women seek personal health information.
- 7) Provide door-to door awareness campaigns as an alternative for women who are housebound.
- 8) Deliver information in settings which guarantee security, such as Aboriginal women's shelters and safe houses; women's wellness centres can serve the same service.

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# 1. The Project

Oshki-Pimache-O-Win, an organization mandated to advance Aboriginal education, together with the Ontario Native Women's Association and the Centre for Rural and Northern Health Research, developed this project in response to the Ontario Women's Health Council call for research on the most effective ways of disseminating health information to Aboriginal women across the province.

The study was designed to help the council achieve its goal of ensuring that Aboriginal women – like all women in Ontario – have access to accurate, understandable information about things which affect their health and well-being, and to make sure that it is presented in culturally appropriate ways. The project activities were structured to accomplish three objectives outlined in the request for proposals issued by the council.

## Research Design

The study used a participatory research design of the type widely recommended and accepted as the

### Objectives:

- ◆ 1. Determine what information exists for Aboriginal women about the health issues affecting them and whether its content and format meets their needs.
- ◆ 2. Identify how Aboriginal women access health information resources, including traditional approaches.
- ◆ 3. Recommend means of filling information gaps, as well as the best media and methods for widely disseminating health information to this audience.

most culturally appropriate and effective strategy for conducting research with Aboriginal populations (World Health Organization, 2002). Participatory designs also follow the recommendations of the Canadian Institutes of Health Research and the Institute of Aboriginal Peoples' Health. In the most recent directives on research with Aboriginal peoples, the Institutes have affirmed the importance of using participatory

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strategies in any research involving Aboriginal subjects (CIHR, 2002). In the definitive Canadian study on participatory research, Green states that its distinguishing characteristics are:

*(a) extensive collaboration between traditionally-defined researchers and the community in each research stage, from identifying the problem to applying and disseminating results; (b) a reciprocal educational process between community and researchers; and (c) an emphasis on taking action on the issue under study (1995:3).*

The study employed a participatory model in which, ultimately, decision-making responsibility rested with the Aboriginal partners, represented by a steering committee of eight individuals, all knowledgeable about Aboriginal health. The committee included two representatives of Aboriginal partner organizations and six other individuals from stakeholder groups. All were knowledgeable about Aboriginal health at national, provincial, regional and local levels. A Youth and an Elder were selected for two of the positions to give voice to the special perspectives of these age groups.

The steering committee met regularly with the research group during the development and implementation of the project, offering feedback, insights, and suggestions that shaped

### **Project Steering Committee Membership**

- *Ruth Baxter, Executive Director, Oshki-Pimache-O-Win*
- *Josephine Mandamin, Executive Director, Ontario Native Women's Association*
- *Rosalie Davis, Health Director, Shibogama Tribal Council*
- *Charles Fox, Ontario Regional Chief, Chiefs of Ontario*
- *Tracy O'Hearn, Senior Policy Analyst, National Aboriginal Health Organization*
- *Peggy Kinch, First Nations Inuit Health Branch, Health Canada*
- *Noella Kwisses, Health Outreach Worker, Ontario Métis Aboriginal Association*

and guided the research decision-making process. They also served as a link between the research group, participating communities and organizations, ensuring close and continuing collaboration.

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## The Research Group

- ◆ Oshki-Pimache-O-Win, the Ontario Native Women's Association and the Centre for Rural and Northern Health Research and associated staff formed the core research group for the project.

The research group worked collaboratively, each organization devoting time, resources and staff to the project. (See *Appendix A*, for details on project research team.) Oshki-Pimache-O-Win, an Aboriginal organization with a mandate to advance post-secondary education and learning for the Nishnawbe-Aski Nation, served as the administrative support for the study. Oshki-Pimache-O-Win has developed and delivered a number of community-based education and training initiatives, including those designed to improve Aboriginal women's health.

The Ontario Native Women's Association (ONWA), a voluntary, non-profit organization representing the interests of Aboriginal women across the province, collaborated with Oshki-Pimache-O-Win in the development and delivery of this project. The organization serves as a forum for First Nations, Métis and Inuit women, regardless of status or locality, encouraging them to become actively

involved in solving problems in ways which are unique to Aboriginal culture.

The Centre for Rural and Northern Health Research (CRaNHR), is funded by the Ontario Ministry of Health and Long-Term Care and based at Lakehead and Laurentian Universities. The centre, which has extensive experience in collaborative research with Aboriginal communities, provided technical research support.

Project staff were based at Oshki-Pimache-O-Win. Staff included a project researcher and two research assistants, a part-time administrative assistant and several clerical assistants. Staff were chosen for their awareness and understanding of Aboriginal cultures, experience working with Aboriginal organizations and research skills.

Two Aboriginal consultants served as advisors for this project. Mae Katt, BScN, MEd, RN (EC), provided ongoing research assistance and direction. She is a member of the Bear Island First Nation, the former Regional Director (Ontario), First Nations and Inuit Health Branch, Health Canada and currently a nurse practitioner at Anishnawbe Mushkiki, one of the province's six Aboriginal health care access centres. Kimberly Scott, Kishk Anaqut Health Research, was engaged as the informatics consultant. She has extensive experience as a researcher specializing in evaluation of health policies and programs.

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## Literature Review

The development and implementation of the research project was shaped by a comprehensive literature review, which encompassed information on First Nations, Métis and Inuit health. The review used Internet and library search facilities to scan academic journals, governmental and non-governmental publications.

The results of the review informed research decision-making process, including methodological choices and interpretation of results. Emphasis was placed on identifying the health issues which affect Aboriginal communities, the factors which facilitate or impede access to information, and appropriate dissemination strategies.

## Methodologies

The researchers canvassed methodological options carefully, choosing data collection methods and sampling strategies that had been shown to be acceptable for Aboriginal communities. Reflecting participant needs and preferences, the research design included talking circles, focus groups and surveys, including both oral semi-structured interviews and written questionnaires.

Talking circles, also known as sharing circles, have been deemed most appropriate in communities which have retained their language and cultural traditions. Sharing circles were used to identify Aboriginal health issues (National Aboriginal Network on Disability, 1992; Nova Scotia Mi'kmaq Health Research Group, 2001) and culturally-appropriate health promotion strategies for Aboriginal communities (Hodge, Fredericks & Rodreguez, 1996; Strickland, Squeoch & Chrisman, 1999).

While talking circles and focus groups are the method of choice for documenting Aboriginal communities' views, other recent studies suggest that oral interviews and written surveys can be equally effective in assessing the views of key informants. These methods have been used to document the views of professional providers who are knowledgeable about some of the more general issues affecting provision of health services to Aboriginal populations (Auer & Andersson, 2001).

Oral interviews are demonstrated to be effective in documenting perspectives of community members, leaders and traditional healers (Hodge, Fredericks & Rodriguez, 1999). The method also demonstrated as useful for exploring experiences of community health representatives who perform a combined advocacy and education role (Minore & Boone, 2002). As well, the method has proved to be culturally appropriate in gathering data on sensitive topics such

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as diabetes, cancer or mental health (Minore, Boone, Katt, Kinch & Birch, 2001; Strickland, 1999).

Focus groups have been used effectively in urban settings to assess health issues among Aboriginal women from diverse backgrounds and conditions (Dickson, 2000). The method has also been used to determine health beliefs, behaviours and intervention strategies (Baldwin, Trotter, Martinez, Stevens, John & Brems, 1999; Speier, 2001; Strickland, Squeoch & Chrisman, 1999).

Written surveys, on the other hand, are most suitable for documenting the accessibility of audiovisual and print information (Osedowski, 2001; Peterson, Trapp, Sellers, Kottke, de Groen, Nicometo & Kaur, 2002). As well, surveys have been used to identify provider views on appropriate needs and dissemination strategies (Silverman, Goodie, Ladouceur & Quinn, 2001).

These techniques were tailored to reflect the needs and preferences of groups with differing life experiences, educational attainment and levels of literacy. Methods were matched to the preferences of participating communities, organizations and individuals. The goal was to ensure that methods respected and reflected community, organization and individual preferences.

## Sampling

The literature review suggested that a combination “sentinel community design” (International Development Research Centre, 1997) and “organizational affiliation” (Sullivan, 2001) sampling strategies have been widely used in participatory research projects. In the present study, sentinel site selection and organizational affiliation were used as strategies to ensure that the research reflected the many different situations under which Aboriginal women lived and sought health information.

“Sentinel community design” represents a technique specifically developed for use with participatory research projects. It involves the purposive selection of a small number of sites to represent the distinct community characteristics like size, access to health care, income levels and other factors that are believed to impact on health (International Development Research Centre, 1997). It should be noted that a sentinel *community* is not only determined by geography. It can also be a service-delivery agency or an advocacy organization serving a specific community of clients. This method was used to select sites for a recent evaluation of Aboriginal women’s

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views on health in Saskatchewan (Deiter & Otway, 2001).

“Organizational affiliation” represents an alternative way of identifying key informants who are believed to be knowledgeable about specific issues (Sullivan, 2001). It is also effective as a method of capturing the views of hard-to-reach populations, such as urban Aboriginal communities (Day, Blue & Raymond, 1998).

Taking into account the diversity of circumstances under which Ontario's Aboriginal women live, the study specified a minimum of 10 sentinel sites. An additional site was added to the sampling framework to ensure adequate participation from isolated communities. The sites chosen gave access to the different life experiences and wide-ranging opinions of women across the province. Collectively, the sites chosen reflect the diversity created by geography, population, access to health services, language and cultural retention or, among organizations, clientele. (See *Appendix B* for detailed site profiles.)

Organizational affiliation with the Ontario Native Women's Association (ONWA) was used as a means of capturing additional consumer viewpoints. This organization offers health and social services to Aboriginal women through its 84 locals, divided into northern, southern, eastern and western regions. ONWA members, who come from First Nations (on reserve and off), Métis and Inuit backgrounds, constitute a clearly

### **Sentinel Sites**

- *Whitefish Lake First Nation, a rural Ojibway community, is located 15 km southwest of Sudbury.*
- *Temagami First Nation is an isolated Ojibway community situated on Bear Island, in Lake Temagami, 100 km from North Bay.*
- *Eqay-Wuk Native Women's Association (Sioux Lookout) provides health and education support to women and youth in 30 First Nations.*
- *Ontario Association of Indian Friendship Centres (Toronto) offers health, education, justice and cultural programs to Aboriginal families and youth.*
- *Asubpeeschoseewagong First Nation, formerly Grassy Narrows, is a rural Ojibway community, located 60 km northwest of Kenora.*
- *The Ontario Métis Aboriginal Association (Sault Ste. Marie) delivers health and education support to families, women and youth.*
- *Moose Cree First Nation is located on Moose Factory Island, 300 km north of Timmins.*
- *Oneida Nation of the Thames, formerly known as Onyota'a:ka, is situated 16 km southwest of London.*
- *Chippewas of the Thames, an Ojibway First Nation, is located 24 km west of St. Thomas.*
- *Tunngasuvingat Inuit (Ottawa) is a cultural, social and counselling organization serving Inuit residents.*
- *Fort Severn First Nation, a Cree community, is the northernmost settlement in Ontario, located 740 km northwest of Sioux Lookout.*

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defined interest group. The ONWA membership is well informed about issues of concern to the Native women of Ontario, including those related to health. Organizational affiliation was also used to provide further insights into health information issues by document perspectives of key informants from organizations which deliver services and disseminate information to Ontario's Aboriginal communities. The organizations included friendship centres, health centres, health and social service agencies, as well as community representatives.

- ◆ Using these methods, we hoped to obtain a sample of 320 consumers and 160 providers<sup>1</sup> that captured the health information issues affecting Aboriginal women throughout Ontario.
- ◆ We more than met our goal of capturing consumer opinions, obtaining information from 474 Aboriginal women who lived in communities across Ontario. We also succeeded in documenting the views of 54 provider informants.

The consumer sample included 296 Aboriginal women who shared their views through focus groups, talking

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<sup>1</sup>Minimum sample estimates. Consumer sample size was estimated on a minimum of 20 responses each from 10 sentinel sites and 20 responses from each of the four Ontario Native Women's Association regions. Provider sample size was estimated on a minimum of 2 responses each from 80 organizations.

circle discussions and individual interviews. An additional 178 women completed questionnaires distributed through the Ontario Native Women's Association.

Provider key informants included 48 women and six men who completed written questionnaires. Although their numbers were less than expected, these individuals represented a wide spectrum of Aboriginal organizations, including 23 health and social service agencies, 20 friendship centres and cultural organizations, and nine regional groups. All provider participants were involved in the dissemination of health information to Aboriginal communities. Some had experience in developing and delivering Aboriginal health information initiatives.

## **Cultural Sensitivity, Literacy & Inclusion**

- ◆ The research project was designed so that issues of cultural sensitivity, literacy, and inclusion were addressed.

Based on the literature, special methodological and ethical issues were addressed to ensure inclusion of women with disabilities (Dickson & Green, 2001), as well as vulnerable populations (Heaman, 2001).

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The project steering committee provided ongoing assistance in addressing these concerns. Providing consultation throughout the development and implementation phases of the research, committee members ensured that the project was conducted with sensitivity to cultural issues, literacy and inclusiveness. This on-going consultation served to educate the research group about relevant issues and ensure that the evaluation accurately reflected Aboriginal women's experiences.

It was anticipated that participants in the research might have different levels of literacy skills in English, the operational language for this project. Some women would have highly developed language skills; others would have minimal education and little or no understanding of the English language. To ensure that non-English speaking women could take part, translation and back-translation techniques were used in focus groups, talking circles and key informant interviews. In the case of written surveys, assistance was supplied by either an on-site support person or telephone support.

Efforts were made throughout the research process to promote and achieve inclusiveness. The research group was committed to creating a supportive context in which participants felt comfortable. Methodologies such as talking circles and focus groups were used to encourage open communication.

Respondents who did not feel comfortable sharing their views in a focus group or talking circle were given the alternative of completing individual oral interviews or written surveys. Support persons were present during interviews, if requested and mandated by the context.

Special accommodation was made to ensure that all women, including those with work, child care, other family responsibilities or disabilities, could participate. Since women needed to feel free of immediate responsibilities related to work, child care or family to participate fully, community-based data gathering activities were scheduled at several times throughout the day.

Research venues were selected carefully and modified, when necessary, to ensure that women with physical disabilities could participate. We also made special provisions for women at risk, selecting venues that provided assurances of safety, security and privacy for participants.

Community representatives assisted during the focus groups, talking circles and interviews, providing translations and arranging for transportation, child care and other supports. They also disseminated information about the sessions, through posters, newsletters and announcements on community radio and television.

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## Tri-Council Guidelines

- ◆ Tri-Council Guidelines were used to ensure that the research conformed to ethical standards.

The project adhered to the guidelines specific to research involving Aboriginal peoples, which include consultation during the design of the project and assurance that Aboriginal organizations and communities have access to results and an opportunity to respond (Medical Research Council of Canada, 1998). In the current study:

- ◆ Aboriginal women were asked for feedback throughout the research process, providing community-specific advice on the design, implementation and dissemination.
- ◆ Individuals from the communities were trained and employed as facilitators, interviewers and interpreters.
- ◆ Nonprofessional participants, in accordance with accepted practice, received a modest sum (\$40) in recognition of the fact that many women incurred costs in order to participate in the research (e.g. for child care or transportation).
- ◆ Analysis of the data was conducted collaboratively, with the Steering Committee, partner organizations

and community leaders having opportunities to provide feedback on findings, recommendations and preferred dissemination processes.

The researchers were aware of the needs and concerns of Aboriginal people regarding research initiatives and made every effort to reduce harm and maximize benefits. To this end, the research accommodated language and cultural needs throughout the study. Researchers respected and valued individual and community differences and endeavoured to maintain working relationships that were mutually beneficial. All research procedures were reviewed and approved by the Lakehead University Research Ethics Board.

Participating individuals, organizations and communities were fully informed about the purposes of the evaluation, its potential benefits and procedures used to ensure confidentiality. Introductory letters and statements informed participants that no risk was associated with the research, other than the possible discomfort of discussing sensitive issues. They were assured participation was voluntary and would have no impact on their employment or access to services.

Participants were informed fully about the provisions made for ensuring confidentiality. People who took part in focus groups and talking circles were reminded that "confidentiality is a must" (Sandy, 1996) and asked not to share any information revealed during discussions. Participants in all phases

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of the study were assured that findings would not be linked to individuals, organizations or communities. Further protection was given by removing all identifying information during processing and reporting responses as grouped, descriptive data. Each participant was asked to sign a consent form before they took part, indicating their understanding about the purpose of the study, provisions for confidentiality and access to a summary of findings, on request, at project completion.

## Analysis

- ◆ Data analysis involved creation of a comprehensive cross-source database, including 450 pages of transcribed material from focus groups, talking circles<sup>2</sup> and oral interviews, as well as written documentation supplied by 370 consumers<sup>3</sup> and 54 community health care providers and representatives.

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<sup>2</sup> Three sessions were not audiotaped; two could not be taped because of technical problems; one session was not taped due to respondent concerns about confidentiality. These sessions were documented using verbatim notes made by research assistants.

<sup>3</sup> 120 consumers who took part in focus groups elected not to provide written documentation.

Whenever possible, data was validated using cross-source comparisons and inter-rater assessments of reliability. The analysis explored Aboriginal women's diverse health information needs, the quality and cultural appropriateness of the health information available, gaps in content and barriers to accessing health information. As well, attention was given to identifying the best ways to disseminate health information to women of Aboriginal heritage.

As a secondary consideration, the analysis looked for variations, between consumers and providers, among urban, rural and remote community types and between younger and older consumers. It also explored the specialized health information needs of women with disabilities, HIV/AIDS, youth and elders.

Upon completing the initial analysis, the research team met with the steering committee to verify interpretations, seek clarification, and alternative explanations for findings. The committee also participated in ongoing discussions concerning the development of appropriate dissemination strategies, reports and presentations. Members of the steering committee took an active role in formulating recommendations for the study, offering valuable insights, suggestions and suggestions for addressing Aboriginal women's health information needs.

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## **Time Frame & Limitations**

- ◆ The project spanned twelve months, with three months devoted to data collection.

Activities included: (i) research team meetings (monthly for months 1 to 9, then biweekly throughout months 10, 11 and 12); (ii) steering committee meetings, including on-site and teleconferenced (bimonthly); (iii) project development, including literature review and ethics review (months 1, 2, 3, and 4); (iv) data collection (months 5, 6, and 7); (v) data compilation (months 7, 8 and 9); (vi) interim reports (months 4 and 9); (vii) data analysis, including cross-source comparisons (months 9, 10 and 11); (viii) feedback on findings, preliminary formulation of findings (months 10, and 11); (ix) preparation of final report, summary, revision of recommendations, and dissemination strategies (months 11 and 12).

- ◆ The principal constraints on the project resulted from delays in the process of negotiating access to communities and organizations.

Because participating communities and organizations were occupied with other concerns, it took multiple contacts over a period of many weeks

before permission was granted for the fieldwork to take place. Similar delays slowed down the process of data collection and limited time available for follow-up. Taken together, these factors may account for the lower-than expected response rate from the provider category. Otherwise, the response rate was good.

## **This Report**

In this report, information is presented in both qualitative and quantitative formats. Sections offer both visual and written summaries. The discussion of issues is illustrated by direct quotes from respondents, to give a sense of their importance and ensure that their views are reflected accurately.

Sections document the diverse ways in which Aboriginal women accessed and understood health information. Differences of opinion, when they occur, have been highlighted to show how geography, demographics and other circumstances affect access to information and understanding. The report also identifies gaps in available information and the appropriate strategies for addressing them. It is hoped that this information will help Aboriginal organizations respond to the needs of the women that they serve.

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## Dissemination

- ◆ At the request of the participating communities and organizations, ongoing dissemination of findings will continue for a time after the report is completed.
- ◆ Dissemination activities will include both visual and written presentations.

These will be directed towards Aboriginal women and the organizations and individuals who provide health care to their communities. Strategies will be tailored to the participating communities, organizations and audiences being addressed.

Community-specific strategies will incorporate the language, cultural traditions and issues that are important locally. With the permission of stakeholders, results will also be disseminated to a broader audience, including health care providers, policy makers and decision-makers. As well as sharing findings, efforts will be made to highlight diversity and stimulate discussion of timely solutions to the problems identified in the report.

### Proposed Dissemination Activities

- ◆ Publication of final report and executive summary, in print and web-based formats. The goal in publishing the reports will be to make materials accessible to consumers and providers of Aboriginal health care information.
- ◆ Development and delivery of visual materials, including posters and pamphlets, to present findings from the report to participating sentinel site communities and organizations; dissemination of the executive summary, including Aboriginal-language translations.
- ◆ Preparation of summaries of findings for organizations and individuals who provide care to Aboriginal women and their families; this will include Aboriginal communities, policy-makers and decision makers.
- ◆ With permission, the team will also endeavour to disseminate findings from the study through academic conferences, workshops, and publications.

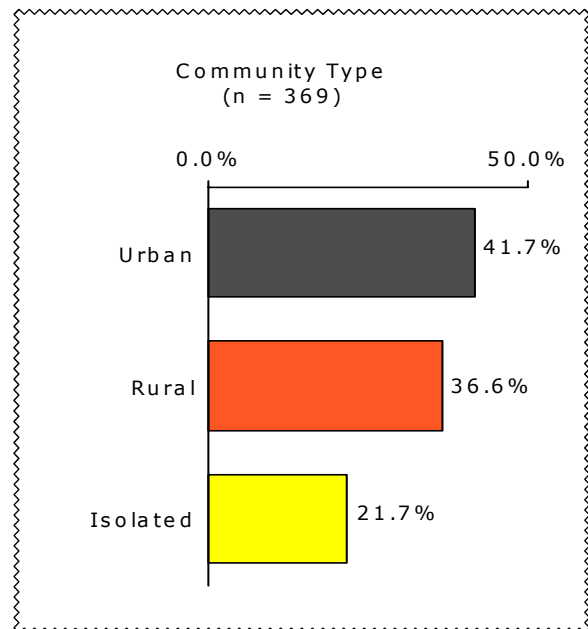
## 2. Participants & Perspectives

To give readers an opportunity to familiarize themselves with the study participants and their perspectives, this section introduces the Aboriginal women and providers who took part. It highlights information about consumer participants, their families and community life. It offers background on providers and the Aboriginal organizations which they represent. The section also presents a brief overview of participant perspectives on the health issues which affect Aboriginal communities.

### Scope

The Aboriginal women and providers who shared their views on health information represented over 100 Ontario communities and several locations outside the province; all consumers were currently accessing health services in Ontario. (See *Communities.*)

- ◆ Respondents lived in urban centres (41.7%); small towns and rural areas (36.6%); and isolated communities, accessible only by air



*Figure 1 - Community Type (Consumers & Providers)*

or winter ice-roads (21.7%).

- ◆ With a concentration from the central regions, the study surveyed women from the northern, southern, western and eastern parts of the province. Collectively, these areas are home to most of the province's 188,000 Aboriginal residents (Statistics Canada, 2003: 10).

## Communities Represented

- Alderville
- Antler River
- Atikokan
- Barrie
- Batchewana
- Bear Island
- Capreol
- Carleton
- Cedar Point
- Chippewa Nation
- Chippewas of the Thames
- Christian Island
- Cochrane
- Crystal Beach
- Cutler
- Desbarats
- Fort Albany
- Fort Erie
- Fort Frances
- Fort Severn First Nation
- Fort William First Nation
- Garden River
- Georgina Island
- Geraldton
- Gloucester
- Grassy Narrows
- Hamilton
- Hornepayne
- Ironbridge
- Kapuskasing
- Kenora
- Kettle Point
- Kingfisher Lake
- Kingston
- Lac LaCroix
- Lafontaine
- Lake Helen
- Lake Nipigon
- Lake Simcoe
- Little Current
- Lively
- London
- Magnetawan
- Manitoulin
- M'Chigeeng
- Michipicoten
- Midland
- Mishekeegogamang
- Moose Factory
- Moosonee
- Mount Bridges
- Muncey
- Munsee-Delaware Nation
- Naughton
- Niagara Falls
- Nishnawbe-Aski Nation
- North Bay
- Orillia
- Ohsweken
- Oneida Nation
- Orillia
- Ottawa
- Parry Sound
- Pays Plat First Nation
- Penitanguishene
- Perkinsfield
- Pic River
- Port Colborne
- Port McNicoll
- Rama
- Rankin
- Red Lake
- Red Rock
- Ridgeway
- River Valley
- Rockland
- Roseneath
- Rosspoint
- River Valley
- Sault Ste Marie
- Schreiber
- Seine River First Nation
- Sucker Creek
- Sudbury
- Sioux Lookout
- Six Nations
- Sudbury
- Taykwa Tagamou First Nation
- Temagami First Nation
- Thunder Bay
- Timmins
- Toronto
- Wabigoon
- Wabushene
- Wahnapiatae
- Wakefields
- Wapitanae
- Wawa
- Whitefish Island
- Whitefish Lake First Nation
- Woodstock
- Wyeville

*Figure 2 - Community Representation (Consumers and Providers)*

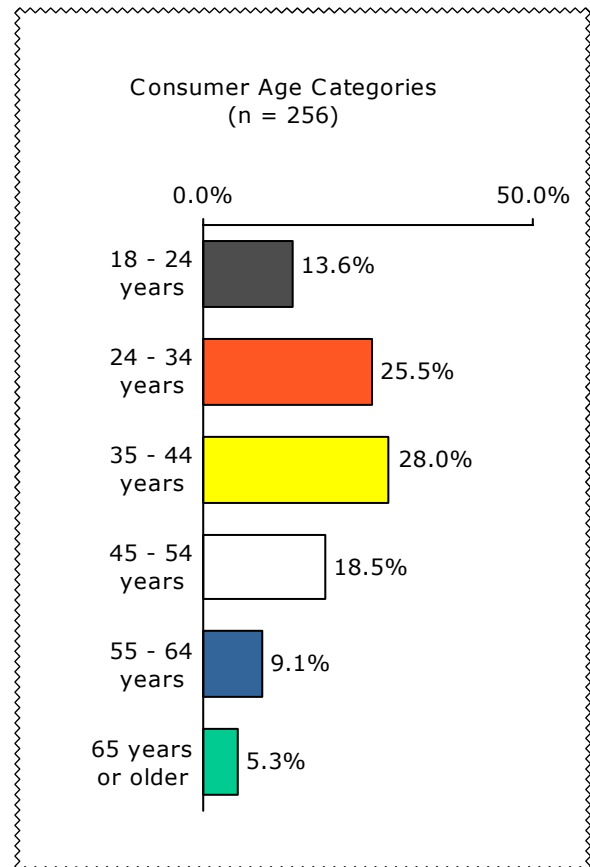
## Consumers

The consumers who took part in this study were drawn from a diversity of life situations. The project captured the views of women of varying ages, with differing types of family, work and community commitments.

### Age

While young adults and middle-aged women were well-represented, all ages participated in the study. The youngest woman who took part had just turned 18 years of age; the oldest was 81 years old. Of every ten women who stated their age:

- ◆ One was between 18 and 24 years of age (13.6%).
- ◆ Two were between 25 and 34 years old (25.5%).
- ◆ Three were between 34 and 44 years of age (28.8%).
- ◆ Two were between 45 and 54 years of age (18.5%).
- ◆ Two were over 55 years of age (14.4%).
- ◆ On average, respondents were 37 years of age.



*Figure 3 - Age Categories (Consumers)*

On the subject of age, the consensus was that while some health problems were more common at some ages than others, women of all ages were affected by the entire range of health issues that were experienced in their communities. A young woman, thinking about the situation in her own remote settlement, summed up the situation by emphasizing that *"all women in this community have these health issues."*

## Family

- ◆ The women who took part in this study were very much involved in their homes and family life.

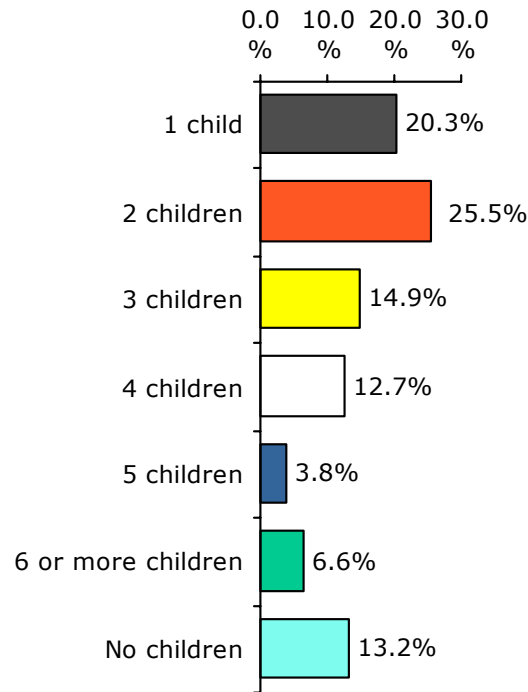
Most women were mothers; many were grandmothers or great-grandmothers. The extent of their immediate family commitments differed, however, often reflecting variations in family size:

- ◆ Most women had one (20.3%), two (30.5%) or three children in their care (21.5%).
- ◆ A minority had larger families, with four (15.3%), five (4.5%), six or more children (11.9%).
- ◆ Only a few respondents did not have any children (13.2%).

Those who commented on family responsibilities emphasized that their commitments often extended well beyond their immediate family. Many women not only cared for their own children, they welcomed their grandchildren, nieces, nephews and foster children into their homes. Women also took care of partners, parents and elders.

In talking about their lives, they made it clear that "family health" was their primary priority. Women emphasized that family health was the essential element required to establish and maintain a healthy community. They also felt that adopting a healthy family

Number of Children  
(Consumers, n = 212)



*Figure 4 - Family Size (Consumers)*

lifestyle was the key to addressing the health issues that affected their communities. Several participants shared thoughts similar to those of a young mother who said:

*Healthy family living is really important. Common health issues tie into healthy lifestyles.*

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## Work

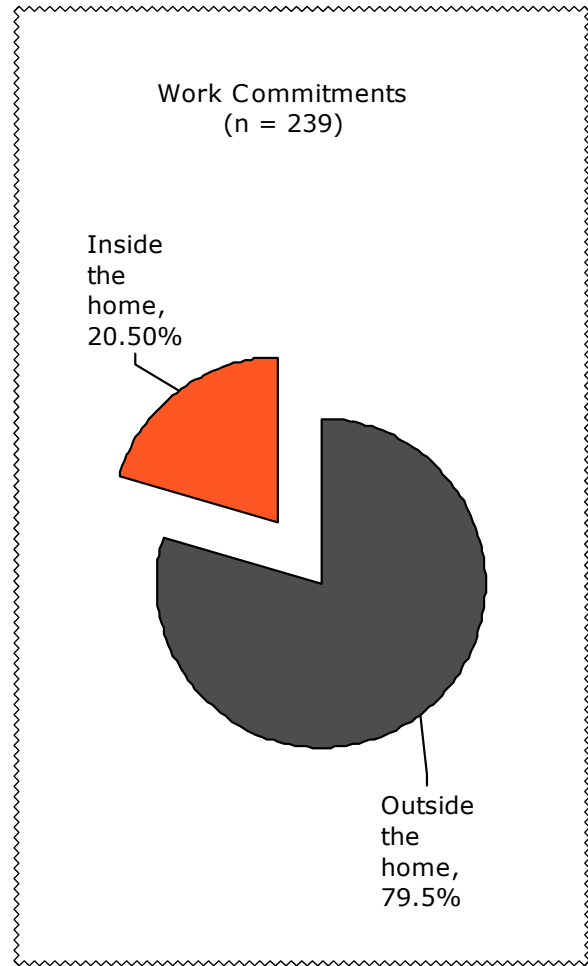
As well as their significant domestic responsibilities, most women worked outside their own homes:

- ◆ Eight in every ten worked outside the home (79.5%).
- ◆ One in five worked exclusively in their own homes (20.5%).

