

Rural, Remote and Northern Women's Health:
Policy and Research Directions

Appendices

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APPENDIX A

Contributors to the Study

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Names of Women who Agreed to be Identified

Labrador:

***Forteau, Mary's Harbour and
Port Hope Simpson***

Tania Keats

Janet Dumaresque

Kathy Farell

Margaret Pye

Cheryl Rumbolt

Newfoundland:

Marystown

Linda Murphy

Florence Walsh

Debbie Hillier

Amanda Power

Linda Oldford

Ontario:

Lion's Head

Mavis Kyler

GINNY WOOD

Colette Sauve

Vicki Travnicek

Woodstock

Mary Jane Bennett

Helen Dunlop

Francophone:

Solange Chevrier

Maria Lepage

Janice Murphy

Marie Dussault

Hélène McCarthy

Annette Richard

Ramona Le Bouthillier

Corinne Gagnon

Laurette Deveau

Ginette Deveau

Aline Bourgeois

Charline Roy

Doris Riopel

Gisèle Séguin

Doris Thibodeau

Madeleine Paquette

Lizanne Thorne

Colette Arsenault

Élise Arsenault

Karen Gilmore-Thomson

Diane Brault

Rita Martel

Nancy Caron

Muriel Bittar

Catherine MacDiarmid

Manitoba:

Oakbank

Jeannette Johnson

Marlene Lussier

Mae Louise Campbell

Catherine Cook

Jeannette Goertzen

Judy Andrew

Angela Livingston

Marielee Nault

Irene Rockhill

Saskatchewan:

Watrous

Lillian Sabiston

Mary O'Hagan

Irene Karol

Natalia Schrader

Cathy McMann

Cathy Spencer

Mary Smillie

Sherron May Reid

Liz Gordon
Gayle McMartin
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Carolyn McDonald
Arlene Pickard
Doreen Holden
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Clive

Louise R. Bell
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Avis Sayers
Marion Grose
Roberta Proctor
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Darlene Brown

Fort Chipewyan

Maureen Clarke
Wendy Nelson
Dana Wylie
Freda Fraser

Vermillion

Johanna Wasylik

British Columbia:

Creston

Korlaina Huber
Carol Nagy
Amanda Chirico
Rachel Chirico
Wendy Palesch

Port Alice

Leanne Farrell
Leann Miller
Penny Bondue
Chandra Hovde

Tumbler Ridge

Cheryl Hayden
Sharon Bray
Rose Colledge

Northwest Territories:

Fort Smith

Gisela Becker
Julia Sewell
Joanne Gauthier
Lauraine Armstrong
Denise Coulthard
Sister Angnes Sutherland
Marcia DeWandel
Louise Beck
Colleen Macza
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Camilia Zoe-Chocolate
May Gauthier
Lesley Paulette
Marlene Wolki
Cheryl Cooper

Hay River

Liz Pope
Gloria Lennie
Anne McGuire-Smith
Brenda Hall

Inuvik

Ann Kasook
Jessie Colton
Nancy Chinna
Barb Lennie
Arlene Jorgensen
Miki O'Kane
Alice Kimiksana
Connie Alanak
Mary Teya

Yellowknife

Fiona Traynor
Diane Jamieson
Margaret Beauchamp
Susan Affleck
Marsha Argue
Kim Riles
Mary Anne Gauthier

National Roundtable

Saskatoon, October 20, 2001

List of Participants:

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Mary Crawford

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Veronica Dewar
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Marjorie MacDonald
Rosella McKay
Edith McPhedran

Marilou McPhedran
Barbara Neis
Barbara Parker
Jan Pitblado
Lilliane Sabiston
Rebecca Sutherns
Wilfreda (Billie) Thurston
Pamela Wakewich

Policy Roundtable

Toronto, November 18-19, 2002

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Associate Professor,
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Biographic Sketches of Contributors

Deborah Barron-McNabb

Deborah is a Registered Nurse who resides in rural Manitoba and is of Métis descent. Her work as a Health Consultant is primarily concentrated in research, analysis, facilitation and negotiation on policy and program issues in a broad range of areas; and currently most specifically with an Aboriginal and Métis focus within provincial, national and international levels. She has served as co-chair of the Federal Government's Aboriginal Working Group on the National Children's Agenda and chair of the National Aboriginal Reference Group on HIV AIDS; advisor on the Federal Provincial Territorial Aboriginal (FPTA) Social Policy Agenda; participated in various processes and delegations (NGO and Official Government Foreign Affairs) to the United Nations including pre-Beijing (Women's Rights) and Cairo plus 5 (Sustainable Development) and Human Rights and the Freedom of Expression and Speech. In the past year she presented to the Romanow Commission. She currently continues to serve on numerous committees including the Ministerial (Manitoba Provincial Government) Advisory Committee on Diabetes, National Aboriginal Health Organization-Métis Centre Governing Committee, Winnipeg Regional Health Authority Continuum of Care Committee, as well as others. At present, Métis Rights specific to Health within the Canadian Health Care System and Health Information Privacy and Ethics are of particular concern and focus for her.

