

# Taking care of chronic disease: realizing approaches for Canada's aging ethnic population: a workshop

Final Report

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### ***Many thanks as well to our participants***

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## *Taking care of chronic disease: realizing approaches for Canada's aging ethnic population: a workshop ~ Executive Summary*

### **Background and Purpose of Workshop**

*Taking care of chronic disease: realizing approaches for Canada's aging ethnic population* was a workshop held in Vancouver, British Columbia, Canada in February 2011. The purpose of this workshop was to begin to address an existing evidence gap on approaches to self management support that meet the needs of immigrant older adults with chronic conditions. This gap was identified by participants in a multi-stakeholder forum and subsequent community consultations with Mandarin- and Punjabi-speaking older adults organized by the Immigrant Older Adults: Care, Accessibility, Research and Empowerment (ICARE) team.

In response, we conducted an environmental scan that resulted in an annotated bibliography. From this exercise we concluded that:

(1) Literature on self-management supports for ethnocultural minority older adults is sparse and varied; (2) Evaluations of U.K. and Australian programs revealed that they predominately appeal to “white middle-class people with long-term conditions who already viewed themselves as effective self-managers”; (3) Viable alternative models of self-management supports for ethnocultural minority older adults are not reported in the literature; and (4) Individual self-management needs to be situated within a collective understanding of empowerment.

Our workshop aimed to facilitate the exchange of ideas between a group of 32 diverse Canadian stakeholders (plus five student volunteers) such as immigrant older adults with chronic conditions and their friends and family members, policy makers, clinicians, multicultural settlement workers, and academics. Ultimately, we seek to develop evidence-based approaches to self-management supports that acknowledge the various challenges faced by this disadvantaged population and build on existing strengths within our communities.

### **Terms of Reference**

The **Chronic Care Model** is a widely adopted multi-pronged strategy aimed at preventing and managing the increasing incidence of chronic disease worldwide. Central to the model is the notion of the “informed activated *patient*” who interacts with a “prepared proactive *practice team*.” This model has since been expanded to better account for the social determinants of health, or factors that influence chronic conditions and their care that fall outside the purview of the health system.

**Self-Management Support** encompasses health care, social services, and community-based initiatives aimed at supporting individuals and their families to live well with chronic conditions. This broad definition is well-suited to immigrant older adults, since it appears that much of the care they seek for chronic conditions (together with their families), is found in the community and multicultural sectors rather than the health care sector, per se. In parallel with the expanded chronic care model, it also highlights the importance of considering the interface between the health system and broader community supports and the ways in which both influence the personal skills of the individual, delivery system design, decision support and information systems. *This report seeks to contribute to our understanding of what is needed in terms of supports from the community and supports from the health system in order to enhance the ability of immigrant older adults to self-manage their chronic conditions.*

## **The Workshop**

Following a presentation panel (see below for details), participants were engaged in discussions that adopted the World Café model in order to address two main questions:

- (1) To what extent do current self-management support models address the needs of immigrant older adults? (And what are the barriers to their use by this population?)*
- (2) What are ‘promising practices’ for this population and what can we learn from them?*

Each of a total of six discussion tables (three per one-hour time frame) were led by 2-3 participants pre-selected on the basis of their experience and knowledge of these various domains as well as their representation of the different stakeholder groups.

### **a. Panel Presentations**

Panellists were selected for their varied expertise and experience with chronic-disease self-management supports. Their presentations represented policy, clinical and academic perspectives:

- (1) Chronic Disease Self-Management Supports for Ethnocultural Minority Older Adults by Kelly McQuillen (Director, Patients as Partners, B.C. Ministry of Health);
- (2) Self Management Support Approaches: A Key Solution to the Problem by Sue Mills (Ph.D., New Investigator, BC Centre of Excellence for Women’s Health);
- (3) Ethno-cultural minorities and chronic disease: Clinician–patient interactions by Charlotte Jones (MD, PhD, Associate Professor of Medicine, University of Calgary); and
- (4) Self-Management Supports for Ethnocultural Minority Older Adults: What We Know and What We Don’t Know by Karen Kobayashi (PhD, Associate Professor of Sociology, University of Victoria).

### **b. World Café Discussions**

Subsequent to the workshop, all of the notes taken for each World Café table were transcribed, as were posters developed to summarize the contributions of the three sets of “traveling” participants to each table. We wanted to let the collective wisdom of our

participants speak for itself; however, we were also curious as to whether and how the participants' conversations reflected the strategic directions recommended by Mills *et al.*'s (2011) framework for Chronic Condition Self Management Support.

## Conclusions

There are numerous barriers and constraints preventing immigrant older adults from accessing and fully benefiting from chronic disease self-management supports. These include constraints at the systems, social, family and individual levels.

**REACHing out** to this relatively vulnerable subpopulation of older adults is therefore extremely important. Raising awareness of chronic health issues, overcoming stigma and cultural beliefs that regard chronic diseases as a normal part of aging and connecting individuals, families and communities to services and programs were all seen as components of REACH. In order to reach seniors, families need to be targeted. Immigrant older adults depend on their families, specifically their adult children, to access and navigate the health care system.

The importance of **BUILDING LINKAGES** among health care providers and through community partnerships was emphasized. For example, general practitioners need to “work with others,” not in isolation. Service providers expressed the importance of “target[ing] health from a community standpoint,” “ask[ing] the community what adaptations are needed”, “building good community and increasing capacity”, and “building partnerships with community infrastructure.” Participants also emphasized the limited capacity (time, infrastructure, funding, training) of community partners to assume the full burden of providing self-management supports for their clients; the health care system needs to change in order to facilitate their increased involvement.

Also important is the provision of appropriate **SUPPORTS TO HEALTH CARE PROVIDERS** who play an essential role in chronic disease self-management support. Changes are needed at the systems level to facilitate an inclusive and culturally sensitive approach to self-management. Workshop participants felt that building trust and a good relationship with GPs and other health care providers is vital to the success of such programs. In addition to healthcare provider education and training, health systems must provide incentives for health care providers to spend more time with patients and address more than one problem at a time. Providers must also be aware of available self-management supports for different communities to which they can refer their patients.

Our multistakeholder dialogue underscores the importance of pursuing research that examines what supports are needed for (a) community partners (including multicultural agencies, family members, etc.) and (b) diverse health care providers *to work collaboratively* in order to ensure that immigrant older adults have the skills they need to self-manage their chronic diseases. This examination must take into account the interactive effects of social determinants of health on both the prevalence and ways in which chronic diseases are experienced and the capacity of individuals and communities to manage them. Research that distinguishes between different types of support that are more salient at different points along the trajectory of a chronic



disease is needed. Most critically, our research will continue to engage all stakeholder groups so as to ensure its relevance and the uptake of any emergent recommendations.

# *Taking care of chronic disease: realizing approaches for Canada's aging ethnic population: a workshop ~ Final Report*

## **Background and Purpose of Workshop**

### **ICARE**

The ICARE (Immigrant Older Adults—Care Accessibility Research Empowerment) team was founded in 2009 with an infrastructure team grant from the Women’s Health Research Institute of BC by co-PIs Dr. Sharon Koehn (Centre for Healthy Aging at Providence Health Care) and Dr. Karen Kobayashi (University of Victoria). With this funding we developed dense networks and consulted with diverse stakeholders, such as interdisciplinary academics, clinicians, multicultural settlement and community service sector staff, policy makers and older adults.

Two research priorities and working groups emerged from this process: chronic disease self-management supports and community mental health. This workshop is the result of the successful application of the ‘chronic disease’ team for a Meetings Planning and Dissemination Grant (#90605) from the Canadian Institutes of Health Research. Our work has

*Taking care of chronic disease: realizing approaches for Canada's aging ethnic population* was a workshop held in Vancouver, British Columbia, Canada on February 11<sup>th</sup>, 2011.<sup>1</sup>

The purpose of this workshop was to begin to address an existing evidence gap on approaches to self management support that meet the needs of immigrant older adults<sup>2</sup> with chronic conditions. This gap was identified by participants in a multi-stakeholder workshop (Spence, Koehn, & Kobayashi, 2009) and subsequent community consultations with Mandarin- and Punjabi-speaking older adults organized by the Immigrant Older Adults: Care, Accessibility, Research and Empowerment (ICARE) team. In response, we conducted an environmental scan that resulted in an annotated bibliography (Spence, Nagatani, & Koehn, 2010). From this exercise we concluded that:

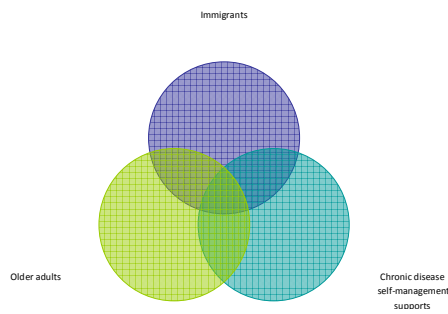
1. Literature on self-management supports for ethnocultural minority older adults is sparse and varied. Two evaluations of the [Chronic Disease Self-Management Program, or] CDSMP for older African-Americans indicate some improvements in health behaviours and health status, slight or no improvement in self-efficacy, and no change in health service utilization (Gitlin *et al.*, 2008; Rose *et al.*, 2008).
2. Evaluations of U.K. and Australian programs, similar to the CDSMP in that they are based on a model developed by Lorig and her colleagues, revealed that they predominately appeal to “white middle-class people with long-term conditions who already viewed themselves as effective self-managers”; males, indigenous people, people of non-English speaking background and those with multiple responsibilities were less likely to participate in these courses (Rogers *et al.*, 2008).