The women who discussed work outside of their homes were employed in a variety of occupations. They were administrators, analysts, technicians, and advisors; teachers, nurses, social workers and therapists; community care, health, home, mental health, childcare, youth and elder personal support workers; student advisors, educational assistants and school bus drivers; cashiers, retail clerks and waitresses; administrative assistants, secretaries, bookkeepers and accountants.

Women who resided in more populous areas of the province had access to additional employment opportunities, in factories, government offices, hospitals or long-term care facilities. Many also worked in restaurants and retail operations.

Some women were self-employed, working independently or with family-owned businesses. Others were employed as independent consultants and contractors. They included full-time and part-time workers. Some combined part-time employment with



*Figure 5 - Work Commitments (Consumers)*

education at college, university, or upgrading courses.

A number of women had been in the work force but were not currently employed. Some were looking for work; others had recently retired from the workforce, due to age, family commitments, or disability.

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## Community Activities

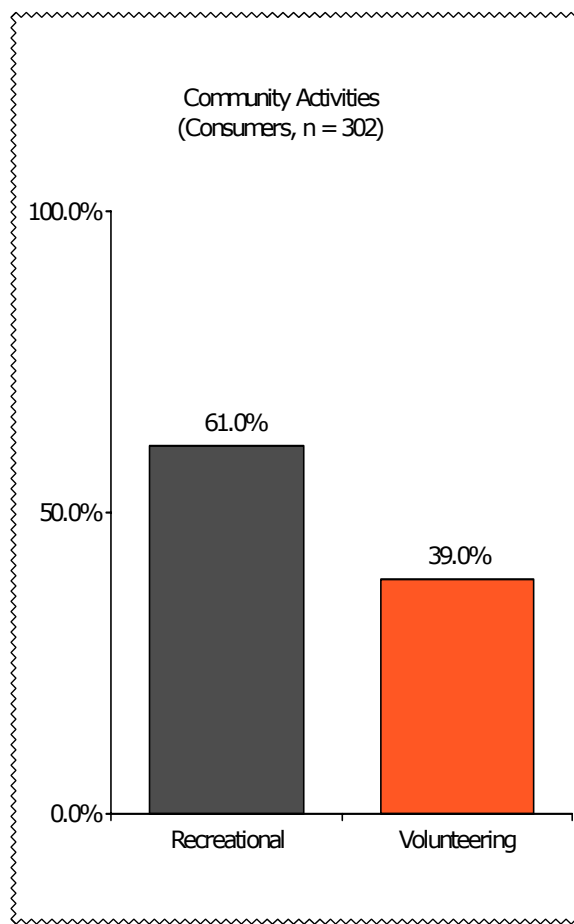
In talking about themselves, women made it clear that involvement in their communities was an important part of their commitment to a healthy family and work life. Of those who offered commented on community activities:

- ◆ Six of every ten women were involved in recreational activities (61.0%).

Those who took part in recreation enjoyed widely differing types of activities. Many women reported that they liked outdoor pursuits, including walking, biking, hiking, camping, fishing, hunting or skidding; other women were active with baseball, bowling, hockey, golf, soccer and volleyball, taking part themselves or supporting their children's participation; some preferred reading, listening to music or watching movies; others liked to attend the bingo games, craft classes, traditional dancing, feasts, seasonal celebrations and pow-wows that were a part of community life.

- ◆ Four of every ten also volunteered (39.0%)

Women took active roles on boards, committees and advisory groups. They supported their churches and other community programs for preschoolers, youths, elders and the disabled; they worked with food banks, housing programs, and community gardens; they also offered their time to healing



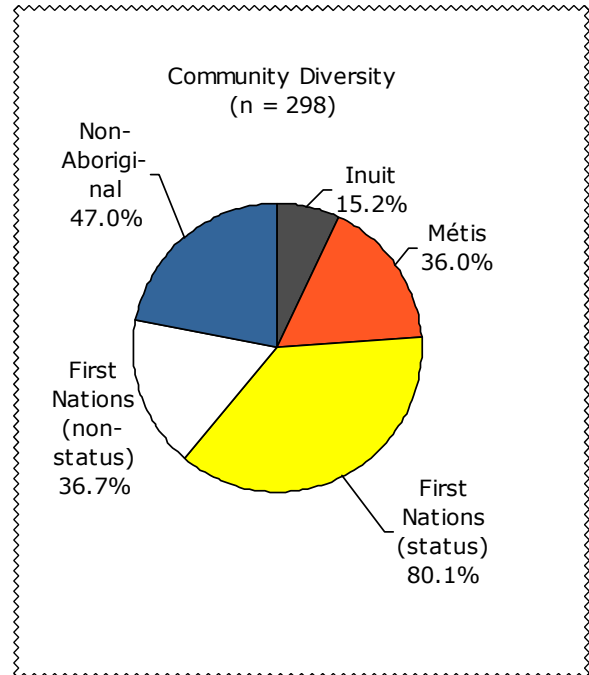
*Figure 6 - Community Activities (Consumers)*

centres, health clinics, hospitals, women's shelters and safe houses, youth groups, and diversion programs. They believed that volunteering was an important part of community life. They wanted to help others, taking an active role in ensuring that their community was a good place to live. They also wanted to "set an example" for their children to follow.

## Community Diversity

Aboriginal women also recognized cultural diversity in their communities, which typically had residents from two or more groups:

- ◆ Most women said that their communities had First Nations (status) residents (80.1%); significantly fewer reported First Nations (non-status) (36.7%), Métis (36.0%), or Inuit populations (15.2%).
- ◆ Close to one-half reported that their communities that had non-Aboriginal residents (47.1%).

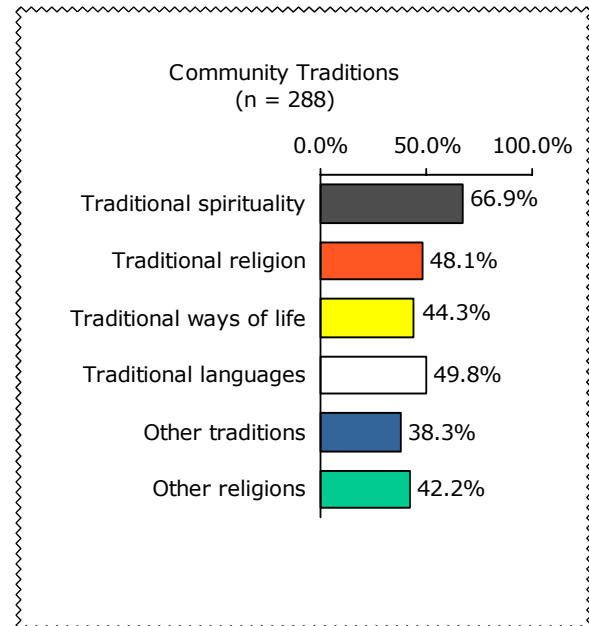


**Figure 8 - Community Diversity (Consumers)**

## Traditions

Aboriginal women also reported that traditions were being maintained in their communities. They indicated that some women in their community followed:

- ◆ Traditional spiritual practices (66.9%) and traditional religions (48.1%).
- ◆ Traditional languages (49.8%) and traditional ways of life (e.g., living off the land, hunting, fishing or trapping) (44.3%).



**Figure 7 - Community Traditions (Consumers)**

## Providers

The 54 providers who shared their views on Aboriginal women's access to health information represented a broad spectrum of First Nations, Métis and Inuit communities. Some organizations delivered services to a particular community; others supported a wider geographical area and more than a dozen communities:

- ◆ One in every four represented an Aboriginal Health Centre, Healing Lodge or Hospital (24.1%).

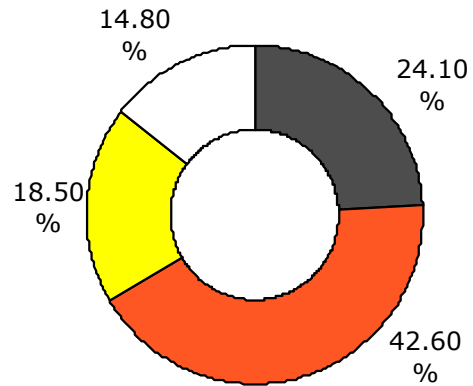
Aboriginal Health Centres offer comprehensive services including family medicine and nurse practitioner care, nutrition counselling, health education, mental health supports, and traditional healing. Healing Lodges offer traditional and contemporary healing for addictions and other dysfunctions, both through residential and outpatient care.

- ◆ A significant number represented Friendship Centres (42.6%).

Aboriginal Friendship Centres, located in metropolitan areas, cities and larger towns, support Aboriginal families with education, justice, wellness and health outreach programs, for mothers, children, youth and seniors.

- ◆ The remainder were associated with community based health and

Providers  
Type of Organization  
(n = 54)



**Figure 9 - Organizations Represented (Providers)**

social service agencies (18.5%) or tribal councils (14.8%).

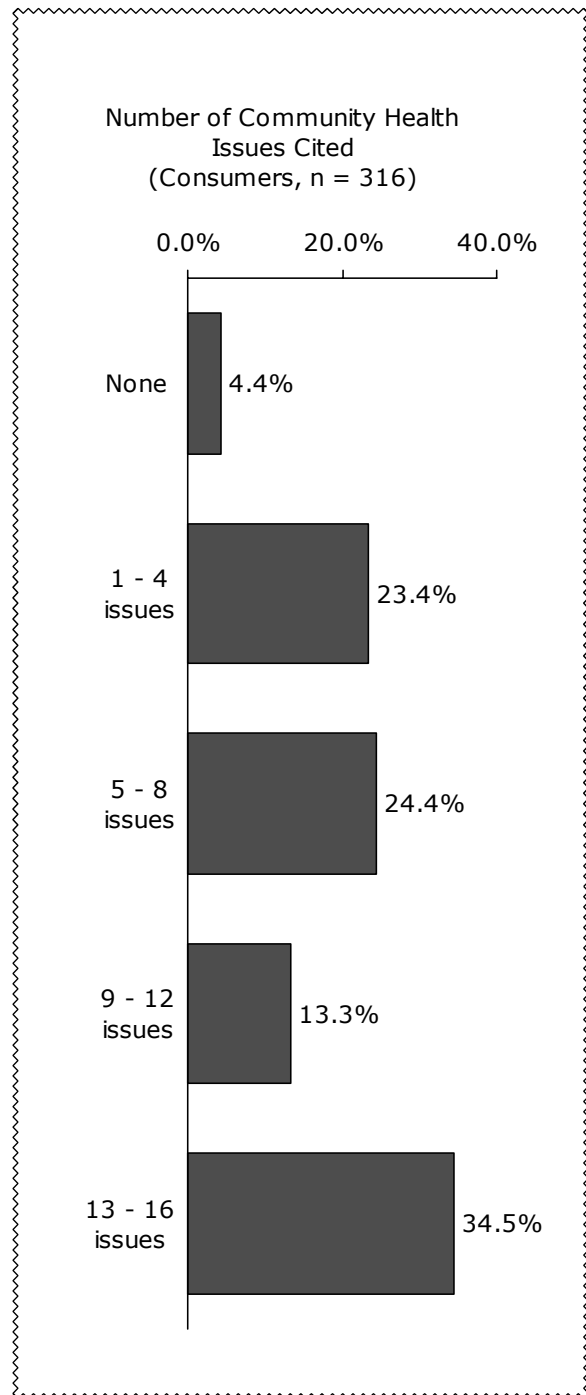
Community-based agencies provide health administration, education, and referral supports. Tribal councils facilitate dissemination of health information and health program development.

# Community Health Issues

To assist in understanding the health issues currently affecting Aboriginal communities, we asked respondents to tell us about the health matters which they faced on a daily basis. Almost all participants surveyed identified several different issues that were of concern to their communities:

- ◆ One-third (34.5%) of the women surveyed felt that the entire spectrum of health issues was important; these women cited more than a dozen issues as current concerns.
- ◆ On average, women identified eight health problems that were important to their communities. Providers made similar observations, reporting an average of nine serious health conditions affecting the communities that they served (not shown)

Aboriginal women and those who provided their care were in agreement that communities were affected by a wide array of health problems, including serious illnesses, mental health conditions, lifestyle concerns, women’s and children’s issues.



**Figure 10 - Number of Issues Cited (Consumers)**

- ◆ A significant number of women and providers gave examples health issues negatively affecting the health of Aboriginal communities (44.1%).
- ◆ They specifically cited over 100 problems currently seen in their communities. (*Figure 11*).

They emphasized it was important to recognize that their communities experienced the entire spectrum of health problems, everything from minor ailments through life-threatening conditions.

It also was insufficient to look at one problem or one disorder in isolation. The health issues experienced by communities were inter-related, complicated by lack of local resources and difficulties accessing care at a distance. Just getting to a doctor, for example, was a serious problem in many locations, because there were no physicians practising in the communities.

Finding appropriate health information was even more of a challenge. The consensus was that "Aboriginal people face all of these health concerns in one way or another" at many points in their lives.

### **Community Health Issues A - F**

- Abuse
- Alcohol abuse
- Allergies
- Alzheimer's
- Amputations
- Anxiety
- Arthritis
- Asthma
- Attending to health problems early
- Baby blues
- Back problems
- Bladder infections
- Bladder incontinence
- Breast cancer
- Budgeting
- Cancer
- Cervical cancer
- Child abuse
- Child neglect
- Child poverty
- Child safety
- Chronic pain
- Cocaine abuse
- Colds
- Colon cancer
- Constipation
- Contraception
- Depression
- Diabetes
- Dialysis
- Diarrhea
- Disabled children
- Disadvantaged children
- Domestic violence
- Drug abuse
- Emergencies
- Emotional well-being
- Endometriosis
- Environmental illness
- Eye health
- Family counselling
- Family violence
- Fetal alcohol syndrome
- Fibromyalgia
- Finding a doctor
- Fitness
- First Aid
- Flu
- Foster parenting
- Gambling
- Getting to a doctor early
- Getting to know your doctor
- Glaucoma
- Grieving

***Figure 11 - Community Health Issues (Consumers & Providers)***

## **Community Health Issues H - Y**

- *Headaches*
- *Healthy eating*
- *Healthy relationships*
- *Heart attacks*
- *Heart disease*
- *Hepatitis*
- *High blood pressure*
- *HIV/AIDS*
- *Homelessness*
- *How to ask for medical help*
- *How to access family physician on-reserve*
- *Hunger*
- *Infections*
- *Kidney disease*
- *Knowing your body and symptoms*
- *Lack of Aboriginal health professionals*
- *Lack of doctors*
- *Lack of education*
- *Lack of emergency care*
- *Lack of employment*
- *Lack of fresh foods*
- *Lack of front-line workers*
- *Lack of health care information locally*
- *Lack of income*
- *Lack of support*
- *Lack of recreation*
- *Lack of treatment*
- *centres*
- *Lack of transportation*
- *Lactose intolerance*
- *Learning disabilities*
- *Meningitis*
- *Mental health*
- *Miscarriages*
- *Multiple sclerosis*
- *Obesity*
- *Overeating*
- *Over prescribing drugs*
- *Palliative care*
- *Panic attacks*
- *Pap tests*
- *Parkinson's disease*
- *Pneumonia*
- *Pollution*
- *Poor eating habits*
- *Poor quality of health services*
- *Post-traumatic stress disorder*
- *Poverty*
- *Pregnancy complications*
- *Rheumatoid arthritis*
- *Safe sex*
- *Seizures*
- *Self care*
- *Self-inflicted injuries*
- *Sexual assault*
- *Sexually transmitted diseases*
- *Smoking cessation*
- *Stress*
- *Stroke*
- *Substance abuse*
- *Suicide*
- *Stillbirths*
- *Support groups*
- *Teenage pregnancy*
- *Thyroid conditions*
- *Tobacco use*
- *Trusting doctors*
- *Water pollution*
- *Weight problems*
- *Wellness*
- *Women's health*
- *Women's mental health*
- *Women's wellness*

**Figure 11 - Community Health Issues (Consumers & Providers)**

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## Summary

Looking at the data in more detail, it is apparent that serious illnesses were a concern for most communities. While the importance placed on specific disorders varied from one individual to another, there was consensus that these disorders were widespread:

- ◆ Diabetes is the most generally recognized concern, cited by 8 of 10 respondents (84.5%)<sup>4</sup>.
- ◆ Other serious illnesses, such as cancer, arthritis and heart disease, were reported by 6 in every 10 (66.4%, 58.8%, 57.6%).
- ◆ Lung conditions, such as asthma, bronchitis and allergies, while a lesser concern, were cited by one of two respondents (50.3%).
- ◆ Digestive disorders, including food intolerances, were an issue for a minority of participants (37.0%).

Looking around their communities, women and their health care providers also were aware of the need to maintain a healthy lifestyle. They saw

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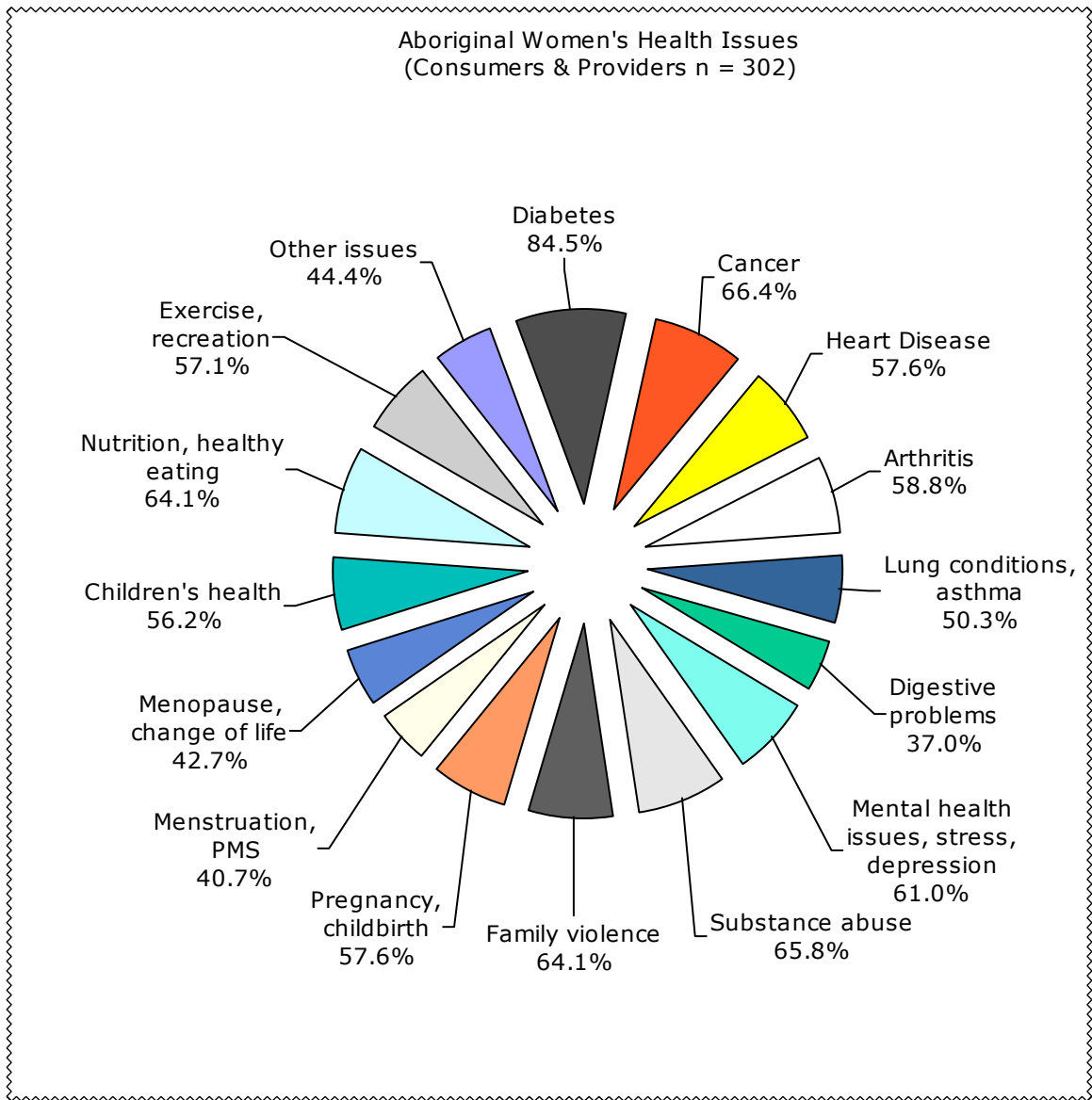
<sup>4</sup> Multiple response analysis, % based on the total number of respondents offering information in at least one category in the set.

associations between lifestyle issues and serious illness and recognized that their communities experienced:

- ◆ Problems with nutrition and healthy eating were reported by two in three respondents (64.1%).
- ◆ Inadequate exercise and lack of recreational opportunities were community health concerns for 6 in 10 respondents (64.1%, 57.1%).

As well, there was acknowledgement that Aboriginal communities are equally affected by ongoing health issues that are directly or indirectly related to mental health. Most respondents identified a cluster of problems in this area:

- ◆ Substance abuse and family violence were reported as community concerns by two in three (65.8%, 64.1%).
- ◆ Stress and depression were equally important (61.0%).
- ◆ Respondents also placed emphasis on the health problems of women and children. Specifically:
- ◆ One in two respondents reported problems related to pregnancy and childbirth-related (57.6%), along with children's health (56.2%).
- ◆ Menopause and menstruation were a concern recognized by many women and health care providers (42.7%, 40.7%).



**Figure 12 - Summary - Community Health Issues (Consumers & Providers)**

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## 3. Needs

A cornerstone of this study was an assessment of Aboriginal women's needs for specific types of health information. Previous studies suggested that relatively little is known about the health problems that affect Aboriginal women (Lavallee & Bougault, 2000) and their children (Harris, Glazier, Eng & McMurray, 1998). Available data, however, suggest that Aboriginal women in Ontario have poorer health status than women in the general population (Grace, 2003). Their health, moreover, is reflective of the health issues faced by their families and communities (Dion Stout, Kipling & Stout, 2001).

To this end, respondents were invited to discuss the health matters which their communities face on a daily basis and the information which was available on these concerns. They were also asked to identify their needs for generalized and specialized health information. Discussions centred around specific issues identified in the literature as important predictors of the health status of Aboriginal populations (Young, 2003; MacMillan, MacMillan, Offord & Dingle, 1996).

### Research Questions: Needs

Thinking about your community, what are the most common health issues that women face every day? (If so, what kinds of health information are needed?)

- *diabetes, cancer, heart disease, arthritis*
- *lung conditions/asthma, digestive problems*
- *mental health, substance abuse, family violence*
- *pregnancy/childbirth, menstruation/PMS, menopause/change of life*
- *children's health*
- *nutrition, exercise/recreation*
- *other issues (please explain)*

Are there any women in your community who have special health needs? (If so, what types of information do they need)

- *Women with disabilities, HIV/AIDS, eating disorders*
- *Women caring for small children, elders*
- *Teens, Elders, Others (please explain)*

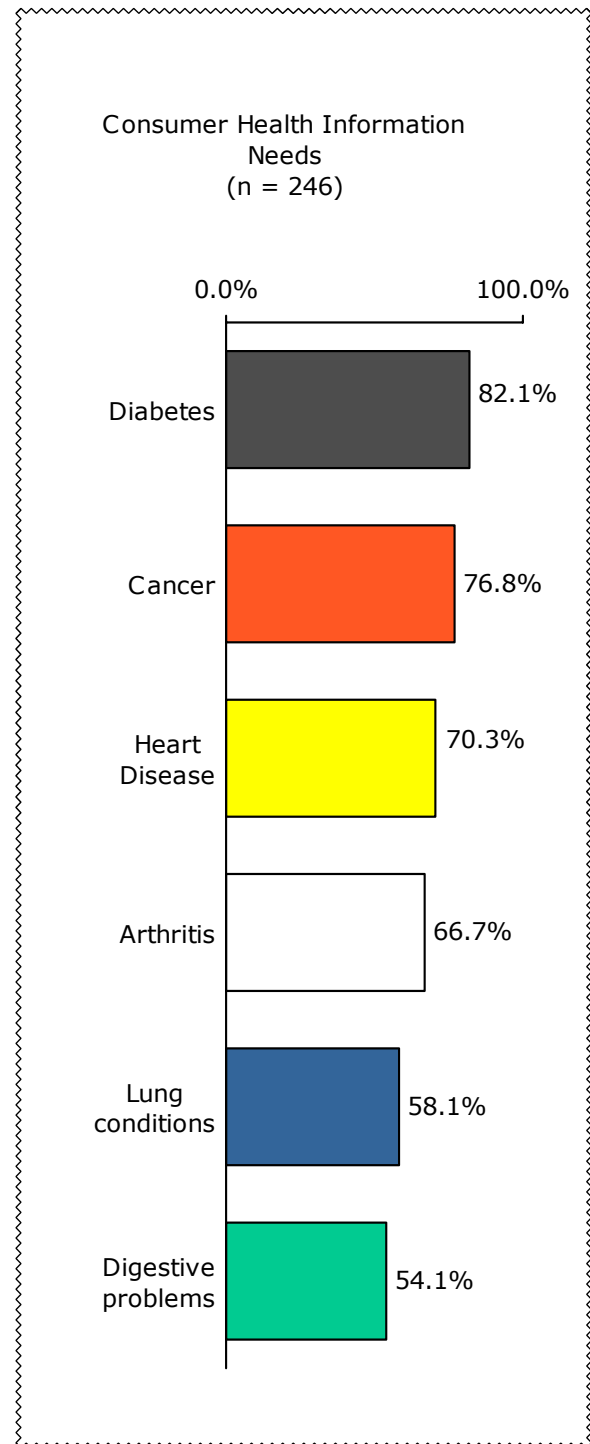
## Serious Illnesses

In discussing their health information needs, women repeatedly emphasized the need for additional information resources to assist community residents who were coping with serious illnesses. Their most immediate concern was to obtain information that would help them understand and control diabetes, which affected increasing numbers of Aboriginal women, men and children:

- ◆ Eight in every ten women placed priority on having information on diabetes (82.1%).

Those who talked the need for enhanced information on diabetes were especially concerned when they saw pregnant women and young children developing the disease. They were especially anxious about the numbers of younger people being diagnosed and feared that their own children were at risk.

They were also concerned about getting more accurate information about the complications of diabetes, including heart problems, high blood pressure, and kidney failure, along with the disabilities caused by amputations. People who had diabetes required specialized information so they could stay healthy:



**Figure 13 - Needs - Serious Illness (Consumers)**

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*We need more information on diabetes and how to keep ourselves healthy. Such as foods to eat and exercise. It is very important for those in the community.*

Women also were alarmed by the rising numbers of people in their communities who had been diagnosed with cancer, arthritis, heart disease, and lung conditions, such as bronchitis, emphysema and asthma. Some respondents also noted increasing numbers of people with digestive problems and intolerances:

- ◆ Three-quarters identified a need for information about cancer (76.8%).
- ◆ Two-thirds wanted enhanced information about heart disease and arthritis (70.3% and 66.7%).
- ◆ One-half also needed specialized materials about lung and digestive problems (58.1% and 54.1%).

Discussions that occurred in focus groups and talking circles revealed that women were very worried about the fact that these conditions, which they believed had been relatively rare a generation ago, were now becoming common. They were concerned about the numbers of young people who were developing diabetes. They were also alarmed by knowing people who had been diagnosed with cancer; for women, breast and lung cancers were particular concerns:

*They're getting diabetes, which was unknown. They're getting cervical cancer. They weren't that when they were kids. Now we're having to face that. . . The only thing that I heard about when I was growing up was TB. . . . But now, they are getting more diabetes and cervical cancer, breast cancer.*

## **Environmental Health**

- ◆ In their discussion of serious illness, Aboriginal women were very concerned about the lack of environmental health resources.

The absence of environmental health information was a serious gap in the health resources which were available in the communities. They needed information that would help them to identify and address environmental health problems.

They were especially concerned about the hazards of long-term exposure to toxic chemicals in the food and water supply. Rural and remote locations were most seriously affected, because they still depended on traditional food supplies and had minimal water treatment facilities. Residents needed to know which foods and water could be used safely and which were not to be used. Communities which followed traditional hunting and fishing

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lifestyles needed to know what was safe

*There is a strong sense to hunt and fish in the community. The only concern that the hunters and fishers have is the quality of meat that is out there. If it is the same as before, with all the pollution and everything? Now, they can't eat all the fish.*

Women from communities which were built near the sites of former mines or military installations saw a need for information on environmental contaminants and cancer, neurological and skin disorders. An Inuit woman told about the serious health problems that were experienced when people lived in a toxic environment:

*Coming from High Arctic, mining community ...United States set up their line bases ...didn't know what to do with the PCB, so they mixed with paint and painted the homes ...It's very chemical, contaminated environment. Many of our people are dying with unknown cancers ...Also the women who move into that community ... have eczema infections. It doesn't heal, on your hands or on your feet .... I had no knowledge that it came from the land or the chemical pollutants.*

In other locations, women saw a connection between contaminants in the water supply and illness,

specifically the high rates of cancer occurring in their communities. They wanted to know more about these issues, so they could take the steps needed to address the problems:

*Recently people getting cancer has been high and this is because of the running water people drink are contaminated ... The high school tested our water system and did a little experiment. What they found was that [pollution] was at a dangerous level.*

Environmental contaminants also appeared to be linked to respiratory problems in some communities. Women from these areas reported that their children had increasing difficulties with allergies, asthma, and infections. Study participants associated these illnesses with mould and water damage in their homes, schools, community centres and other buildings. They needed community-specific information to assess and deal with these problems now, so their children didn't experience more serious health effects later on:

*A lot of our kids, our next generation ... have asthma because of the environment they live in, their community ...in the long term, it will affect them in their lives ...All of this is necessary.*

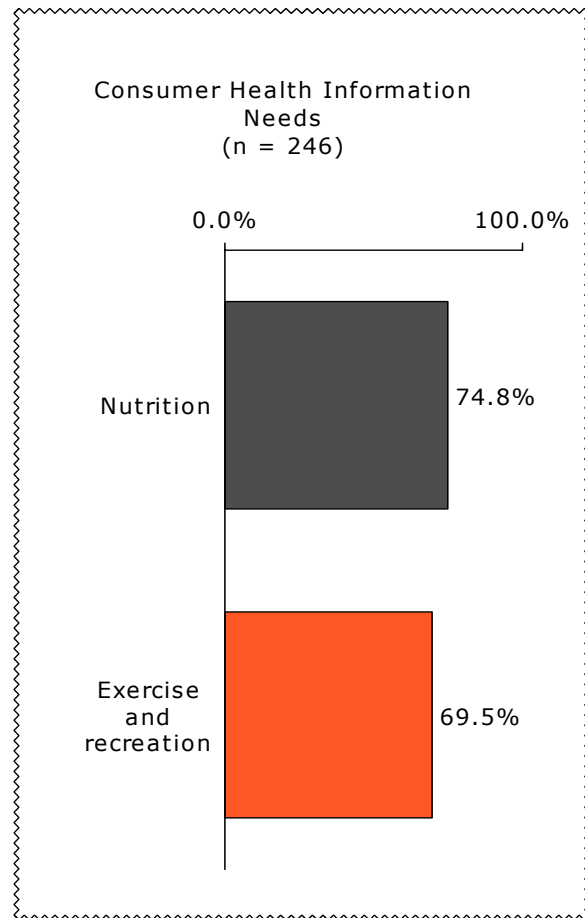
## Healthy Lifestyles

In discussing serious illnesses, women believed that their families and communities were not getting adequate preventive information about the importance of healthy eating and regular recreation:

- ◆ Seven of every 10 women wanted improved information on nutrition and exercise (74.8% , 69.5%).