Madeline Boscoe

Madeline is the Executive Director of the Canadian Women's Health Network (CWHN). The CWHN is a partner in the Centres of Excellence in Women's Health Program where she serves as a member of the Steering Committee. She is a long-time staff person of the Women's Health Clinic, a community health centre for women where she currently coordinates their advocacy program and the Health Promotion and Counselling Team. Madeline is also a member of the Advisory Board of the Institute of Gender and Health of the CIHR where she chairs the Knowledge Transfer and Communication Committee and the co-chair of the federal Advisory Committee on Reproductive and Genetic Technologies. Prior to moving into community health and policy work she worked as a registered nurse in the Intensive Care Unit of the Hospital for Sick Children in Toronto and as a nurse-educator for Toronto's Public Health Department. With her husband and two children, she is a long-time resident of Winnipeg, though she remains home-sick for the rain and mountains of the west coast.

Ivy Lynn Bourgeault

Ivy is an Assistant Professor in the Health Studies Program and Department of Sociology at McMaster University. She also holds a New Investigator Award with the Canadian Institutes for Health Research and is heading a five-year study of the impact of gender and place on the rationalization of the health-care division of labour in Canada and the United States. Ivy is a feminist medical sociologist who has published extensively in national and international journals not only on midwifery and maternity care in Canada and the United States, but also on alternative medicine, patient consumerism, and the relations between health professions and the state. Ivy has been involved extensively within the women's health research community in Canada through the National Network on Environments and Women's Health at York University, and the Centre for Research on Women's Health at the University of Toronto. She is a member of the CIHR Gender, Sex and Health Review Panel.

Aimee Clark

Aimee has lived in the Northwest Territories for 14 years. Currently, she lives with her 5 children in Fort Smith. Having 24 years of progressive experience in accounting, she opened her own small accounting business. In 2002, she completed a report "Falling Through the Cracks" distributed across Canada. As an indirect result of this report, she was nominated and elected to the National Anti-Poverty Organization (NAPO) as the board member for the Northwest Territories. She is currently working on the anti-poverty coalition in the Northwest Territories and is developing a Pan-Northern group in conjunction with other Northern NAPO board members.

Barbara Clow

Barbara is the Senior Research Officer at the Atlantic Centre of Excellence for Women's Health. As a social historian of medicine, her research deals with various

aspects of the history of medicine and women's health. She is currently involved in a study of Black women's health in rural and remote communities of Nova Scotia, as well as the history of drug regulation in North America. In May 2003, Barbara became Acting Executive Director of the Atlantic Centre of Excellence for Women's Health.

Christine Dallaire

Christine is an Assistant Professor at the School of Human Kinetics in the Faculty of Health Sciences of the University of Ottawa. Much of her research interests focus on Francophone minorities, particularly issues of youth identities, women and health. She is presently collaborating on a research project examining the Franco-Ontarian community's interest and intervention in health. She is also part of a research team that received Health Canada funding to investigate public perception and acceptable levels of health risk among Canadians.

Lorraine Greaves

Lorraine is a well-established researcher in women's health and gender, focusing on a range of topics of concern to women, women's health researchers, policy makers and community advocacy groups. She is the Executive Director of the British Columbia Centre of Excellence on Women's Health and a member of the research team of the Cross-Centre Initiative on Rural and Remote Women's Health, a project of the Centres of Excellence for Women's Health Program (CEWHP). She is the lead investigator on the Gender and Women in Rural Research project, funded by CIHR. She was the principal investigator of the CHSRF/SSHRC Institute Design Grant on Women's Health and the lead author of CIHR 2000: Sex, Gender and Women's Health (1999). She has written extensively on integrated multi-sectoral health research in Canada. Her expertise lies in applying a gender-based analysis to health issues and policies such as tobacco use, addictions, violence, physical activity, FAS, and economic-costing models. It is this expertise that offers a base for extending the principles of gender analysis and gender mainstreaming to research, policy, and community development issues in rural and remote health.

