

# Diabetes Education Programming for Women of Colour



## Linking Evidence with Promising Practices

A Report on the 2010 Knowledge Exchange Workshop hosted  
by the Centre for Urban Health Initiatives, University of Toronto  
& Ryerson University, School of Nutrition

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## Diabetes Education Programming for Women of Colour

### LINKING EVIDENCE WITH BEST PRACTICES: A Knowledge Exchange Workshop

In order to gain a better understanding of delivering culturally-tailored education programs to women of colour with diabetes, the Centre for Urban Health Initiatives (CUHI) at the University of Toronto, and the Ryerson University, School of Nutrition held a knowledge exchange workshop entitled “Diabetes Education Programming for Women of Colour: Linking Evidence with Promising Practices”.

Sixty-five participants (50 invited and 15 others) attended a workshop on April 30th, 2010. Academics and practitioners presented theoretical approaches, promising practices and current research including systematic reviews of the literature. Presentations were followed by facilitator led break-out sessions to discuss the materials’ relevance to local programs and to define areas for improvement in practice and policy settings and priorities for research.



#### Workshop Objectives

The workshop had six knowledge exchange objectives:

1) Share peer-reviewed knowledge on effective diabetes self management programs for women of colour with policy makers, researchers and Diabetes Education Programming (DEP) facilitators.

2) Share examples of promising programs already in use for this target population.

3) Provide a forum for discussion of the gaps between research and practice in the field.

4) Work towards consensus building a research agenda to address gaps in research.

5) Facilitate collaboration among researchers, service providers and policy makers interested in diabetes self management strategies for women of colour.

6) Set the groundwork for the development of best practice guidelines for the delivery of diabetes care and self-management practices for women of colour.

#### Workshop Follow-Up

Following the workshop, ten small group facilitators and workshop developers met to review and refine the outcomes of the workshop. Specifically, the working group aimed to: clarify and further develop the key messages and themes resulting from the workshop; prioritize research, practice, and policy recommendations; and advise on knowledge translation strategies of workshop results.

#### Why this Report?

This report reflects the presentations and discussions of a knowledge exchange workshop and follow-up workgroup meetings on diabetes education programming for women of colour. It also documents recommendations for policy, research and diabetes education programming practices in the greater Toronto area. This report is intended to inform future research and approaches to diabetes education programming for women of colour.

## Background: Diabetes and Women of Colour

### Diabetes and Women of Colour

The prevalence of diabetes is increasing in Canada at an alarming rate (1). A major reason for increased prevalence of diabetes is the increased rates of immigration from high-risk source countries (2). Furthermore, racialized groups such as South Asian, Latin American and the Caribbean, sub-Saharan African, and North Africa and Middle East are at greater risk for developing diabetes-related complications than the general population in Ontario(3). Women are at especially high risk of developing diabetes-related complications; for example, women with diabetes experience a greater risk of cardiovascular disease (4;5) and mortality from both coronary heart disease (6,7) and stroke (8) than men with diabetes. Therefore, women from racialized groups appear to be at greater risk for diabetes-related complications.



Many diabetes-related complications can be averted with self management (9-14), but observance is often poor (15). This may be because women encounter greater barriers to achieving effective diabetes self-management than men (16-22) due to greater family responsibilities. Women with diabetes may be more involved with food purchases and preparation than men with diabetes (23), and they are more likely to sacrifice their own diet for the food preferences of their families (24;25). African-American women in the U.S. not only have a higher prevalence of diabetes (2.5 times that of the entire U.S population), but they also have poorer adoption of self-management behaviours than African-American men, and men and women from non-ethnic populations (26).

### Diabetes Education Programs

Diabetes education programs (DEPs) facilitated by multidisciplinary teams including diabetes educators are highly effective at helping patients adhere to management recommendations (27), but participation rates are often low (28-35) and attrition rates are high (36). The literature suggests culture and gender-specific issues may affect DEP attendance (37-40). Transportation costs to attend DEPs is a particular concern for low income individuals with diabetes (41;42). Language and literacy issues also pose significant barriers (41). A U.K. study involving South Asians revealed that

health literacy was a more significant determinant of access to education than language (43). Other issues that were of greater concern to Asian women versus men were coping with health problems and self-management, and some were uncomfortable discussing their problems with male physicians or

participating in mixed-gender education groups (43). In one study, both male and female African American participants stated that DEPs should target women because they are primarily responsible for food purchase and preparation (42).

### The Canadian Context

Although data from the U.S and the U.K. suggested that women of colour are a high risk group for diabetes and poor diabetes self management, there was little Canadian research on the effectiveness of diabetes self management interventions for this population. Effective programs cannot be designed in Canada unless more is known about their management and education needs.