Preventive information about the importance of good nutrition and exercise was a priority for people of all ages. Women were especially worried about the numbers of people, including children, teens and young adults who were overweight and inactive. They knew that obesity and lack of exercise were health risks, and, acknowledging this, wanted to make sure that their communities had the information needed to address these problems.

Their goal, as individuals, families and communities, was to learn “healthy ways.” Many respondents suggested that specialized outreach programs would work best, because they could encourage individuals, families and communities to adopt better eating and exercise habits. Thinking about her own history, a woman emphasized the need to include individualized



**Figure 14 - Needs - Healthy Lifestyles (Consumers)**

information and counselling:

*I have diabetes and heart problems in my family ... I myself have gained a lot of weight and that is an issue for me as well and I don't want to end up in the same situation as my mother ... I try to eat healthy .. I know they have the workers there but not necessarily reaching out.*

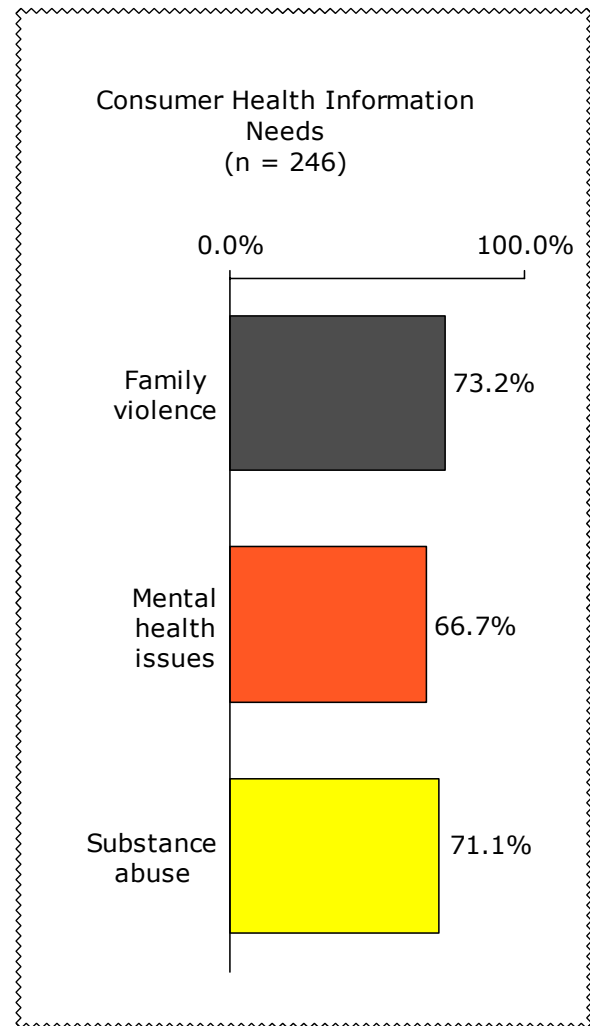
## Mental Health

Most participants recognized a need for information about mental health issues, which impaired family and community life. They also needed resources to assist them in managing stress and depression which occurred in their own lives. Specifically, they wanted resources on:

- ◆ Family violence (73.2%).
- ◆ Substance abuse (71.1%)
- ◆ Stress and depression (66.7%).

In discussing mental health, women emphasized that their priority was for practical information that would help them cope with everyday issues, including anxiety. They also needed preventive information to help them recognize mental health issues before they became serious. Women's lack of knowledge about mental health contributed to their personal stresses:

*There's lots of it. ...you got to worry about everybody else's health. You're putting a lot of extra stress on your body, and yourself and you're affecting your insides. ...We don't even think about those things that are affecting us.*



**Figure 15 - Needs - Mental Health (Consumers)**

- ◆ Augmented information on substance abuse and related programming was another priority.

As a woman said, these problems could happen "anywhere .. substance abuse is pretty big." While some areas had well-established programs to help people, there were many localities in

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which programs were lacking entirely. As a result, there were inconsistencies in the types of information available. Some areas had information about alcohol abuse, but nothing to help with drug abuse. Other locations had information about specific types of substance abuse, but not others.

- ◆ A related issue was the fact that Aboriginal mental health services did not usually have resources designed specifically for women.

Ideally, there was a need for a range of pamphlets or videos on mental health problems. They wanted more resources for women who were coping with substance abuse and family violence. They also needed specialized mental health resources that would explain stress, anxiety, depression, or panic attacks from an Aboriginal woman's perspective. Speaking about her own needs, a woman said that having better information about mental health issues was an essential first step:

*I could have some more information about mental health ... Whatever happens in your life, you know, you can function but you need to be mentally and emotionally healthy and you have to understand that if you don't have those things that it just makes everything else much more difficult.*

They also needed to know how to access emergency mental health

services and ongoing care, if none were available locally:

*How to access emotional and mental health care ...how to receive help on that is very important ...and trying to find services on that.*

Information on accessing mental health care was essential in smaller communities that lacked on-site services. Sharing her story, a young woman from a rural community said:

*I had to go to another town four hours away to access those services. I come back here and there is barely any of those services, especially for someone my age.*

The priority was knowing where the mental health supports were, how to access them and, in an emergency, how to get immediate attention. There were serious risks entailed, if help was not reached soon enough. Relating how she tried to get help for her young daughter, a mother emphasized how difficult things were if mental health care was lacking locally:

*My daughter was 12 and very depressed and was told by doctors that it was adolescent depression. It was in her chart and not followed up. I had to go after them for them to see her. She attempted suicide a couple of times. They kept her overnight and no help for follow up from any of the community*

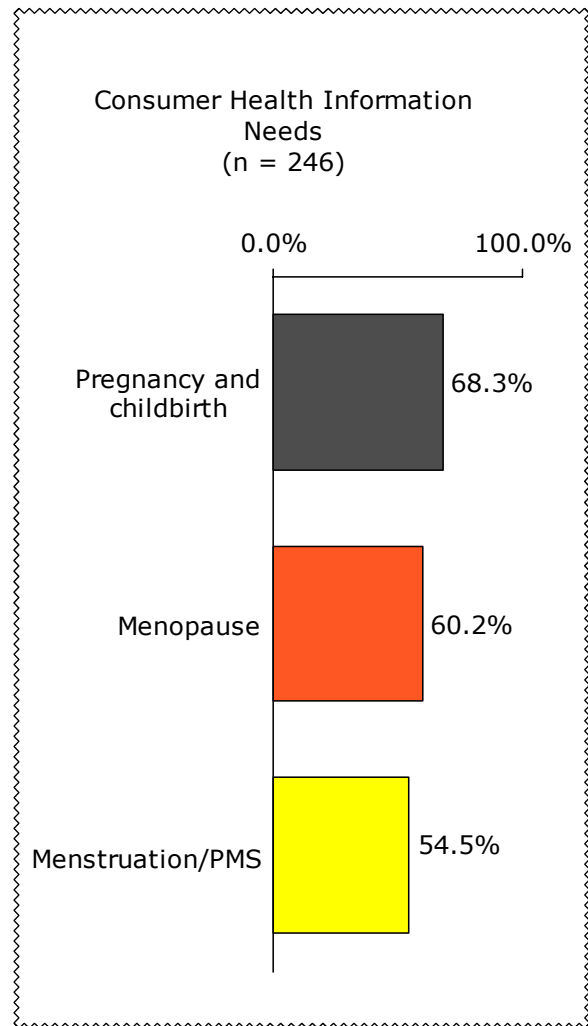
*counselling and addiction services. They never did see her and I couldn't believe it .. I was frustrated with them and finally asked them if they were going to do something about it when I found her dead ... I was told not to question that ... There needs to be more services in regards to mental health and substance abuse. When you see the Doctor, that is where they are going to refer you and they will see you but don't follow up? Then what? Your problem is still there. Where can these people go?*

## Women's Health

Women were equally concerned about the lack of information about their own health. They needed resources on:

- ◆ Pregnancy and childbirth (68.3%).
- ◆ Menopause (60.2%)
- ◆ Menstruation, including problems related to premenstrual syndrome (54.5%).

On these topics, the resources which were available in their communities on reproductive health issues were often not current. They needed accurate, up-to-date pamphlets, posters and videos that were easy to understand. These materials would help them



**Figure 16 - Needs - Women's Health (Consumers)**

understand what was normal or not, so they knew when they should seek professional care. They also wanted additional specialized resources that were age-specific, on the health problems experienced by their daughters, sisters, and other women in the communities.

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## Pregnancy & Childbirth

- ◆ Regarding pregnancy, they wanted more information on problems such as miscarriages and premature birth.

These resources were needed so women had enough information to recognize difficulties and seek prompt medical attention:

*More information on miscarriages and why they occur. There is no information out there and women think it is their fault. This happened to me three times from when I first had my first child who is eight to my last who is two years old. I did not know why this was happening and I didn't receive proper medical treatment.*

Women also wanted more information about midwifery as a childbirth option. They welcomed the possibility of having midwives who were familiar with Aboriginal ways, beliefs and traditions. Those who had been attended by midwives were positive about the experience for mother, baby and community:

*There are many women in the community that have taken midwives as their health care during their pregnancy. For myself, I did have a midwife.*

*And I think that it is a great way for women to really get in touch with women being a mother, and to really have a positive experience birthing, and having and raising their children by midwifery... I would encourage more women in this community to take that step ... it's a really positive way as women we could celebrate our ability to have children, to raise children.*

## Birth Control & Hormone Replacement Therapy

- ◆ Current information on the long-term side effects of birth control pills and hormone replacement therapy was needed.

Women had difficulty with available information on birth control and hormone replacement therapy, which often was too complex to understand. Not understanding increased their fears that taking these medications would increase their risk of cancers. They needed easy-to-read written materials, videos and individual health teaching to make sure that they understood the benefits and risks of taking these medications. Several women said how they appreciated the explanations from pharmacists who were willing to answer their questions and understood their situation:

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*They should have something, so people aren't left wondering what those big words mean. I find that there are a lot of questions unanswered. I find that the guys at the drugstore, they're very nice. They're good at sharing information. They sit with you and look at you and they go over what it is. "This is how you take it, and it's for this." .. and you understand ... Those kinds of relationships have to be developed.*

## **Self Care**

- ◆ Participants emphasized how important it was for Aboriginal women to learn how to take care of themselves.

Women needed to value themselves and learn more about wellness, so they could take the steps which were needed to assure a healthy life. It was important to learn about self-care "early in life .. rather than waiting 'til it is harder to change." A health outreach and advocacy worker said:

*Women, particularly Aboriginal women, need to realize how important they are and in need of looking after themselves. They put family first, without realizing in order to look after their families, they need to be alive and healthy.*

## **Women With Disabilities**

- ◆ There was almost no information available in Aboriginal communities for women who are disabled and their caregivers; two-thirds of consumers saw this as a need (68.6%).

Women with disabilities were often housebound, without transportation, and, as such, experienced difficulty in accessing the specialized supports needed to ensure full participation in community life. They also often could not participate in health initiatives, such as group education sessions. As well, they needed to know how to access practical assistance and services, that would help them with daily activities.

Knowing how to get home supports, assistive devices, and transportation was important, along with where to go to access specialized rehabilitative care, when such care was lacking in their communities. In addition, they required information about managing their condition, controlling pain, adjusting to their disability and coping emotionally. Speaking from her own experience, a woman with diabetes said information was especially critical when people were newly diagnosed:

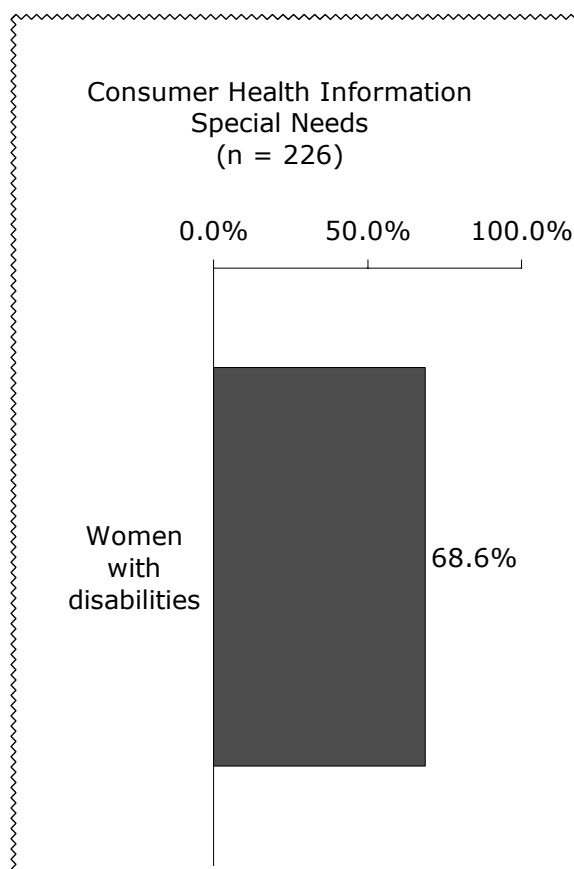
*I ended up in a wheelchair two years ago when my leg got infected. I was on pain killers but they did not help. When I*

*was first diagnosed, I had lots of questions. "What types of help you needed and why me?" Being sick was all new stuff to learn, to live with. When I went through diabetes, I was in denial. I still eat what I'm not suppose to eat. ...The first diagnosis is hard on a person.*

As well, women with disabilities required innovative ways to access health information. Women who had mobility problems, for example, were unable go into the community for workshops and could not, in most cases, access information unless it was delivered directly into their homes. They thought community health representatives, personal support workers or health outreach workers, who already provided home services, could assume a health teaching role:

*Home visits would help a great deal. Many women, children and families can't always get out to attend education events and many are housebound or are shy to ask questions. Home visits are one way to reach people and gives the personal touch that shows concern and caring.*

They also suggested special transportation, accessible locations and having support persons present would make women with disabilities had the option of attending health education sessions:



**Figure 17 - Special Needs - Women With Disabilities (Consumers)**

*Women with disabilities in my community are quite common and really there is nothing out there for Aboriginal women, where to go, how to get help, who's got the voice ...who's got the voice for disabled people in the community, there doesn't seem to be one.*

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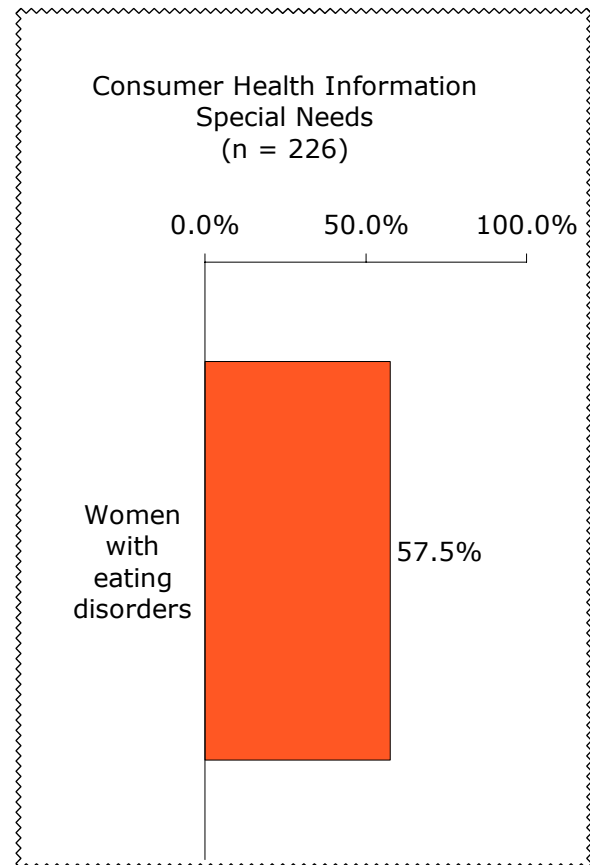
## Eating Disorders

- ◆ There was also an absence of Aboriginal-specific information for women with eating disorders; one in every two saw this as an issue (57.5%).

Many participants personally knew women who were struggling with eating disorders. Some were anorexic or bulimic; others had problems with over-eating. A young woman who had recently moved to an urban area, noticed Aboriginal women were dissatisfied with their body image and needed to hear positive messages:

*I haven't been here that long but I knew a lot of women with eating disorders. It's all because of commercials and stuff to keep up with that image that's portrayed. It's pretty ridiculous and shouldn't be that way. It should be talked about more to make a woman feel better about herself.*

As a woman who had an eating disorder said, "First Nations culture likes to eat and people did not understand why I did not." She recommended "nutrition and exercise for young women need to be culturally advertised." Others emphasized the need for culturally appropriate healthy lifestyle supports:



**Figure 18 - Special Needs - Women With Eating Disorders (Consumers)**

*The biggest daily health issue I think that women deal with is with nutrition and exercising .. if they had better support workers or nutritionists on or off-reserve, the problems wouldn't be so high. We used to eat traditional foods and I grew up on it .. in the last 18 years, I haven't done that .. So we're not eating our traditional foods and I think that's a big issue.*

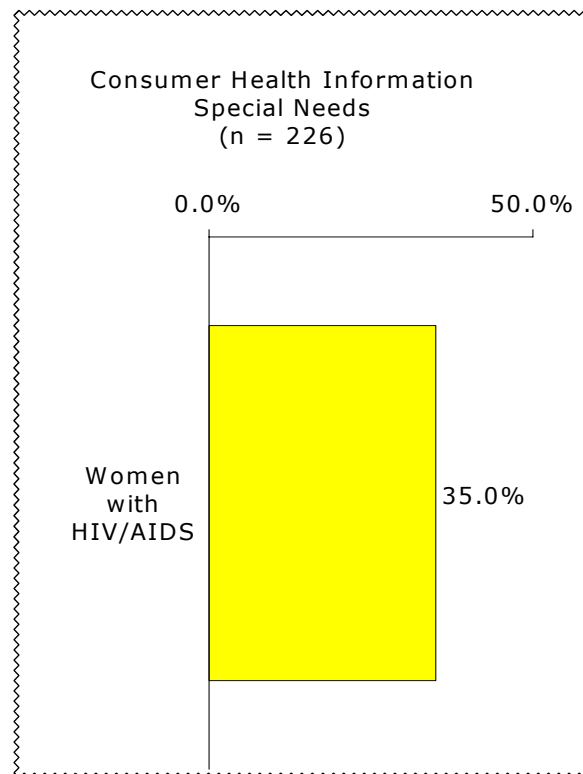
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## HIV/AIDS & Healthy Sexuality

- ◆ Although just one in three women saw needs for special information to assist people with HIV/AIDS (35.0%), there was widespread agreement that Aboriginal communities needed better information on healthy sexuality.
- ◆ While individuals of “all ages” needed to hear messages about healthy sexuality, the priority was sexual health resources for teens and young adults.

Youth needed better access to information about sexually transmitted diseases, such as HIV/AIDS, chlamydia, and human papillomavirus (HPV), because these conditions were being diagnosed even in the most isolated areas. Young women also did not know about links between STDs, impaired fertility and cancer. Summing up her thoughts, a woman from a small city said:

*We have to remember those young women ... health sexuality. It's a very big thing and should be taught in schools. They don't know that if you contract STDs you can get cervical cancer. This information isn't hardly, if not at all, available for the youth. ...There has to be more education on that area.*



**Figure 19 - Special Needs - Women with HIV/AIDS (Consumers)**

Study participants also emphasized the need to inform youth about the health risks of very early pregnancy and “babies having babies.” A young woman said:

*There are so many young woman, including myself, with young babies, had I had the information and access to these programs, things could've been a lot different.”*

Information about pregnancy risks should be developed specifically for older children and teenagers to be effective. Videos were thought to be

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very effective because they gave “a perception of what is going on.” There was also value in producing materials highlighting the combined risks of sex and substance abuse:

*There should be more that cover more areas .... maybe more on substance abuse. A lot of them go out and drink and end up getting pregnant. Maybe if they had more information, this would be prevented ...Although the information is there, it's not necessarily reaching the target.*

Ideally, information on sexual health for teens should be given by younger persons, because teens would feel more comfortable asking questions of someone close to their own age. This supports would also help when youth needed to go to a clinic for care:

*Would have to be given by a young person. They are likely to trust someone closer to their age group. A youth with these training tools would have an easier time to bring in those youth and teach them healthy sexuality. Someone who can go to the doctor's office with you and give you encouragement to get a pregnancy test or even an STD test.*

Other respondents felt that telephone or Internet resources could be an equally effective way of delivering information about healthy sexuality. Those who were comfortable with the

technology, appreciated the confidentiality offered. Telephone resources also could meet needs of people who had literacy problems. A woman from an urban area said:

*I'd also like some kind of hotline phone-in for teens who are illiterate, who can't read and write because all this stuff comes in pamphlets or brochures .. if they had someplace for them to call, like a hotline, it might be a lot easier for teens to get information and .. they love using the phone!*

As well, teens really did not have any way of getting information or asking questions about relationship issues. There was also a need for more open discussion about emotional and social aspects of sexual relationships:

*I really think they should promote healthy sexuality for young teens. That is the age where they are starting to develop relationships. Teach them that's it okay to lead a certain lifestyle. We don't have a lot of that around here. There are a lot of gays in this town that are targeted and not a lot of information for them to lead healthy lifestyle .. They teach you stuff in school and give you a diagram but you are not allowed to question certain topics.*

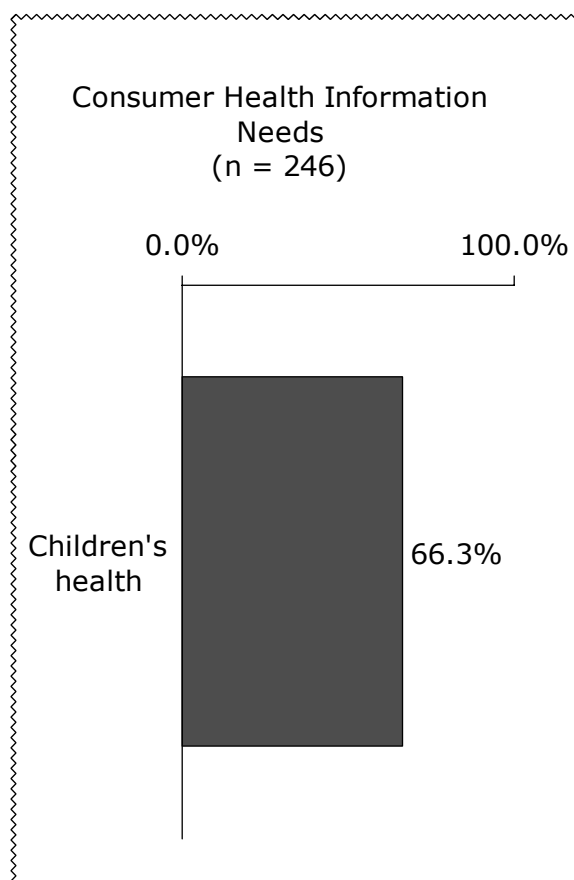
- ◆ Communities also needed to explore innovative approaches to overcome reluctance to discuss healthy sexuality.

Focus group participants said that “people are too shy to talk about it, like it’s a really bad thing.” They emphasized the need for positive messages that would show “to be careful means that you are doing something good and healthy for yourself.” Information on healthy sexuality also needed to be “more accessible and culturally appropriate,” ideally developed through collaborative partnerships between Aboriginal organizations and health agencies.

## Children’s Health

- ◆ Two-thirds of women surveyed (66.3%) placed priority on obtaining information about children’s health.

Aboriginal women told us that their communities often struggled to find appropriate resources to assist them in caring for their children. There just wasn’t enough information available and what was available, often was too generalized to be useful. They needed a variety of resources, on parenting skills, safety, nutrition and care of children with special needs.



*Figure 20 - Needs - Children's Health (Consumers)*

## Practical Parenting

- ◆ Caregivers needed workshops on parenting skills and practical age-specific parenting information. Information for caregivers of small children was especially important; two-thirds of women surveyed saw this as a special need (69.5%).

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First-time parents required special assistance in caring for newborns and toddlers, everything from practical advice on daily care to information on what to expect as their child develops. Those getting ready to send their children to school for the first time wanted information on managing infectious diseases, like chicken pox, head lice, or ringworm, that periodically occurred at school. Parents of preteens and teens needed to know how to help youth cope with school, relationships and self-esteem.

- ◆ There was a consensus that parenting education sessions should be open to anyone who cared for children.

Mothers, fathers, grandparents and foster parents needed to learn practical parenting skills. Women especially liked the idea of parenting classes for husbands and single fathers:

*This is concerning women who are working or have to go out [to help others] or get sick themselves. Men need to go to workshops on parenting and how to care for their family.*

- ◆ Not enough attention was being paid to the health information needs of single parents.

Struggling with lack of supports, budget constraints, often living apart from their extended family, parents on their own were in need of specialized

assistance. Just knowing where to go and how to get there was a challenge:

*I just moved .. I don't know where the closest doctor's office or anything ..I was in a situation last week where my child had chickenpox. I had no money, no transportation and I called around to see if I could get anybody to help me get a ride .. And, everywhere I called they said that they couldn't help ... maybe you should have assistance for single parents, mothers or fathers.*

## Safety

- ◆ Safety of children in the home and community was a concern.

Parents wanted to know how to make their homes and communities safe for their children. This included putting supports in place to ensure their safety in schools, community centres and other areas. Knowing how to identify and remedy safety hazards was important. Families also needed practical advice on supervising children. Relating her husband's experiences with looking after a small and very active child, a woman said:

*My children were in the care of their dad and my husband did not know how to properly care for our youngest daughter. He went to work and left her in the*

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*care of her older brothers and sisters who are just children themselves. She is two years old and will get into things and got hurt and had to put a cast on. Things like that, safety for our families.*

## **Children's Nutrition**

- ◆ More information on preparing nutritious yet economical meals for children was a priority.

These resources had to reflect food availability, costs, preferences, and the specialized dietary needs of children. Women wanted to learn how to plan nutritious meals that were within their budgets and reflected the foods that were available in their communities. Those from isolated areas, for example, needed to know how to adjust diets because fresh foods were not available, of poor quality or too costly to purchase. Those from traditional communities wanted to know how to include country foods in their children's diets.

Respondents also emphasized the need for Aboriginal-specific nutritional guides. They also had to know how to adjust diets to accommodate problems such as diabetes or lactose intolerance, which were common among people of Aboriginal heritage. As a woman said, "the Canada Food guide doesn't apply to us ...it's not natural to us."

## **Children With Special Needs**

- ◆ Women faced serious challenges in acquiring information to help them care for children with special needs.

In their experience, information about programs and practical assistance for caregivers of children with physical, emotional and behavioural problems was very difficult to find. Necessary information also did not get disseminated as widely as was required and did not always find its way into small rural communities or isolated areas. Parents in these communities also lacked the range of services and supports that were available in larger communities. As the mother of a child with special needs said, "smaller communities are not aware of a lot of things."

Parents, grandparents and foster parents of children with FAS/FAE, for example, pointed out that these initiatives were generally only available in communities that had programs such as *Healthy Babies*, *Healthy Children*, or *Aboriginal Head Start*.

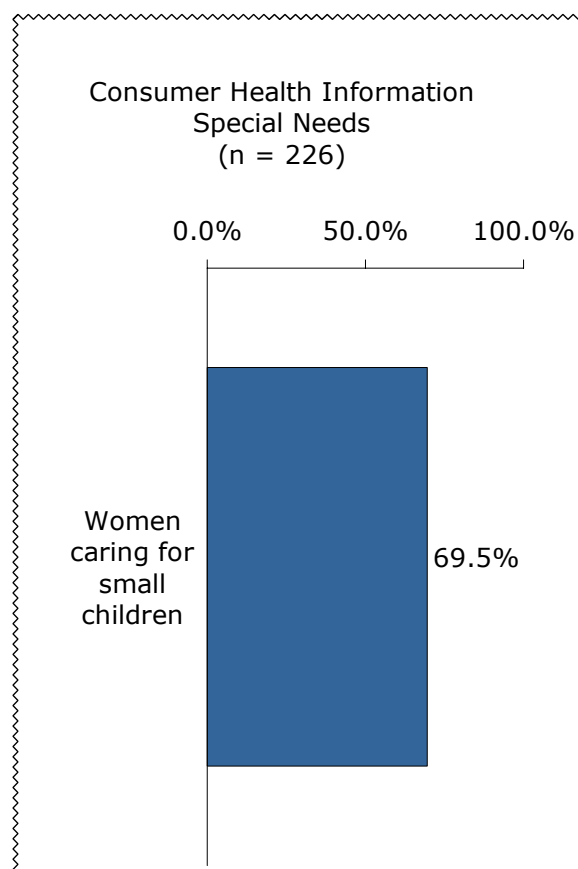
Parents of children who had learning disabilities, speech and language impairments, or neurological conditions, as well as emotional and behavioural problems, told us that

they experienced considerable frustration in finding appropriate information. They also located few Aboriginal-specific resources. Caregivers of children born to crack, cocaine or heroin-addicted mothers were equally disadvantaged:

*One thing that we do see in our neighbourhood are children with disabilities, drug babies, crack babies, this kind of thing ... That is one of the major issues in our neighbourhoods. There is no place we can get information about these kinds of kids, they kind of lump them in with Fetal Alcohol Syndrome and that is not what they are.*

Lack of information about special needs was a challenge all around. Caregivers did not know what to do, where to go, or where to find resources that would help in caring for special needs children. The absence of resources also creating frustration and delays in getting children assessed, diagnosed and needs addressed. Speaking of difficulties with her son, a mother said:

*There is a need to make people, teachers, etc. aware ... More information should be submitted to schools, so children with those diagnoses would be treated ... He had a hard time last year, because people and self were unaware of disorder ... If I hadn't pushed to get son looked at, he might not have been diagnosed.*



**Figure 21 - Special Needs - Women Caring for Small Children (Consumers)**

- ◆ There also was a noticeable absence of Aboriginal-specific information on care of special needs children.

With the exception of FAS/FAE initiatives, there was no information to help Aboriginal families deal with developmental delays, learning disabilities, or communication disorders. There also was nothing for “disadvantaged youth, older youth” with developmental delays.

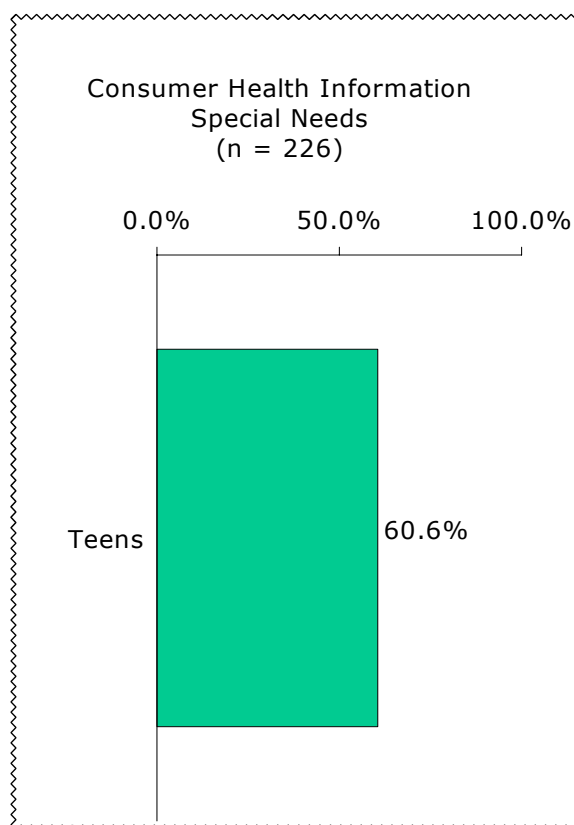
- ◆ Caregivers of children with special needs looked to Aboriginal health care organizations to develop and distribute specialized material directly into the homes of parents and grandparents. They also needed extra help, such as respite care and transportation, so they could attend information sessions and other activities held in the community. Speaking of her difficulty in attending a health information session, a mother of a small child with special needs said, "I think there should be something in place like that here."