Karima Hashmani

Karima is the Research Assistant who has provided invaluable and indefatigable coordination for this Project. Although she is based in the office of the National Network on Environments and Women's Health (NNEWH) and reports to the NNEWH Executive Coordinator, she liaises with all the Centres of Excellence in this cross-centre initiative. Karima has international experience in qualitative research on rural women's health. Having graduated from the Faculty of Environmental Studies (FES) at York University, she extended her academic knowledge to the field when she travelled to the state of Gujarat to work on a sustainable water project for women living in rural and remote areas of India. Her work included interviews with women to conduct an assessment of their needs in relation to their health, the health of their families and clean water access. She also evaluated the outcomes of water projects already in operation and wrote up "lessons learned" to be shared with other communities.

Margaret Haworth-Brockman

Margaret is the co-director of this Study and the Executive Director of the Prairie Women's Health Centre of Excellence. Trained as a biologist, Margaret worked for over 12 years in wetland biology, conducting and publishing work from a variety of quantitative research projects on the Prairies. In 1994 she was appointed Chair of the Equity and Access Committee of the Midwifery Implementation Council, by the Manitoba government. She consulted with women throughout Manitoba and co-authored many of the documents, policies, procedures and strategic planning as part of the operations of the College of Midwives of Manitoba. She served as the first Registrar and Executive Director of the College of Midwives of Manitoba. Margaret has written over 30 published papers, articles and presented papers including a chapter in the 2000 National Guidelines for Family-Centre Maternity and Newborn Care. She is a member of numerous steering committees for women's health in Winnipeg, concerning women and poverty, services for addicted women, Aboriginal women's health issues, and care giving.

Noreen Johns

Noreen is a farmer from Zelma, in central Saskatchewan. She has long been an activist in the agricultural and women's communities. She is a founding member of the Saskatchewan Women's Agricultural Network (SWAN) and the Canadian Farm

Women's Network (CFWN), and has encouraged and supported the participation and recognition of women in all aspects of the agricultural industry. Noreen has been an active member of several community and provincial boards and associations. She has served as Vice Chairperson for the Provincial Health Council, chairperson of its subcommittee on Health Physical Environment, member of the Farm Stress Line Advisory Committee, chairperson of the Carlton Train Regional College Board of Trustees, and the rural consumer representative on the Saskatchewan Health Information Network (SHIN). She is currently a volunteer Board Member of the Saskatchewan Heart and Stroke Foundation, serves on the Advisory Board for the Centre for Rural Studies and Enrichment at St. Peter's College, Meunster, and is a member of the Farm Support Review Committee.

Catherine Kulisek

As a 1984 masters graduate of Carleton University, Ottawa, Catherine has expertise in the justice and health portfolios of the Government of Canada. Catherine's early career was spent as a case-management officer and researcher in federal penitentiaries. In 1988, she joined Justice Canada and was involved in policy and program development related to legal aid, crime prevention through social development, women in conflict with the law and child custody and support. She joined the Women's Health Bureau in July 2001, as the Manager of the Women's Health Contribution Program. Together with the Centres of Excellence for Women's Health, Canadian Women's Health Network, and other women's organizations, Catherine participates in the development of evidence-based initiatives intended to improve the health of women and girls in Canada.

Marlene Larocque

Marlene has worked with the Prairie Women's Health Centre of Excellence and numerous other community-based organizations dedicated to justice for First Nations women. She has facilitated community-based research and projects at the regional, national and international level and has worked with Indigenous Women's organizations throughout the Americas while she was based in Quito, Ecuador.

Guylaine Leclerc

Guylaine conducted the Francophone focus groups, with Christine Dallaire, for this Study. She is the Executive Director of l'Union culturelle des franco-ontariennes, the largest non-profit group for Francophone women in Ontario, and has been for the past 12 years. She has been a member of the Coordinating Committee of La Table féministe Francophone de concertation provinciale de l'Ontario for a number of years and is responsible for the health committee of the organization. It is in this capacity that Guylaine represents La Table as a Community Partner in the National Network on Environments and Women's Health (NNEWH).

Gail Lush

Gail is the coordinator of the Women's Health Network, Newfoundland and Labrador and a facilitator for focus groups in this Study. She is also a part-time graduate student at Memorial University in the Department of History. She is studying the history of nutrition and health education at the Grenfell Mission in Newfoundland and Labrador, and has a research background in women, health, and science in the 20th century.