3. Viable alternative models of self-management supports for ethnocultural minority older adults are not reported in the literature. The chronic disease self-management supports literature specific to this population primarily examines the more informal self-care practices of these populations. Available evidence indicates that a collaborative model of self-management supports, specifically, a partnership between local community service networks, primary care, and health authorities is most effective for marginalized groups. Chronic care services should be embedded within existing community structures to ensure ongoing participation and relevance (Dennis *et al.*, 2008; Glazier, Bajcar, Kennie, & Willson, 2006; McDonald *et al.*, 2004). Self-management supports models for ethnocultural minority older adults must also consider barriers to health service access [e.g. health literacy] faced by these populations (e.g., Baker *et al.*, 2007; Kaufman *et al.*, 2006; Kripalani *et al.*, 2006; Ntiri & Stewart, 2009). Cultural competency training within self-management supports service delivery must extend beyond translation of program materials into an understanding of the cultural context of the chronic disease experience (Huang, 2007; Owens & Randhawa, 2004).
4. Individual self-management needs to be situated within a collective understanding of empowerment (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). Conventional self-management supports models focus primarily on individual autonomy and personal responsibility but neglect to address systemic barriers to access experienced by marginalized communities. Instead of reinforcing the status quo, self-management supports for ethnocultural minority older adults should build on family and community strengths and bolster capacity to meaningfully engage in self-management (Sotomayor, Pawlik, & Dominguez, 2007).

This review initially included literature published since 1990 from Canada and countries with similar immigrant populations and/or health service delivery systems (principally the United Kingdom and Australia). However, very few articles specific to self management supports for immigrant older adults existed within these parameters. The review was thus expanded to include data from the United States on African-American and Hispanic populations. The findings reported above are therefore primarily based on research with these populations and may not be as relevant to the distinct profile of ethnocultural minority older adults found in Canada and British Columbia.<sup>3</sup>

Accordingly, our workshop aimed to facilitate the exchange of ideas between diverse Canadian stakeholders such as immigrant older adults with chronic conditions and their friends and family members, policy makers, clinicians, multicultural settlement workers, and academics. Here we record what we have learned from one another with the goal of laying the foundation for future research collaboration. Ultimately, we seek to develop evidence-based approaches to self-management supports that acknowledge the various challenges faced by this disadvantaged population and build on existing strengths within our communities.

The thirty-two participants (plus five student volunteers) in the workshop were carefully selected to represent each of the following stakeholder groups: immigrant older adults, academics, clinicians (non-physician), physicians, government employees, health authority employees, and multicultural settlement sector workers (see Appendix A). Most were from the Lower Mainland of British Columbia (BC), Canada (including Vancouver, the North Shore, Burnaby, Richmond, Coquitlam and Surrey), one traveled from Kamloops in the interior of BC, four came from Vancouver Island, two from Calgary, Alberta, and one joined us from the nearby U.S. city of Seattle.<sup>4</sup> Seniors and those working with a specific ethnocultural or ethnolinguistic group represented the Punjabi, Chinese (Cantonese & Mandarin-speaking), Iranian (Farsi-speaking) and Latin-American (Spanish-speaking) communities.<sup>5</sup> This workshop is unique in bringing together this diverse combination of individuals to consult on chronic disease self-management supports, in which they all have a vested interest. Upon registration, participants were asked to rate their knowledge of the types of supports that immigrant older adults need in order to self-manage their chronic diseases. Twenty-seven of the 32 registrants responded to this question. The majority (16) felt that they understood the types of supports needed “fairly well”, with the remainder responding as follows: “well” (7), “not very well” (3) and “extremely well” (1). We suspect that this apparent lack of confidence relates to the different types of knowledge that people possess as depicted in Figure 1, below.



Knowledge of all three domains (immigrants, older adults, and chronic disease self management) and their interactive effects is rare. Moreover, different types of knowledge are typically not evaluated as equally worthy, either by researchers or by those possessing the knowledge. Anecdotally we know that self-knowledge of one’s experience as an older immigrant trying to self-manage a chronic disease (where all three domains overlap) is greatly undervalued by older immigrants themselves.

**Figure 1: Different domains of knowledge that contribute to an understanding of the issue**

The inclusion of diverse stakeholders and their active engagement in the knowledge generation process in this workshop sought to address this imbalance. Following a presentation panel (detailed below), participants were engaged in discussions that adopted the World Café model (The world café, 2010) in order to address two main questions:

*To what extent do current self-management support models address the needs of immigrant older adults? (And what are the barriers to their use by this population?)*

*What are 'promising practices' for this population and what can we learn from them?*

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Each of a total of six discussion tables (three per one-hour time frame) were led by 2-3 participants pre-selected on the basis of their experience and knowledge of these various domains as well as their representation of the different stakeholder groups (see Appendix B – Panelist and Table Facilitator Bios). All other workshop participants rotated every 20 minutes between each of the three concurrent groups. The role of the table hosts was twofold: (a) to provide enough information on the assigned topic to provide a foundation for participants to offer their views and/or ask questions; and (2) to ensure that *all* participants contribute at least once to the discussion. Each 'team' of hosts was given a topic that related to their expertise. They were asked to be prepared to speak for no more than five minutes of the 20 allocated to each rotating group, and to provide us with 2-4 questions per team that would guide their efforts to elicit the engagement of participants in that topic. The advisory team reviewed these questions in order to ensure that they were (i) aligned with the workshop goals and guiding questions; (ii) clear and succinct; and (iii) that each table's questions were relatively distinct from the others'.

## **World Café I: Understanding the needs of immigrant older adults with chronic disease**

*(A) Understanding the influence of socio-cultural factors (Dr. Sue Mills and Dr. Karen Kobayashi)*

*(B) Community-based practice and consultation (Ms. Laura Ng, Ms. Elizabeth Stacy)*

*(C) The Chronic Disease-Self-Management Program –Punjabi (Dr. Patrick McGowan, Mr. Jay Bains, Ms.Saroj Sood)*

## **World Café II: Meeting the need for chronic disease self-management supports by immigrant older adults**

*(A) The challenges of delivering self-management supports at the HA and primary care levels (Ms. Maylene Fong, Dr. Shirley Sze)*

*(B) Health literacy and self-management (Dr. Marina Niks; Dr. Connie Coniglio)*

*(C) Gaps between evidence, policy and practice (Ms. Carole Gillam, Mr. Juan Solorzano)*

The questions listed in Appendix C reflect our suggested amendments and were used by hosts to guide their relatively open discussions with each group of approximately ten participants. These discussions were recorded in detail by our volunteer note-takers and the hosts were charged with the responsibility of preparing a poster at the end of the table sessions. This was limited to one piece of flip chart paper, to which they had the option of affixing 1-2 pieces of letter size paper with bullet points of the content of their 5-minute presentation on the topic. The goal of the poster was to capture approximately three key themes that arose out of their discussions with each of the three groups. These succinct syntheses were subsequently delivered to all participants in presentations of no more than five minutes per team. Given these parameters, hosts were remarkably successful at staying within their time limits to deliver strong messages that clearly captured the discussions and held the attention of all present.

The World Café model was adopted as one of several strategies to ensure that all relevant stakeholder voices were heard within and beyond the workshop. Based on extensive discussions among members of the advisory team and the World Café table hosts, we also decided to group participants relative to their connection to the subject matter as follows:

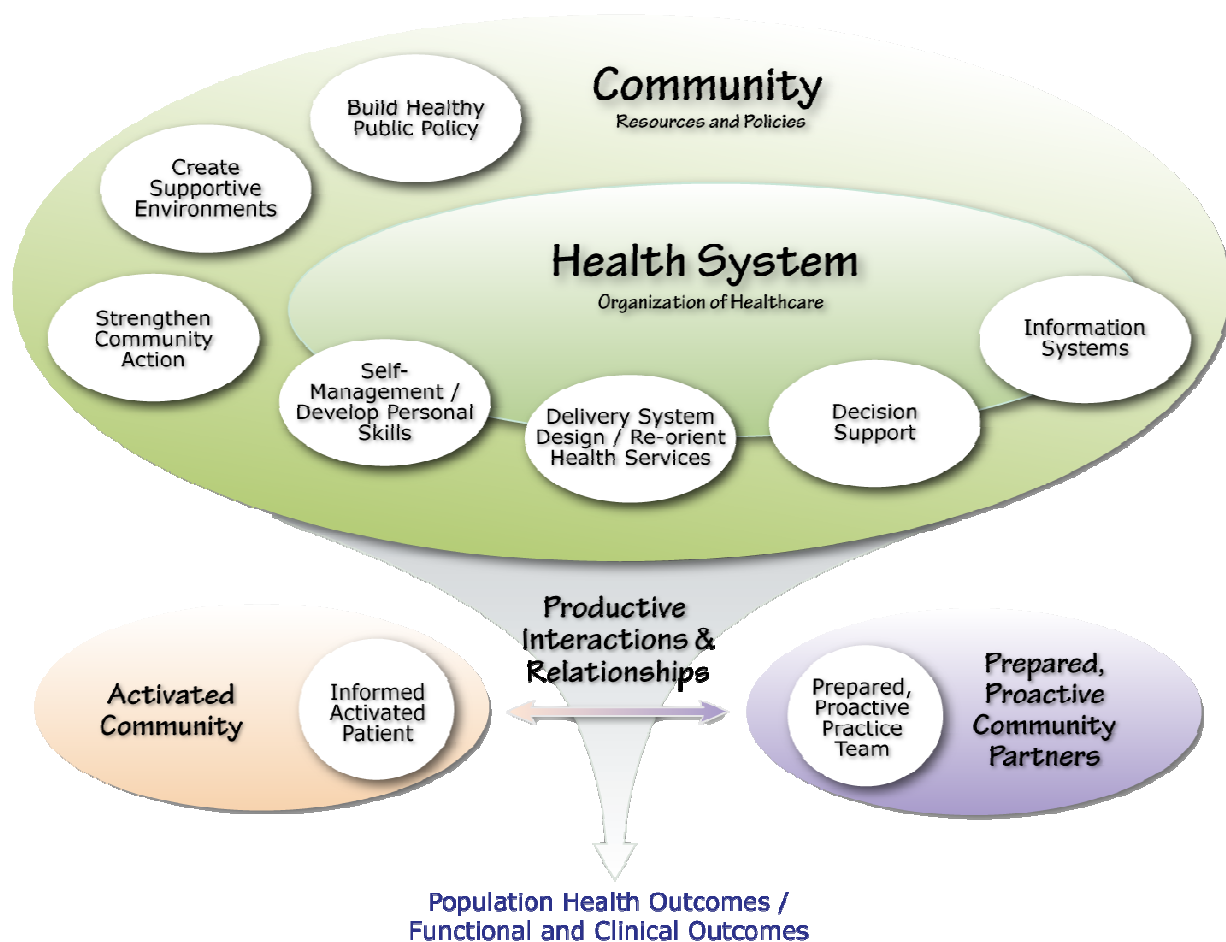
<b><i>Relationship to CDSMS<sup>6</sup> &amp; immigrant older adults</i></b>	<b><i>Stakeholder types grouped together</i></b>
Conceptual/planning	Academics; government and health authority decision-makers
Experiential (as members of immigrant communities)	Older adults; multicultural sector service providers
Health services delivery	Health authority employees; physicians

In so doing we hoped to maximize the likelihood of each person's participation due in part to similarities in communication styles (e.g., professional vocabularies, framing of the issues) and lived experiences. We also anticipated that perceptions of power imbalances among them that serve to silence the least powerful would be reduced. In the ensuing full group discussion we hoped to encourage a greater cross-fertilization of ideas among the different groups of stakeholders. Interestingly, however, only those individuals who self-identified and were viewed by others as leaders chose (or felt qualified) to speak in this arena. By contrast, participants were reluctant to end their lively discussions in which all were actively engaged at the World Café tables, underscoring the appropriateness of this format for this diverse group of stakeholders.

## Terms of Reference

### Chronic Disease Self-Management Supports

The **Chronic Care Model** is a widely adopted multi-pronged strategy aimed at preventing and managing the increasing incidence of chronic disease worldwide. Central to the model is the notion of the “informed activated *patient*” who interacts with a “prepared proactive *practice team*” (Wagner, Austin, & Von Korff, 1996; Wagner et al., 1999). This model has since been expanded to better account for the social determinants of health, or factors that influence chronic conditions and their care that fall outside the purview of the health system, as reflected in the diagram below (Barr *et al.*, 2003).



**Figure 2: The expanded chronic care model (Barr *et al.*, 2003).**

There are many definitions of **Chronic Disease Self-Management** and **Self-Management Support** that reflect the *context* within which they were developed and the *purpose* for which they were created. The chronic condition self-management support framework and community of practice project team, led by Dr. Sue Mills, had this to say:

[I]ndividuals and their families self-manage chronic conditions in the context of their daily lives which often include interactions with a wide range of services. From this perspective, [**Self-Management Support**] encompasses health care, social services, and community-based initiatives aimed at supporting individuals and their families to live well with chronic conditions (Mills, Brady, Sargious, Ziabakhsh, & Jayanthan, Forthcoming 2011).

This broad definition of self-management supports is well-suited to immigrant older adults, since it appears that much of the care they seek for chronic conditions (together with their families), is found in the community and multicultural sectors rather than the health care sector, per se. In parallel with the expanded chronic care model, it also highlights the importance of considering the interface between the health system and broader community supports and the ways in which both influence the personal skills of the individual, delivery system design, decision support and information systems. **This report seeks to contribute to our understanding of what is needed in terms of supports from the community and supports from the health system in order optimize the ability of immigrant older adults to self-manage their chronic conditions.**

It is therefore important to specify how these two core concepts—self-management and self-management support—are defined within the domain of health, on the one hand, and community on the other. Here we draw on the definitions used by B.C.’s Ministry of Health to understand how they are conceptualized within the health care context:

- **Chronic Disease Self-Management** refers to the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the *confidence* to deal with medical management, role management and emotional management of their conditions.
- **Self-management support** is understood as the systematic provision of education and supportive interventions by health care staff to increase *patients’ skills and confidence* in managing their health problems, including regular assessment of progress and problems, *goal setting, and problem-solving support*.<sup>7</sup>

Reporting on the projects of the Diabetes Initiative of the Robert Wood Johnson Foundation,<sup>®</sup> Fisher *et al.* (2007, p. 221S) suggest that “self management can be viewed in broad contexts of (1) communities, structures, and organizations that provide the base for (2) the resources and supports that are available to people and (3) the self-management behaviors that result.” This expansion of Wagner’s chronic care model thus recognizes “the built environment, community organizations, worksites, informal social networks, and families” (2007, p. 222S), as well as health care organizations, as relevant to individuals’ daily self-management experiences. Expansion of our understanding of these contributing factors is essential if we are to successfully support self-management efforts.

A review of research in this area by Sanders and Rogers (2008, p.16) identified the many ways in which social networks and support influence how people with chronic conditions “are supported inside and outside of formal health service provision”:

“[S]upport (or lack of it) from existing networks [plays a role] in adapting to chronic illness” (Sanders & Rogers, 2008, p.17). Also important is the maintenance of “valued social roles, coherent identities and a ‘normal life’” (Townsend, Wyke, & Hunt, 2006, p. 185). Social support also impacts “recovery from chronic illness episodes (e.g. see review by Kaplan & Toshima, 1990). For some individuals and groups, aspects of social support are not easily separated out from individual self management. . . . [T]he structure and content of social networks may [also] impact on who gains access to, and engages in, self-management programs. There is evidence that such programs may be operating an ‘inverse care’ law (Hart, 1971), with recruitment skewed in favor of those who are more affluent and see themselves as good self managers; whilst those who could benefit the most are least likely to engage with such programs (Kennedy, Rogers, & Gately, 200[6])” (Sanders & Rogers, 2008, p.17).

These various interpretations of chronic disease self management and self management support are reflected throughout the literature, in practice and in everyday reference to the topic by the lay public. It is therefore important to specify what we mean when we use these terms, in order to be clear about the types of supports needed and the relationship among them. Future research questions must be precise in this regard. However, this precision is not possible in the context of lively discussion among diverse stakeholders. Participants in our forum would often not distinguish between the nature of self management versus the barriers to acknowledging a need to self-manage, for example. Similarly, they did not always articulate whether they were referring to formal or informal self-management supports. This ambiguity is therefore apparent in our reporting of the World Cafe discussions.

### **Immigrant older adults**

Older adults are the most rapidly expanding population in Canada, expected to grow from 13.7% today to almost 24% by the year 2031 (BC Ministry of Health Services, 2004). Equally dramatic has been the increase of ethnocultural older adults, who now comprise more than one quarter of Canadians 65 years and over (Statistics Canada, 2006). A report just released on the findings of the 2008 Canadian Survey of Experiences with Primary Health Care (Health Council of Canada, 2010) found that 72% of Canadians aged 65+ reports having at least one of seven selected chronic conditions. Moreover, while people in this age group are most likely to have multiple chronic health conditions, they are least likely to receive some kind of self-management support.

Recent immigrants who move to Canada after age 65 have poorer overall health compared to their Canadian-born counterparts (Gee, Kobayashi, & Prus, 2004), and chronic disease morbidity is elevated in certain minority populations. For example, foreign-born populations from South Asia experience higher rates of diabetes mellitus and heart disease (Fikree & Pasha, 2004; Gupta, Singh, & Verma, 2006; Raymond *et al.*, 2009); yet knowledge of these diseases and their management is relatively low among these populations (Ford, Mai, Manson, Rukin, & Dunne, 2000; Grunau, Ratner, Galdas, & Hossain, 2009). Older immigrants are variously challenged in their efforts to access health care relative to the intersecting effects of their charter language abilities, socioeconomic status, gender, immigration category and status, place of residence and so on. Oppressions experienced throughout the life course influence their social capital which may be further diminished in the face of role reversal and loss of status, as well as discrimination experienced post-migration (Guruge, Kanthasamy, & Santos, 2008; Koehn & Kobayashi, 2011; Koehn, 2009; Koehn, Spencer, & Hwang, 2010; Sadavoy, Meier, & Ong, 2004).