## Teens

- ◆ Six in every 10 consumers saw specialized information for teens as an important need (60.6%).

People were very concerned about the health of teens. Young people were struggling with physical and mental problems, without access to special health resources that addressed their age and lifestyle concerns.

People talked at length about the problems that young people faced when diagnosed with diabetes. Thinking of her own daughter, a mother said how much there needed to be specialized information about diabetes for younger people. She said that personalized health teaching and follow-up would make a great



*Figure 22 - Special Needs - Teens (Consumers)*

difference to teens who were coping with this disease:

*My daughter has diabetes and there is really nothing here in town for her. There is a diabetes coordinator but I don't find him very good at all because of the fact she has different needs as a teenager ... They need to improve on follow up ... teenagers think they are invincible ... they are not going to remember and think back .. It's got to be an everyday reminder to them.*

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- ◆ Mental health was another important topic on which young people needed special information.

There was a consensus that mental health issues should be taught at an early age. On the subject of family violence, for example, young people needed ongoing reinforcement that domestic violence was wrong. People suggested that these messages should be introduced to children in the first few years of schools with additional education continuing in the community:

*Domestic violence comes in various forms and how it starts. This isn't just for women but it should start in the schools. Both male and female and start at an early age. Young men and young women should have that teaching so that it doesn't become a normal thing. It's not right.*

Communities which experienced mental health problems expressed an urgent need for information on substance abuse issues. Alarmed by the numbers of young people who were struggling with addictions, they wanted Aboriginal-specific and age-appropriate resources on substance abuse. They worried about their health, and the impact that addictions would have on future generations. They wanted more open discussion of these issues to help people who were recovering from addictions:

*One comment on two issues, drugs and alcohol. That's one of the main concerns in a community. I know because I am an alcoholic. I go to Alcoholics Anonymous and I'm not shy to talk about it, it is a part of me. I'm an addict too. I know that a lot of our youth get involved in this, and we don't talk about this very much. If we can get more information, or find a way to be open about it, maybe we can lessen that disease.*

## Elders & Caregivers

- ◆ One in two respondents reported that their communities had needs for elder and caregiver-specific information (51.8%, 59.3%).

People who discussed serious illnesses such as diabetes or cancer which affected the health of elders recognized a need to tailor health information to this age group. Elders needed material that was in their own language, that reflected their traditions and customs.

Language issues were a serious barrier that prevented elders from getting appropriate health information. Even with translation provided by family members, elders often could not understand fully the information given to them by professionals. Elders and

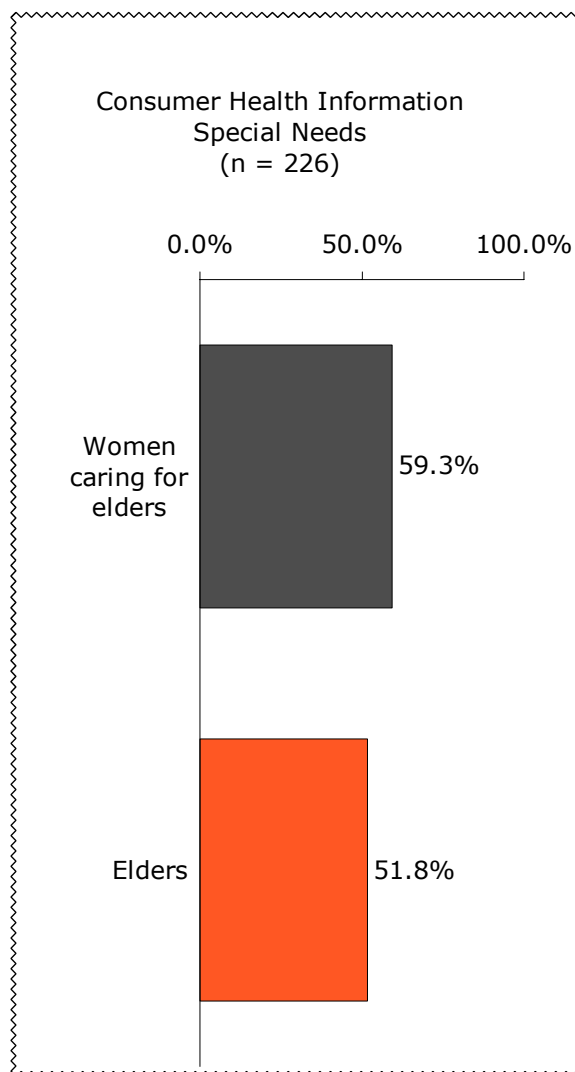
family members who were providing translations needed additional supports to make certain that information was accurately translated and everyone understood the instructions which were given:

*Our parents, the older parents, they usually speak through us the ones that can speak English to the health professionals .. These parents or elders they'll just believe whatever is told of them because they're professionals ... And sometimes what they believe is not always the case.*

Caregivers also required specialized information on "how to look after older people" who were having memory problems. The most urgent need was for Aboriginal-specific information on elders who were experiencing disorientation or confusion. They wanted practical advice to know what to do to keep their elders safe in their homes and communities.

They also needed to know how to provide care to elders in a respectful way which recognized the great importance of elders to the community and their contributions. As well, caregivers needed to know where to go if additional help was needed. Relating her experiences in caring for an elder, a woman from a small settlement said:

*I never prepared myself for the care of looking after an elder ... When I learned about my*



**Figure 23 - Special Needs - Elders & Caregivers (Consumers)**

*culture I was told that our elders are important and that our elders need to be respected ... And when I take care of her, I see where she has difficulties. Yesterday, she doesn't remember having the door wide open and it's freezing cold out there .. and there she is outside*

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*with no coat on, and no boots on ... I need something to read here right now, how do I explain to the elder, so that I don't disrespect them . . . Who can I go talk too, so that I won't lose it, so that I could be gentle with them. I think that we need something like that to be brought into the home. There needs to more information for the family and for the elders.*

- ◆ As well, information about the special needs of elders needed to be given to extended family and community members.

Caring for elders was all-day and all-night occupation that took more time and resources than immediate family members could provide. Community members often assisted with care, giving families respite, helping with transporting elders for care, or translating information for the elders and caregivers. Information about elder caregiving issues and approaches needed to be distributed widely, because "it takes the community as a whole to help."

## Screening

- ◆ Women were very worried that they were not being given appropriate information about cancer screening programs.

In almost all of the focus group and talking circle discussions, women raised concerns that they were not getting information about screening programs "soon enough." Several related examples of women who were diagnosed with cancer at a late stage, because they did not understand the risks, the symptoms and the importance of early detection.

Women told us they had to know what was normal and what was not. They also had to learn how to ask for help when they felt something was wrong and, if needed, persist in asking for additional tests or consultations. Learning how to be assertive was a difficult but necessary thing for them to do. Relating her own experiences, a cancer survivor said:

*We have to be persistent, to say, this is not normal for me, this is something serious going on. We have to push, and I didn't do that. If I had persisted, I don't think that I would've went this far with cancer, like, where I have to have surgery and all that. I think that it's really important to know our bodies and what's happening to them.*

As well, there was concern that materials about cancer screening were not being presented in a way that was culturally acceptable. In turn, material that was not culturally acceptable was harder to understand and more difficult to apply. Not knowing what was expected or how to ask a

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professional for screening was a significant barrier, especially for young women:

*A lot of young girls don't get pap smears either but you need them. They might not want to go or are scared, there could be numerous reasons and if they have information they may feel better about it.*

- ◆ Women also had to know what to expect when they went for a screening procedure.

Most women told us they did not know what to expect the first time that they went to a doctor for a physical examination or screening procedure and were offered no explanation about what was going to happen. They related very personal examples of the fear and physical discomfort they experienced when examinations were given without explanation:

*Going to the doctors, you know, for your first exam, and he starts pulling all this stuff on you. I'm thinking "Oh my God. ...What are you going to do with that? Oh my goodness." I got freaked out. He got the nurse to come in, so the nurse came in. If he explained it first what he was going to do, maybe one visit then I go back again, so I have time to prepare for this. I didn't know what I was going for, I just figured that he was going to look at my heart, and that he was going to get me to*

*take some breaths and stuff. I had no idea, I got really scared and the nurse came in and I held her hand and I squeezed her hand. She kept on saying "relax, relax, it's okay." I did relax. We should be more aware when you first go for your first examination. What's going to happen and what they're going to use.*

Information about screening also needed to be distributed to Aboriginal women of all ages, young and old alike. There was a need to tell women that regardless of age, they could be affected by illness and so should be screened. Relating her experience trying to convince an older relative to go for cervical cancer screening, a respondent said she wanted:

*Pamphlets and stuff, so that they can read it themselves, so that they know that they should go. I was telling her, "Yeah you're old, but you should still get a pap test." Things like that. She's like, "I don't want to talk about that, I don't have sex anymore." ...The importance of it, even at my age, that you should still go to the doctor. But I think that pamphlets would still help, so that they can read it, in big black letters.*

- ◆ In addition, women needed to know about other screening tests, such as those for colon cancer.

- 
- ◆ Women knew that diseases such as colon cancer were poorly understood, but became an increasing risk as they became older.

They needed to know what the risks were and what types of screening procedures could be done. People who discussed the difficulties of accessing screening programs also thought that women had to learn how to request these procedures. They knew that women often had to ask for screening because busy physicians often didn't routinely do these procedures:

*I know that it is a big issue now, things that are involved with a woman's body. The testing that doctors normally don't do anymore. I feel that Native women, myself included, some other people that I know, that haven't had these examination previously, but getting them the last 5-10 years. Which is a real health risk for people. When it is colon cancer, that kind of test, those are the tests that women should be demanding when they go for their annual examination. Very rarely, do they ask.*

## Other Needs

- ◆ Both consumers (34.1%) and providers (44.0%) offered written comments on other health resources that were needed in Aboriginal communities.
- ◆ Participants also identified special needs topics for which additional material was required (23.0% and 12.2%).

As listed on the following pages, consumers and providers identified over 100 additional health information needs. Their needs involved a host of issues, from general information about minor ailments, to very detailed information about life-threatening conditions. Specific resources, on everything from budgeting and cooking, through exercise programs, to relationship issues and stress relief were important. Above all, they needed to understand when professional help was needed and how they could access that assistance. They also had to know where they could go for more information and quality health information, that was easy to understand. They wanted:

*Any information is good information, as long as they can understand it and know where to get more information.*

---

## **Other Health Information Needs A - G**

- Access to health care
- Addictions
- Addictions to over-the-counter painkillers
- Addictions to solvents
- Alcoholism
- Allergies
- Alternative recreation
- Amputations
- Anger management
- Attention Deficit Disorder (ADD)
- Arthritis
- Asthma
- Back problems
- Bipolar disorders
- Birth control
- Bladder problems and constipation
- Blood clots in veins
- Bone disease
- Breast cancer
- Breast screening
- Breathing techniques
- Bronchitis
- Budgeting
- Caring for small children with special needs
- Childbirth
- Childcare
- Childhood sexual abuse
- Children's health (preschoolers)
- Children's health (school-aged)
- Children's nutrition
- Chiropractic
- Cholesterol
- Common illnesses
- Common colds
- Cooking healthy
- Counselling
- Crisis intervention
- Dental health
- Depression
- Diabetes
- Diabetes and pregnancy
- Diabetes support groups
- Disability supports
- Discrimination and health
- Drug abuse
- Drugs and alcohol
- Elder abuse
- Empowerment
- Environmental health
- Environmental pollution
- Eye problems
- Exercise programs
- Family health
- Family values
- Family violence
- Family violence and children
- Fetal alcohol effects (FAE)
- Fetal alcohol syndrome (FAS)
- Fitness
- Foot problems
- Gambling
- Getting a doctor's appointment
- Getting health care in an emergency
- Getting to know the health care system
- Getting to know your doctor
- Grieving

**Figure 24 - Other Health Information Needs (Consumers and Providers)**

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## **Other Health Information Needs H - R**

- *Health coverage*
- *Health resource centre*
- *Healthy eating*
- *Healthy exercise*
- *Healthy lifestyles*
- *Healthy parenting*
- *Healthy pregnancy*
- *Healthy relationships*
- *Healthy sexuality*
- *Hearing problems*
- *Hepatitis*
- *Hereditary diseases*
- *Hip and knee replacements*
- *HIV/AIDS*
- *Holistic care*
- *Home care*
- *Hormone replacement therapy*
- *How health team works*
- *How to avoid diseases*
- *How to express yourself*
- *How to take care of yourself*
- *Hysterectomy*
- *Impact of sexual abuse*
- *Infections*
- *Infectious diseases*
- *Infertility*
- *Information for caregivers*
- *Information in traditional languages*
- *Injury prevention*
- *Intergenerational trauma*
- *Isolation*
- *Kidney disease*
- *Learning how to access health care*
- *Learning how to use health care*
- *Learning disabilities*
- *Legal issues*
- *Life cycle teaching*
- *Life skills*
- *Loneliness*
- *Long-term illness*
- *Maintaining health*
- *Managing medication*
- *Medical advocacy*
- *Medical alternatives*
- *Menopause*
- *Mental health for families*
- *Mental health for women*
- *Mould and fungus*
- *N numbers for Inuit*
- *Native women's health centres*
- *Naturopathic medicine*
- *Obesity*
- *Osteoporosis*
- *Overweight*
- *Pain management*
- *Parenting*
- *Parent nutrition*
- *Parent supports*
- *Parkinsons' disease*
- *Pesticides*
- *Post-traumatic stress disorder*
- *Premenstrual syndrome (PMS)*
- *Preventive health*
- *Racism and health*
- *Raising healthy children*
- *Relationship issues*
- *Residential school trauma*
- *Respiratory diseases*
- *Respite care*

**Figure 24 - Other Health Information Needs (Consumers and Providers)**

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## **Other Health Information Needs S - Y**

- *Safety awareness*
- *Second-hand smoke*
- *Self-care*
- *Self-defence*
- *Self-esteem*
- *Sex education*
- *Sexual health*
- *Sexually transmitted diseases (STDs)*
- *Smoking*
- *Smoking cessation*
- *Sobriety*
- *Social health*
- *Sterility*
- *Stress*
- *Stress management*
- *Stress relievers*
- *Stroke*
- *Substance abuse*
- *Substance abuse and pregnancy*
- *Substance abuse and women*
- *Suicide*
- *Support groups*
- *Symptoms of disease*
- *Talking circles*
- *Thyroid problems*
- *Tobacco*
- *Traditional ceremonies*
- *Traditional holistic treatment*
- *Traditional language information*
- *Traditional medicines*
- *Teenage pregnancy*
- *Traditional values*
- *Tuberculosis*
- *Understanding health benefits*
- *Water testing*
- *Women's anatomy*
- *Women's health*
- *Yoga*
- *Youth substance abuse*

*Figure 24 - Other Health Information Needs (Consumers and Providers)*

## Consumer Priorities

Although Aboriginal women made it clear that their collective priority was to obtain information about *all* health issues, they had greater needs for some resources than others. Looking at general and special needs combined<sup>5</sup>, their priorities were for resources on:

- ◆ Diabetes (80.2%).
- ◆ Cancer (75.0%)
- ◆ Nutrition (73.0%)
- ◆ Family violence (71.4%).
- ◆ Substance abuse (69.4%)
- ◆ Heart disease (68.7%)
- ◆ Exercise (67.9%)
- ◆ Pregnancy/childbirth (66.7%)
- ◆ Arthritis (65.1%).

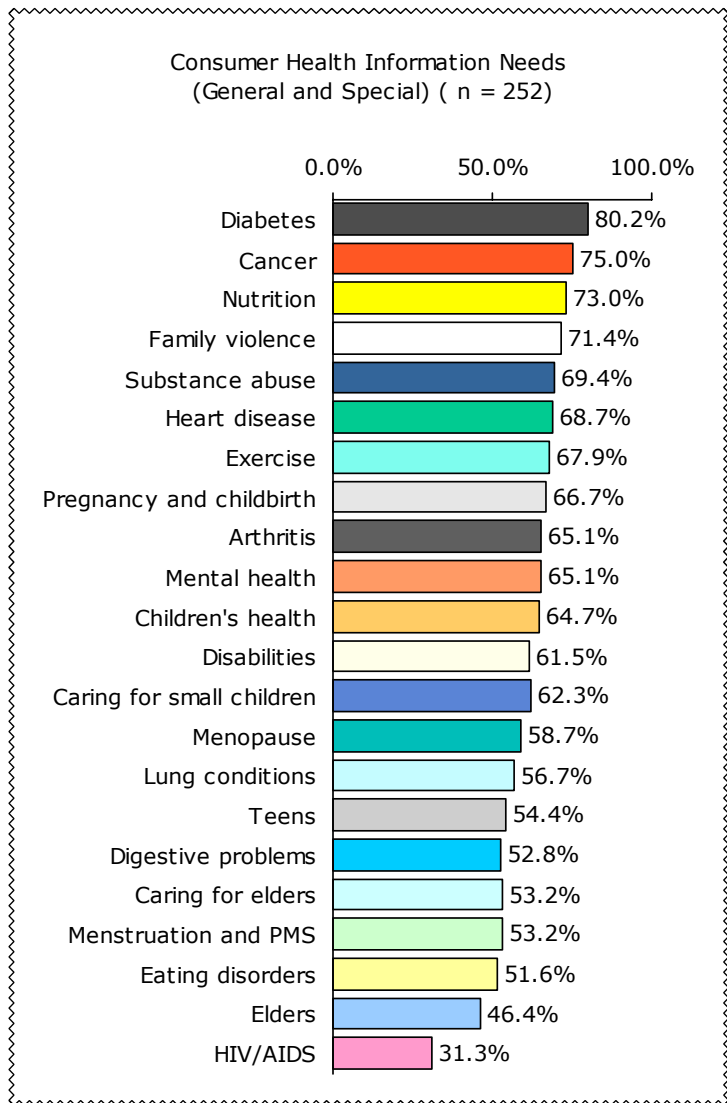


Figure 25 - Priorities (Consumers)

- ◆ Mental health (65.17%)
- ◆ Children's Health (64.7%)
- ◆ Disabilities (61.5%)
- ◆ Caring for small children (62.3%)

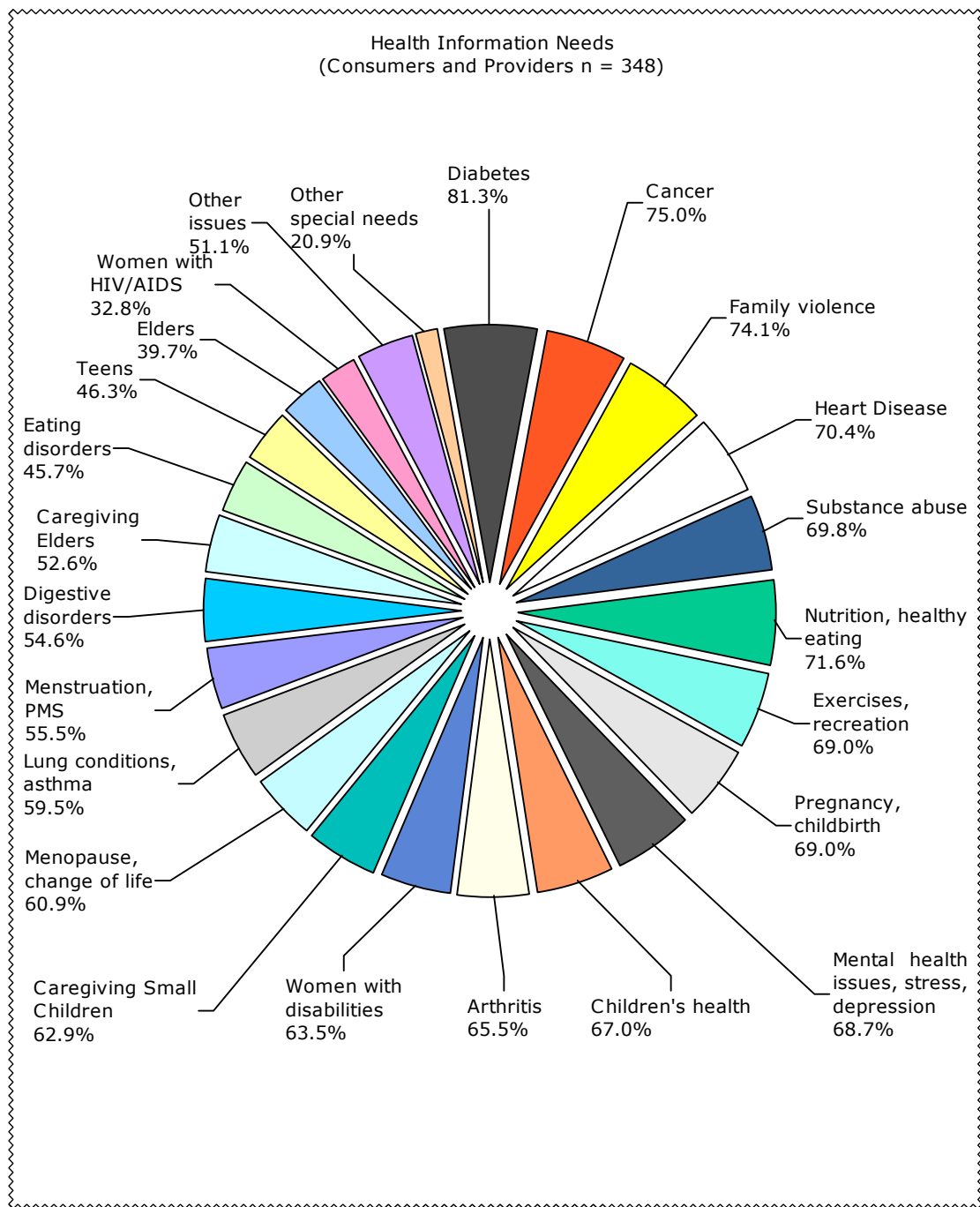
<sup>5</sup> Percentages of cases reporting at least one general or special need.

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## Summary

Aboriginal women and those who provided care for them were in agreement about needs for information on almost all health issues, including a number of special needs. Their opinions reinforce the need for information on:

- ◆ Diabetes (81.3%).
- ◆ Cancer (75.0%).
- ◆ Family violence (74.1%).
- ◆ Nutrition, healthy eating (71.6%).
- ◆ Heart disease (70.4%).
- ◆ Substance abuse (68.9%).
- ◆ Pregnancy, childbirth (69.0%).
- ◆ Exercises, recreation (69.0%).
- ◆ Mental health, stress and depression (68.7%).
- ◆ Children's health (67.0%).
- ◆ Arthritis (65.5%).
- ◆ Women with disabilities (62.5%).
- ◆ Women caring for small children (62.9%).
- ◆ Menopause (60.9%) .
- ◆ Lung conditions/asthma (59.5%).
- ◆ Menstruation and premenstrual syndrome (55.5%).
- ◆ Digestive problems (54.6%).
- ◆ Women caring for elders (52.6%).
- ◆ Teens (46.3%).
- ◆ Elders (39.7%).
- ◆ Women with HIV/AIDS (32.8%).
- ◆ One in two respondents identified that they lacked information on other issues that affect the health of Aboriginal women (51.1%). They cited a wide range of concerns, encompassing access issues, children's health, long-term illness, mental health, preventive health, relationship issues, safety awareness, stress, traditional holistic care, and women's health.
- ◆ Other information needs were experienced by people with special needs and their caregivers (20.7%). They needed detailed information about accessing services and supports for women with disabilities, people with HIV/AIDS, teens, elders and their caregivers.



**Figure 26 - Summary - Priority Needs (Consumers & Providers)**

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## 4. Access

A central purpose of this project was to explore the ways that Aboriginal women access information about the health issues that are important to them. The literature suggests that they commonly experience difficulties in accessing health information, due to a lack of Aboriginal-specific materials, linguistic and cultural barriers (Dion Stout, Kipling & Stout, 2001). They may also experience difficulties in obtaining information from health care professionals, if cultural competence is lacking (Browne & Fiske, 2001). While specially-trained community health workers may be an alternative, these workers are not widely available (Swider, 2002).

Aboriginal-specific information is also not generally available through the media. Even Aboriginal-specific newspapers (Hoffman-Goetz, Shannon & Clarke, 2003) and web sites have uneven coverage of issues (Marton, 2001). As well, Internet technology is often unavailable or too costly to access (Golic, 2003). Considering these factors, we documented the ways that Aboriginal women looked for health information, with an emphasis on community resources.

### **Research Questions: Looking for Information**

Thinking about the most common health issues that women face everyday, where in your community can they get information about these issues?

- *talk to health care provider*
- *talk to health care centre*
- *talk to pharmacist/pharmacy staff*
- *talk to other women*
- *magazines/advertising*
- *pamphlets*
- *videos/television/commercials*
- *tapes/radio*
- *workshops*
- *health fairs*
- *women's groups*
- *workplace*
- *schools/childcare centres*
- *band office/co-ops*
- *other*
  
- *If none of the above, please explain where else women can get information about these issues?*

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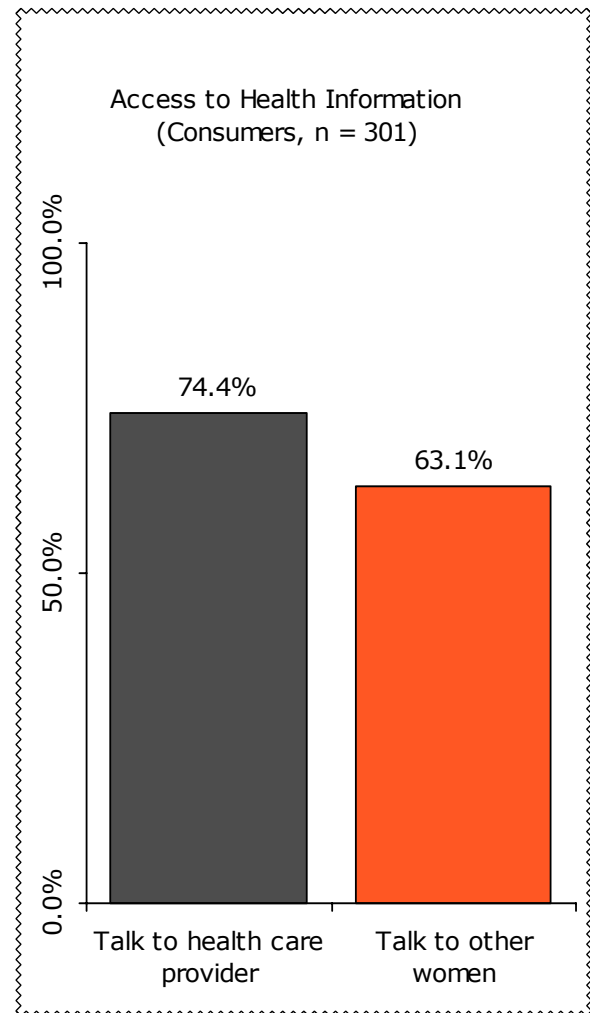
## Talking To People They Know

The evidence suggests that Aboriginal women were active in their search for information, talking to people that they knew, turning to places they knew, and using print and audiovisual resources. While many women depended mostly on the information that was available locally, they also looked elsewhere, going beyond their communities for help.

Although the methods varied, women usually began their search for information by asking questions of local health care providers or turning to other women for information:

- ◆ Three-quarters talked to health care providers, including nurses, physicians and community health representatives (74.4%).
- ◆ Almost two-thirds of the women surveyed also turned to other women for information (63.1%).

In discussing these issues, women often emphasized that friends and family were usually their first source of information and health care providers, a secondary source that they turned to when professional advice was needed:



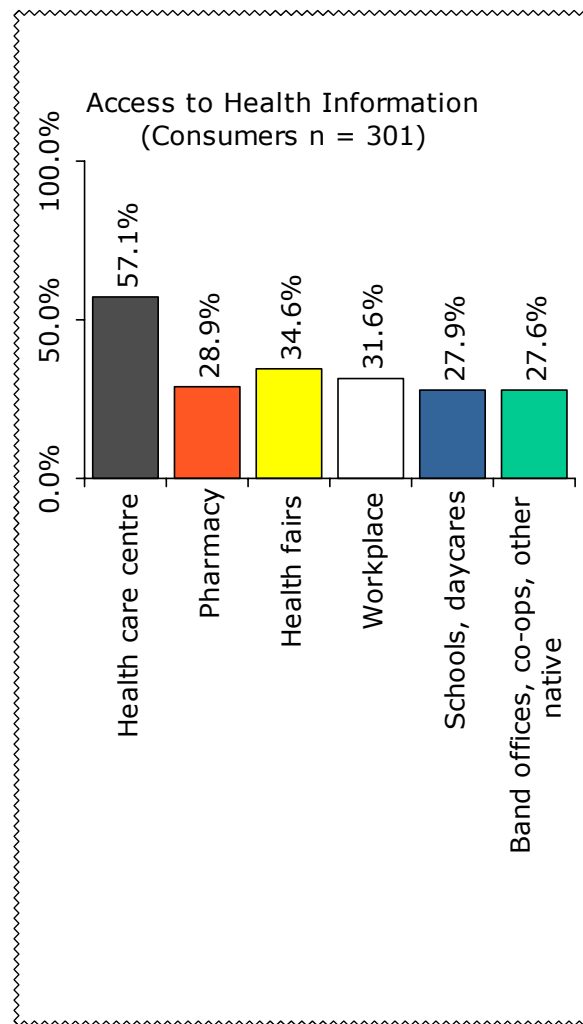
**Figure 27 - Access - Talking To People They Know (Consumers)**

*I usually go to a friend that has a similar problem or a problem that we've had in the past recently and see what they did to help them get better ... And if any my friends or relatives, or close members of my family can't help me, then I would address the matter to a doctor.*

## Turning To Places They Know

Women also turned to specific places in their communities to obtain needed information. Many looked to local health care centres. Some went to local pharmacies. Others attended community health fairs or made use of the resources which were available in workplaces and schools. They also sought information through social service agencies which served their communities:

- ◆ One-half looked for information at their local health centre (57.1%).
- ◆ One-quarter turned to the local pharmacy (28.9%).
- ◆ One-third accessed information through health fairs (34.6%).
- ◆ Equivalent numbers found workplace resources (31.6%).
- ◆ One-quarter located material in schools or childcare centres (27.9%).
- ◆ Equivalent numbers turned to band offices, co-ops, friendship cultural centres, social service agencies, and other native organizations (27.6%).



**Figure 28 - Access - Turning to Places They Know (Consumers)**

Recounting their experiences in looking for information, women were especially appreciative of people in community organizations who took the time to answer their questions or locate resources. They also liked the convenience of being able to access information at a number of different places in their communities. This saved them time and the cost of travelling from one place to another.