Edith McPhedran

Edith has chosen to live rural area for the past 26 years, where she has had the pleasure of raising her two teenage daughters. She is passionate about maintaining the quality of life in rural areas. Edith works as a community facilitator in rural central Alberta for Child and Family Services. Her social work experience includes front-line crisis intervention, community development, social action and advocacy. She has been involved in special projects including the Central Alberta Women's Single Parent Review and Rural Women's Leadership in western Canada.

Marilou McPhedran

Marilou is the co-director of this Study and the Executive Coordinator of National Network on Environments and Women's Health (NNEWH), the Centre of Excellence based at York University in Toronto. Trained as a lawyer, she has provided strategic counsel in health and human rights to public and private institutions for the past 25 years. Marilou chaired Canada's first task force on the sexual abuse of patients in 1991 and a second task force in 2001 reviewing Ontario legislation based on their widely-adopted policy of zero tolerance of sexual abuse. As founding director of York's International Women's Rights Project, she directed the ten-country impact study on

the United Nations Convention on the Elimination of All Forms of Discrimination Against Women from 1998-2000 and is currently writing a book on prevention of sexual abuse.

Barbara Neis

Barbara is the chair of the National Research Steering Committee for this Study and is the co-director of Safety-Net, A Research Alliance in Workplace Health and Safety in Marine and Coastal Work at Memorial University, St. John's, Newfoundland. She is also a Professor in the Department of Sociology. Dr. Neis has researched many different aspects of the Newfoundland and Labrador fisheries and has recently begun linking that research with international fisheries-related developments. Her current areas of research focus include occupational asthma to snow crab and fishing vessel safety (funded by CIHR.), the human health impacts of restructuring in the Newfoundland and Labrador fisheries (funded by SSHRC and NSERC, Health Canada, the National Network on Environments and Women's Health), and local ecological knowledge and science (funded by SSHRC and NSERC).

Lilliane Sabiston

Lilliane is a self-employed farm partner and co-owner of Sabiston's Wood Grain Products near Kelliher, Saskatchewan. Her interests in promoting family farms with their issues and women's issues, especially concerning health have led her to become involved in a variety of committees. She has been involved in Saskatchewan Women's Agricultural Network (SWAN) as the chair and a board member. She sits on numerous affiliated committees and boards with some common interests. Lilliane is currently chair of the Farm Stress Advisory Group, board member of the Prairie Women's Health Centre of Excellence, Alcohol and Drug Abuse Advisory Council and co-chair of the Farm Family Opportunities Initiatives. She has recently been appointed Returning Officer for Lost Mountain-Touchwood Constituency. She was vice-chair of the Touchwood-Qu'Appelle Health District for seven years and also was appointed to the Board of Trustees of the Carlton Trail Regional College from 1992-1999. She has established valuable networks while attending various workshops and conferences over the years.

Lynn Skillen

Lynn is a Professor in the Faculty of Nursing, University of Alberta. She holds a PhD (Sociology), MHSc (Health Care Practice), and BScN (Nursing). Her research focuses on the promotion of women's health and safety in paid and unpaid work environments in urban and rural communities. She teaches courses on health assessment, international health, and occupational health. Currently, her projects include: research on the promotion of personal safety among nursing students in high risk community areas with colleagues in Mexico, Colombia, Peru, Chile, and Alberta; research with Western Canada colleagues on a model for effectiveness in occupational health practice; and delivery of capacity-building courses in Spanish in Latin America.

Lana M. Sullivan

Lana is a Research Associate with the British Columbia Centre of Excellence for Women's Health. Her current research includes understanding the impacts of economic restructuring and health care reform on rural populations. Previous research included projects on social capital, social cohesion, and community capacity in rural and small towns; the role of the voluntary (third) sector; housing transition in single-industry towns; and commuting patterns between rural and urban towns.

Rebecca Sutherns

Rebecca holds a post-doctoral research and teaching position at McMaster University, funded by the Canadian Health Services Research Foundation. Her research interests include women's health and sustainable rural communities, having recently completed a qualitative study of women's experiences of rural maternity care for her PhD in Rural Studies. Prior to returning to academia, Rebecca worked in the nongovernmental sector in the areas of international development and advocacy. She is an experienced facilitator, speaker and adult educator.