## A Knowledge Exchange Workshop

Participants involved with policy, research and DEP delivery were invited to attend a full day workshop held at Ryerson University in Toronto, Ontario. Morning podium speakers presented emerging Canadian research and local policies highlighting gender, diversity and health equity in the self management movement; results of two systematic literature reviews on diabetes self management and effective features of diabetes self management interventions for women of colour; and the migration experience effect on managing and preventing diabetes.

The afternoon comprised of presentations by practitioners from DEPs throughout the greater Toronto area on topics ranging from culturally tailored curriculum to key issues for women of colour. Presentations were followed by facilitator led break-out sessions discussing key learnings on policies, programs and research that support health equity for women of colour with diabetes and to summarize discussions on needs, barriers and facilitators of diabetes education and management. Small groups were asked to report back to the larger group in a concluding session on defined areas for improvement in service delivery and practice, policy changes and priorities for future research.

While the research presentations offered an evidence-based context and considerable knowledge sharing of current and relevant research, participants generally followed areas of inquiry that were of most interest to practitioners (eg. the practical implementation of strategies) in the break out sessions. As a result, participants had few comments on policy changes. In the follow-up session on May 25th, 2010, small group facilitators and the workshop organizers aimed to clarify recommendations reported within the small groups during the workshop.

Based on these discussions, participants and facilitators identified key messages and themes relevant to their practice and research experience in diabetes programming for women of colour. These messages and themes are described in the remainder of this report and can be used to inform further research and diabetes education programming for women of colour.

## Workshop Presentation Key Messages and Themes

Four speakers made presentations in the morning plenary session focusing primarily on policy and practice trends, research findings from recent studies including systematic reviews of the literature, and recommendations for practice and research.

### POLICY AND RESEARCH PRESENTATIONS

**PRESENTATION:** Policy Pathways to Health Equities – Diabetes Education and Programming for Racialized Women

**Presenter(s):** Notisha Massaquoi, Executive Director, Women's Health in Women's Hands, and Lynne Raskin, Executive Director, South Riverdale Community Health Centre and Co-chair, Toronto Central Local Health Integrated Network Diabetes Strategy Steering Committee.

**Key Theme(s):** Referenced the Ontario Diabetes Strategy as the current, relevant, public policy document and why health disparities constrain choices, increase risk and ability to self manage diabetes.

**Key Intervention Strategies:** Mainstream diabetes prevention services need to be culturally competent and accessible; Provide up scale provider training; Engage communities in research and knowledge transfer and Increase economic opportunities for racialized women.

**Key Policy Implications:** Revise accreditation standards to reflect anti-oppression primary healthcare reform and renewal practices for health service providers; Increase secure funding for the non-insured and ensure the cost of non-OHIP services and procedures reflect the socio-economic realities of people in economic need.

**PRESENTATION:** Gender, Diversity and Health Equities in the Self Management Movement  
**Presenter:** Dr. Sue Mills, New Investigator, BC Centre for Excellence for Women's Health,

**Key Theme(s):** There is a gap between self management directions that benefit white, middle-class women versus women with greatest needs. How current self management strategies consider gender, diversity and inequities and some reasons they don't.

**Key Intervention Strategies:** Shift away from dominant biomedical/health education and behavior approach and start by addressing gender, diversity and social inequities in the self-management of chronic disease. Recognize the role of social context and community in self management.

**Key Policy Implications:** Situate self management initiatives in a broader context by promoting linkages in health and social sectors; Think of interventions beyond the individual level, e.g., community level, multi-level (policy and practice) and focus on marginalized groups.

**PRESENTATION:** Systematic Literature Reviews on Diabetes Self Management Issues and Effective Intervention Features of Diabetes Education for Women of Colour Living with Type 2 Diabetes

**Presenter:** Dr. Enza Gucciardi, Assistant Professor, School of Nutrition, Ryerson University

**Key Theme(s):** Referenced a literature review of primarily American data for what factors facilitate or challenge self-management among women of colour, the modifiable factors, and what intervention features have positive success rates in HbA1c, anthropometrics, physical activity and diet outcomes.

## Workshop Presentation Key Messages and Themes cont...



Toronto, and Khaleda Yesmin, Peer Researcher, Access Alliance Multicultural Health and Community Services

**Key Theme(s):** Prevalence and risk of diabetes is increasing, especially among recent immigrants from South Asia, Latin America/Caribbean and sub-Saharan Africa. There are profound differences between non-immigrants and recent immigrants and within recent immigrant communities regarding what causes diabetes and how to stay healthy. Multiple barriers to health and diabetes care were identified among recent immigrants with diabetes and gender differences were pronounced.

**Key Intervention Strategies:** Social Determinants of Health (SDOH), especially income, contribute to diabetes inequities in newcomer communities; Adopt intersectoral strategies and service partnerships to reduce the challenges faced by newcomers and health providers alike; Work with newcomer communities to increase the accessibility of diabetes information and care; Identify and remove systemic barriers to diabetes information and care; Increase the capacity of health providers to provide culturally consistent care; Develop immigrant and gender sensitive programs and services.