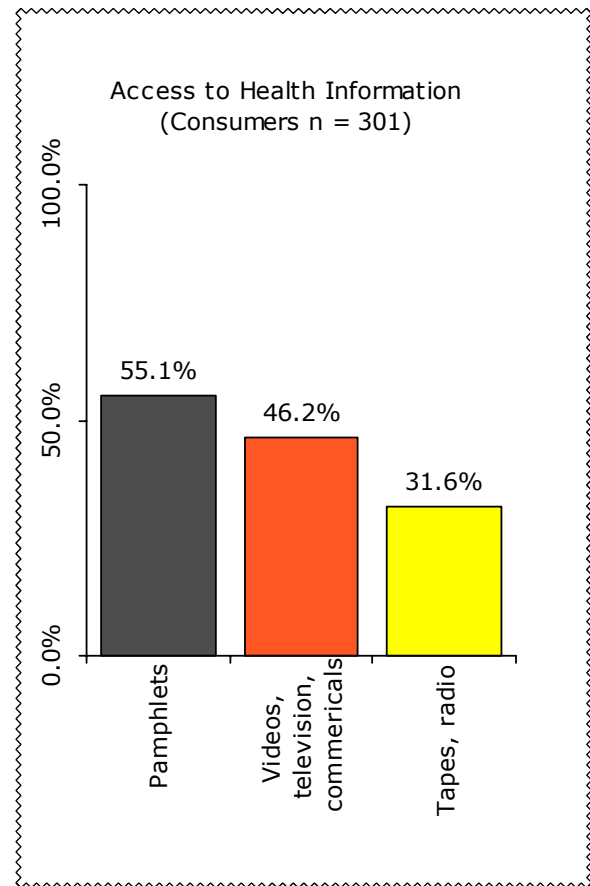
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## Turning To The Written and Spoken Word

Aboriginal women also relied on the written and spoken word, in a variety of formats, for the information that they needed. Many found pamphlets to be useful. They also sought information from videos, television, audiotapes or radio:

- ◆ One-half relied on pamphlets were (55.1%).
- ◆ Many also turned to videos, television or commercials (46.2%).
- ◆ Fewer than one-third obtained information through audiotapes or radio (31.6%).

In discussing access, women noted that it was not easy to locate appropriate materials. Pamphlets, while easy to read, often contained only the most general information about health issues, services and the process of accessing care. Print materials also became dated quickly. Although television and radio often presented the most-up-to-date information on health topics, women told us that Aboriginal content was hard to find. The only places where they could reliably find these resources were the Aboriginal Peoples' Television Network (APTN) or



*Figure 29 - Access - Turning to Written and Spoken Words (Consumers)*

community radio networks, such as Wawatay. Otherwise, there was little Aboriginal-specific content. Women who turned to "mainstream" media also found that Aboriginal content did not always reflect their traditions or communities. As a young woman said:

*Not culturally appropriate. It didn't appeal to me .. My friend told me to take the message out of it and never mind the fact of it.*

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## Accessing Information At a Distance

- ◆ Women also had problems accessing more information at a distance, when resources were not available locally.

Reflecting on the types of health information that were available to Aboriginal women in her small rural community, a woman said: "What is not easy, is *going* to get the information." Access to additional information was a serious concern for all of the individuals who took part in the study.

Women who lacked full-time physician care were most disadvantaged. They were unsure about where else they might turn for needed information. While a few said that they could get information about medications from a pharmacist or screening from a nurse practitioner, they were hesitant about asking questions when providers were unfamiliar to them. As an urban woman said:

*I don't know the answers to these questions and I don't have a full time doctor to ask these concerns. That's kinda scary and important to me.*

Not knowing where else to go for more information, women sometimes turned to emergency wards for assistance with their health issues or family health problems. The experience of going to a busy emergency ward for information and assistance, however, was very frustrating and took up a lot of time:

*For our experience, we went straight to the Emergency. We weren't educated besides run to the emergency...It was a long wait while waiting to see a doctor. ...You wait for up to three hours and only see the doctor for less than five minutes. You are worried and have tons of questions. It was quite scary, especially when you aren't given the time for your questions to get answered.*

Given the challenges of finding health information when family physician care was limited and difficult to access, women thought that it might be appropriate for Aboriginal health care organizations to consider other ways of delivering information. Women who had received care from nurse practitioners thought that this represented an acceptable alternative. Others suggested that specially-trained Aboriginal support workers could provide information and direct them to assistance. They also liked the idea of learning through women's groups. As a focus group participant said, "more information sharing with other women" was important, too.

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## Other Sources

- ◆ Considering that the range of health care services was limited in many locations, it is not surprising that one-half of respondents (50.6%) remarked that, of necessity, women turned to other sources for health information.
- ◆ They cited over 70 additional resources that they had used. (*Listed on the following page*).

They needed better access to information to ensure that their families and communities were healthy, as well as to maintain their own health. Underlining the seriousness of access issues, Aboriginal women repeatedly told us about the difficulties they had in acquiring needed information.

They relied heavily on the resources that were available from Aboriginal organizations located in their home communities or nearby locations. They also turned to churches, cultural and friendship centres, as well as child and family service agencies. In larger centres, they sought information from “mainstream” organizations, including health clinics, public health units, and community child and family service agencies.

Women also looked for information and notices about health issues posted in places that they frequented every day. Some told us that they especially appreciated the information that was posted in grocery stores, post offices, or schools. Those who resided in larger cities said that they looked for similar information, as well as for announcements of educational events, on billboards or notice boards in the public transit systems.

A number of women from more isolated places pointed out that it was difficult to have information sent into their communities, because there was not even any regular mail service. Some residents brought back information when they travelled to access care in other locations; going elsewhere just to obtain information, however, was too costly for families with limited budgets. Most people had to depend on the health information that was available locally.

Only a few women felt comfortable seeking information at a distance through the Internet, Telehealth numbers, and help-lines. Those who used these services were generally satisfied; however, most women felt that these resources were difficult to access and, at present, beyond their means. They also were uncomfortable in accessing resources that were not Aboriginal-specific, for fear that they would be misunderstood.

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## **Other Sources of Information**

- *Aboriginal Head Start*
- *Aboriginal Peoples Television Network (APTN)*
- *Aboriginal health access centres*
- *Alcoholics Anonymous (AA)*
- *Billboards*
- *Blue book of community information*
- *Books*
- *Breast Cancer Foundation*
- *Canadian Diabetes Association*
- *Chiropractor*
- *Church*
- *Community centres*
- *Community feasts*
- *Community health nurse*
- *Community health representative*
- *Community newsletters*
- *Community nursing station*
- *Community workshops*
- *Computer*
- *Council*
- *Crisis Line*
- *Cultural centre*
- *Cultural coordinator*
- *Demonstrations*
- *Diabetic educator*
- *Elders*
- *Elders and handicapped worker*
- *Elders group*
- *Family resource centre*
- *Flyers*
- *Friendship centre*
- *Government website*
- *Grocery store board*
- *Group health centre*
- *Hands-on activities*
- *Healer*
- *Healing and wellness centre*
- *Health centre*
- *Health fairs at schools*
- *Health food stores*
- *Health outreach workers*
- *Health unit*
- *High school*
- *Home doctor*
- *Homeopathic teachers*
- *Hospital*
- *Hospital lobby*
- *Internet*
- *Library*
- *Local help-line*
- *Local radio station*
- *Magazine drug ads*
- *Mail*
- *Medical dictionary*
- *Medical translator*
- *Mental health worker*
- *Program newsletters*
- *Narcotics Anonymous*
- *Native centre*
- *Native child and family services*
- *Native web health*
- *Native women's program*
- *Naturopathic clinic*
- *Newsletters*
- *Nurse at clinic*
- *Nurse practitioner*
- *On-line libraries*
- *Posters*
- *Presenters*
- *Public health*
- *Radio in library*
- *Reader's Digest*
- *Referrals*
- *Resource people*
- *Safe house*
- *Schools*
- *Sexual care centre*
- *Specialist*
- *Sue Johanson (Sunday Night Sex Show)*
- *Tapes*
- *Telehealth 1-800*
- *Women's healing and wellness*
- *Wawatay Radio Network*
- *Women's sharing circle*
- *Women's shelter*
- *Women's wellness group*
- *Workshops on special topics*

**Figure 30 - Access - Other Sources (Consumers & Providers)**

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## Summary

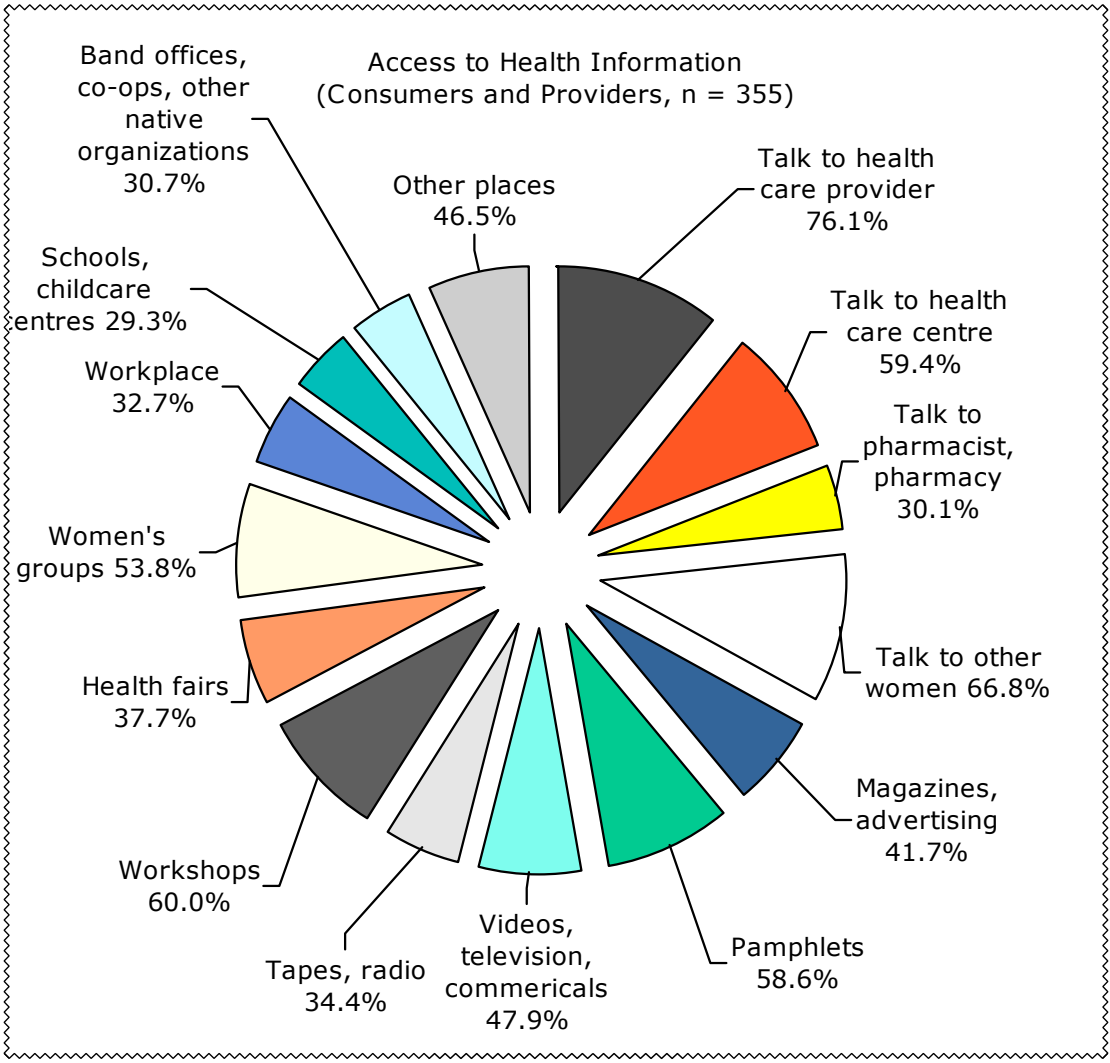
Looking at combined consumer and provider opinions, there was general agreement about the principal ways that Aboriginal women accessed health information. Relying heavily on providers and other women, they used shared learning, print resources and audiovisual materials:

- ◆ Talking to health care providers is the most important way of getting information (76.1%).
- ◆ Women also seek information by talking to one another about health (66.8%).
- ◆ Shared learning is very important; participants thought that women depend equally on the information that is delivered through workshops (60.0%) and community health centres (59.4%).
- ◆ Pamphlets are also a widely-available source (58.6%).
- ◆ Women's groups are an important resource that was cited by one in two study participants (53.8%).
- ◆ Videos/television or magazines, are less accessible (47.9%, 41.7%).

- ◆ Some also found information available through health fairs (37.7%).
- ◆ Only a small minority indicated that radio or audiotaped health information was available (34.4%).

At the same time, health resources were not widely available at other places in their communities. Only a few women had access to:

- ◆ Workplace based health information (32.7%).
- ◆ Information offered through band offices, co-operatives and other Aboriginal organizations (30.7%).
- ◆ Pharmacies (30.1%).
- ◆ Schools and childcare centres (29.3%).
- ◆ Almost one-half reported that women looked elsewhere, going outside their communities for information (46.5%).



**Figure 31 - Summary - Accessing Information (Consumers & Providers)**

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## 5. Understanding

Recent Canadian assessments suggest that people who have difficulty understanding health information generally have poorer health as well as more difficulty accessing health services (Rootman, 2003; Rootman & Ronson, 2001; Smith & Haggerty, 2003). Research, moreover, suggests that Aboriginal peoples' ability to understand and apply health materials is closely tied to their languages, way of life, traditions and world view (Antone, 2003).

Evaluations of Aboriginal health initiatives provide further evidence that understanding is improved if information is developed and delivered in full partnership with communities (Fisher & Ball, 2003; Garwick & Auger, 2003). Partnership programs designed to prevent cancer (Lantz, Orians, Liebow, Joe, Burhansstipanov, Erb & Kenyon, 2003; Messer, Steckler & Dignan, 1999) or diabetes (Daniel, Green, Marion, Gamble, Herbert, Hertzman & Sheps, 1999; Potvin, Cargo, McComber, Delormier & Maccaulay, 2003) have been most successful. With these ideas in mind, we explored women's perceptions about the factors that made health information easy or not to understand.

### **Research Questions: Understanding**

Thinking about the information that is available, like pamphlets or videos, is it easy for women to understand?

(If so, why?)

(If not, why not?)

Easy to understand because:

- *in our language*
- *easy to read, simple*
- *places like our community/relates to our community*
- *talks about our ways*
- *other issues*

Not easy to understand because:

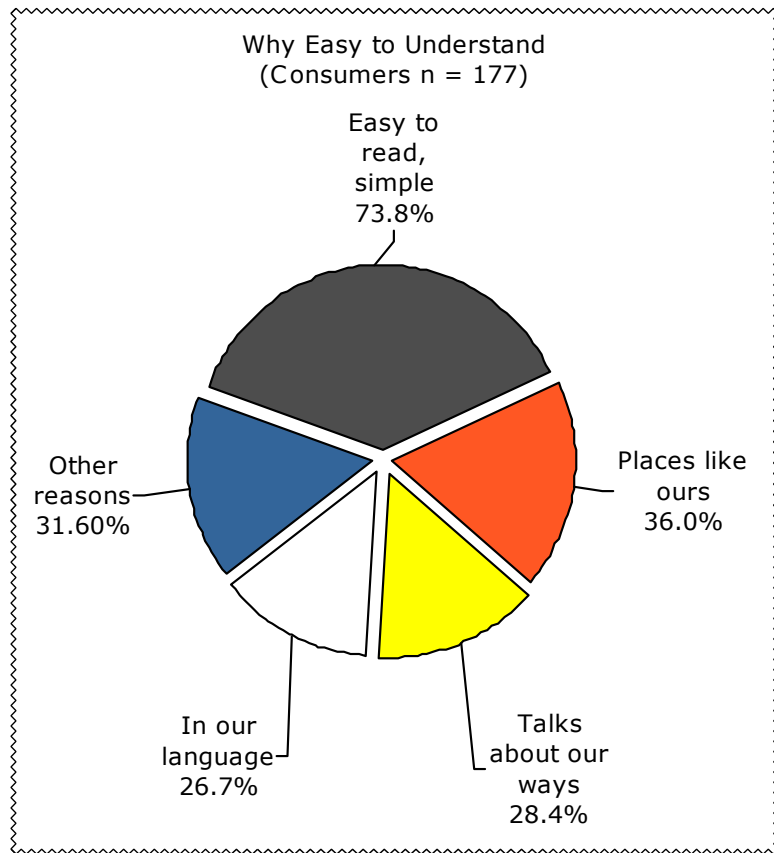
- *not in our language*
- *not easy to read, too complex*
- *not places like our community/does not relate to our community*
- *does not talk about our ways*
- *other issues*

# Why Things Are Easy To Understood

While it was clear that most Aboriginal women who took part in this study had access to some types of health information, there were concerns that available resources were not always in formats that could be readily understood:

- ◆ Three-quarters said the most understandable information was easy to read (73.8%).
- ◆ One-third preferred information which showed communities like their own (36.0%).
- ◆ More than one-quarter liked resources which talked about Aboriginal ways (28.4%); materials in Aboriginal languages also helped them to comprehend (26.7%).

Information could best be understood if it was easy to read and presented simply; these materials, however, were not easily found. As a woman noted, "some pamphlets are easy to read while others just go over my head." Pamphlets or videos depicting



**Figure 32 - Why Information Is Easy To Understand (Consumers)**

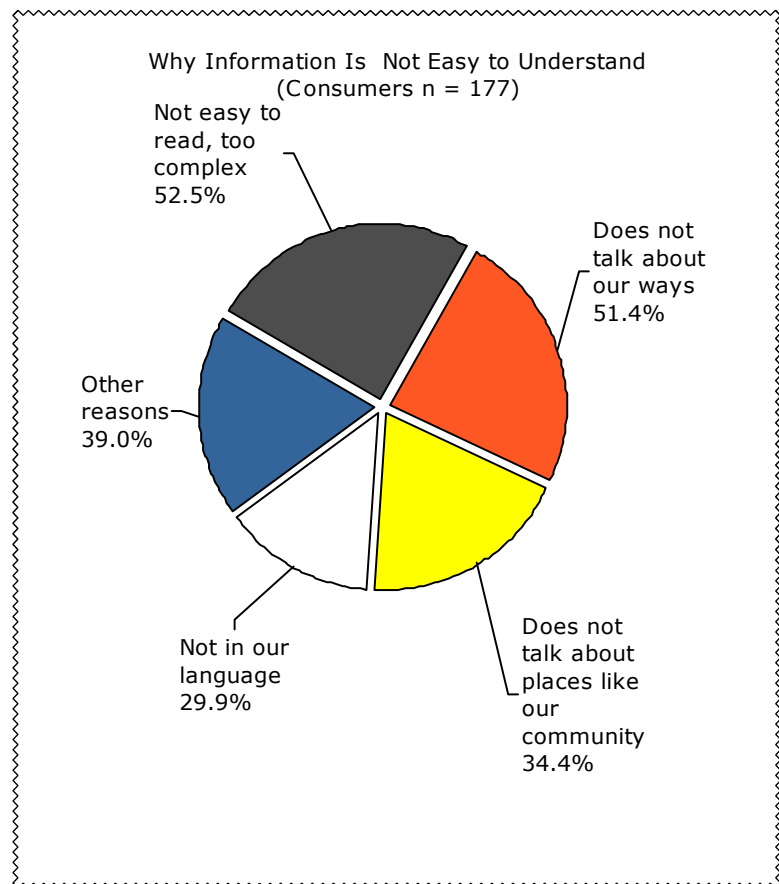
Aboriginal communities and ways were helpful though not widely available:

*Thinking about pamphlets or videos, to tell you the truth I've never seen a pamphlet on Aboriginal health. I've been in quite a few hospitals and I've been in tons of doctors offices and I've never seen anything on Aboriginal health, so that's kind of scary to me.*

## Why Things Are Not Easy to Understand

Women also offered opinions about factors which impaired their comprehension of health information:

- ◆ One-half said materials were hard understand if they were too hard to read (52.5%) or did not talk about Aboriginal ways (51.4%).
- ◆ Comprehension was equally difficult if health resources depicted unfamiliar community settings (40.7%).
- ◆ More than one-quarter said people had problems when materials were not in their language (29.9%).
- ◆ One-third felt there were other reasons why difficulties occurred, such as unfamiliarity with issues, lack of relevance or discomfort (39.0%).



**Figure 33 - Why Information Is Not Easy To Understand (Consumers)**

*It's not always easy to understand and it's because it doesn't always talk about our ways .. they can't put the answers in a way that it fits into the context of our lives, the way we live .. your health has to do with your history too.*

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## Additional Barriers

In discussing understanding, women cited a number of additional barriers that impeded their access to health information. These barriers included an absence of instructions for initiating referrals, using telephone help-line resources, and finding help when people moved to the city.

The absence of appropriate language materials was also a serious impediment to understanding. Women who spoke traditional languages had difficulty locating Aboriginal-language materials and translation services. Those who had limited English-language reading ability had similar problems finding health materials that were easy to understand.

## Initiating Referrals

- ◆ Pamphlets or videos were hard to understand when they advised referrals to professional services, without offering instruction on how to initiate referral process.

Participants in the focus groups, talking circles and surveys told us that they often had trouble understanding material that told them to seek professional help. Without specific instructions, they didn't know how to

start the process of initiating referrals, where to go or who to ask for assistance. The problem of initiating referrals was especially serious if communities had no on-site professional services. It was also difficult if there was no continuing access to physician care. Summing up her frustration, a woman said, "no professionals in community ... so where to go?"

Women who experienced these problems suggested that health materials which direct people to go elsewhere for further information or assistance need to give enough information so people can find care elsewhere. They preferred resources that included step-by-step directions for accessing appropriate care, including where to go, who to talk to, and, ideally, what to do if they needed further information.

They also thought that instructions should be community-specific and reflect the actual resources and services found in different types of Aboriginal communities. Materials designed for rural and isolated communities, for example, needed specific instructions for initiating referrals at a distance, if services were unavailable locally. Materials designed for urban areas needed to specify the range of agencies in which specific services could be accessed. Instructions should be clear and concise, leaving no room for error.

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## Asking Questions

- ◆ Aboriginal women also felt that they needed coaching about the best ways to approach providers for information and other assistance.

While they had many questions about health that needed answering, women often felt unsure and uneasy about asking health care providers for explanations. They also knew that busy providers did not routinely provide information, unless questions were asked. On this issue, women wanted coaching about the best ways to ask questions of health care providers. They also needed support and encouragement, so they could overcome shyness and feel comfortable about asking questions.

Learning how to ask questions was especially important for women who moved from traditional communities to urban centres. Raised in traditional homes, they were taught to learn by listening and observing, so asking questions was foreign to them. They had the difficult challenge of learning to overcome their shyness:

*We were brought up to a lot of traditional way of living. To deal with things, to pray for things that you can not seem to resolve ... I think, how do I get there? That's the hardest part of it, to get more. Because we were always taught not to talk very much, in that area and not*

*ask so many questions. That's another way of learning to do the whole process, when you move out to big cities.*

They had learned, through trial and error, to communicate effectively with health professionals and hoped that other women could benefit from their experiences. Special sessions, showing women how to ask questions and how to interpret the answers, were needed to teach women these critical skills. They needed to understand when it was appropriate to ask questions, how to ask a physician or nurse questions and, if the information was not forthcoming, how to request additional explanations. Learning how to ask questions was a difficult but essential part of getting health information:

*As a mom who looked after a child who's been treated by the doctors. There's a couple of things that I learned over the years. Looking after the one in the hospital and living here. Medical practitioners will not tell you, they will only tell you a certain section unless you learn to ask specific questions .. and try to understand what they were saying. Sometimes I learned to ask "What are you not saying?" Also, "What kind of medication are you giving her? What does it do?"*

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## Using Telephone Help-Lines

- ◆ Women also needed more instruction before they would be comfortable in accessing phone help-lines, such as *Telehealth Ontario*.

While those who used *Telehealth Ontario* and other phone help-lines were satisfied with the services, there were many women who were reluctant to try. They told us that telephone-based services, designed to give consumers easy access to health information, were not always as user friendly as they might be.

Not understanding how the services worked, some women had concerns that they would be misunderstood when they made requests for assistance. Others felt reluctant to use services because they thought that translators were not available and they would have difficulty understanding instructions. They were also anxious because they believed that professionals staffing the service might not understand Aboriginal ways.

Participants in the study said that *Telehealth* and other phone help-lines would be much-better utilized if supports, such as availability of translators, were well-publicized in Aboriginal communities. They also liked the idea of using Aboriginal nurses to staff *Telehealth Ontario* or similar services to give added assurances that Aboriginal concerns would be understood. Resources

permitting, a dedicated Aboriginal service, similar to *Keewaytinook<sup>6</sup> Telehealth*, could be an acceptable alternative. People liked the idea of telephone-based health resources, but they needed more Aboriginal support:

*They need to have more helpful talking phone lines, like 1-800 numbers ...but they need to have a Native operator.*

## Finding Help in the City

- ◆ Problems locating appropriate services also occurred when Aboriginal women moved from small communities to cities.

Women who had relocated from small rural or isolated communities to urban areas told us that they had problems because health materials did not explain the different ways that services were delivered in the city. While there were more services in the city, the services were more difficult to access, because they were delivered by many more organizations. As a young First Nations woman said, "when you live in town, it is harder and more difficult to receive help." Without specific instruction about accessing services in the city, it was

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<sup>6</sup>*Keewaytinook Telehealth* uses telemedicine workstations, and cameras to improve First Nations access to health professionals and programming in seven remote First Nations in Northwestern Ontario.

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challenging to find out where the services were and how to access them. Women often relied on word of mouth to put them in touch with appropriate agencies. As an Inuit mother said:

*There's a big difference when you've been living in a small community and moving down here. We get so well taken care of when we are in a smaller community ... Everybody knows everybody. But the thing is, it's totally different down here ... What I'm getting here, it's difficult to access all, basically word of mouth. Getting your health information, that's how you get it is word of mouth and all that.*

People who had moved into urban areas also had difficulty dealing with the sense of isolation from their families and communities. The loss of personal support made it even more difficult to take the steps needed to find appropriate information and access care. As one woman said:

*I feel isolated. I'm not with my family. I'm not with, although I'm in a city...You know what I mean, you're not in this community.*

Those who had experienced such frustrations made a number of useful suggestions about the ways that newcomers could be given needed information. Pamphlets, posters and video displays placed in clinics and

community centres would help direct women to assistance. Information sessions or workshops for newcomers could be an equally effective method of explaining the differences in services. Home visits could also be used to give newcomers information about the services available.

Respondents suggested that the role of orienting newcomers to urban services could be taken on by Aboriginal women who were familiar with the city. Working from Aboriginal organizations, health centres or hospitals, as volunteers or staff persons, these individuals could assist newcomers in locating and accessing appropriate services. As a woman said, "you need to know where to get the information and how to get it."

## **Finding Aboriginal-Language Resources**

- ◆ The absence of health materials in Aboriginal languages was a serious barrier to accessing information.

Women whose first language was Aboriginal told us that they could not understand the English-language information that was available in their communities. They relied on family to translate and, if family was unavailable or unable to translate, sometimes they gave up in frustration and set the resources aside.

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The absence of Aboriginal-language materials affected elders the most, because they generally only spoke and read traditional languages. Elders told us that there were very few resources available in the Aboriginal languages which they spoke and read. As one Cree-speaking elder said, they needed “more syllabics!” Another woman, from an Inuit community, had similar needs; she wanted “more Inukituit written information.” Sharing her aunt's story, a woman said:

*My great-aunt, she couldn't understand what the health services were providing for her ... she couldn't understand videos, pamphlets. She went to the elder's centre and she couldn't understand what they were talking about.*

## **Finding Clear English-Language Materials**

- ◆ People with limited English-language skills had problems locating health resources that were written in simple, clear language.

Participants in the study proposed that language difficulties could be overcome if dissemination strategies were modified to ensure that women with limited English language skills could understand. Simple, clear, easy to understand language was needed. Thinking about her own difficulties

comprehending health information, a woman reminded us that people who spoke English did not necessarily understand written materials as well:

*Even though we are English speaking, we do still have a hard time reading English writing.*

Another woman said:

*Why can't they have those native documents, that are more clear, proper English that we would understand?*

Those who had trouble reading pamphlets and other written material found that audiovisual material was easier to understand. They also responded well to audiovisual information when it depicted Aboriginal communities and lifestyles like their own. As a woman said, for her:

*The easiest way to understand is by watching movies. I think for me it would be easier because I can understand what they are saying more. By reading a pamphlet, I don't get half the words.*

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## Other Issues Affecting Understanding

Over 60 study participants offered additional reasons why health information was easier or more difficult to understand. Their opinions, listed in the text box, underline the importance of developing material that is easily comprehended. Material was easy to understand if it presented health information in simple language, with translations if needed. visual information, step by step instructions, and, when needed, definitions of medical terms. Information presented through workshops or women's groups was also easier to comprehend because it gave women a chance to discuss issues and share opinions.

Resources were difficult to understand if they used complex words, were filled with medical terminology or lacked directions about where to go for more assistance. People also found it hard to relate to mainstream material that showed non-Aboriginal role models. Information that did not accurately depict rural and northern health care systems created difficulties in understanding and applying material. Lack of Aboriginal-language resources and plain English-language materials were also barriers to understanding.