JoAnne Zamparo

JoAnne is an Associate Professor at the School of Social Work of Lakehead University. Her interest is in community mobilization and social action that leads to social and health policy development and changes. She uses participatory-action research methods in the area of Inuit traditional knowledge, family and kinship as well as youth engagement in northern, rural communities.

APPENDIX B

Committees' Terms of Reference

National Management Committee

The National Management Committee: Funding and Modifying the Study

As a cross-centre initiative, this Study benefited from the management expertise of the Executive Directors of the four Centres of Excellence, the Canadian Women's Health Network and the CEWHP Manager in the Women's Health Bureau, (or designates).

The Terms of Reference accepted by the Management Committee were to:

- Be available to the co-directors for consultation on key decisions
- Assist the co-directors in guiding the conduct of the project, including finances and reports to funders, principally the WHB
- Direct facilitation and reporting of the regional focus groups
- Help identify key informants for focus groups and national Think Tank
- Consult with the Research Steering Committee in the development of remaining phases of the project
- Determine the emphasis on findings, conclusions and recommendations
- Liaise on the progress of the project with the Research Steering Committee
- Oversee coordination of national consultation
- Consult with the research steering committee in the development of communication and implementation strategies for the project results.

National Research Steering Committee

The National Research Steering Committee was established with the following Terms of Reference:

Tasks:

- Refine the scope of the project;
- Define the population to be studied; formulate key research questions;
- Determine methods appropriate to the population under study (e.g. thematic literature review with gaps analysis, focus groups for recommendations, discussion papers, roundtables, consultations, policy framework, research and action plans)
- Identify key contributors, informants and participants;
- Receive reports from NNEWH on the progress of the focus groups and other research;
- Review draft and final reports from NNEWH in order to provide feedback on findings, policy and research recommendations;
- Advise the PWHCE on the structure, content and participation of the National Consultation; and
- Make recommendations for the development of communication strategies for the dissemination of project results to achieve policy impact.

Diversity in the membership of the National Research Steering Committee should bring a wide range of perspectives to the development and consideration of the research evidence. The members are equally valued for their expertise and experience reflecting diverse interests, skills and locations.

APPENDIX C

Contact information for Women's Health Bureau, the Centres of Excellence for Women's Health, and National Coordinating Groups

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National Coordinating Group on Health Care Reform and Women

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Appendix D

Demographic Survey

Rural and Remote Women's Health Focus Group Demographic Survey

Thank you for agreeing to participate in this joint research project involving Centres of Excellence for Research in Women's Health in four regions of Canada. This research has been funded by the Women's Health Bureau of Health Canada. The research in this project is being administered by the National Network on Environments and Women's Health (NNEWH), based at York University in Toronto. Dr. Suzanne MacDonald and Marilou McPhedran are responsible for this study at York University. You can reach Marilou at marilou@yorku.ca or by phoning 1 416 736 5941 if you have any questions or concerns. Collect calls will be accepted if you mention that you are a focus group participant.

Before we begin today's focus group discussion, we are asking you to take a few moments to write your answers to the short survey in the space provided below. You will not be identified in the report on the results of this focus group. Information from this survey will be used to produce a summary profile of focus group participants in different parts of Canada, without any individual being identified.

Completion of this survey is voluntary. You may refuse to answer any specific questions on the survey. Please place your completed survey back in the unmarked envelope and put it into the box near the focus group facilitator. If you do not wish to complete this survey, please place the blank survey form back in its envelope and place it in the box. Thank you very much!

Questions

1. How old are you?
☐ 16-25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 65+
2. What level of schooling did you complete? _____
3. Is your personal annual income, after taxes:
☐ \$15,000 – 24,999 ☐ \$25,000 – 34,999 ☐ \$35,000 – 44,999 ☐ Above \$45 000
4. What is your occupation? _____
5. What is the approximate population of your community in the rural or remote area where you live? _____
6. What is your present marital status?
☐ Single ☐ Married ☐ Unmarried and living with partner
☐ Separated ☐ Divorced ☐ Widowed
7. If you have children, what are their ages? _____
8. a) Do you live in the same geographic area as where you work? _____
 b) How many miles one way do you have to travel to work? _____
9. If different from where you live, what is the approximate population of where you work? _____
10. Approximately how far/how long do you (or your clients/ the women you represent) have to travel to reach the closest:

nurse?	distance _____	travel time _____	don't know _____
nurse-practitioner?	distance _____	travel time _____	don't know _____
physician?	distance _____	travel time _____	don't know _____
specialist?	distance _____	travel time _____	don't know _____
alternative health care provider?	distance _____	travel time _____	don't know _____