## **Panel Presentations**

Panellists were selected for their varied expertise and experience with chronic-disease self-management supports. Their presentations represent policy, clinical and academic perspectives. Brief overviews follow, but readers are directed to Appendix B for information on the panellists and Appendix D for the presentation slides.

### **Chronic Disease Self-Management Supports for Ethnocultural Minority Older Adults**

*Kelly McQuillen (Director, Patients as Partners, B.C. Ministry of Health)*

Objectives:

- To provide a high-level overview of Patients as Partners
- To focus on Patients as Partners' framework for with supporting chronic disease self-management at the provincial level
- To describe current community self-management programs in BC
- To introduce the BC logic model and Provincial self-management support evaluation

Outline:

- Introduce Primary Health Care Charter, Triple Aim, Family Centred Care and the Three Charters (re: individual, system, community)
- The expanded chronic care model; BC definitions of self-management and self-management support
- Descriptions of the BC Chronic Disease Self-Management Program (CDSMP)—Punjabi version (McGowan); Health Care Professionals Delivering Self-Management Support program
- Population-based chronic conditions management, Self-Management Support Steps of Expertise for BC, logic model (and associated activities) developed by Impact BC, provincial workgroup to evaluate self-management education and support efforts

### **Self Management Support Approaches: A Key Solution to the Problem**

*Sue Mills (Ph.D., New Investigator, BC Centre of Excellence for Women's Health)*

Objectives:

- To explore how social determinants of health (including social and physical environments) as well as more micro factors, such as personality, knowledge, skills etc., influence individuals' and their families' capacity to manage chronic disease.
- To identify how these factors influence people's ability to access and participate in self-management support interventions, particularly more disadvantaged groups who experience greater social inequalities.

- To illustrate how the delivery, design and content of many self-management support interventions fail to account for these important factors and some encouraging directions that are attempting to address these limitations.

Outline:

- Statistics: Not all members of society are equal in regards to developing chronic conditions (prevalence in different sectors of the population), nor are they equal in how they do once they are diagnosed (health outcomes, comorbidities). These inequalities lead to inequities.
- Factors that make the difference: social determinants of health.
- Research evidence outlining examples of ways in which the social determinants of health influence how people manage their chronic conditions.
- Current dominant approaches to self-management interventions and research evidence on how social determinants of health-related factors are influencing how particular subgroups are accessing and using SM interventions.
- Relevance of content of self-management interventions to complex social contexts and limitations of current approaches in considering social determinants of health
- Promising directions forward.

**Ethno-cultural minorities and chronic disease: Clinician–patient interactions**

*Charlotte Jones (MD, PhD, Associate Professor of Medicine, University of Calgary)*

Objectives:

- Outline major known determinants of health.
- Review literature on clinician-patient interactions.
- Review published studies and knowledge outlining interventions to optimize clinician-patient interactions.

Outline:

- Institute of Medicine report: Unequal Treatment.
- Quality of the clinical encounter - patient and physician roles: physician uncertainty; quality of patient-physician relationship; patient mistrust and refusal; patient reactions to clinician's beliefs and attitudes.

- What helps? Symmetry of beliefs (patient:physician); physician education re: existence of stereotyping and bias; performance feedback; public awareness of inequity; research on access and utilization disparities; evidence-based resource allocation; address barriers to access (e.g. language, etc.); improve continuity within systems; community-based and multi-disciplinary approaches to treatment; community capacity building; community liaisons.
- Legal/policy/regulatory guidelines that support health care provider-patient relationships: equality of public and private systems; case load limits, time flexibility, multidisciplinary teams, representative hiring practices.

### **Self-Management Supports for Ethnocultural Minority Older Adults: What We Know and What We Don't Know**

*Karen Kobayashi (PhD, Associate Professor of Sociology, University of Victoria)*

#### Objectives:

- To provide an overview of Self-Management Support for Ethnocultural Minority Older Adults: An Annotated Bibliography.
- To assess the quality and limitations of studies available on this topic.

#### Outline:

- Self-management support for marginalized or disadvantaged populations, older populations and ethnocultural minority groups.
- Self-management support for immigrant older adults: CDSMP adaptations for immigrant older adults; alternative self-management programs (to CDSMP) for immigrant older adults; Cultural competency in self-management support; CDSM, coping, and lifestyle practices among immigrant older adults.
- Health literacy and self-management supports.
- Complementary and Alternative Medicine: self-management support, older adults, ethnocultural minorities, immigrant older adults.
- Capacity-building/community development: self-management support, older adults, ethnocultural minorities, immigrant older adults.
- Conclusions – where we need to go from here?

## World Café Discussions

Subsequent to the workshop, all of the notes taken for each World Café table were transcribed, as were the posters developed to summarize the contributions of the three sets of “traveling” participants to each table. These were then imported into the data management program, Atlas.ti 5.0<sup>®</sup>. Both inductive and deductive coding strategies were employed simultaneously. We wanted to let the collective wisdom of our participants speak for itself; however, we were also curious as to whether and how the participants’ conversations reflected the strategic directions recommended by Mills *et al.*’s (Forthcoming 2011) framework for Chronic Condition Self Management Support. This draft framework is the outcome of an international roundtable of policy and academic experts on self management supports for chronic conditions convened in Vancouver by Dr. Mills in June, 2009. The Framework, currently under development, identifies eight guiding principles and seven strategic directions aimed at “fostering a culture that creates structures, enacts policies, and offers services to reduce the impact of chronic conditions and support people’s self-management behaviours” (p. 6).

Codes for each of the following strategic directions were applied to the transcribed text in addition to the inductive codes that emerged from the data. Each framework code coincided with a unique cluster of inductive codes as follows:

<b>Framework code and definition</b>	<b># of quotations*</b>	<b>Co-occurring inductive codes**</b>
FW – ENGAGEMENT: “support people with chronic conditions and their families to be meaningfully engaged in decision making, planning and evaluation of self-management support initiatives.”	7	Capacity building {5} Education {20} Health literacy {20}
FW- ACCESS, REACH, RANGE: “expand reach and range of, and access to self-management support interventions, programs, and services in healthcare systems and communities. Relates to identifying and reducing barriers, educating providers and program leaders (cultural competency training, etc.).”	41	Constraints {44} Cultural competency building {6} CULTURAL CONTEXT {31} Education {20} FW - LINKS {18} Health literacy {20} Language barrier {12} Level - Family {13} Level - Individual {5} Level - Systems {31} Social Isolation {3} Social media {9} Staff {7} Working with community {16}

FW - EVIDENCE building: "advance evidence on the effectiveness and appropriateness of self-management support interventions and other kinds of self-management support-related initiatives"	12	Education {20} Level - Systems {31} Resources {12} Working with community {16}
FW - QUALITY improvement: "improve quality of self-management support services, programs and interventions"	11	FW - QUALITY improvement {11} Constraints {44} CULTURAL CONTEXT {31} Doctor/Patient Relationship {5} Health literacy {20} Level - Systems {31} Resources {12}
FW – LINKS: “forge and strengthen linkages within and between sectors, policies, programs, and service providers"	18	Education {20} FW- ACCESS,REACH,RANGE {41} Level - Systems {31} Social media {9} Staff {7}
FW – LEADERSHIP: “foster leadership, commitment and accountability for self-management support at all levels of health care and social and community services."	3	Education {20} Working with community {16}
FW - INFRASTRUCTURE building: “build infrastructure to support self-management support initiatives and provide resources and funding to support these initiatives."	4	Level - Systems {31}

**Table 1: Associations between CCSMS Framework and inductive codes for World Café discussions**

\*The term 'Quotations' in Atlas.ti refers to segments of text to which a specified code is assigned and may encompass a single word up to the entire document. The program enables the generation of reports by code while still identifying the source document which, in this case, refers to all materials associated with each of the World Café tables.

\*\*{#} refers to the number of quotations for this code

While Mills *et al.*'s framework has yet to be finalized, our findings support the distinctions it makes between each of the seven strategic directions. The clusters of inductive codes associated with each are relatively unique. Our data provide examples of actions for each and/or illustrate their different dimensions. Using the framework as a lens through which to organize our inductive categories facilitates their translation into action and provides direction as to gaps in understanding and evidence.

It is evident from Table 1 that the key strategic direction needed is "to expand the reach and range of, and access to SMS interventions, programs, and services in healthcare systems and communities." This in turn overlaps with the importance of forging and strengthening "linkages within and between sectors, policies, programs, and service providers." This framework does not incorporate all of our inductive codes, however.<sup>8</sup> We also feel that the complex notion of access warrants some clarification.

The seven dimensions of access to self-management supports depicted in Figure 3 were originally identified relative to access to health care for vulnerable populations by means of a critical interpretive synthesis of the literature on that topic (Dixon-Woods et al. 2005, 2006). Koehn (2009) has subsequently applied the framework to primary data on immigrant older adults and found that it fully and systematically accounted for the phenomenon of access and the way in which vulnerabilities arise in relation to it. Here we have adapted the framework to the broader scope of self-management supports that extend beyond the health care system to include formal social care supports as well as the support received through less formal networks and mechanisms. Each dimension of access was evident in our data from the World Cafe table discussions and is elaborated below. Visual depictions of most dimensions can also be found in Appendix E.