### Why Easy To Understand

- *APTN (Aboriginal Peoples Television Network)*
- *Breaking down big words*
- *Chance to talk with other women*
- *Culturally appropriate*
- *Culturally relevant*
- *Culturally specific posters*
- *Definitions included*
- *Detailed*
- *Diagrams*
- *Easy to read*
- *Health nurse that comes to community once a month helps*
- *Goes step by step with things*
- *Information from community programs, counsellors*
- *Illustrations*
- *Laid out easy to understand*
- *More pictures for people*
- *More personal*
- *Native visuals*
- *Not patronizing*
- *Programs at Health Centres, Friendship Centres*
- *Relevant to our community*
- *Respectful of academic barriers*
- *Short and simple*
- *Simplified for people*
- *Something important to talk about*
- *Specifically targeted to us*
- *To the point*
- *TV programs about health issues*
- *Very direct*
- *Videos easy to follow*
- *Visuals easier to understand*
- *Women's groups are better*

*Figure 34 - Other Reasons Easy to Understand (Consumers & Providers)*

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## **Why Difficult to Understand**

- *All the information is in English*
- *Boring*
- *Cannot understand medical terminology*
- *Doctors hard to understand*
- *Hard to find out where to get more information*
- *Hardly any Native based resources*
- *Illiteracy*
- *Information from videos don't stick*
- *Information is geared to mainstream*
- *Information needs to be simplified*
- *Little on Aboriginal health issues in main media*
- *Look too much into the past*
- *Made by Western society*
- *Medical terminology too difficult*
- *Most material is somewhat complicated*
- *Most resources are from outside places*
- *Need to break terms down*
- *No tools to deal with today's issues*
- *Not all women have the literacy skills*
- *Not enough information*
- *Not available in different Aboriginal dialects*
- *Not easy for people who do not speak English and need translation*
- *Not enough real details*
- *Not much designed for Northern communities*
- *Not much for elders*
- *Not specific to Aboriginals*
- *Nothing in syllabics for elders*
- *Nothing from traditional perspective*
- *People cannot get to most services*
- *Reading is difficult for some*
- *Reference books needed*
- *Role models are non-Aboriginal with different cultural dilemmas*
- *Some information you get is hard for some people to believe*
- *Some women are not highly educated*
- *Too complex*
- *Too complicated*
- *Too hard for elders who are non-English speaking*
- *Too general*
- *Too much big words*
- *Too much translation needed*
- *Translation too difficult*
- *Unable to read*
- *World views too contrasting*

**Figure 35 - Other Reasons Information Difficult to Understand (Consumers & Providers)**

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## Summary

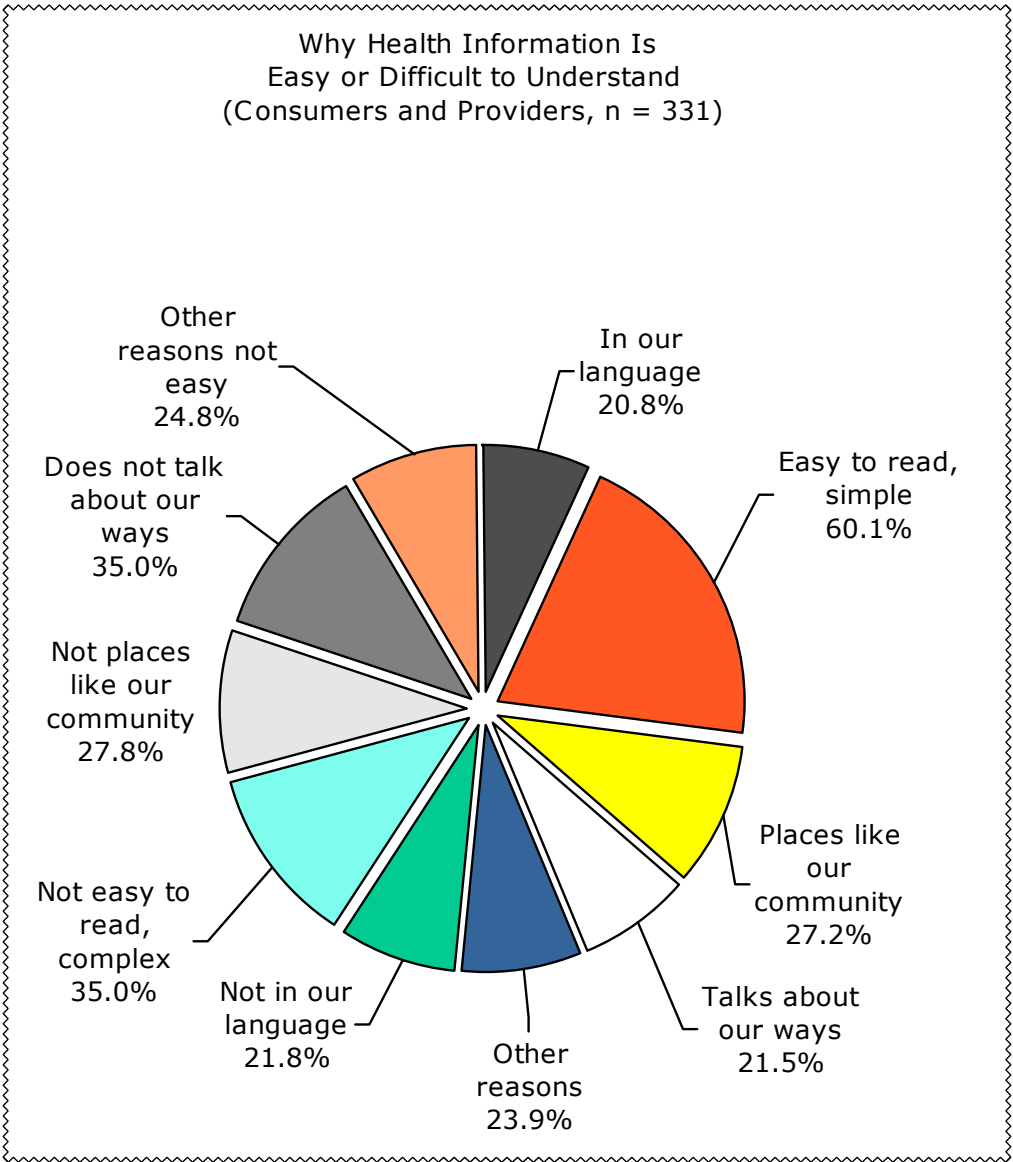
The study suggests that many Aboriginal people face many barriers in understanding the health information that is available to them. Both consumers and providers emphasized how essential it was to recognize and address these issues:

- ◆ Easy to read, simple materials were a priority; six in every ten respondents identified this as the factor which made health information easy to understand (60.1%).
- ◆ A minority thought it was important to have materials that were community-specific; over one-quarter recognized this as an aid to understanding (27.2%).
- ◆ Equivalent numbers believed that information in traditional languages improved understanding (20.8%).

There was less agreement on the factors which made health information difficult to understand. On this subject, study participants felt that women had most difficulty with material that did not accurately reflect their cultural background:

- ◆ One-third felt that material which did not reflect Aboriginal ways was more challenging (35.0%).

- ◆ There were also issues with information which did not depict Aboriginal communities (27.8%).
- ◆ For some individuals, health information was less accessible if it was not available in Aboriginal languages (21.8%).
- ◆ As might be expected, complexity also created barriers to understanding (35.0%).
- ◆ Respondents also offered information on additional factors facilitating (23.9%) or impeding (24.8%) utilization of available health information.
- ◆ Their comments revealed that Aboriginal-specific materials, with clear language and accompanied by diagrams and visuals, were the easiest to comprehend.
- ◆ Difficult materials were those which included medical terminology, complex instructions or unclear directions about where to go for additional information or assistance.
- ◆ Mainstream materials were also hard to understand, when they referred to elements of the health care system that were not generally accessible in rural and remote areas.



**Figure 36 - Understanding - Why Health Information Is Easy or Difficult to Understand (Consumers & Providers)**

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## 6. Traditional Approaches

Evidence from a number of evaluations suggests that traditions enhance the well-being of Aboriginal communities, families and individuals. First Nations residents who participate in traditional activities, for example, are more likely to report good health than people who do not take part (Wilson & Rosenberg, 2002).

Aboriginal women who practice traditional customs more often follow a healthy lifestyle (Guilliano, Pampenfuss, Geurnsey de Zapien, Tilousi & Nauvayestewa, 1998). Participation in traditions also means that people are less likely to engage in risky behaviours, such as substance abuse (Herman-Stahl, Spencer & Duncan, 2003). As well, cultural factors influence the effectiveness of educational interventions (Messer, Steckler & Dignan, 1999; Fisher & Ball, 2002). Traditions such as storytelling, for example, are effective in promoting wellness (Cesario, 2001; Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002). Considering this, it was important to know the ways in which women used and benefited from traditional approaches.

### **Research Questions: Traditional Approaches**

In your community, would women ever go to traditional healers for information about wellness?

(If so, who would they go to?)

- *Traditional healers*
- *Medicine people*
- *Midwives*
- *Elders*
- *Clergy*
- *Other (Please explain)*
- *None of the above (Where else?)*

What would women learn from traditional healers about wellness?

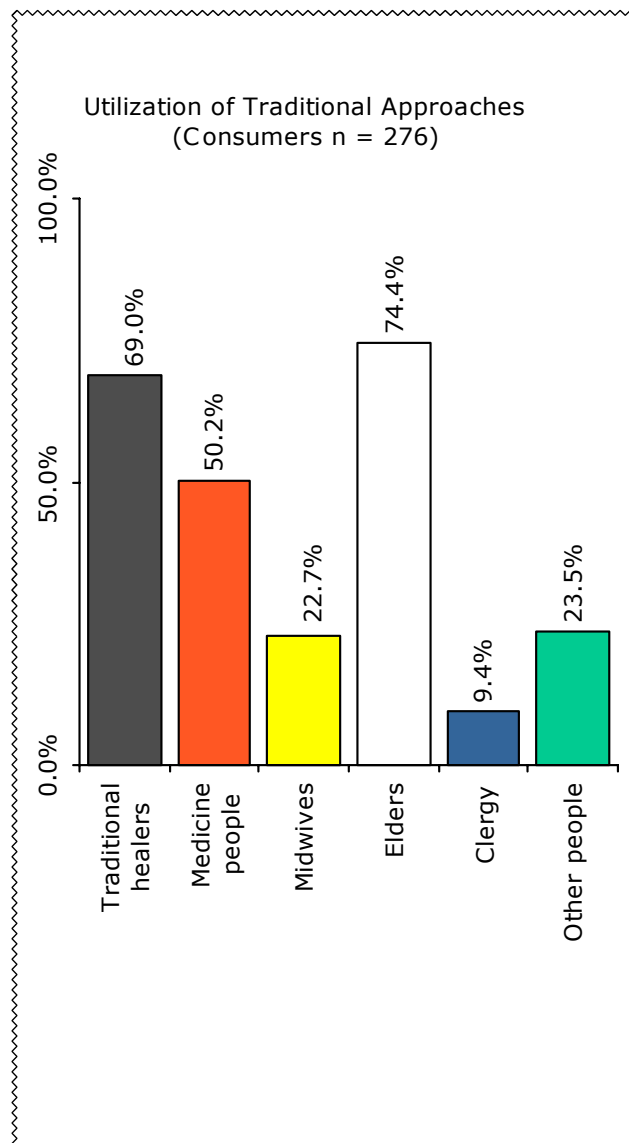
- *Keeping in balance*
- *Using sacred medicines*
- *Using sacred ceremonies*
- *Traditional health teachings/story telling*
- *Other learning (Please explain)*
- *None of the above (What else?)*

## Using Traditional Approaches

Aboriginal women confirmed that many people turned to members of their communities for information about traditional health teachings:

- ◆ About seven in every ten went to elders and traditional healers for information (74.4%, 69.0%).
- ◆ Five in ten also looked to medicine people (50.2%).
- ◆ Very few reported going to traditional midwives (22.7%) or clergy (9.4%).
- ◆ A significant number turned to other people and places for information on traditions (23.5%).

Those who turned to other sources said there many places inside and outside their communities where they could receive traditional teachings. Some access healers through an Aboriginal Health Centre, Healing Lodge or Friendship Centre (n=20). Others had access to traditional knowledge when healers were brought into the community or when they travelled to a larger centre (n = 24). On a day to day basis, they



**Figure 37 - Using Traditional Approaches (Consumers)**

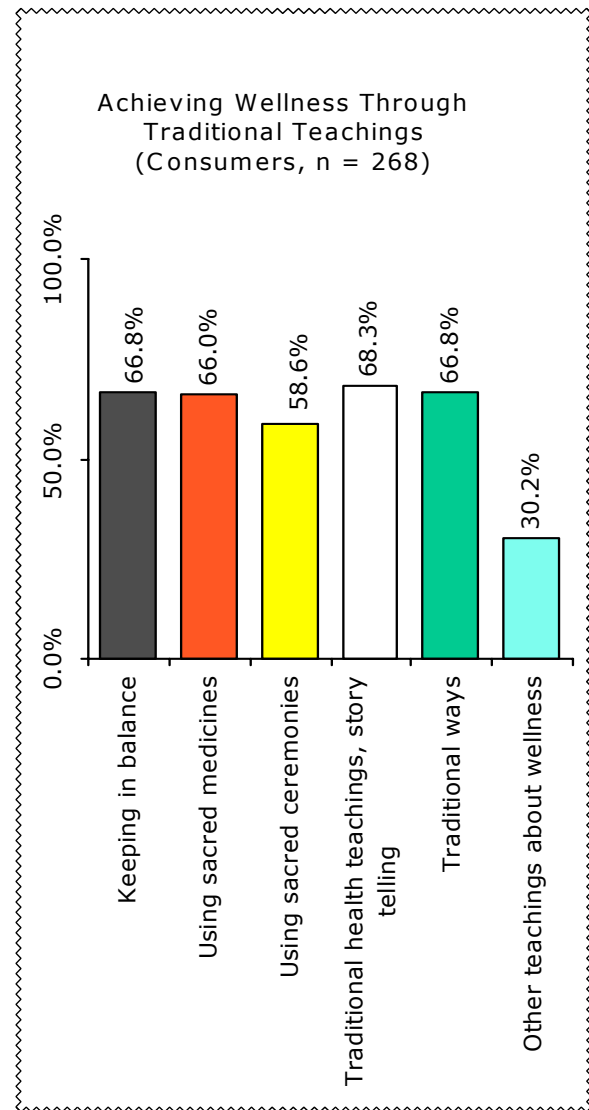
relied on local people who had knowledge of traditional ways, family and friends (n = 26), women's groups (n=10) and community workers, counsellors and community health representatives (n = 10).

# Achieving Wellness Through Traditional Teachings

Given the importance of culturally-specific information, women were asked to elaborate what they would learn from traditional healers about wellness. Their answers emphasized their strong belief in holistic health and affirmed the importance of cultural beliefs in maintaining health:

- ◆ Two-thirds who expressed an opinion on this issue felt that women benefited from traditional health teachings and story telling (68.3%).
- ◆ Equivalent numbers achieved wellness through keeping in balance, traditional ways and sacred medicines (66.8%, 66.8%, 66.0%).
- ◆ More than one-half recognized value in learning about sacred ceremonies (58.6%); more than one-quarter saw additional benefits (30.2%)

Traditional teachings encouraged women to adopt healthy lifestyles and feel better about themselves and their communities. Women who learned



**Figure 38 - Achieving Wellness Through Traditional Teachings (Consumers)**

about traditional teachings also realized how important it was to support one another and look towards the future. As one woman said, learning about her peoples' traditions taught her the importance of "looking in the right direction of life and keeping their lives on track."

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## Valuing Traditional Approaches

- ◆ In their discussions about traditional approaches, women made it clear just how much they valued culturally-appropriate health information.

They found holistic approaches and Aboriginal-specific material appealing. They especially appreciated health information which respected the diversity of their traditions. Women also discussed cultural comfort and safety issues, including training of support workers and health professionals.

## Holistic Health

Holistic health approaches that recognized the importance of wellness and the value of balance in life were widely appreciated as a source of the strength and understanding. Teachings about health, to be effective, should recognize the “whole value of self,” encompassing “the whole emotional, spiritual, physical component.” In the words of a woman who had recently become

acquainted with traditional healing through an urban women’s group:

*I hear them talk about traditional healers and I know that it’s available. And I think it’s such a great thing, ‘cause those are the people that will take into account ourselves as a whole person. Where I think that, when you go and you ask specific questions to people outside the traditions, they don’t take into, they generally don’t take into account our mental and our physical and our spiritual selves, which I think is not helping us or I know it doesn’t help me. I need to be looked at as a whole person not just as my physical body.*

Looking at health issues from a traditional perspective also helped them take responsibility for their own health and follow recommendations which had been given:

*When you go see a traditional healer, he is not going to give you medicine but also teach you how to be well emotionally as well. It is your responsibility to follow instructions and follow-up. It is up to you to exercise and eat well to avoid certain illnesses. To follow the traditional balance, we have followed from our ancestors. Regularly attending sweats and talking to the creator. It’s a way of connecting your spirit to the creator.*

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Health information which took a holistic approach also helped women to understand “the connectedness” in their lives and the importance of achieving “balance.” It added to their comfort, the information more relevant and helped them to follow recommendations. Given these benefits, women suggested holistic approaches could serve as a model for many types of Aboriginal health education. A First Nations woman who had observed a traditional diabetes circle observed:

*I seen a diabetic circle done the native way at one of the First Nation. It is good, because they were speaking the language and understanding. They learned all about diabetics. That model would be beneficial to any community.*

## **Aboriginal-Specific Material**

The women who took part in this study offered many examples of the health information that they liked and disliked; Aboriginal-specific material was very appealing, mainstream resources less so. They generally appreciated the posters, videos and pamphlets that had been developed for programs such as *Aboriginal Head Start*, *Healthy Babies*, *Healthy Children* or the *Fetal Alcohol Initiatives*. They liked *Health Canada* pamphlets, posters and workshops that had been developed for specific

regions of the Province. Many also mentioned resources developed by Aboriginal organizations, such as the *Ontario Native Women’s Association*, the *Ontario Association of Friendship Centres* or the *Aboriginal Health Access Centres*.

Aboriginal designs used for posters, pamphlets and videos caught their attention and increased the likelihood that they would understand the information which was presented:

*I think when we develop our resources ... with our people, when they see a picture of an eagle, it is more eye-catching. I know for me, that has a native design on it, opposed to a non-native design that is really plain. People tend not to pick up those kinds of brochures. Even when we look at videos ... Our people should try to design more of the resources, than non-native. We can relate more to it ... I think when we do, when our people are doing things, it hits home and it brings us closer.*

Women were especially attracted to visual materials depicting Aboriginal women, families, and community settings. As a participant said: “Billboards and posters that show Aboriginal children make them feel comfortable.” Others liked “videotapes with our own people and our own ways.” Stating her own preferences very clearly, another respondent said “you should see *native people* when

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videos are made for *native people*.” Summing up her opinions on the importance of having Aboriginal-specific presentations, a woman said:

*When native presentation is presented, we are more likely to listen to the teaching. It makes a huge difference ...and that has an impact on me, as with others I’m sure.*

## Diversity

- ◆ Although they respected one another’s traditions, Aboriginal women revealed that they found material difficult to understand if it talked about traditions that were different from their own.

Inuit and Métis women, for example, said that they had difficulty relating to First Nations material; conversely, First Nations women had problems understanding resources prepared for Inuit or Métis communities. They were most “culturally comfortable” with health information which was specific to their Aboriginal traditions.

They also appreciated the cultural understanding embedded in health materials that reflected their own community's traditions, language, symbols and beliefs. Given the importance of this issue, they felt that organizations that produce health information should work with Aboriginal communities to develop

materials that are culturally-specific and, resources permitting, community-based.

Ideally, women wanted health information that acknowledged the diversity of traditions, beliefs and values in their communities. They suggested, if feasible, government departments with an Aboriginal mandate should fund and support separate health information initiatives for First Nations, Métis and Inuit communities. As well, Aboriginal women saw a need to take an active role in designing programs for their communities, to ensure that their concerns were voiced and needs were met. Speaking of a successful program, an Inuit woman said:

*Another good thing that we do .. we have a substance abuse treatment program ..The participants are able to design the program, using our cultural and traditional values. So it could be held in our own language. We light the kooluk. We talk about how we designed the program from our own perspective and come up with our own solutions.*

Women who had experience with Aboriginal-designed programs felt that organizations with responsibility for design and development of health materials should make use of First Nation, Métis and Inuit women who have specialized language and cultural knowledge. There are knowledgeable women in every community who could

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collaborate with professionals to develop effective health information. As consumers, Aboriginal women wanted to make sure that their needs and suggestions were heard. As one woman said:

*No native people on videos, need native designed..why not community like here?*

## Cultural Competence

Given the difficulties that they had in accessing appropriate Aboriginal-specific information, study participants suggested a number of ways in which their cultural comfort could be increased. Their suggestions included specialized supports to increase the cultural competence of mainstream health care providers and Aboriginal health workers.

They wanted “comfortable” and “consistent” messages to teach their children, extended families and communities how to live a healthy life. They also wanted positive messages that focussed on the possibilities, rather than the problems:

*Focus on positive and wellness, not negative statistics!*

## Mainstream Providers

Women also said that their level of cultural comfort would be enhanced if there was special training to improve health and social service providers’ knowledge of Aboriginal culture and language to enhance their sensitivity to cultural issues. Women told us about the frustrations that occurred when physicians and nurses lacked an awareness of Aboriginal peoples’ beliefs in the value of traditional approaches to care:

*I feel that western doctors don’t relate to holistic ways of practising health ...they don’t understand, ...but try and make them understand !*

Women also felt uncomfortable interacting with providers, as cultural differences caused misunderstandings and discomfort. An absence of appropriate explanations and understanding sometimes made these interactions very uncomfortable:

*It shouldn’t be like that, I think. We shouldn’t feel scared to talk about our health problems with someone whose supposed to know, like a doctor or whatever.*

When discomfort occurred repeatedly, women felt reluctant to discuss their problems and shy about asking

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questions. Sometimes they avoided going for care when they should have:

*I haven't been able to find a family doctor in a really long time to feel that connection ... I need western medicine as well as the natural way, the native way, and trying to combine those two and having the western doctors respect that. ...Like they just don't understand it and I don't like that.*

Lack of cultural awareness on the part of health professionals contributed to ongoing communication difficulties when elders were receiving care. Recounting her father's experience, a woman from an isolated First Nations community related how such misunderstandings lead to serious problems:

*Elders are sometimes given medicine they don't need. My father was seeing this one Doctor who prescribed medication after medication, soon he was taking ten different ones daily. He was getting sicker and sicker as days went by. He saw a different Doctor who cut seven of them and he's doing much better. We have to ask questions and sometimes Doctors don't like that we do, but we must. Just look at my Dad's situation!*

An Inuit woman observed that culture, language and contrasting world views

made communication between mainstream providers and Aboriginal peoples extraordinarily difficult. So much so, she felt there was no communication at all:

*Where we're coming from and they're coming from, it's going to be two ships crossing in the night. One person is going this way and the professional is going that way. So, either that or they're talking cross references. And that is often the case.*

Thinking about their interactions with "mainstream" health care providers, respondents recognized that most health and social service professionals who came into their communities had limited knowledge of Aboriginal ways and little understanding of their beliefs and traditions:

*In a medical voice you really don't have anyone who knows what they're talking about. What the professionals are talking about ... They don't talk the same language as common people, regular people.*

Women who had experienced these situations thought that specialized "hands on" cultural sensitivity training should be offered to physicians, nurses and other professionals who work with Aboriginal women. Training would enhance providers' ability to communicate health information to Aboriginal women. It also would alert professionals to areas of potential

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misunderstanding and confusion, making them aware of problems with pamphlets and other health materials:

*Health professionals need to be more culturally aware, so the health professionals will know that we can't read those things, and stop giving them to us .. I really think that the cross cultural awareness between health professionals and First Nations have to be more.*

## **Aboriginal Health Support Workers**

Those who took part in this study suggested that specially-prepared health support workers would be of assistance in helping Aboriginal people get appropriate care. They talked about the need to have someone in busy clinics and hospital emergency rooms who would understand their situation, their concerns and their ways. Someone who knew their community, their culture and language would be ideal:

*You need support workers that understand our culture and there needs to be that training for them to understand what our needs are and where we're coming from.*

Women talked about the need for workers to advocate for people who

required support during interactions with health professionals:

*Advocacy workers, to go with people. Help explain things, mediate. Get the women what they need. Get the doctors to treat women natives with more respect.*

They also recommended training for Aboriginal home support, mental health, and health outreach workers, so that these individuals could deliver health information to their clients. Specialized support workers, who could speak traditional languages, were also required to assist in communications when elderly people required care. Participants in the study recounted several examples when elders from their communities had difficulty because they could not communicate with health providers:

*Many people can't speak for themselves because they can't communicate in English that well ... This is what I think causes poor treatment ... Sometimes our elders are sent out for appointments without escorts and who is there to translate for them and get their point across? This causes misdiagnoses.*

Another participant shared a similar story. She related how ongoing communication difficulties caused serious delays in diagnosing her father's condition:

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*The doctors told him that it was a really bad cold and that it was going on for a long time. A year later he died. Diagnosed with cancer. That is so common up in the north. They go to see the health professionals and ... the general public who hardly speaks English or who doesn't speak English will be told that this is a common cold or this is a common illness. When they're diagnosed it's too late.*

Women proposed that Aboriginal health and social service organizations should work with their funding agencies to develop specialized positions for Aboriginal health support workers in urban hospital emergency rooms and community clinics. They would be able to provide culture-specific supports, including translations. A provider said:

*I believe women's health issues would be better related to them by Aboriginals. I know many physicians and other health care workers who are not sensitive to cultural diversity, just the difference in communication alone ...ie., just because a woman doesn't ask question, doesn't mean she actually understands.*

As well, some respondents emphasized the need to train Aboriginal women to provide the health information required by their communities. They thought these workers, as women, would better

understand their concerns. Specially-trained women support workers would be more sensitive to cultural issues, traditional health beliefs and practices. From a practical point of view, support workers would have more time to listen than busy health professionals. Expressing her desire for this kind of assistance, a woman said:

*I know I have some issues that I do not know where to turn. Sometimes, most times, a doctor is too busy to really listen. A health worker put there for women only would be good. A woman that could understand what we go through ... available through the family doctor ... also through hospitals and clinics.*

Aboriginal women who were trained to provide health information would be able to offer support in an empathetic way, because they understood the circumstances. They also could also give encouragement, helping women, families and communities work towards wellness:

*We need more Aboriginal women workers who will do their job in providing the information to keep Aboriginal women healthy in body, mind, and heart, and spirituality ... It begins with ourselves, our family, and then our community.*

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## Safety & Security

- ◆ In talking about cultural comforts, women emphasized their need to feel safe and secure when they were accessing health information.

They needed assurances that any information that they shared would be kept confidential and that they would be treated in a respectful and nonjudgmental manner:

*Confidentiality, trust and non-judgmental environment or person is a must for women to get the health information they need. Finding this environment, person or program is key, as well as easily accessibility.*

- ◆ Safety was an important issue for all women and essential for those who had been in abusive relationships.

Women who had experienced abuse did not feel comfortable accessing health information through some of the current initiatives. They could not participate in door-to-door or home visiting health information campaigns, because the presence of an abusive partner made it impossible for them to ask questions or relate concerns. Thinking about the situation of women in her community, a respondent said:

*Women living with family violence know what it is, a door to door campaign wouldn't work as partner would be controlling situation ... a woman needs to feel safe and be comfortable in a learning environment to be able to express herself.*

Women who had experienced abusive relationships were equally reluctant to attend community sessions, because their security could not be guaranteed. Assurances of safety, security and protection could be provided by offering health information initiatives through Aboriginal women's shelters in larger centres and safe houses in smaller communities. Women's wellness centres, staffed by female doctors, nurse practitioners and healers would serve equally well to ensure that they could access information in safety:

*Feeling safe is one huge thing. Having more clinics that serve women. ... I'd like to see a women's centre for native women, period, that only women are running and that women are taken care of ... just native women to go and they have their referrals to elders and healers, women.*

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## Summary

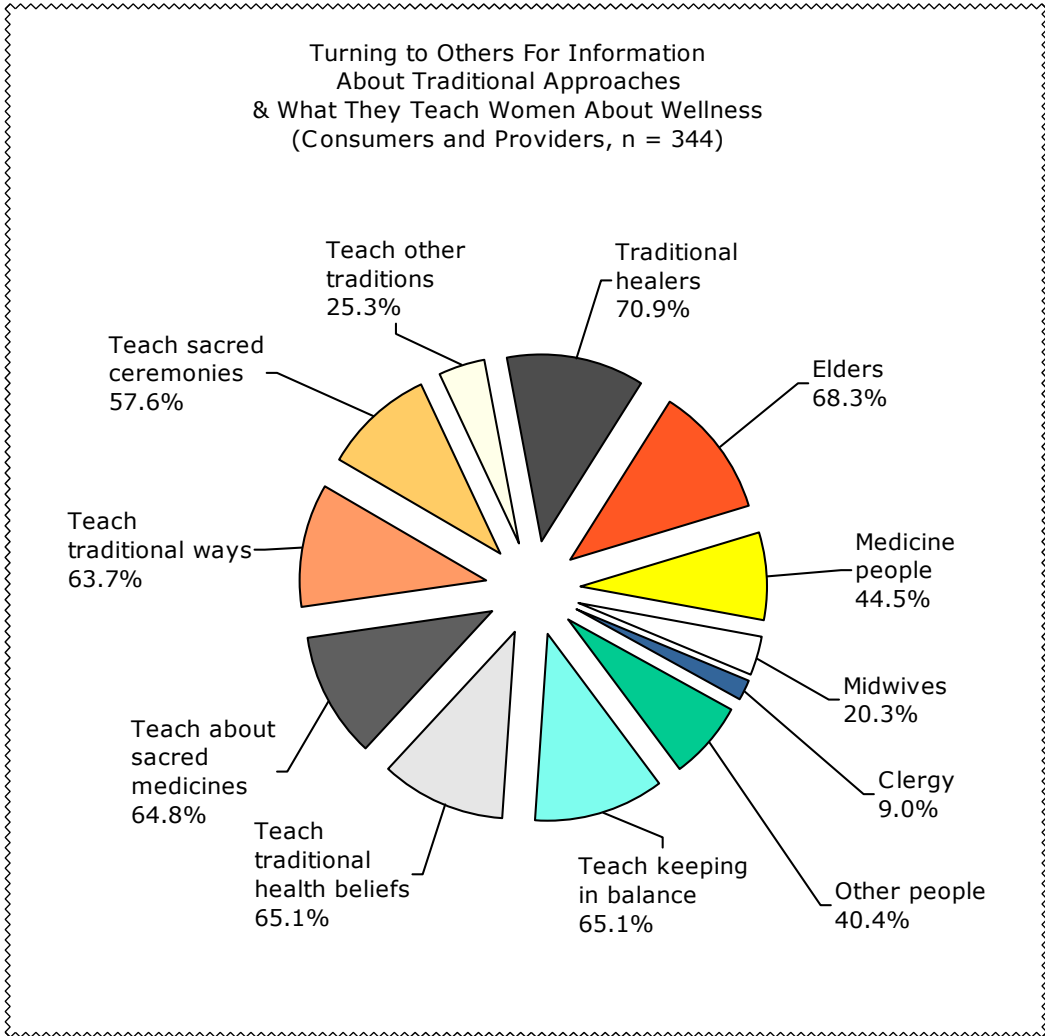
Results from this study suggest that there is considerable support among Aboriginal women and providers for traditional approaches to wellness:

- ◆ More than two-thirds of respondents acknowledged that women in their communities turn to traditional healers and elders for assistance in achieving wellness (70.9%, 68.3%).
- ◆ Nearly one-half believed that medicine people fulfilled a similar role (44.5%).
- ◆ Equivalent numbers saw value in the traditional health teachings shared by other community members (40.4%).
- ◆ Although not widely available, midwives were appreciated for their traditional knowledge (20.3%).
- ◆ Four in 10 respondents reported that women turned to other people for information about traditional approaches to wellness (40.4%).
- ◆ Six in 10 respondents believed that teachings encouraged wellness by helping women to keep in balance, value traditional health teachings,

use sacred medicines and follow traditional ways (65.1%, 65.1%, 64.8%, 63.7%).

- ◆ They also recognized the link between wellness and participating in traditional sacred ceremonies (57.6%).
- ◆ One-quarter offered examples of other advantages which could be gained by adopting traditional approaches to wellness (25.3%).

Respondents recognized the value in these approaches and identified needs for additional culturally-specific supports, including enhanced cultural competence for professionals. They also saw the importance of ensuring safety and security, so that all women could access health information in their communities.



**Figure 39 - Traditions - Turning To Others About Traditional Approaches & What They Teach About Wellness (Consumers & Providers)**

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## 7. Strategies

To explore preferences for specific health information strategies, we turned to the literature evaluating Aboriginal health initiatives. These studies suggest that shared learning and individualized health teaching are preferred. Workshops are useful for educating people about diabetes (Struthers, Hodge, Geishirt-Cantrell & DeCora, 2003) and cancer (Hodge, Fredericks & Rodriguez, 1996). Community health fairs (Thomas, 2002) and women's groups (Dickson, 2000) are equally effective.

One-on-one education sessions have been used to teach Aboriginal women about cervical cancer (Lanier, Kelly & Holck, 1999), environmental health (Kegler, Stern, Whitecrow-Ollis & Malcoe, 2003), HIV/AIDS (Vernon & Jumper-Thurman, 2002), pregnancy risks (Gray-Donald, Robinson, Collier, David, Renaud & Rodrigues, 2000) and substance abuse (Saylor, 2003). Information strategies combining print resources and audiovisual materials, including the Internet, also have been successful (Buchanan, Morris & Kauley, 1999). The study asked participants to indicate which of these strategies would be the best ways of getting health information to women.

### Research Questions: Strategies

What would be the best way of getting health information to the women in your community/communities?