Appendix E

Focus Group Interview Guide

- *Health*
 - What are the things, such as assets/resources/services that promote your health/the health of your clients? (Facilitator may need to prompt people here to think broadly beyond physical health and health care, e.g. spirituality, economics, workplace issues, division of labour; mental health, threats of violence, environmental concerns etc.)
 - What are things, such as barriers/attitudes/rules/lack of services that threaten your health/the health of your clients?
- *Rurality*
 - When you think of rural and/or of living remotely, what comes to mind?
 - Do you think of yourself as a rural woman? As someone who lives rurally or remotely? Both?
 - What makes your life rural and/or remote?
 - In what specific ways does living rurally or remotely affect your health or the health of those in your care? (e.g. geographic dispersion of services, income, employment conditions, access to education, social expectations and attitudes, weather/seasonality, degree of social support, quality of social relationships, housing, recreation etc.)
- *Policy Framework:*
 - “If you could have the undivided attention of key health-decision makers to talk about the state of women’s health in your community, what issues would you raise?”
 - “If you could change two things to promote better health of women in your community, what would they be?”
 - “How satisfied are you with the quality of health and health care for women and girls in your area?”
 - “Do you think the quality of health care for women in your area has changed in the past two years? In the past five years? For better or worse? Please give examples.
- *Research Agenda:*
 - “How would you define “your community”? Are there women’s health issues about which you think more information is needed in order to prompt appropriate action in your community or region?”
 - “To put it another way, have you ever felt concerned or curious about some aspect of women’s health care in your area and wished that someone would look into it further?”
 - “Based on a review of research that has already been done, the following gaps in research were identified: [**insert gaps listed in Wakewich paper here**] How important is it to the women and girls of your community for more research on each of these topics to be done?”
 - The Centres of Excellence do research that involves community members from the start. Do you have any suggestions on how to improve this model?
 - Are there any other issues relevant to policy, research and the health of rural women and girls that you think we should address?
- *Wrapping Up:*
 - “Although all of this information will be given to the Centres of Excellence for Women’s Health to be included in the research project, there may be a few themes or issues which have particularly stood out for you as you listened to everyone’s perspectives today. What are they? Is there anything else you would like to say?”
 - “I want to thank you for your time and your very helpful contributions. Your willingness to meet with me today makes this focus group possible. The focus groups of women in rural and remote areas across Canada will produce the core of the knowledge that this research project will generate. It could not be done without you. I’ve been asked by the women who are working on this project who are not here with us today to give you their sincere appreciation for helping in this way. We all hope that by giving our time and expertise to this project that we can make some real changes for women and girls living in rural and remote areas of our country. Thank you very much.”

Appendix F

Instructions to Facilitators

This is a community/academic partnered research initiative of the four Centres of Excellence for research in women's health (the Centres) and the Canadian Women's Health Network, funded by the Women's Health Bureau of Health Canada. The co-investigators of this project are Dr. Suzanne MacDonald and Marilou McPhedran of York University in Ontario. The following guidelines were developed by the Research Steering Committee of this project, chaired by Dr. Barbara Neis of Memorial University in Newfoundland and coordinated through the National Network on Environments and Women's Health—NNEWH, the Centre of Excellence based at York University. These Guidelines are to be followed by all of the Centres and their contractors in developing, conducting and reporting on focus groups with women in different regions of Canada, as an integral part of this research initiative. All documents and materials, in original form, as specified in these Guidelines and in the agreements made between NNEWH and other Centres as well as between Centres and those retained by the Centres to facilitate, record and report on the focus groups are to be delivered to Marilou McPhedran at NNEWH, 214 York Lanes, York University, 4700 Keele Street, Toronto, ON M3J 1P3, for further analysis and secure storage. Questions and suggestions should be directed to the Research Steering Committee, through Marilou at marilou@yorku.ca.