Sorting data into these seven dimensions was easily accomplished because distinct groups of our inductive codes could be readily associated with each of the seven categories.

## Accessing self management supports

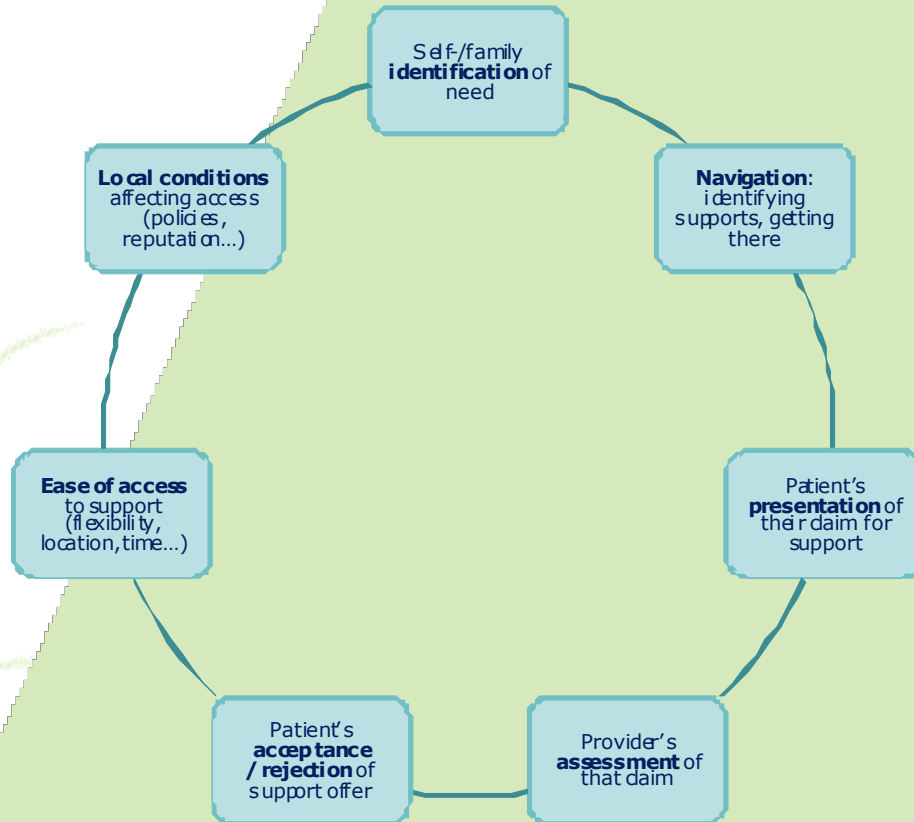


Figure 3: Dimensions of access to self-management supports

## ***Seven dimensions of access to self-management supports***

### **Self-/family-identification of need to self-manage**

The first step in gaining access to self-management supports is determining that you need to self-manage and deserve to be supported in your efforts to do so. Our participants described four barriers to the identification of the need for self-management of chronic disease by the immigrant older adults under discussion.

First, the increasing dependence of the elderly was noted by several participants. As with all older adults, dependence in some aspects of life may increase with declining health and increasing frailty. For immigrant seniors, however, migration to an alien sociocultural and linguistic environment in late-life can add to this dependency. Cultural factors also come in to play. Men are often thought to be better equipped than women to make decisions for family members. More commonly we heard that seniors viewed their adult children as their ‘safety net’ in later life and relied upon them to determine if and how they should seek care. Immigration policies that render sponsored parents and grandparents dependent for their first ten years in Canada and limit the services to which they have access also reinforce this dependency. One participant also noted that adult children may intercede with care providers to protect elderly parents from a fatal diagnosis. We should note, however, that our own research shows that considerable variation exists within cultures and it is unwise to generalize such beliefs to an entire population, since cultures are known to transform over space and time (Koehn, Neysmith, & Kobayashi, under review). Finally, there is research and even legislation that examines the increasing inability of immigrant families to provide for the needs of their ailing elderly parents.

There was considerable discussion about the normalization by many older immigrants of the pain and suffering they experience in old age. This took several forms. Without knowledge of healthy aging and specific chronic diseases, the two were thought to be inevitably intertwined and therefore nothing could be done about it. Some felt that the suffering they experienced was their “fate” (e.g., Karma, or ‘health is governed by the Sun’). Another interpretation was that tolerating suffering was a virtue. A related theme is the unwillingness to acknowledge a chronic condition because of the stigma associated with illness and death in some cultures.

The fact that many older immigrants have very limited financial resources is reflected in the unwillingness of some to spend money on treatment when they’re ‘just going to die anyway’. Comments like this also relate to the considerable loss of self-esteem that many immigrant older adults endure when they are sponsored by their adult children. With no or little income and few opportunities to engage in paid work, many experience role reversals with the younger generation and a considerable demotion in status. Without an understanding of the difference in diagnoses, older immigrants sometimes share unwanted medications with others who cannot afford them.

Finally, our participants told us that older immigrants often will not initiate a search for care for their chronic conditions, seek out ways to self-manage them, or look for support with this task, because this type of care is not available in the countries from which they have arrived. Nor do they have the language skills or access to information to be able to find out about services in Canada, particularly if they are new to the country. Increasingly this type of information is being channelled through social media such as Facebook and Twitter, to which many older immigrants do not have access.

### **Navigation**

Once the decision to seek care is made, people must invest a great deal of effort and resources to find their way to and through the health and social-care systems. The ability to do so depends, to a great extent, on their access to informal supports, such as family members who most often provide transportation, translation and interpretation services.

Participants mentioned both individual and systemic barriers, both of which are acknowledged by the concept of 'health literacy' referring to "The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course" (Rootman & Gordon-El-Bihbety, 2008). Older persons in general tend to have lower health literacy. Some older immigrants are further handicapped in this regard by their lack of charter language skills, recency of immigration, and low/no literacy in their own language (more often true of older women). Without these skills it is harder for older immigrants to gain knowledge of the benefits of self management and the health and social care systems as well as written materials that can support these efforts. Accessing transportation is also very difficult with limited language and literacy skills. Other barriers, such as limited mobility, little or no income, and limited time or motivation (e.g., due to childcare responsibilities or the nature of the chronic condition itself) further isolate immigrant older adults from the care and supports they need.

As a result, their adult children are required to take on the role of interpreters and cultural brokers for their aging parents. It is therefore beneficial to target information on self-management supports at this younger generation as well. There are numerous ethical concerns with conveying sensitive information to an older adult via a younger family member (who may be an abuser, who may not be able to convey gender-specific information, who may not be confident in their interpretation skills and fear they have not conveyed the necessary information accurately, etc.). The role of liaison, transportation provider and interpreter for older parents is also stressful in terms of the competing demands on their time as parents, as employees, etc. As a result, not all adult children can assume this responsibility and not all older immigrants have children in Canada. Others are therefore needed to assist and advocate for older immigrants. Examples are volunteer drivers from within the community and 'culture brokers' who can liaise between the older adult and the health and social care systems.

Efforts to make the health care system more responsive to those with low health literacy include translation of key documents into different languages, and guarantees that both original and translated documents are written in 'plain language.' Other media that do not rely on literacy are also essential to convey important information. Considerable emphasis in health literacy discussions was placed on the doctor-patient relationship, to be addressed below. For example, some family physicians ask their patients how they would like to receive information about their chronic conditions. More extensive efforts to address organizational issues so as to ensure continuity of care throughout our very complex health care systems are also necessary, as is investment in interpreter services and locally accessible self-management supports.

### **Presentation of a claim for self-management support *or* –provider-patient interactions**

For both immigrants and older people in general, the process of presenting well in order to demonstrate the authenticity and legitimacy of a claim to support is complex. Language and cultural incongruence between the health-care recipient and provider, already discussed, clearly limits the ability of the recipient to make a credible claim. Most importantly, this takes more time. Older patients in general are known to need more time with physicians, as are those with multiple chronic conditions for whom management is complex. Our participants repeatedly raised concerns about the current funding model for family physicians which instead encourage physicians to stipulate that they can only treat one illness per fifteen-minute visit. One participant noted that new incentives for physicians to spend more time with patients with multiple chronic conditions are forthcoming. More widespread changes of this nature are needed in order for physicians and/or other health care providers to spend the time they need with older immigrant patients to ensure that they have developed sufficient rapport and an appropriate style of communication (possibly with the assistance of an interpreter) to fully understand the patients perspectives on health and healing and to determine what they need in order to successfully manage their chronic condition(s).

Non-profit community organizations can play a role in improving supports by informing family doctors in their neighbourhoods of the services they provide. Physicians and other health care providers in turn need to take the time to become acquainted with these language and culture-appropriate supports in order to be able to provide immigrant patients, particularly older adults, with concrete referrals to additional supports. Several of our participants nonetheless warned that the community sector cannot be expected to assume full responsibility for translation/interpretation and chronic disease self-management supports without the resources to train and pay committed staff (as opposed to much more transient volunteers) who can work responsibly with them.

A few participants also expressed concerns about the judgements that some health care providers make about their older immigrant patients based on ageist or culturalist/racist assumptions that influence their decisions to refer them to appropriate treatment or supports. Health care providers therefore need training in patient communication techniques and the self-examination of their own biases.