- Pamphlets
- Posters
- Flyers, newsletters
- Newspapers, magazines, advertising
- Bookmarks, magnets
- Audiotapes
- Videotapes
- Radio shows, commercials
- Television shows, commercials
- Internet
- Workshops
- Health fairs
- Women's groups
- Individualized one-on-one sessions
- Door to door awareness campaigns
- Other (Please explain)
- None of the above (Please explain)

*Is there anything else that could be done to help women get the health information that they need?*

*(If so, what do you think would work best?)*

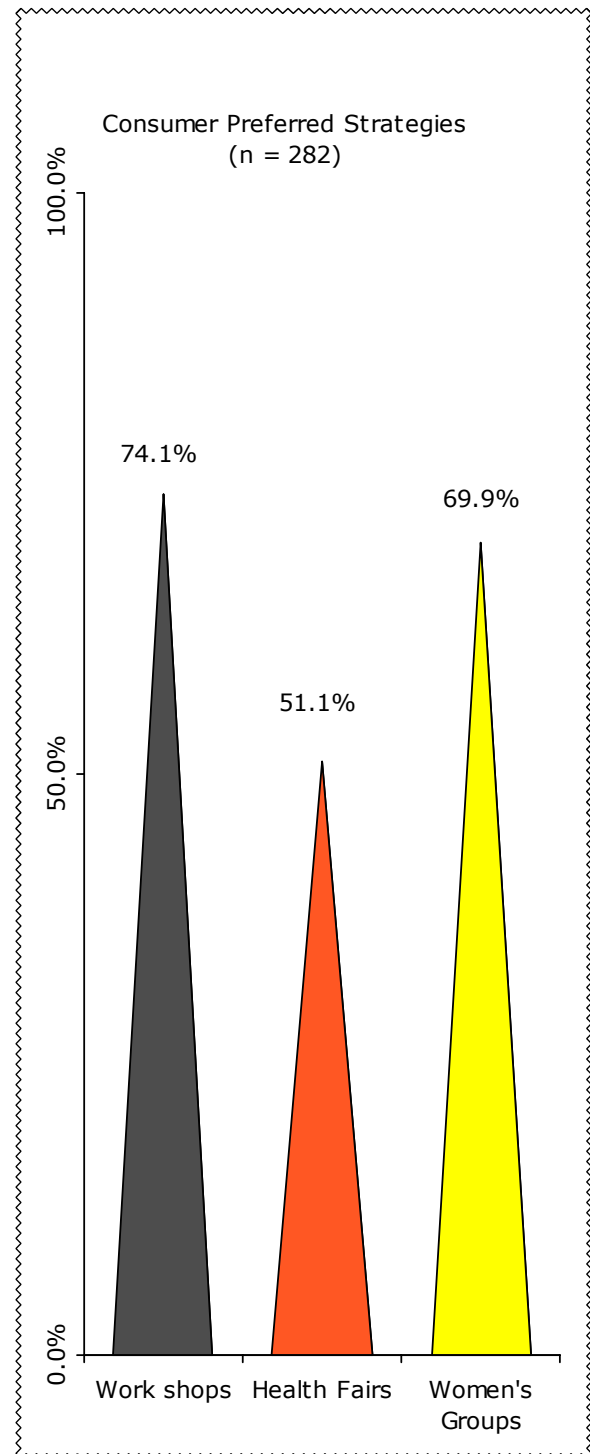
## Shared Learning

Three-quarters of the women surveyed preferred shared learning strategies, which gave them the opportunity to learn with other members of their community:

- ◆ Workshops (74.1%)
- ◆ Women's groups (70.2%).
- ◆ One in every two also liked health fairs (51.1%).

In explaining their preference for shared learning, women said they felt comfortable in these settings. They especially liked sessions which were warm and welcoming, "friendly services, where information is provided." Discussion groups gave women an opportunity to talk about health concerns, learn from each other, and offer support. Groups and health fairs also provided chances to take home vital pieces of information:

*That it is the most effective way of getting health information out to the community. They tend to be a big thing and someone always walks away with something whether it be a key chain or a pen .. and they might call that place for information.*



**Figure 40 - Strategies - Shared Learning (Consumers)**

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Women liked the achievement and accomplishment that they felt after group discussions. They found encouragement in talking to other people and sharing their experiences. They also enjoyed the positive messages and support that was offered. Speaking of the sharing circles that were held in her community, a woman liked:

*Sharing circles, or just the women going forth for themselves, meaning, when certain things are available concerning women matters, they should go ahead on these matters, and learn. Just basically to help themselves, to live a healthy life.*

Their preference was for community-based initiatives which brought women together to talk about their problems, acquire needed information and explore the solutions which might be appropriate for their communities. In talking about these events, women made it clear that they not only liked the information that was presented; they also liked the chance to get together and hear other women talk about their experiences. They felt that workshops and other group education sessions provided an effective method of disseminating health information.

Educational sessions also offered a supportive environment in which women could discuss the health issues that affected their communities. They especially enjoyed the programs which were locally developed and delivered.

Including presentations, skits and talking circles, gatherings allowed plenty of time for women to listen and learn from one another. The key was to create:

*Accessibility, relaxed approach, support from others  
experiencing similar difficulties,  
a holistic approach that would promote the entire family to participate in workshops.*

They also saw value in the informal sharing of information that occurred after the sessions, when women continued their discussions over refreshments. Offered by community centres, cultural organizations, schools, churches, and women's groups, shared learning events were well attended and appreciated:

*All of these ways would be and are effective. I think workshops and health fairs that promote a gathering, food, traditional values and culture would be effective for getting people to attend.*

As well, Aboriginal women's groups often sponsored sessions with age-specific activities. Workshops that had learning sessions for mothers and childcare activities for children, for example, gave mothers and children a chance to learn. So too did sessions that had activities designed to interest teens, young adults or elders. As one woman said, "different ages, different issues."

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Participants encouraged organizations who sponsored these events to make sure that the sessions were well-publicized, so that no one would miss out. Notices should be distributed widely, on posters, and bulletins on community radio and television. As one respondent said, they needed to place information in:

*Doctors' offices, day cares, grocery stores ...places women frequent!*

Providers who had sponsored successful health workshops recommended that attendance would be improved if people could be assured that they would "enjoy these types of gatherings." Women who had attended educational sessions reported attendance was better when sponsors offered supports such as transportation and childcare. Many people did not have their own transportation and, in smaller communities, there simply was no public transportation. Mothers who lacked childcare supports could not attend sessions, unless childcare was provided. The recipe for a successful workshop was simple:

*Make it easy, provide childcare, transportation, food, etc.!*

Summing up the benefits of their own shared learning experiences, women said that they not only learned new information, they gained confidence to put it into practice. This was the real advantage of shared approaches:

*Women need to be more assertive in their lifestyles and whatever they are dealing with ...to have an information sharing circle group with other women. This way women in our community will begin to feel more confident about themselves. Health information is available here and also in different organizations, but it is what you do with the information is what is more important.*

## **One-on-One Health Teaching**

In talking about shared learning, women noted that this format was not suitable for all types of information. Many said that one-on-one health teaching as being equally effective and advantageous in any number of situations. As shown in the chart on the following page, they favoured:

- ◆ One-on-one health teaching (59.6%)
- ◆ Door-to-door awareness campaigns (37.2%)

Those who spoke about the need for individualized health education strongly supported the need for one-on-one health teaching. This alternative was more comfortable for

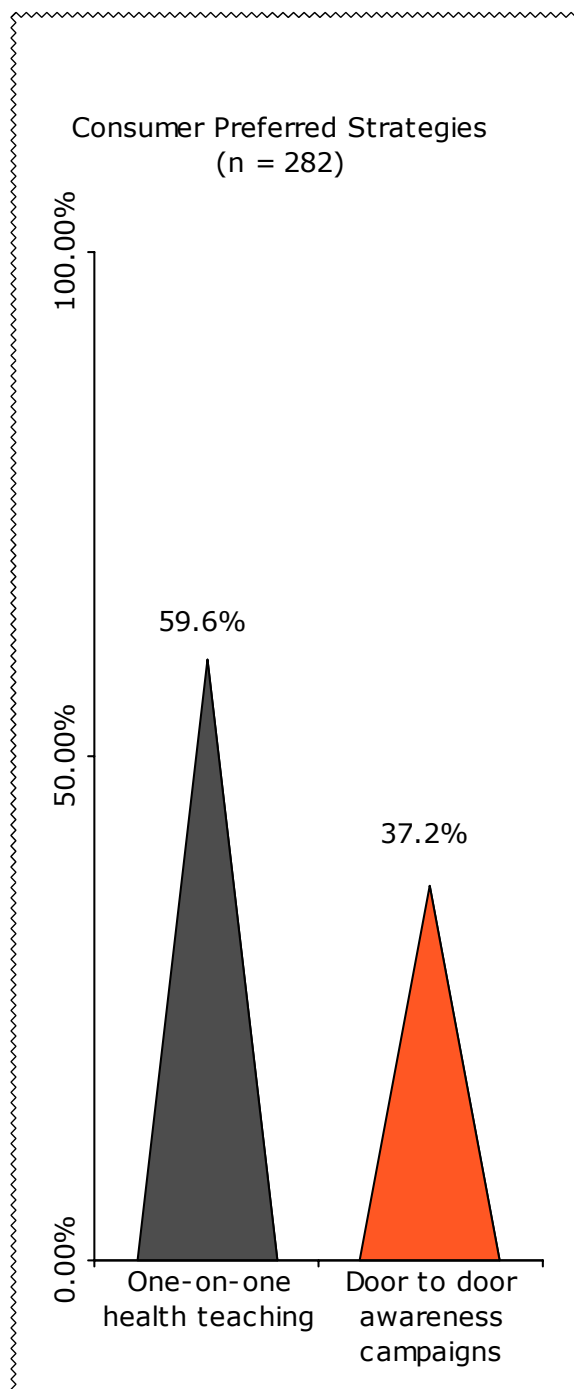
many people. As a resident of a small community noted, "not everyone feels comfortable" discussing health issues in a group setting. Another said individual health teaching encouraged women to come forward with their problems:

*A lot of women are shy to speak in front of a group, so one-on-one would be beneficial. But the woman has to be able to step forward and ask for the help.*

Women also preferred one-on-one teaching because the setting allowed them to be more open and trusting. It also gave them greater assurances of confidentiality than could be found in a group setting. People who had confidentiality concerns would only take part in educational initiatives, if individual health teaching was an option.

One-on-one health learning offered more privacy than could be achieved in a group. Having access to individualized teaching was especially important when women needed information about their personal health, family relationships, sexuality, or mental health. As one woman said:

*I'm not sure that I would join [a group] because I consider myself to be shy and there is a trust issue. There are few people here that you or I can trust. [I don't] want people to know about me or who I am and my health.*



**Figure 41 - Strategies - One-on-One Health Teaching (Consumers)**

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- ◆ As well, one-on-one teaching was preferred when the information or health condition was difficult to understand.

Individualized instruction worked well when people need to follow detailed instructions or access services. They had the chance to ask questions, get personalized information, and explore issues. It also gave them additional confidence, simply because a knowledgeable person was present to give them feedback. A health professional said that individual instruction also worked well when women needed to understand complicated instructions for managing an illness:

*Hands on is probably a better approach for what can be difficult to decipher information. Having someone at hand who can help make sense of terminology and to answer questions.*

Offering in-home teaching as an option was especially important for the elderly and women with disabilities, who had difficulty finding the transportation and supports needed to attend educational sessions held outside their homes. It was also appreciated by busy young mothers, who were pressed for time and lacked resources to attend community sessions. These women depended on the information which came into their homes. For them, "Door to door is the only effective way to get information, one on one."

In-home health teaching was an equally effective as a way of reaching people who were too shy to take part in group sessions and uncomfortable with going to a health care centre or other organization for information:

*For other people, especially native women, they are shy. Its hard for them to ask for information and often times, have to be coaxed.*

Home-based health teaching also was a very effective way of telling women about services and how to access them. It also offered extra encouragement to get needed help:

*It's not lack of knowing where to go but lack of time to do it. That's the big issue for me. For me, if I know where all these services are, I'll know where to go and access this information.*

## Print Resources

Women also placed great importance on having written health resources in their communities. They wanted:

- ◆ Flyers and newsletters (60.3%).
- ◆ Pamphlets (57.1%)
- ◆ Posters (47.2%).

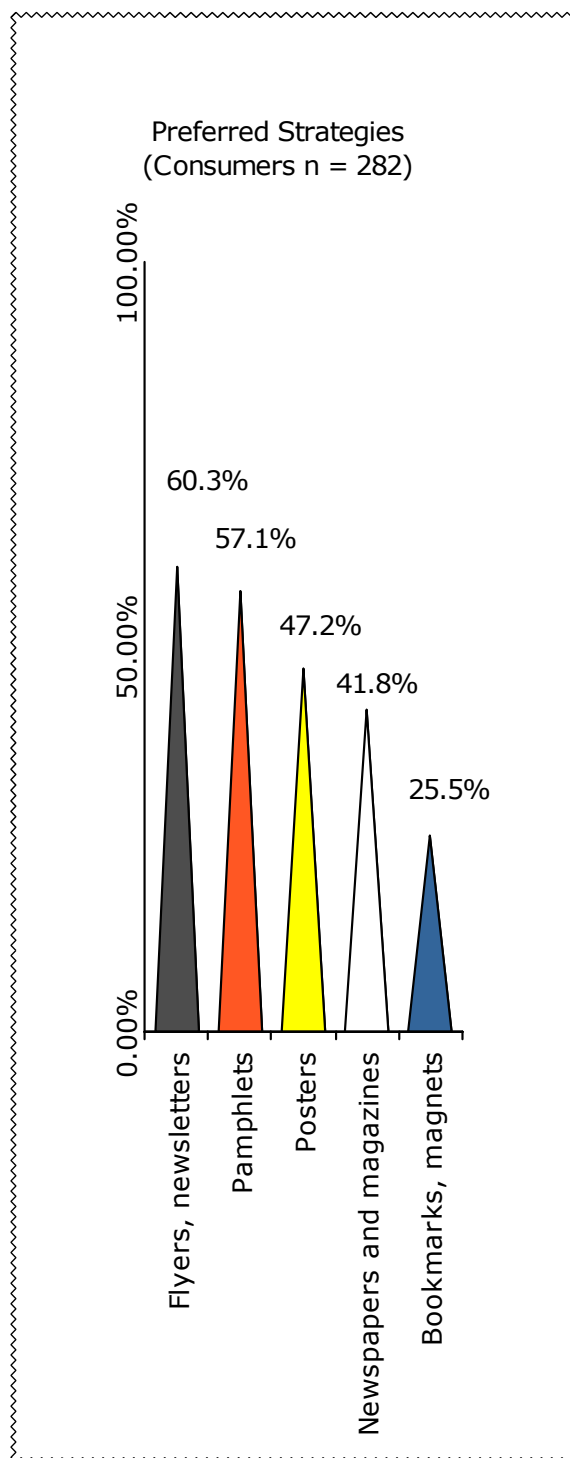
- ◆ Newspapers and magazines (41.8%).
- ◆ Some also liked bookmarks or magnets (25.5%).

People who favoured print materials saw these strategies as being a way of ensuring widespread distribution of health information. They thought flyers and newsletters were especially effective as a way of publicizing community health initiatives or changes in services. Flyers and newsletters were delivered to every household, assuring that no one was left out who might need the information. These methods were also viewed as being comparatively low-cost, suitable for organizations with limited resources. As one respondent said, "flyers only cost 8.5 cents to mail!"

Although the availability of pamphlets varied significantly, many respondents believed that they were an equally attractive means of distributing essential health information to Aboriginal communities. Some liked bookmarks or magnets, which could be placed in a convenient spot, liked these visible reminders of the services which are available.

- ◆ More widespread distribution of print resources was a priority.

In talking about print materials, women sent a very strong message to the organizations, both "mainstream" and Aboriginal, which disseminate pamphlets, brochures and other types



**Figure 42 - Strategies - Print Resources (Consumers)**

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of printed health information. Their goal should be to ensure widespread distribution of printed materials within Aboriginal communities. If resources were limited, organizations should concentrate on distributing information through health care centres and cultural centres, that were accessible and used by large numbers of Aboriginal women. Summarizing these issues, a woman who worked with a national organization said:

*It's not always available to all the communities. You either have to begin even if you don't know, even if you live here where to have access to that. So, I think [Aboriginal health care centres are] that best place, like I think most people go there, I think most native people go there.*

- ◆ At the local level, respondents thought Aboriginal organizations could take a more active role in distributing health information.

They suggested that community centres, cultural groups, friendship centres, or schools should consider using their mailing lists to distribute health information to the families that used their services.

Print materials, such as pamphlets and flyers, were usually straightforward, simple, and contained the essential information that people needed to know. Newsletters, formatted in large type and easy to read, were more accessible to the elderly and other

individuals with reading or vision problems:

*I think that the information that we get in the monthly newsletter. It is useful, if you could understand, because it is in big print. That's good. A lot of us have bad eye sight, especially the elderly, and it's easier to read. It's good if they take sections out, as opposed to putting in. Trying to make it so that we can understand it, I think that it is helpful.*

People who liked print resources suggested pamphlets and brochures might be more accessible if specialized "packages" were prepared, containing all the information that was needed by a person with a particular problem. These could be delivered by a trained volunteer or support person, who would take the time to go over the information, assist clients in understanding the material, and give support:

*Put together packages of health information especially with specific needs. Have volunteer sit with them to review material, with resources for ensuring understanding, comprehension.*

At the same time, print materials such as pamphlets and newsletters were only picked up and read if they featured appealing and culturally appropriate designs. People were also more likely to read materials produced

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by native organizations. An Aboriginal health care provider said:

*Every time I see a native theme or from a native organization I want to grab them because that is what catches the eye of my clients. When you see natives on a pamphlet or native art, they are more appealing to a native person but they are very rare.*

- ◆ It was clear that further work had to be done to improve the accessibility of print resources.

Women called for collaboration between health care professionals and Aboriginal health organizations, to ensure that pamphlets, newsletters and other print materials were accessible. They needed plain language explanations that people could understand. Speaking from a rural community, a First Nations woman saw it this way:

*To go along with that, the health professionals, let's say, a medical professional has many native women as clients. For him/her to really be aware of their clients that they have, and if there are a high percentage of native people in their office ... [that we] don't understand the big words in those pamphlets ... They were in simple letter I would understand ... Give us something that we can read!*

## Audiovisual Resources

Only a minority of women favoured getting health information using audiovisual resources. television, radio, videotapes, audiotapes, or the Internet. Their preferences were for health information delivered using:

- ◆ Television (49.6%).
- ◆ Internet (42.9%).
- ◆ Videotapes (40.1%).
- ◆ Radio (37.9%).
- ◆ Audiotapes (18.8%).

As noted in the preceding section on access, audiovisual materials were not always easy to locate. Aboriginal communities and homes did not yet have the necessary technological supports. Unless additional resources were provided, Aboriginal peoples could not use these strategies to access information.

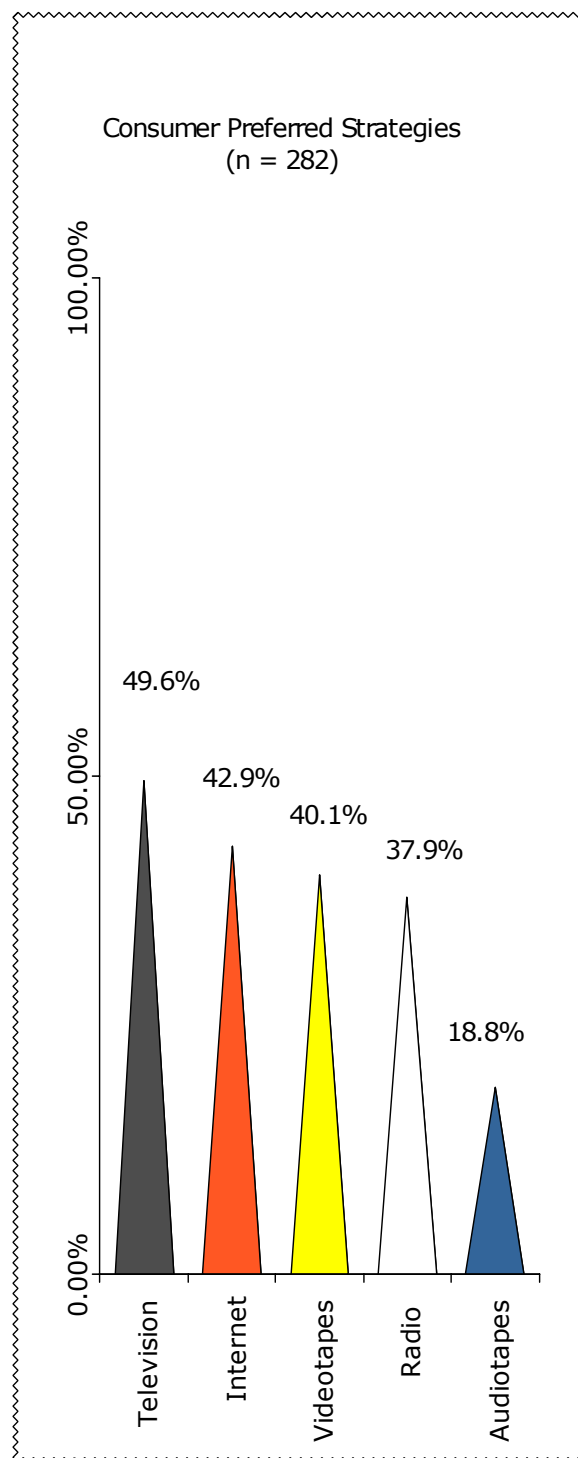
A related barrier was the fact that there was limited Aboriginal health information available through these technologies at present. Those who saw potential in audiovisual resources offered several suggestions for addressing difficulties locating

Aboriginal content. Television or radio broadcasters, for example, could ensure that health information with an Aboriginal focus was well-publicized and distributed nation-wide. Organizations producing health promotion materials also could make sure that there was Aboriginal content broadcasted:

*There should be more on television also. Health Canada has the new diabetes one but you don't see those commercials on TV? Why not? But you see a mainstream person walking and you see all these test strips falling down. Why isn't the diabetes one on TV? Why isn't there more native culturally appropriate television? Especially when diabetes is so high among aboriginal people.*

Women who liked the option of videotapes or audiotapes also saw areas for improvement. Existing audiovisual materials, designed to be delivered by professionals, were too complicated for people to understand on their own. Simpler videos were needed for home viewing:

*There needs to be more educational videos that way if someone that picks it up can understand it, there may not be someone around who can explain it.*



**Figure 43 - Strategies - Audiovisual (Consumers)**

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## The Internet

- ◆ Consumers who favoured the idea of Internet-based Aboriginal health resources pointed out a number of improvements that had to be made before these resources would be user-friendly.

The most serious issue was that the technology needed to support Internet health initiatives was not yet generally available in Aboriginal communities. Rural or isolated locations rarely had Internet access; some of the most remote regions did not even have telephone services. Other locations had the technology, but few Internet terminals available for residents to use. Terminals, located in schools or administrative offices were not generally open to the public. Only libraries, in larger communities, offered Internet access to everyone.

Women who liked the idea of having access to Aboriginal-specific information through the Internet were looking forward to the day when more Aboriginal women could access these resources. They saw a need for more public-access computers and specialized training to enable women to access the Internet. As a young woman said, once they had access to the technology and training in its use,

people would like the Internet and use it for health information:

*The interest would be great, but as of now, we still don't have telephones in our homes. Hopefully by summer we will and with a computer we can access our own information, especially when it pertains to something we don't feel comfortable [discussing] with anyone else.*

People who talked about Internet resources also saw a need for specialized funding for Aboriginal organizations to support Internet-based initiatives. They envisioned dedicated Aboriginal health web-sites, offering a wide spectrum of health and wellness concerns.

The Internet also would have the ability to support many different versions of the same content. Internet-based information could provide a variety of Aboriginal language and culture-specific materials. This technology also had the capability of supplying the community-specific health information that was so urgently needed:

*The Internet would be good to have a site for native people in each community to access since every community is different. A lot of people are shy and this would be better.*

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## Additional Suggestions

Aboriginal woman and those who provided care in their communities offered numerous suggestions about the ways that dissemination strategies could be enhanced. Their thoughts included ideas about where health information could be provided, how it might be delivered and what would work best for their communities:

- ◆ They emphasized the need for responsive and flexible dissemination strategies.

Their preferences generally included several distinctive approaches, encompassing shared learning, one-on-one health teaching, print materials and audiovisual materials. Access to resources was a central concern. Each resource had to be understandable, easily approached and well-publicized. As a focus group participant said: "You need to know where to get information, before you get information."

They needed to have ready access to information. Health information was accessed most easily if available at places where people gathered on a regular basis. They told us that classrooms, common rooms, cultural centres, and community conferences were all settings in which information

### Suggested Strategies A - F

- *Aboriginal 1-800 Health Info*
- *Aboriginal Peoples Television Network (APTN)*
- *Aboriginal role models*
- *Advertising*
- *Age-specific workshops*
- *Audiotapes with booklets*
- *Bingo health information sessions*
- *Books*
- *Bulletin board*
- *Community common room*
- *Community cultural centre*
- *Community conferences*
- *Community feasts*
- *Community health bulletins*
- *Community health conferences*
- *Community health resource centre*
- *Community newsletters*
- *Community television channel*
- *Community visits*
- *Counselling*
- *Daycare centres*
- *Demonstrations*
- *Doctor's office*
- *Elders drop-in centre*
- *Elders group*
- *Elders meeting monthly*
- *E-mails*
- *Family gatherings*
- *Free health programs*
- *Friends and families sessions*
- *Friendship circles*
- *Front-line workers*
- *Fun to learn activities, not lecture*

*Figure 44 - Strategies - Suggestions  
(Consumers and Providers)*

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could be given. Daycare centres, schools, recreational facilities or drop-in centres were suitable places for resources needed by the age groups who frequented these locations.

Weekly events, such as socials, bingo, or sports, could also serve as a point for distributing information. Some communities had regular meetings of women's groups, elder's groups, friendship or sharing circles as well. Seasonal events, including feasts or gatherings, served the same purpose.

- ◆ Women also saw a need for local health resource centres, where people could go to get information.

Both smaller and larger communities would benefit by improved access to information. Smaller communities, with no information on site, could use a lending library, of pamphlets, books and videos, located in a cultural centre, health clinic, or band office. In larger communities, these resources could be located in friendship centres, community cultural centres, or health access centres.

Some people also liked the idea of portable displays, which could be set up at different locations. In smaller communities, travelling displays could be moved efficiently from one place to another, as the need arose. Similar displays could be moved around urban areas, set up in shopping malls, community centres, recreational facilities, schools and hospitals.

### **Suggested Strategies G - O**

- *Family gatherings*
- *Free health programs*
- *Friends and families sessions*
- *Friendship circles*
- *Front-line workers*
- *Fun to learn activities, not lecture*
- *Games, activities*
- *Gatherings*
- *Grocery stores*
- *Guest speakers*
- *Health care workers*
- *Health centre initiatives*
- *Health question period*
- *Home care*
- *Home visiting nurses*
- *Home visits*
- *Home workers*
- *Individualized learning packages*
- *Information sessions*
- *Information clearing house*
- *Internet*
- *Lending library*
- *Letters*
- *Local radio*
- *Mailing lists*
- *Mall displays*
- *Memos*
- *Mothers' club*
- *Mother and child sessions*
- *Men's group*
- *Native organizations*
- *Networking*
- *One on one*
- *One stop shop for health*

***Figure 44 - Strategies - Suggestions  
(Consumers & Providers)***

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- ◆ Women wanted health information delivered in multiple formats, to accommodate the preferences of different age groups and varying circumstances.

They recognized that not all formats were equally accessible, because of differences in age, language and interests. Some strategies, such as telephone or Internet, were better suited to young people who were familiar with the technology. Other ways of delivering health, such as home health teaching, were preferred by older people, women with disabilities, and caregivers, including busy mothers.

Personalized health teaching was also seen as appropriate for people who were coping with long-term illness, family issues, or difficult situations. They needed the confidentiality and assurance that was provided by one-on-one teaching. They especially liked the ideal of personalized help for people who were newly-diagnosed or dealing with crises.

Women also felt that community organizations could incorporate health topics into existing programming. Schools, youth groups and drop-in centres could do more to educate young people about health. Community centres, clinics, churches and women's groups could offer workshops and health fairs.

### **Suggested Strategies P - Y**

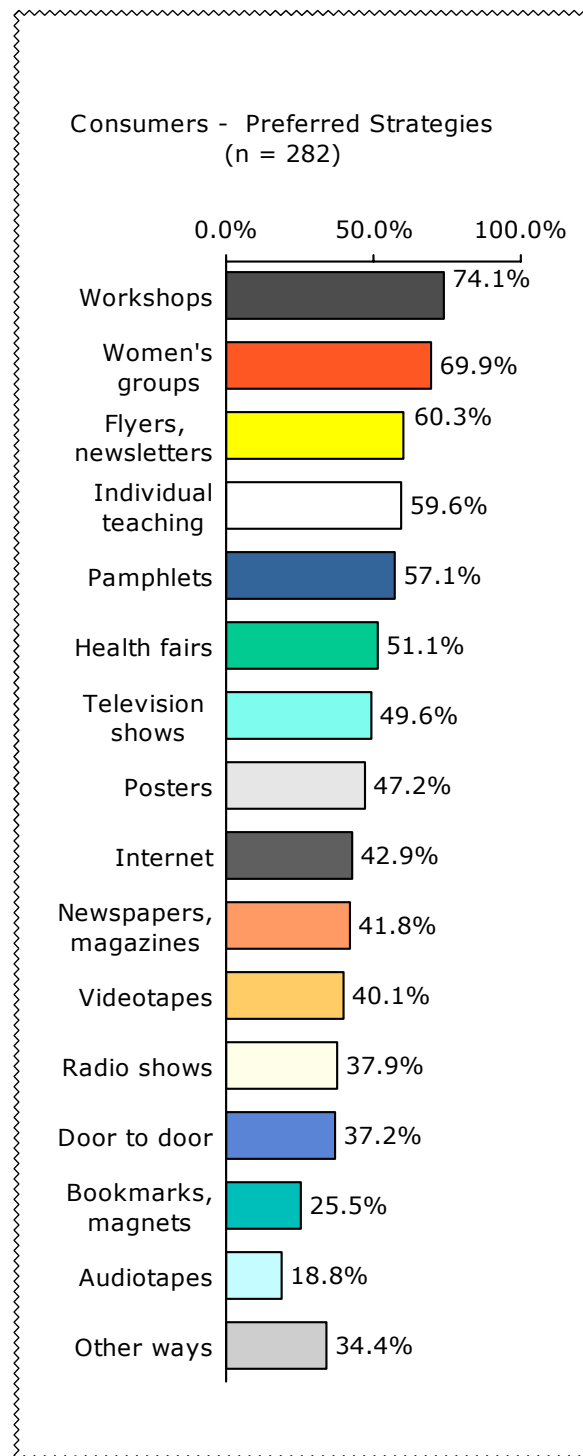
- *Parenting group*
- *Person to person*
- *Personal information packages*
- *Personal invitations*
- *Quarterly workshops*
- *Rides to workshops*
- *School classes for children*
- *School information centre*
- *School sessions*
- *Session with local doctors and nurses*
- *Sharing circles*
- *Socials*
- *Support groups*
- *Telephone awareness campaign*
- *Telephone support network*
- *Television community channel*
- *Traditional teachers*
- *Twelve-step programs*
- *Videos along with pamphlets*
- *Visiting nurses*
- *Volunteer support person*
- *Volunteer health workers*
- *Weekly workshops*
- *Women's group*
- *Women's health hotline*
- *Women's resource centres*
- *Yearly gatherings*
- *Youth drop-in centre*
- *Youth hotline*
- *Youth Internet health website*
- *Youth groups*

**Figure 44 - Strategies - Suggestions  
(Consumers & Providers)**

## Consumer Preferences

The women who took part in this study emphasized the best ways to ensure that health information was accessible was to offer a variety of formats. They preferred:

- ◆ Workshops (74.1%).
- ◆ Women's groups (69.9%).
- ◆ Flyers, newsletters (60.3%).
- ◆ Individual teaching (59.6%).
- ◆ Pamphlets (57.1%).
- ◆ Health fairs (51.1%).
- ◆ Television shows (49.6%).
- ◆ Posters (47.2%).
- ◆ Internet (42.9%).
- ◆ Newspapers, magazines (41.8%).
- ◆ Videotapes (40.1%).
- ◆ Radio shows (37.9%).
- ◆ Door to door (37.2%).
- ◆ Bookmarks, magnets (25.5%).
- ◆ Audiotapes (18.8%).



