



Research Circle
UBC Centre for Excellence in Indigenous Health
“Making Healthcare Decisions: Aboriginal Experiences”
Date: Wednesday, June 18, 2014 2:00-4:00pm

Overview of “Supportive Healthcare Decision Making for Diverse Populations: A Needs Assessment Tool and Relational Guidelines”

Purpose:

This document provides an overview of the “Supportive Decision Making” project, particularly as it relates to the perspectives of participants who self-identify as belonging to an Aboriginal community. This Research Circle, supported by the UBC Centre for Excellence in Indigenous Health, will present and discuss some of the project’s preliminary findings. We hope to share some insights we have learned and in turn invite your reflection and feedback to help shape the project going forward. We hope you will consider our invitation to participate in collaborative dialogues at this Research Circle.

Today’s Presenters / Who We Are:

Anita Ho, Ph.D, Principal Investigator
Associate Professor, Centre for Applied Ethics, UBC
Director, Ethics Services, Providence Health Care (anita.ho@ubc.ca)

Jenny Morgan, MSW, RSW (Research Assistant)
Member of the Gitxsan First Nation
Executive Director, Aboriginal Mother Centre Society

Kim Taylor, MA (Graduate Research Assistant)
PhD Student, University of British Columbia; Clinical Ethics Fellow, Providence Health Care; Clinical Ethicist, Vancouver Coastal Health.

Other Members of Our Team:

Kerry W. Bowman, Ph.D (Co-Investigator)
Assistant Professor, University of Toronto (Kerry.Bowman@utoronto.ca)

Carol Pavlish, BS, MS, PhD, RN FAAN (Co-Investigator)
Associate Professor, University of California, Los Angeles (Cpavlish@sonnet.ucla.edu)

Anita Silvers, PhD (Co-Investigator)
Professor, San Francisco State University (asilvers@sfsu.edu)

Dr. Soodabeh Joolae, PhD (Post-doc Fellow)
Associate Professor, Nursing & Midwifery School
Tehran University of Medical Sciences, Tehran, Iran

Dr. Lovepreet Mutti, MBBS (Research Assistant)

Goal of Presentation and Feedback Session:

We wish to share our preliminary research findings on participants' views of how their cultural values, background, and other social realities affect their decision-making preferences as well as their recommendations on supporting patients and family members through complex healthcare decision making. Some themes will include participants' views regarding information provision around their diagnosis, prognosis, and treatment options, the time/relationship with healthcare providers, and the need for greater cultural awareness and incorporation of traditional practices into patients' care plans. We would like to engage in a dialogue with you regarding your thoughts and reflections on the project findings and any recommendations you may have on the direction and design of the research project going forward.

Project Goals:

The study has three key objectives:

1. To understand patients' and families' healthcare decision-making process;
2. To identify patients', families', and healthcare providers' views of individual and system barriers and strengths in promoting supportive decision making;
3. To develop a needs assessment tool and supportive decision making guidelines.

This study is particularly interested in hearing the experiences of patients and/or their family members from diverse economic, cultural, and linguistic backgrounds who made or are making important and difficult healthcare decisions. We have specifically targeted recruitment of Aboriginal, Punjabi, Chinese, and Persian patients and family members in the Lower Mainland, as these populations' perspectives on the challenges and resources in healthcare decision-making have been underrepresented in the mainstream literature.

As a qualitative study, the goal is to translate lessons from the lived experiences of participants into informed practices and resources to help support patients and families faced with complex healthcare decisions. By listening to the experiences and recommendations that patients and family members of diverse backgrounds have regarding healthcare decision making, we can integrate their views into our recommendations to health care providers, which in turn can help improve the health care these populations receive.

Project Funding Sources:

Canadian Institutes of Health Research and the Institute of Aboriginal People's Health

Time frame for the study:

It began in April 2012, and funding will continue until April 2015.

Research Ethics Review:

This research study has received approval from UBC's Behavioral Research Ethics Board, Providence Health Care, and Vancouver Coastal Health.

Aboriginal Participant Recruitment sites:

Providence Health Care, Aboriginal Friendship Centre (Vancouver), Vancouver Native Health Society, VCH Aboriginal Health and Strategic Initiative, FNIH Health Canada, Vancouver Native Housing Society, PHSA Aboriginal Health, Providence Health Care Aboriginal Health, First Nations Health Authority, Sorella House, Skwachays, Carnegie Hall, Aboriginal Front Door, Grace Mansion, VANDU, Sheway, Crabtree Corner, Native Courtworker and Counselling Association of BC, Chrysalis Society, Healing Our Spirit, Hey-Way-Noqu, IRSSS, Kla-how-eya, Métis Nation of BC, Vancouver Métis Citizens Society, Vancouver Métis Community Association, Red Road HIV/Aids Network, Healthiest Babies Possible, Sulsila Lelum Wellness Centre, VACFSS, Vancouver Aboriginal Transformative Justice Society, VAFSC, VAFCS Elder's Group, Sundance Daycare, UNYA, ACCESS, Northern BC HIV/Aids Coalition, CAAN, Squamish Nation Health Services, Musqueam Nation, Tsleil-Waututh Nation, WAVAW.

Total Aboriginal Participants in the Study:

To date, 14 (out of a total 54) patients, 8 (out of a total 28) family members, and 4 (out of a total 37) healthcare providers have self-identified as Aboriginal. Recruitment is ongoing.

Confidentially:

All information provided by the study participants is treated with the utmost respect. All audio files, transcripts and consent forms are identified by a unique pseudonym, password protected, and kept on a password-protected computer and in a locked filing cabinet in the project offices at the University of British Columbia. The only persons who have access to the data are the immediate members of the research team (listed above) and the research assistants working directly with members of the research team. Personal questions are limited to issues related to the participants' medical decision making. The original audio recordings and transcriptions will be kept for at least 5 years and then destroyed, unless otherwise indicated.

Contact Information

Should you wish to receive further information, or would be interested in talking further about possible arrangements for a meeting, gathering, or event, please contact: research assistant, Jenny Morgan or project assistant, Lisa Dook by email: sdm.project@ubc.ca. You may also contact the principal investigator, Anita Ho, by email: anita.ho@ubc.ca or phoning 604-822-4049.