### **Acceptance/rejection of offer of support**

Offers of support may be rejected by those in need for many reasons. These include differences in the perception of their utility between care provider and recipient, cultural taboos or stigma, the fact that the supports recommended are not feasible, due—for example—to competing demands on time, such as the need to provide care for a grandchild or spouse, among others. These issues emerge throughout the World Café table discussions and have been identified in previous sections.

Participants also pointed to two types of incongruence that may result in the rejection of chronic disease self management supports offered by health care providers. The first speaks to a lack of representation of consumer or client populations among health authority staff. Correcting this imbalance has been complicated in the past by restrictions on advertising for job candidates of specific ethno-linguistic backgrounds. Even when ethno-linguistic minorities are hired, gender distributions and other sub-cultural or religious distinctions made within a particular cultural group must be heeded in order to match patients with care providers. And this type of matching is typically only feasible for larger cultural groups with a sufficient pool of trained health care providers to draw from.

A second type of incongruence that may result in a patient's rejection of support is that between the medical model of disease—the framework within which most self-management supports are offered—and cultural models of health and illness held by older immigrants that may be less individualistically focused or more holistic in nature. As previously noted, community organizations are well-equipped to assume this role, but will require additional resources if they are to be effective. The assurance of quality should be maintained by establishing measures of trustworthiness for community agencies providing such supports. Community leaders should be recruited and trained to lead educational workshops, but undue reliance on volunteers is not recommended.

### **Systemic issues– suitable options**

Dixon-Woods *et al.* (2005) use the metaphor of a membrane through which people must find their way in order to gain access to the services or supports that they need. Services that have low “permeability” (e.g., require referrals, have limited access hours etc.) require the mobilisation of many resources (such as language skills, transportation, health literacy, knowledge of the system, time, etc.) of which older immigrants are typically in short supply.

Many of these issues have been addressed in the previous sections. Strategies to increase the ‘permeability’ of the system suggested by our participants are as follows (and see Appendix E):

- Culture brokers / interpreters on medical teams
- Culturally congruent SMS models and staff
- Training of HC providers: National Cultural Competence website
- Group medical visit - peers with condition, family members, more time

- Culturally appropriate coaching
- Focus on health literacy of care provision context
- Flexible funding of supports - non-'health' (community) services

### **Local conditions affecting access**

Local conditions that influence the production of candidacy range from geographic proximity to services to provincial policies, the effects of which can be profound. Our participants strongly emphasized the importance of working closely with local and ethnocultural communities (including immigrant societies) and building community capacity in order to increase community awareness and develop affordable, effective and sustainable supports. Involving the community maximizes enrolment; they know where to find people and how to motivate them to participate. Communities are also more effective than researchers at lobbying government. MPs and MLAs should be invited to community events to share good and bad experiences, successes and struggles alike.

### **Conclusions**

Of the three dominant themes that emerged from our World Cafe discussions, “Reach” is most fully developed. This primary theme is also a strategic direction that is identified in the framework document, “Building bridges: An international framework for promoting self-management support in the care of chronic conditions” (Mills *et al.*, 2011), as follows:

*Expand reach and range of, and access to self-management support interventions, programs, and services in healthcare systems and communities. Relates to identifying and reducing barriers, educating providers and program leaders (cultural competency training, etc.).*

This strategic direction can only be attained if we attend to the key points raised under our two other most dominant themes, “Building Linkages” and “Health Care Provider Supports.”

There are numerous barriers and constraints preventing immigrant older adults from accessing and fully benefiting from chronic disease self-management supports. These include constraints at the systems, social, family and individual levels. **REACHing out** to this relatively vulnerable subpopulation of older adults is therefore extremely important. This theme was reiterated in all groups. Service providers emphasized the need to target hard-to-reach patients. These are seniors who are not seeking help for a variety of reasons. For example, they may be isolated and have difficulties in accessing programs due to transportation issues, language and health literacy barriers or may accept chronic disease and suffering as a normal part of aging.

Raising awareness of chronic health issues, overcoming stigma and cultural beliefs that regard chronic diseases as a normal part of aging and connecting individuals, families and communities to services and programs were all seen as components of REACH.

In order to reach seniors, families need to be targeted. The important role of families was brought up repeatedly across all groups. Immigrant older adults depend on their families, specifically their adult children, to access and navigate the health care system.

Service providers discussed strategies in reaching out to them. Their suggestions included using social media, such as radio and TV; utilizing currently established programs and services; holding meetings at places where people traditionally gather; working together with community leaders (persons of influence who are well respected in the community); training and working with peer volunteers.

The importance of **BUILDING LINKAGES** among health care providers and through community partnerships was emphasized in all groups. For example, general practitioners (GPs) need to “work with others,” not in isolation. Service providers expressed the importance of “target[ing] health from a community standpoint,” “ask[ing] the community what adaptations are needed”, “building good community and increasing capacity”, and “building partnerships with community infrastructure (temples, etc.)” Participants also emphasized the limited capacity (time, infrastructure, funding, training) of community partners to assume the full burden of providing chronic disease self-management supports for their clients; the health care system needs to change in order to facilitate their increased involvement. True partnerships need to be built with appropriate resources, where “NGO’s, community organizations and volunteers” work together with the healthcare system and patients. As the projects of the Diabetes Initiative of the Robert Wood Johnson Foundation<sup>®</sup> have demonstrated, “working together extends the range, variety, and coordination of services and supports available” (Fisher *et al.*, 2007, p. 220S).

Also important is the provision of appropriate **SUPPORTS TO HEALTH CARE PROVIDERS** who play an essential role in chronic disease self-management support. Changes are needed at the systems level to facilitate an inclusive and culturally sensitive approach to chronic disease self-management. Workshop participants felt that building trust and a good relationship with GPs and other health care providers is vital to the success of chronic disease self-management. This can be facilitated if there are incentives for health care providers to spend more time with patients and address more than one problem at a time.

There was a strong emphasis on working with health care providers to raise their awareness of available chronic disease self-management supports for different communities to which they can refer their patients. Healthcare provider education and training (cultural competence) were viewed as essential to the enhancement of chronic disease self-management supports for immigrant older adults. Suggestions included volunteers to coach healthcare workers on how to interact with patients from other cultures; using “cultural brokers”; incorporating cultural competency training as a health policy for staff; and hiring and retaining staff from different cultures.

Our multistakeholder dialogue thus underscores the importance of pursuing research that examines what supports are needed for (a) community partners (including multicultural agencies, family members, etc.) and (b) diverse health care providers *to work collaboratively* in order to ensure that immigrant older adults have the personal skills they need to self-manage their chronic diseases as per the Expanded Chronic Care Model. This examination must take into account the interactive effects of social determinants of health on both the prevalence and ways in which chronic diseases are experienced and the capacity of individuals and communities to manage them.

Sanders and Rogers (2008) point the way to useful critical (realist and constructionist) theoretical and methodological approaches to this work. Especially valuable is research that distinguishes between different types of support that are more salient at different points along the trajectory of a chronic disease. These and other distinctions “are likely to assist with mapping the nature of support mechanisms and range of resources linked to everyday ways of living with chronic conditions within specific residential areas” (2008, p.28) Qualitative methods are especially useful “for examining aspects of relationships and community structures that are often hard to measure” (2008, p. 32) but mixed method approaches are optimal if we choose to focus on the relationship between social networks and health inequalities. Most critically, our research will continue to engage all stakeholder groups included in this forum so as to ensure its relevance and uptake of any emergent recommendations.

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## Appendices

### Appendix A: Workshop Participants

#### Facilitators (F), Table Facilitators (TF), Presenters (P)

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## *Appendix B - Panel presenters and workshop facilitator bios*

### **Facilitator and Panellists**

Sharon Koehn, PhD, is a Research Associate at the Centre for Healthy Aging at Providence Health Care. She is the co-lead of the Immigrant Older Adults: Care, Accessibility, Research and Empowerment (ICARE) team. Trained as a medical anthropologist, she has been conducting interdisciplinary community-based research with immigrant older adults since 1990.

Kelly McQuillen is the Director of Patients as Partners, Integrated Primary and Community Care, with the BC Ministry of Health Services. She is committed to patient-and family-centered care as an innovative approach to the care, redesign and quality improvement. Her current position enables and facilitates patient and family voice, choice and representation in the care, quality improvement and system redesign of integrated primary and community care in BC.

Sue Mills, PhD, does research looking at how women in disadvantaged groups self-manage their chronic conditions and how current self-management related policies and interventions reflect those experiences. She is also developing an international framework for how we should move forward in self-management research, policy and practice.

Charlotte Jones, PhD, is currently an associate professor of medicine at the University of Calgary. She practices as an adult Endocrinologist and is medical director of the Calgary Zone Alberta Health services Hypertension and Cholesterol Center. She has been involved in developing and implementing the CHAMP (Cardiovascular health, awareness and management program) programs. These programs have been implemented in numerous communities across Alberta. Her CHAMP programs in the Indo-Asian community are in the process of being disseminated across Canada.

Karen M. Kobayashi, PhD, is an Associate Professor in the Department of Sociology and a Research Affiliate at the Centre on Aging at the University of Victoria. On the research front, she co-leads the ICARE team with Sharon Koehn and the Ethnicity and Aging theme team for the National Initiative for the Care of the Elderly (NICE) with Daniel Lai.