Focus Group Outcomes

- Each focus group facilitator should deliver to her respective contracting Centre, which in turn will be delivered by each Centre to NNEWH:
 - The originals of the signed consent forms, as well as the written demographic surveys completed by each focus group participant;
 - A summary of the demographic survey results, without identifying participants, including commentary on who was or was not in attendance and why, with suggestions for improvement, if any;
 - A synthesis report on findings, organized according to the subheadings of the questions beginning on page 3, below;
 - The original audio tapes of the complete discussion of each focus group (identification of the speakers is not expected), as well as the written summary prepared by the focus group recorder, including all questions asked and any answers. Note: copies of the audio tapes may be made and kept by the Centres but not by the facilitators or recorders, unless specific written permission has been granted by agreement with the respective contracting Centre and NNEWH;
 - A list of names and contact coordinates of possible invitees to the National Think Tank in January 2003, drawn from those participating in the focus groups, who have indicated an interest in attending and, in the opinion of the facilitator, would contribute their perspectives actively and add to the diversity of representation at the Think Tank (see consent forms);
 - A list of names and contact coordinates of those who indicated that they would like to receive the final report of this project (see consent forms).

Focus Group Facilitator's Responsibilities

1. The facilitator is responsible for thorough preparation including: a) ordering appropriate refreshments, b) ensuring that the audio-taping equipments and tapes are ready and in working order, c) ensuring that a recorder is in place to ensure full recording of the entire discussion, and, d) arranging for compensation for reasonable expenses. In the focus groups, the facilitator is responsible for explaining the context, expectations and objectives of the meeting, as well as the intended audiences and follow-up plans for any information generated. Wherever possible, we would like facilitators to provide the

consent form in advance to participants of the focus group(s) to give time for review. The following examples, in quotations, of what should be said to the focus group participants are given to assist facilitators and to ensure that focus group participants in different regions receive similar information:

- a. *Context*: “This meeting is one of several focus groups around the country. This is the second part of a national project hosted by the Centres of Excellence for Women’s Health. The project has an advisory committee, which includes women such as you. We hope to develop a policy framework and research agenda on rural and remote women’s health, which can be used by the federal, provincial and regional governments. The first phase was a literature review and roundtable discussion, late in 2001. Later phases will include a national conference in January 2003, followed by a final report to health policy makers and researchers. You are welcome to receive a copy of the final report. Please just leave your name and address on our mailing list.”
 - b. *Objectives of this session*: “Today we’d like to hear your thoughts about health, health care and its availability for you and your community, and other factors which affect your health. We won’t be making any decisions in this focus group and we don’t expect that we will all agree with each other about many of the points we discuss. But your comments will help us all to reach a better understanding of what health issues are important for women who live in rural Canada. We are interested in what you have to say about the availability and quality of health care services of women you know. We know that women are usually responsible for the health of all their family, but our questions today are not about your personal health or how you help care for family and friends. This afternoon’s focus group is a chance to hear your expertise and experience, which will be included in the findings of this research project. We are interested in your opinions of women’s health issues in your community.”
 - c. *Follow-up*: “The audio tapes from today’s meeting, a written transcript of the audio-tapes, a summary of today’s discussion and a summary of the written survey that you filled out will be delivered to the Research Steering Committee, and then combined with results from across the country. We will include your thoughts in the research report, which will be part of the national conference on rural and remote women’s health in 2003. Finally, a discussion paper with recommendations for a new research agenda and policy framework for rural and remote women’s health will be prepared after the Think Tank and submitted to Health Canada. As the focus group facilitator, I am responsible for preparing the summary report on this focus group without identifying any of the individual speakers and I will send you a copy to review before the summary is submitted to the Research Steering Committee. Please let me know if you would also like a copy of the final report and if you want your name listed in the report in our thanks to focus group participants. I need to have this in writing from you, as part of the consent form that you have already signed.”
2. The facilitator is responsible for obtaining signed informed consent to participate from each person in attendance, as per the attached consent form IN ADVANCE OF THE FOCUS GROUP. Facilitators should be aware of the parameters of the study (e.g. women will not be asked or encouraged to discuss personal health matters).
 3. The facilitator is responsible for ensuring that each participant completes and returns the attached demographic survey at the start of the session.
 4. The facilitator should pay attention to who is and who is not in attendance. (For example, how did people come to be there? How might the process of recruitment have excluded some women or points of view? What is likely to be present/absent in the discussion because of who is there?) This will then be reviewed with the Director of the Centre and

included in the focus group summary. Focus group participants should be invited to comment on this concern.