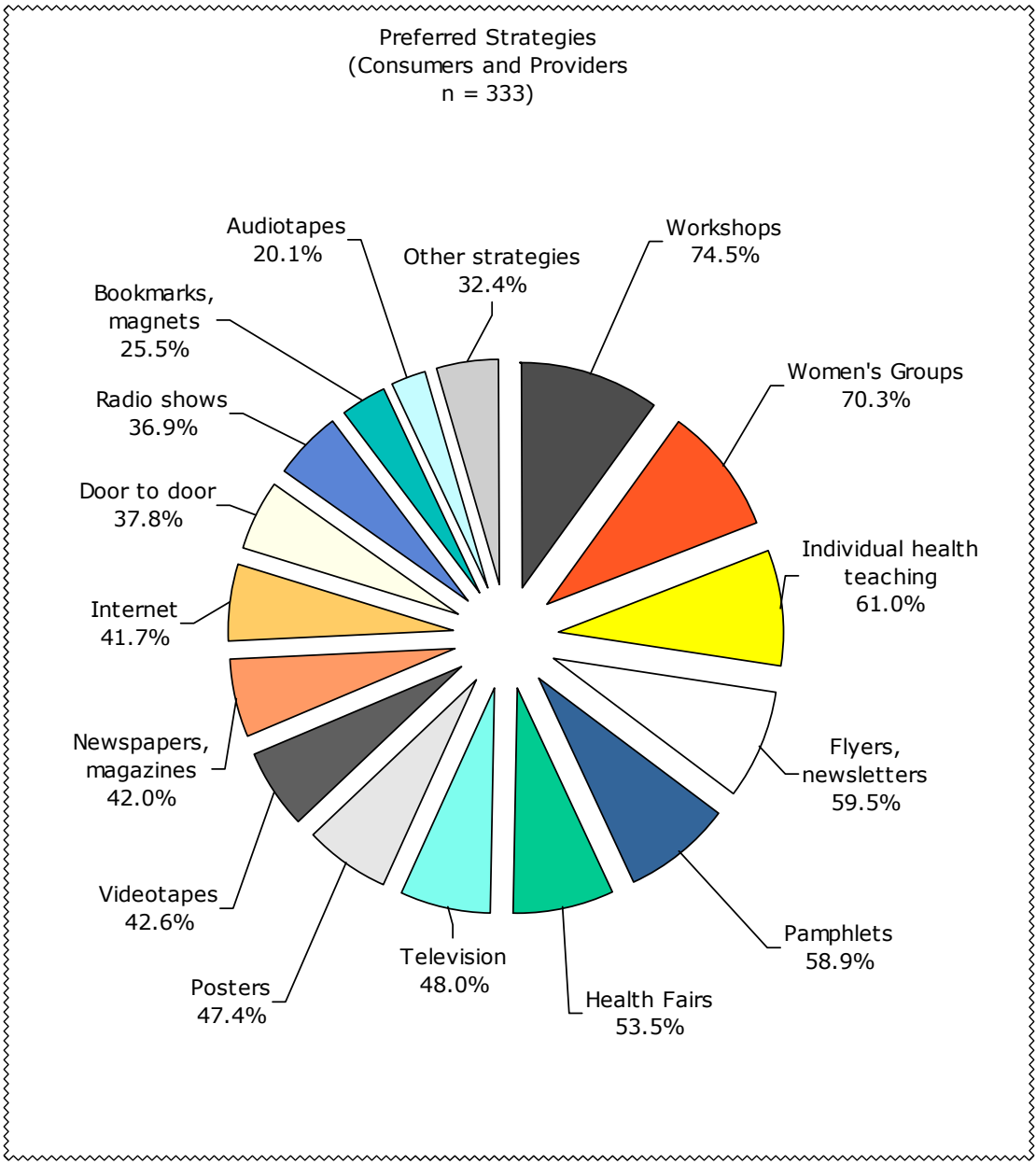
*Figure 45 - Strategies - Preferences  
(Consumers)*

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## Summary

While individual choices varied, the Aboriginal women and providers who participated in this evaluation agreed that a comprehensive range of information strategies could serve their communities well. Their preferred choices, listed in order of frequency cited, were for:

- ◆ Workshops, including information sessions and hands-on demonstrations (74.5%).
- ◆ Women's groups (70.3%).
- ◆ Individualized health teaching, involving one-on-one instruction and guidance (61.0%).
- ◆ Flyers, newsletters (59.5%).
- ◆ Pamphlets (58.9%).
- ◆ Health fairs (53.5%).
- ◆ Television programs and commercials (48.0%).
- ◆ Posters (47.4%).
- ◆ Videotapes (42.6%).
- ◆ Newspapers, magazines (42.0%).
- ◆ Internet (41.7%).
- ◆ Door to door awareness campaigns (37.8%).
- ◆ Radio programs and commercials (36.9%).
- ◆ Bookmarks or magnets (25.5%).
- ◆ Audiotapes (20.1%).
- ◆ Close to one-third of respondents also offered other suggestions about the health information strategies that would work effectively in their communities (32.4%).
- ◆ Their comments reveal that both consumers and providers wanted health information initiatives to be flexible and responsive, accommodating the needs of individuals and communities.



**Figure 46 - Strategies - Summary - Preferences (Consumers & Providers)**

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## 8. Summary & Recommendations

Results of this assessment suggest that finding appropriate health information resources is a serious challenge for Aboriginal women, which will require concerted efforts to address. Nearly all women experience problems accessing health information and understanding available material. A young mother, whose words suggested the title of this report, said that Aboriginal women needed opportunities to learn:

*Everything. We women need to learn more today for ourselves and our children. Just learning makes it a good day. It's very important to talk about everything.*

Recognizing the urgency of these issues, recommendations are directed to the Ontario Ministry of Health and Long-Term Care, to be addressed in collaboration with federal, provincial, regional and local First Nations, Métis and Inuit organizations. They cover funding, developing and disseminating health information to Aboriginal women, their families and communities. For ease of reading, key findings and recommendations are grouped by content areas.

### Key Findings

The Aboriginal women who talked to us emphasized that their communities needed information across the entire spectrum of health issues. They were concerned with getting the information needed to ensure that their families and communities were healthy. They also had to learn how to take care of themselves in order to maintain their own health.

As mothers, grandmothers, sisters and aunts, Aboriginal women play a primary role in keeping their communities healthy. Like all women in Ontario, they need accurate information about the things which affect their health and well-being. They require resources that are understandable, reflective of their circumstances, and presented in culturally appropriate ways. They also want information in a variety of formats, that are responsive, flexible and easily accessed.

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## Needs

Although women had their own priorities, they made it very clear that their collective priority was to obtain information about *all* health issues, since they are the primary caregivers for their families and communities. They offered suggestions about resources which needed to be augmented. They also identified critical areas in which there were serious gaps in the information available:

1) Serious Illness - Women's most immediate concern was to obtain information that would help them understand and control diabetes and other serious illnesses. They were alarmed by the large numbers of people who were experiencing cancer, arthritis, heart disease, and lung conditions, which they believed were relatively uncommon a generation ago. They also wanted preventive information, so their families and communities could "stay healthy."

2) Environmental Health - Aboriginal women pointed out that there was little or no community-specific information on environmental health issues. They needed to know more about the problems of long-term exposure to toxic chemicals in the water and food supply. They wanted to know how to manage contaminants

in their homes, schools and other buildings so they could make sure that their communities would not experience more serious health effects later on.

3) Healthy Lifestyles - Communities needed additional Aboriginal-specific resources to help them lead healthy lifestyles. Women saw a strong connection between the absence of nutritional and exercise information and the serious illnesses, such as diabetes, that are affecting their communities.

4) Mental Health Issues - Most women gave equal weight to needs for information about mental health, substance abuse and family violence. They also wanted to know how to manage the stress and depression which occurs in their own lives. As a woman from an urban community noted, they needed to know: "how to access emotional and mental health ... and how to receive help .. trying to find services."

5) Women's Health - Women were also apprehensive about the lack of information on reproductive health, including pregnancy risks, childbirth, menstruation and menopause. Many had questions about the medications that they were being offered, including the long-term effects of birth control pills and hormone replacement therapy. They also require information about appropriate self-care strategies.

6) Women With Disabilities - Consumers were concerned about the

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lack of information for women with disabilities in their communities. Women with disabilities have difficulty accessing the specialized supports needed to ensure full participation in community activities and needed to know how to get practical assistance, home supports, assistive devices, transportation and rehabilitative services. As a participant said, "women with disabilities in my community are quite common and really there is nothing out there."

7) Women With Eating Disorders - Study participants felt Aboriginal organizations could develop culturally appropriate resources to assist women who were struggling with eating disorders. Increased awareness and promotion of healthy Aboriginal women as role models was also seen as important.

8) Women With HIV/AIDS & Healthy Sexuality - Participants in this evaluation emphasized the need for accessible and understandable information on HIV/AIDS, chlamydia and other sexual health issues. Innovative approaches must be found to overcome the reluctance to discuss these issues; as a young woman said, "people are too shy to talk about it."

9) Children's Health - Women stressed the urgency of obtaining additional resources on children's health. They want instruction about parenting skills -- from the care of newborns and toddlers, through practical advice on preteens and teens. Safety was an equally important concern. Women

also need to learn how to prepare nutritious and economical meals for their children, to adjust diets when fresh foods are unavailable, to include traditional foods and prepare special diets for lactose intolerance or diabetes. As a mother said, "the Canada Food guide doesn't apply to us ...it's not natural to us."

10) Children With Special Needs - Women also experienced challenges getting information to assist them in caring for children who had special needs. They often did not know where to turn for information about FAS/FAE, ADD, developmental delays, learning disabilities, or communication disorders. There were also few resources to assist them in caring for children born to crack, cocaine or heroin-addicted mothers.

11) Teens - There was much concern that teens and young adults were not getting the age-appropriate messages that they needed to hear. Women saw young people struggling to cope with diabetes, mental health and sexual health issues. At the same time, they realized that teens would only listen if they received age-specific messages, preferably delivered by young people themselves.

12) Elders - Elders and those who cared for them need specialized resources. Material for elders should be in Aboriginal languages and reflect their traditions and customs. Elders also need assistance in understanding the information that is given by professionals. Caregivers wanted to

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know how to help their elders in ways that were respectful. Information to help care for elders who are experiencing memory problems and confusion is a priority.

13) Screening Programs - Aboriginal women needed more accessible and understandable materials describing cancer screening programs. They had to understand why screening is advisable and know what to expect when they went for an examination. They also want age-appropriate and culturally-acceptable screening information, to make sure that women of all ages understood the importance of early detection of cancer.

## **Access, Understanding & Traditions**

The study revealed that Aboriginal women were actively involved in a search for information about health issues. They talked to other women, went to their local health centre, attended workshops, and discussed health in women's groups. Some searched farther afield, looking outside their communities. Those who had successfully searched encouraged others to follow their example and "share some information." At the same time, they identified several factors which helped or hindered access and use of health information:

1) Access Issues - Women told us it was not easy to locate appropriate health resources in their communities. Print materials were out-of-date, radio and television programs were poorly advertised, and video or audiotape resources were hard to find. The Internet, *Telehealth Ontario* or help-lines also were out of reach for more remote communities. Better publicity for health programs was a priority.

2) Difficulty Understanding Complex Material - Health information which was available was often too complex to understand. Women experienced frustration because pamphlets were filled with "too many big words." It was also hard for women with limited English-language skills to understand material that contained complex medical terms or complicated diagrams. Simple language, definitions and diagrams are needed.

3) Accessing Information at a Distance - Resources are confusing when they recommend referrals to services that were not available locally. The problem was, "no professionals in community ...so where to go?" People also had difficulty locating services when they moved from rural and remote areas to cities. Instructions for initiating referrals and locating services in larger cities are needed.

4) Asking Questions - As well, women wanted coaching in how to communicate their needs to health professionals. They needed help in overcoming shyness, learning how to

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ask questions or request additional explanations.

5 ) Lack of Aboriginal Language Resources & Translation Services - Women from traditional communities and elders report difficulty comprehending health materials, because Aboriginal-language versions and translation services are unavailable. Multiple-format health materials, including audiotape and video versions, with translations, would help.

6) Importance of Traditional and Holistic Approaches - Acknowledging the importance of traditions, Aboriginal women preferred holistic approaches that emphasized the "emotional, spiritual, physical components" of wellness. They suggested that organizations which prepare information for Aboriginal peoples should present wellness materials "the native way."

7) Additional Aboriginal-Specific Materials - Women very much appreciated Aboriginal-designed pamphlets, posters, videos and workshops. They were most attracted to examples and illustrations showing Aboriginal women, families and community settings. More "native designed" materials are needed.

8) Acknowledging Diversity - Study participants sometimes found material difficult to understand if it talked about Aboriginal traditions that were different from their own. Resources permitting, they hoped that

organizations which produce health materials could develop additional specialized programming, reflecting specific First Nations, Métis and Inuit traditions.

9) Enhanced Cultural Competence - Women believed access to health information would be improved if health care providers were given enhanced preparation so they could "understand our culture .. what our needs are and where we're coming from." Specially-trained Aboriginal support workers were another option for enhancing cultural competence in health care settings.

10) Assurances of Safety & Security - Women needed to be sure that they could access information safely, without incurring risks. They needed assurances that information would be kept confidential and that their physical safety protected. Health programming in women's shelters, safe houses, or wellness centres should address their concerns about safety and security.

## **Preferred Strategies**

In considering the best ways for delivering health information, our respondents emphasize the need for diverse health information strategies. These should include opportunities for shared learning, one-on-one teaching, print and audiovisual resources.

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1) Shared Learning - Aboriginal women's primary preference was for shared learning opportunities, including workshops, women's groups and health fairs. These provide comfortable and supportive places. Given their positive experiences, people felt that shared learning should be an essential part of Aboriginal health information initiatives.

2) One-on-One Health Teaching - While their primary preference was for shared learning, women recognized that one-on-one health teaching was advantageous in many situations. It offered more privacy for discussion of personal issues than could be found in a group. "Door to door" awareness campaigns were equally important for housebound individuals who could not attend meetings. Considering this, women believed that Aboriginal health initiatives should include the option of individual health teaching in the home and other community locations.

3) Print Resources - People placed importance on having written health materials in their communities, in the form of pamphlets, flyers, posters and newsletters; however, resources were not always accessible. To improve access, they suggested organizations which distribute print-based health materials should make sure that they are distributed widely, ideally to *all* Aboriginal communities. Within communities, efforts should be made to place resources in easily-accessible locations, such as clinics, cultural centres, agencies, churches, shelters, schools and stores.

4) Audiovisual Resources - Although women acknowledged there was great potential in television, videotapes, radio, audiotapes and the Internet, there were serious barriers which prevented access to these information sources at the present time. Many areas and homes lack the necessary technology. Women also did not have the training required to use computers. Improved access to technology, including additional public access computers and training in their use, would improve the situation.

## Recommendations

Recognizing that Aboriginal women, as mothers, grandmothers, sisters and aunts, play a primary role in maintaining the health of Aboriginal children, families, and communities, this report makes recommendations directed to the Ontario Ministry of Health and Long-Term Care, that must be addressed in collaboration with federal, provincial, regional and local First Nations, Métis and Inuit organizations that develop and deliver health information to Aboriginal women, families and communities.

To ensure that Aboriginal women have the health resources that they need, it is recommended that these organizations:

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***Target funds to***

- 1) Ensure that Aboriginal women have access to timely, appropriate information on all health issues.
- 2) Augment Aboriginal-specific resources to address the most pressing needs for information about diabetes, cancer, family violence, and nutrition.
- 3) Improve Aboriginal communities' access to information on other serious illnesses, including heart disease, arthritis, lung conditions and digestive disorders.
- 4) Make sure that Aboriginal women have access to resources on mental health issues, including substance abuse, stress and depression, with emphasis on women's perspectives.
- 5) Ensure that Aboriginal women have access to up-to-date material on reproductive health issues, pregnancy, childbirth, menstruation, birth control, and hormone replacement therapy.
- 6) Provide Aboriginal communities with resources promoting healthy sexuality, prevention of HIV/AIDS and other sexually transmitted diseases.
- 7) Deliver "hands on" cultural sensitivity training to enhance health providers' ability to understand the concerns of Aboriginal women.
- 8) Support nurse practitioners as an acceptable alternative for delivering wellness information to Aboriginal

women who lack full time physician care.

- 9) Train and employ Aboriginal women's health support workers to assist in the dissemination of information to Aboriginal women in home, community, and hospital settings.
- 10) Support development and utilization of technology-based Aboriginal health resources, by providing public-access computers and training Aboriginal women in their use.

***Work collaboratively with Aboriginal women's groups to***

- 1) Identify community-specific needs for specialized health information programming for Aboriginal women with disabilities, children, teens, young adults and elders.
- 2) Develop strategies to ensure that Aboriginal women with disabilities have access to information on home supports, assistive devices, transportation and rehabilitative care.
- 3) Develop Aboriginal-specific resources to address children's nutritional needs, food availability, traditional foods, and special diets for diabetes or lactose intolerance.
- 4) Develop Aboriginal-specific resources to assist caregivers of children with special needs, including FAS/FAE, learning disabilities, speech and language difficulties.

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5) Develop specialized information to assist Aboriginal women caring for children who are born drug addicted or developmentally delayed.

6) Develop health resources to inform Aboriginal women about screening programs, including what to expect when they go to a physician.

7) Explore community-specific needs for information on environmental health issues.

8) Develop health materials to assist communities in identifying and addressing environmental health problems, including water and food-borne illness, chemical toxins and environmentally-induced allergies, asthma and infections.

9) Sponsor specialized sessions to help Aboriginal women address issues of shyness and improve confidence in locating information, accessing services and asking questions.

10) Encourage Aboriginal women to take an active role in locating health information and sharing it with their communities.

***Enhance Aboriginal women's understanding of health information by***

1) Modifying health materials so they contain clear language, appropriate pictures and simple diagrams.

2) Explaining medical terms in plain language to ensure that women with

limited English-language reading skills can understand.

3) Including translations, in written or oral formats, to assist women who are most comfortable communicating in an Aboriginal language.

4) Producing health materials that accurately reflect the range of resources and services in Aboriginal communities.

5) Including directions for initiating referrals at a distance, with step-by-step instructions that are clear and concise.

6) Explaining differences between services available in smaller and larger communities for women who move from one to the other.

***Acknowledge Aboriginal women's appreciation of health materials which respect traditions by***

1) Using traditional approaches to enhance understanding.

2) Including Aboriginal content in pamphlets or videos, featuring Aboriginal designs.

3) Using examples and illustrations featuring Aboriginal women, their families and community settings.

4) Developing culture-specific materials that reflect the diversity of traditions, beliefs and values of Aboriginal peoples.

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5) Recognizing Aboriginal women's widespread preferences for holistic approaches, encompassing physical, social, mental and spiritual aspects of wellness.

6) Resources permitting, sponsor separate health information programming for First Nations, Métis and Inuit communities.

7) Making sure that Aboriginal programming on television, radio, video, audio or the Internet is well-publicized.

8) Publicizing the Aboriginal-language translations and supports that are available.

6) Support one-on-one teaching as an alternative when women seek personal health information.

7) Provide door-to door awareness campaigns as an alternative for women who are housebound.

8) Deliver information in settings which guarantee security, such as Aboriginal women's shelters and safe houses; women's wellness centres can serve the same service.

***Work collaboratively with Aboriginal organizations to***

1) Encourage widespread dissemination of health information within Aboriginal communities.

2) Use front-line health and social service workers to disseminate health information to clients.

3) Use pamphlets, flyers and newsletters and organizational mailing lists to publicize community health initiatives and new information.

4) Place information in community settings where women gather, such as cultural centres, recreational facilities and shopping areas.

5) Accommodate Aboriginal women's preferences for shared learning by offering group education sessions.

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## Appendix B - Sentinel Sites

### Whitefish Lake First Nation

- Description: Whitefish Lake First Nation is located on the Whitefish Reserve, on the northeast shore of Lake Panache, about 15 km southwest of Sudbury<sup>7</sup>.
- Population: As of June 2002, the population was 756.
- Cultural Groups: Ojibway
- Services Available: Education Coordinator, Social Services Administrator.
- Health Centre: The Shawenekezhik Health Centre promotes a healthy mind, body, and spirit. Programs offered include Canada Prenatal Nutrition Program, Medical Transportation, Home and Community Care/Long Term Care Services, Mental Health Worker, Alternatives Program, Youth Worker, Cultural Coordinator, Diabetes Programs, Healthy Babies/Healthy Children Program, HIV/AIDS Awareness, Health Information. The centre has Nursing Services, Community Health Representative, Nurse Practitioner, Physician, Registered Dietician, Occupational Therapy, Physiotherapy Services, and Child Psychiatry.
- Other Services: The community also sponsors a Children's Program, Library, Literacy Program, Day Care, Native Child Welfare Prevention Worker, Native Foster Care Recruiter, Band Representative, and Policing.

### Temagami First Nation

- Description: Temagami First Nation is located on Bear Island, a 2 km island in Lake Temagami, about an hour north of North Bay. Access by water or winter ice-road.
- Population: As of April 2003, the total registered population of Temagami First Nation was 614 people, with 200 residents living on the First Nation.
- Cultural Groups: Ojibway
- Health Services: The Doreen Potts Health Centre oversees health and medical services, including non-insured benefits, child welfare, medical transportation, diabetes prevention, community health nursing, healthy babies/healthy children, and elders support.
- Services Available: The TFN Family Healing & Wellness Centre is a women's shelter and educational program. The band also runs its own elementary school and daycare.

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<sup>7</sup> Information compiled from Statistics Canada data and First Nations community profiles.

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## **Equay-Wuk Native Women's Association**

- **Description:** Equay-Wuk Native Women's Association is an independent Aboriginal women's organization, with headquarters in Sioux Lookout. It serves women, youths and their families from 30 different First Nation communities in Northwestern Ontario. These include remote, rural and urban locations.
- **Cultural Groups:** Ojibway and Cree.
- **Services Available:** Programs offered through Equay-Wuk include Community Wellness and Job Readiness Skills Training Programs.
- **Health Services:** Community Wellness Programs, funded by the Aboriginal Healing and Wellness Strategy, provide culturally appropriate support services, resources, information and workshops. Health Information Workshops concentrate on health issues, such as tuberculosis, diabetes, healthy lifestyle, healthy sexuality and pre-natal/post-natal health. The organization also sponsors Parent Support Programs, which offer information and assistance to teen parents and parents of teens. Equay-Wuk also maintains a Resource Centre, which forwards health-related resources to schools within the region.

## **The Ontario Federation of Indian Friendship Centres (Toronto)**

- **Description:** The Ontario Federation of Indian Friendship Centres represents the interests of 27 centres across the province. The Toronto Centre agreed to serve as a sentinel site.
- **Population:** Metropolitan Toronto's Aboriginal population is estimated to exceed 40,000 individuals, representing less than 1% of Toronto's total population of 4,000,000, but 25% of Toronto's homeless.
- **Cultural Groups:** The Toronto Friendship Centre serves First Nations, Inuit and Métis, many of whom have relocated to Toronto from other areas. The Centre also serves immigrant Aboriginal groups, including Arowak peoples from South American.
- **Services Available:** The OFIFC manages and administers a number of provincial programs that are delivered in towns and cities by the local friendship centres. Local initiatives include health, education and training, economic development, children's and youth programs, several justice programs, and cultural awareness.
- **Health Services:** The OFIFC units provide Aboriginal Alcohol and Drug Workers Program, Aboriginal Family Support Program, Aboriginal Healing and Wellness Program, Aboriginal Health Outreach Workers Program, HIV and AIDS advocacy, Life Long Care Program, Noojimawin Health Authority.

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## **Asubpeeschoseewagong First Nation**

- **Description:** The community of Asubpeeschoseewagong, formerly known as Grassy Narrows, is located in Northwestern Ontario, 60 km northwest of Kenora Ontario. This rural community occupies part of the English River Reserve.
- **Population:** There were 1,175 people registered as residents of Grassy Narrows First Nation as of April 2003, with 740 people live on the Reserve.
- **Cultural Groups:** Ojibway
- **Services Available:** Abinoojii Family Services, Ambulance, Canada Post, Grassy Narrows Community Worker, Grassy Narrows Day Care Centre, Grassy Narrows Drug & Alcohol Program, Grassy Narrows Education Authority, Grassy Narrows First Nations Band Office, Grassy Narrows Recreation Committee, Ojibway Tribal Family Services, Ontario Provincial Police, Solvent Abuse Worker, Tribunal Safe House, Wilsookagewin Cultural Centre.
- **Health Services:** The Community Health Centre is staffed by Community Health Nurses from First Nations and Inuit Health Branch. Physicians visit the community on a monthly basis. Physician and hospital care are available nearby in Kenora.

## **Ontario Métis Aboriginal Association (Sault Ste. Marie)**

- **Description:** The Ontario Métis Aboriginal Association (OMAA) Sault Ste. Marie local serves women from Sault Ste. Marie, Echo Bay, Iron Bridge, Michipicoten, Batchewana, Garden River, Hornepayne, Chapleau and Wawa.
- **Location:** In 2001, out of a total population of 74,500 there were approximately 4,530 aboriginal people living in Sault Ste. Marie.
- **Cultural Group:** Métis women from both Cree and Ojibway backgrounds are represented.
- **Services Available:** Programs and services offered specifically by the OMAA include Métis Employment and Training Services, Aboriginal Business Service Centre, and OMAA Healthy Communities Initiatives. Through the Wenuskewin Centre, the Healthy Communities Initiatives encompass Health Liaison, Aboriginal HIV/AIDS Education and Prevention, Responsible Gambling Outreach, Aboriginal Healthy Babies Healthy Children and the Community Action Program for Children (CAP-C).
- **Health Services:** T N'Mninoeyaa Community Health Access Centre offers traditional and contemporary health services to the Aboriginal community. Residents also access care in Sault Ste. Marie.

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## **Moose Cree First Nation**

- **Description:** Moose Cree First Nation is situated on Moose Factory Island, 21 km from the southern tip of James Bay and 300 km north of Timmins. Air and rail services are available at Moosonee, 5 km by water-taxi, helicopter or winter ice road.
- **Population:** The total Moose Cree membership is 3,200, with 1,400 on-reserve.
- **Cultural Groups:** Cree
- **Services Available:** Education, Employment and Training, Business and Tourism, Health and Human Services. Ministik Elementary School (off- reserve), the Delores D. Echum Composite School, the Northern Lights Secondary School (off-reserve), the James Bay Education Centre Campus of Northern College (Moosonee), Chief Munroe Linklater Education Centre and Awashishuk Centre, for young offenders.
- **Health Services:** Weeneebayko General Hospital, a community hospital with 58 beds, is located on Moose Cree First Nation. It serves 7750 First Nations residents of Moose Factory, Moosonee and James Bay. Moose Factory Public Health provides Prenatal/Postnatal Care, Environmental Health, Visiting Nurses, Wellness and Diabetes Groups, Community Kitchens, Daycare, and Smoking Cessation. Moose Cree Healing Centre offers Parenting, Grief Outreach, Crisis Response, Community Watch, Youth and Elders Sharing Circles and Breast Cancer Support Groups, Counselling, Youth Activities, Community Support Services and Homemaker Services.

## **Oneida First Nation of the Thames**

- **Description:** The Oneida First Nation of the Thames, formerly known as Onyota'a:ka, occupies the Oneida Reserve on the east bank of the Thames River, in a rural area 16 km southwest of London.
- **Population:** The reserve is home to 1,685 aboriginal people with another 2,179 living off the reserve.
- **Cultural Groups:** Oneida
- **Health Services:** A Health Clinic, staffed by a Community Health Nurse and Community Health Representatives, provides basic health services. The community also offers Medical Transportation Services, has a Drug and Alcohol Centre. Holistic care is available through the Ganaan De Weo Dis `Yethi Yenahwahse, the Southern Ontario Aboriginal Health Access Centre, located in London. Community residents can also access family physician and specialty care through clinics located in the nearby communities of London or St. Catherines.
- **Services Available:** The community has Education, Native Child Welfare, Social Services and Youth Prevention Services.

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## **Chippewas of the Thames**

- **Description:** The Chippewas of the Thames First Nation is located on the Caradoc Reserve, 24 km west of St. Thomas on the west bank of the Thames River, 40 km from London.
- **Population:** This community is home to about 900 people with another 1,300 living off-reserve.
- **Cultural Group:** Chippewa
- **Health Services:** The community has a Health Centre, staffed by Community Nurses. Residents must travel to the nearby communities of St. Thomas or London to access family physician and specialist care. Holistic care is available through the Ganaan De Weo Dis 'Yethi Yenahwahse, the Southern Ontario Aboriginal Health Access Centre, located in London.
- **Services Available:** The community has Public Library, Day Care, Elementary School, Community Centre and Adult Training Centre. An Alternative School, serving students from three First Nations communities, is also situated in the community.

## **Tungasuvvingat Inuit**

- **Description:** Tungasuvvingat Inuit is a cultural, social, and counselling organization which serves Inuit living in Ontario. Located in Ottawa, the centre was established in 1987.
- **Population Served:** Within the greater Ottawa-Hull area in 2001, with a metropolitan population exceeding 1,000,000, there are approximately 900 Inuit.
- **Cultural Groups:** Inuit who access the services have relocated to Ottawa from Nunavut, the Northwest Territories, Nunavik (Arctic Quebec) and Labrador.
- **Health Services:** Specialized health supports include Addictions Treatment and Diabetes Programs. Community Support Programs provide short-term counselling, crisis intervention and health care support, including referrals. The centre also offers health education programs, interpretation services and access to non-insured health benefits. Members of the community can also access health care through the Wabano Health Access Centre for Aboriginal People, located in the nearby community of Vanier.
- **Services Provided:** The centre offers cultural, social and counselling services, including Employment, Inuit Head Start, Family Resource Centre, Health, Homeless, and Youth programs.

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## **Fort Severn First Nation**

- **Description:** Fort Severn is the northernmost community in Ontario, located on the northern bank of the Severn River, which drains into Hudson Bay. It is a very remote community, about 725 km north of Sioux Lookout, Ontario, accessible only by air or winter ice roads.
- **Population:** As of April 2003, there are 573 registered members in Fort Severn First Nation, 440 of whom live on reserve.
- **Cultural Group:** Cree
- **Services Available:** Band Office, Education Office, Police Station, Crisis Team, Post Office, Radio Station, Youth Centre, Restaurant, Hotel, Garage, and Multipurpose Hall. Education is offered through Wasaho FN Elementary School and Wahsa Secondary Distance Education Program.
- **Health Services:** The community has a Nursing Station with two resident nurses and two community health representatives. Doctors visit the community approximately once a month. Residents requiring specialized care are flown by air ambulance to the First Nations Inuit Health Branch Zone Hospital, located in Sioux Lookout.

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