## Table Facilitators

World Cafe I:	(A) Sue Mills, Karen Kobayashi (see above, presenters)
	(B) Laura Ng, Elizabeth Stacy
	(C) Patrick McGowan, Jay Bains, Saroj Sood

Laura Ng is a Diabetes educator. She teaches and administers the Vancouver Chinese Diabetes Education Centre. Laura has experience working with Chinese diabetes clients and clients with diverse ethnic backgrounds in home health settings. She is involved in chronic disease prevention work.

Elizabeth Stacy is a research coordinator at the eHealth Strategy Office where she focuses on community-based projects working with multicultural and First Nations communities in the province. She has worked on the intercultural Online Health Network (iCON) supporting communities across BC in developing skills and confidence in chronic disease self-management through culturally relevant and language appropriate in-person events and online resources.

Patrick McGowan directs the University of Victoria Centre on Aging, Ladner office. Patrick implements self-management programs throughout the province and trains health care professionals in self-management support strategies.

Jay Bains is a CDSMP trained and certified Master Trainer, affiliated with University of Victoria, Centre on Aging as South-Asian Program Coordinator.

Saroj Sood came to Canada in 1980 as an experienced social worker from India. Since her retirement in 1992 she has been actively involved with the Indo-Canadian Seniors Centre and other projects in her community. Most recently, Saroj was trained as a Chronic Disease Self-Management Program Leader for Punjabi-speaking seniors. She moved to an Assisted Living facility designed to accommodate Indo-Canadian seniors in 2007.

World Cafe II:	(A) Maylene Fong, Shirley Sze
	(B) Marina Niks, Connie Coniglio
	(C) Carole Gillam, Juan Solorzano

Maylene Fong manages the Healthy Living Program in Vancouver Community. This is a health promotion/chronic disease prevention program for the high risk population. She is also the clinical practice lead (Clinical Nurse Specialist) for the Adult Older Adult home care program in home health. Maylene provides clinical lead in all areas of community practice with a focus on chronic disease.

Shirley Sze has been a Family Physician in Kamloops for 30 years. Presently, she is working at Vascular Improvement Program and Palliative Care Team. Shirley is the Physician Lead for the Practice Support Program for Interior Health Program, involved in teaching and developing the Self Management and Mental Health Modules. She is also a Faculty member for the Health Literacy Collaborative 2009.

Marina Niks works in the field of Health Literacy developing and implementing collaborative interventions and community based research projects. She has been involved in convening two Roundtables to articulate a provincial Health Literacy Strategy and is part of the BC Health Literacy Network.

Connie Coniglio is the Director of Health Literacy at BC Mental Health and Addiction Services (BCMHAS), an agency of the Provincial Health Services Authority. Connie is responsible for the direction and management of health literacy initiatives under the BCMHAS provincial mandate. Ongoing initiatives in Connie's portfolio include the Kelty Resource Centre, the Multicultural Translation Project, and the BC Partners for Mental Health and Addictions Information.

Carole Gillam is the Executive Director Primary Care Vancouver Coastal. She participates with Ministry of Health and General Practice Services Committee in policy development. Carole is currently conducting Doctoral research into the professional relationship between patient-as-partners in self-management and nurses' understanding of chronic disease management.



Juan Solorzano is the Team Leader, Chronic Disease Services Leader for Vancouver Coastal Health, and has led the design and development of a comprehensive chronic disease strategy for the North Shore. His duties include strategic planning of health care services, stakeholder consultation, community outreach, partnership building, physician engagement and program design & evaluation. Juan also supervises a number of the ambulatory clinics in the Medical Day Centre at West Community Health Centre and Lions Gate Hospital that includes nurses, dietitians, exercise specialist, social workers and clerical staff.

## **Appendix C - Guiding questions: World Café tables**

### **World Café I**

#### **Understanding the influence of socio-cultural factors**

*(Dr. Sue Mills and Dr. Karen Kobayashi)*

- Do social support factors, i.e., quantity and quality of relationships with family and friends, influence the ways in which EMOA self-manage their chronic conditions? If so, in what ways?
- Do cultural factors, i.e., more “traditional” norms, values and beliefs about health and illness, influence the ways in which EMOA self-manage their chronic conditions? If so, in what ways?
- Do social factors, i.e., gender, SES, geographic place of residence, influence the ways in which EMOA self-manage their chronic conditions? If so, in what ways?
- How might we consider these factors (1-3) in the development and/or revision of approaches to self-management interventions (or self-management support initiatives more broadly)?

#### **Community-based practice and consultation**

*(Ms. Laura Ng, Ms. Elizabeth Stacy)*

- Given what you know about what’s out there in terms of CDM/SMS supports, what practical information and tools do people need?
- What might health professionals/ government/ immigrant service workers, patients... need to know?
- What do you have to say that people need to hear? (“...I have ideas but don’t know who to tell.”)
- What are some creative ways to involve immigrant communities in CDM/SMS programming and the system.
- What types of outreach would help immigrant older adults in different communities? Could technological solutions be used? If so, how?

#### **The Chronic Disease-Self-Management Program – Punjabi**

*(Dr. Patrick McGowan, Mr. Jay Bains, Ms. Saroj Sood)*

- What are challenges and barriers that may make it difficult for Punjabi seniors to participate in group self-management programs?
- What factors facilitate community sustainability of self-management?

- What can self-management leaders and volunteers do to benefit the larger community?

## ***World Café II***

### **The challenges of delivering self-management supports at the HA and primary care levels**

*(Ms. Maylene Fong, Dr. Shirley Sze)*

- Time - how to go about setting aside dedicated time to create self-management goals and effective follow-up? Are time requirements for EMOA different versus other older adults?
- What types of preparation and toolkits would one require to deliver SM supports at the HA and primary care levels?
- How can the HA and primary care providers raise the awareness for SM support within their organizations for EMOA first and then amongst the EMOA community? Are they doing a good job at present?
- How best to link EMOA to SM supports in the community and how do we create SM supports at the HA and primary care level that will respond to the particular needs of the EMOA?

### **Health literacy and self-management**

*(Dr. Marina Niks; Dr. Connie Coniglio)*

- In your experience, how does Health Literacy impact the ability of EMOAs to self manage their chronic diseases?
- What role do NGOs, community organizations and/or volunteers play in supporting EMOAs self-management of chronic diseases? Is it working? How? What difference does it make?
- What challenges do you see in NGOs, community organizations and/or volunteers supporting EMOAs' self-management of chronic diseases? What is needed to facilitate the appropriate use of the sector?

### **Gaps between evidence, policy and practice**

*(Ms. Carol Gillam, Mr. Juan Solorzano)*

- Some research suggests that seniors from ethno-cultural minorities may require different approaches in self-management support. In your opinion, what are the key pieces of evidence that suggest that current policies and practices need to be revised?

- With your understanding of existing policies, identify the main discrepancies between new evidence and current policy/practice.
  - What are some of the main challenges you anticipate in making the necessary policy/practice changes, and how would you address them?
  - List the top three recommendations you would give to a decision maker able to influence policy and practice in this area?
- 

### *Appendix D - Presentation Panel Slides*

Attached as a separate document



## *Appendix E – Dimensions of Access to Self-Management Supports*

Dependence of elderly on others

men

adult children

(children = 'safety net')

avoidance of fatal diagnoses

Family not always willing / available

Normalization of pain and suffering in old age

'fate'

'suffering as a virtue'

'nothing can be done'

stigma of disease/death

Barriers to Self/Family  
Identification of need

Resource limitations

"dying anyways so why get a check-up or  
spend money on treatment?"