5. The facilitator should then guide the group through a discussion of the topics described below. Facilitators should remember that the discussion should not be limited to health care and service delivery, but should reflect a broad understanding of the social determinants of health, for example, education, economics, laws and policies, social services. It should also adopt both an appreciative and critical orientation, soliciting reflection on both what is and what is not working well for women and eliciting suggestions for achievable, positive changes. Facilitators must ensure that the questions listed are addressed, but other issues that emerge as relevant to participants should also be pursued and noted during the discussion.
6. The facilitator is responsible for ensuring that the session is both tape-recorded and accurately recorded on paper. Doing and/or checking the recording during the session should be the responsibility of a recorder rather than the facilitator.
7. The facilitator is responsible for ensuring a smooth flow to the session, including setting a positive tone, staying on topic, keeping time, taking appropriate breaks, encouraging full participation, and taking the time at the end of the group to thank the participants sincerely for their invaluable contribution of time and expertise, on behalf of all the women who are cooperating on this research project.
8. In some cases, face-to-face small group sessions may not be possible. In order to include women living remotely, the process of data collection may need to be modified through the use of telephone and/or video conferencing.
9. The facilitator is responsible for generating a focus group summary in two parts: one of the demographic data and the other of the discussion themes outlined above.
10. The facilitator should create and hold a master list of focus group participants drawn from the completed consent forms and should assume responsibility for sending copies of the summaries to those participants in a timely manner.
11. In consultation with the Centre, the facilitator should review answers on the consent form and, using her own good judgment, generate a list of potential invitees to the National Think Tank.
12. The facilitator should be prepared to provide the participants with follow-up support or appropriate referrals to community supports (if necessary). It is important to have at least one other person with the facilitator who is present and available to record the group discussion as well as to provide support to participants who could experience some difficulties/challenges that may arise during or as a result of the discussions.

Appendix G

Project Consent Form

SCHEDULE B – Consent Form

[NOTE to the Facilitator: Please try to distribute this form to participants in advance of the focus group and to follow up with a phone call in case there are questions or concerns.]

Dear Ms. _____.

Your name was given to me by _____ who suggested you might be willing to participate in a focus group we are conducting. The focus group concerns health issues for women living in rural and remote areas of Canada. These focus groups have been organized to allow us to hear your voice on the nature of the health services that you have accessed and your assessment of the quality of health care actually delivered over the past decade or so. This is a joint research project with Centres of Excellence for research in women's health in different regions of Canada that has been funded by the Women's Health Bureau of Health Canada. The research in this project is being administered by the National Network on Environments and Women's Health (NNEWH), based at York University in Toronto. Dr. Suzanne MacDonald and Marilou McPhedran are responsible for this study at York University.

The focus groups will be held on _____ from _____ to _____. We are asking for approximately a half-day of your time. You will be provided \$ ____ to help pay for any costs associated with taking part in this study (e.g. travel and child care costs). This money will be given to you at the start of the focus group session, and will be yours whether or not you refuse to answer any questions or whether or not you complete the session.

The format of the focus group will be a short written survey with questions for you to answer and some additional questions for the group discussion that will help us understand your perspective on services in rural and remote areas, including social programs and social services related to women's health. We will be asking you to suggest changes to policies and practices that would improve your access to services and improve the services available to you, other women and girls. We will not ask you to discuss your personal health matters. You may refuse to answer any specific questions on the survey or in the group. You should also feel free to offer opinions and information on issues or subjects not raised by the facilitator that you think are relevant to this research. You are free to withdraw comments at any time.

After the focus groups are completed and the tapes are transcribed, a draft report containing summaries and unidentified quotes from the focus groups will be prepared. You will be given the opportunity to review the draft report from your group. Results from these focus groups will be compiled and summarized for the project's research committee, which includes community leaders, researchers and policy makers. Findings will also be summarized in a final report to Health Canada from this project and possibly in publications generated from the research. The contents of the final report will be communicated to local communities, health care professionals, and policy makers through a national "Think Tank" to be held in early 2003.

Please feel free to contact York University Human Participants Review Sub-committee with any questions or concerns - research@yorku.ca or telephone: 1 416 736 5055. Requests for copies of the focus group summary should be directed to Marilou McPhedran, Executive Coordinator, National Network on Environments and Women's Health, York University, 214 York Lanes, 4700 Keele Street, Toronto, Ontario, M3J 1P3. Email: marilou@yorku.ca or telephone: 1 416 736 5941; fax: 1 416 736 5986.

I hereby agree to be interviewed in a focus group on women's health in rural and remote areas of Canada, subject to the conditions listed above. I agree/do not agree to be identified by my name in the acknowledgments in the final report.

I am/am not interested in a possible invitation to the national Think Tank in early 2003.

Your Name [please print]: _____

Signature: _____ Date: _____ /02

Address: _____