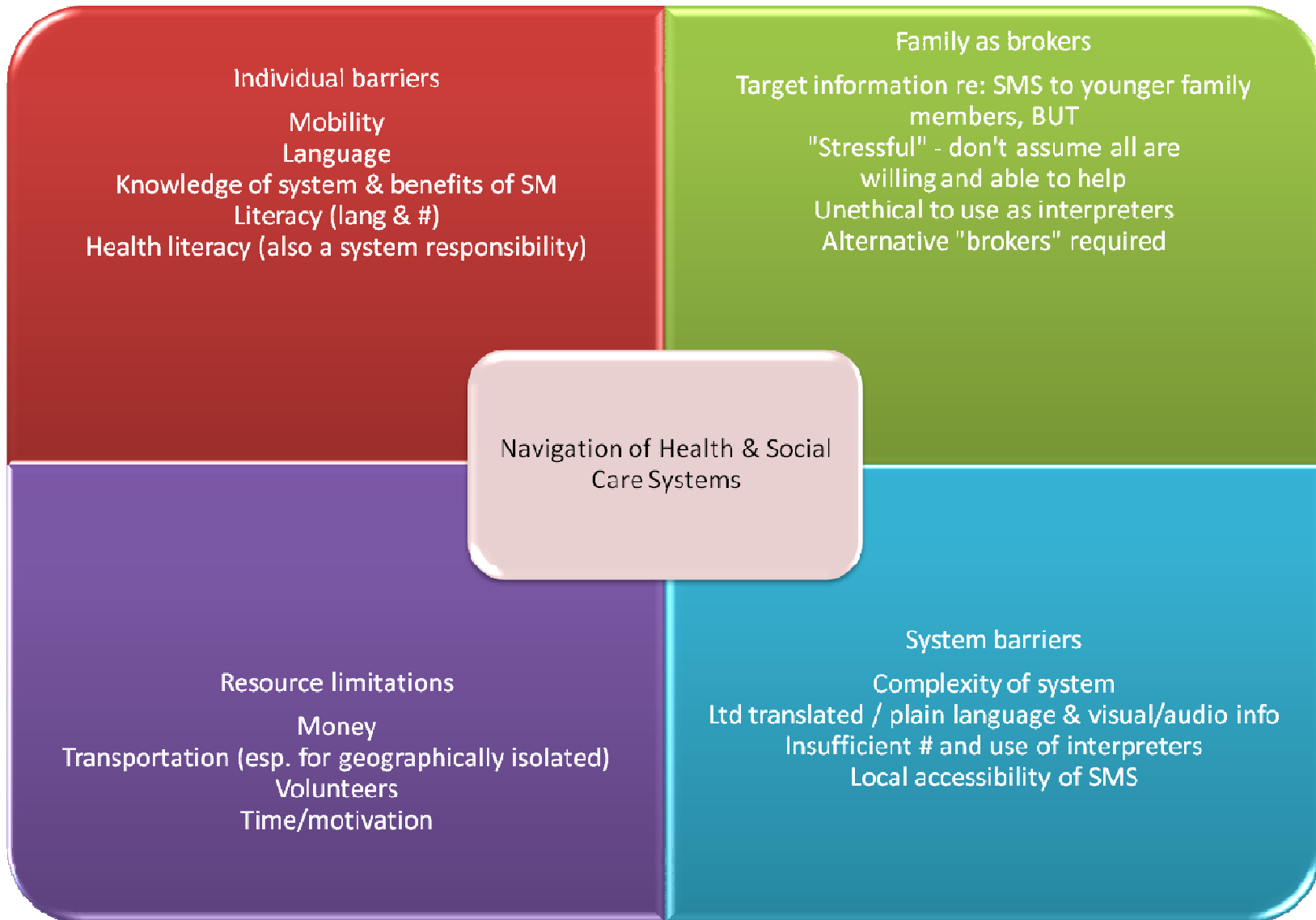
Share meds with others who cannot afford  
them

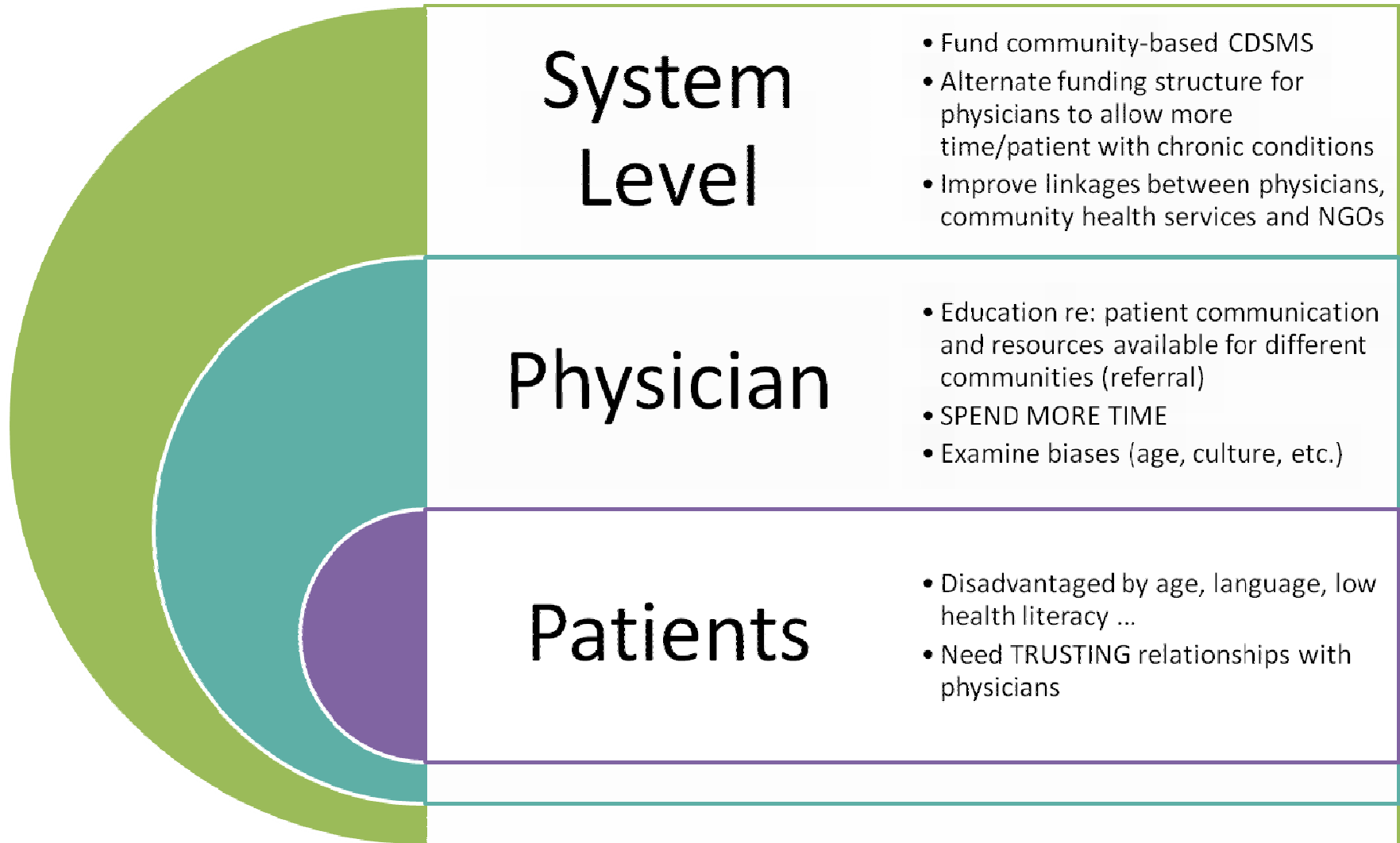
Lack of knowledge of services available

Not found in home country

Language barriers

No access to internet where info is  
increasingly conveyed





## Low permeability/access

- Medical model of care - disease-specific; short visits; low trust

## Strategies to increase permeability

- Culture brokers / interpreters on medical teams
- Culturally congruent SMS models and staff
- Training of HC providers: National Cultural Competence website
- Group medical visit - peers with condition, family members, more time
- Culturally appropriate coaching
- Focus on health literacy of care provision context
- Flexible funding of supports - non-'health' (community) services

## *Endnotes*

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<sup>1</sup> We gratefully acknowledge our funders for this workshop: The Institute on Aging, Canadian Institutes of Health Research (CIHR – Meetings Planning and Dissemination Grant #90605), and the National Initiative for Care of the Elderly (NICE). Support in kind was also received from the Centre for Healthy Aging at Providence Health Care (CHAP) and the Department of Gerontology at Simon Fraser University.

<sup>2</sup> Our focus for the ICARE team and this workshop was on first generation immigrant older adults. However, we refer at times to a broader group of ethnocultural minority older adults, a term which encompasses both new immigrants as well as those who have lived all or most of their lives in Canada or the United States. This expanded inclusion criterion is necessitated by the limited research on either group. Moreover, we believe that while there is much to differentiate them, some lessons can be learned from ethnocultural minorities who by virtue of their outward physical appearance have been racialized, as are many new immigrant older adults.

<sup>3</sup> The two largest groups of immigrants to Canada since 1991 are of Chinese and South Asian origins. These two populations also lay claim to the highest proportions of immigrant older adults (Turcotte & Schellenberg, 2007). Similarly in BC, almost equal proportions of older immigrants to BC from 2005 to 2009 arrived from Mainland China and India, together comprising 55% of all older immigrants to the province during that period (WelcomeBC, 2010). More than half of all senior arrivals to BC reported no charter language ability. This is especially true of those who arrive under the Family Class (i.e., parents and grandparents sponsored by children/grandchildren). In BC, these sponsored older immigrants constitute the majority of recent seniors' arrivals at more than 86% between 2005 and 2009 (WelcomeBC, 2010) and most of these are from India and China (BC Stats, 2006).

<sup>4</sup> The focus of her organization (NAPCA) is on immigrants from Asian Pacific countries, particularly the Philippines and Vietnam, as well as Chinese-speaking and South Asian countries. This individual is charged with developing chronic disease management supports for older adults from these populations. International exchange is therefore feasible and potentially fruitful.

<sup>5</sup> This does not include the many academics, physicians and others in the group who were also from diverse backgrounds, but do not work exclusively with one group.

<sup>6</sup> CDSMS is a commonly used acronym for Chronic Disease Self-Management Supports. A variant is CCSMS, for Chronic Condition Self-Management Supports.

<sup>7</sup> Health care context definitions are courtesy of Kelly McQuillen, Patients as Partner, BC Ministry of Health Services.

<sup>8</sup> Inductive codes that do not overlap with the framework were Beliefs around SM {13}; Level - Social Networks {8}; Navigating systems {5}; Peer Leaders {3}; Quality of life {2}; Transportation {3}