**Key Research and Policy Implications:** Develop and support policies and strategies that recognize the unique needs of racialized newcomer communities as a priority population (e.g., language and other supports); Identify community information sharing networks and community-based support systems (informal and formal) as the foundation for prevention and health promotion strategies; and Encourage data collection (e-health, diabetes registry, provider client data bases) on immigration and racialized group status to better plan, monitor and evaluate strategies to reduce diabetes inequities.

### POLICY AND RESEARCH PRESENTATIONS cont..

**Key Intervention Strategies:** Need to have a sense of the patients' gendered social context including cultural norms, values and beliefs; Need to understand barriers and facilitators to diabetes self management and education for women to develop culturally sensitive and gender specific DEPs, counseling and care for women of colour.

**Key Research Implications:** Difficult to extrapolate the cultural and gendered experience of women of color from US data; We need Canadian data to help inform our health care system of promising intervention practices for women of color.

**PRESENTATION:** Gender, Migration and Self-Management: Findings from the Migration and Diabetes Study

**Presenter(s):** Dr. Ilene Hyman, Dalla Lana School of Public Health and Cities Centre, University of

## Workshop Presentation Key Messages and Themes cont...

### PRACTITIONER PRESENTATIONS

Five community-based practitioners presented in the afternoon plenary session focusing on their experience working with women of South Asian, Caribbean, and Latino descent living with diabetes.



**PRESENTATION:** Outreach for Minority Groups: Mississauga-Halton South Asian Diabetes Education Program

**Presenter(s):** Uma Sebastiampillai, RD, and Nala Sriharan, RN, CDE, Trillium Health Centre,

**Key Practitioner Insights:** Create partnerships with other community groups (e.g., Tamil Senior Centre) to improve health of the 'whole family; Keep it simple and go one step at a time; Personalize services- this is about the clients; Be flexible - clients need to want to see you; and be supportive, clients have enough on their plate.

**PRESENTATION:** Considerations for Women of Caribbean Descent

**Presenter:** Marcia Miller, RN, CDE, Black Creek Community Health Centre

**Key Practitioner Insights:** Community Health Centres and their clients are complex and diverse and often serve individuals who traditionally have problems accessing care from other health care organizations; Consider impact of SDOH, political climate and public policy on diabetes management and practice; May be difficult to measure improvement in some client populations; Prejudices and oppressive attitudes continue to hinder progress at all levels.

**PRESENTATION:** Diabetes Education Program: Latin American Communities

**Presenter:** Sharon Khoo, RD, CDE and Vivia McCalla, RN, CDE, Women's Health in Women's Hands Community Health Centre

**Key Practitioner Insights:** Understand reasons, stages and stress of migration and that experiences differ across communities; Get to know client preferences in the care of their diabetes; Explore clients' lack of choices in healthcare due to SDOH; Be open to discuss traditional medicine practices and take care not to impose provider's own opinion (even if it is professional opinion) onto the client; When possible use interpreters from the same community (and socio-economic status) to foster better understanding of client's background and reduce predisposed personal opinions; Use a multi-disciplinary team approach; Services must be culturally and linguistically appropriate and grounded in the everyday reality of immigrant, refugee and "non-status" women's lives.



## Research Recommendations

### Research Directions

Participants highlighted the need for overall research capacity building in the area of Canadian Diabetes Education Programming. Larger research sample sizes, and a focus on high-risk populations with recognition of the emerging prevalence of first, second and third generation diabetes incidence was stressed as being important for future Canadian research.

### Research Priorities

The following research priorities were identified for Diabetes and Diabetes Education Programming for women of colour:

- Implement Canadian-driven research
- Include diabetes providers and women of colour with diabetes as research partners
- Focus on specific communities of women of colour e.g., South Asian, as sample groups
- Work from SDoH perspective, i.e., broader than gender, ethno-racial & ethno-cultural issues, sexual orientation, geography (rural/urban, infrastructure/design), food security, socio-economic status/poverty, social networks, education, housing, racism & discrimination, age/ generational and religious diversity
- Include Aboriginal models of community health in research studies (less didactic and data-driven; emphasize partnership with the population)
- Include diverse educational and evaluation approaches in research studies, (e.g., use story telling, dance, music, conversation and conversation maps, gardening groups, walking breaks, women's only programs)
- Address priority issues identified by communities themselves
- Include primary prevention focus in research and practice
- Learn from and adapt research and practice experiences from other jurisdictions, (e.g., Europe)
- Build a resource inventory with Canadian research data, (e.g., health centre profiles [populations served, contact person], portals, best practices, research synopses)
- Explore reasons, stages, and stress of migration, settlement and effect on health and health-seeking behaviours

### Community Involvement in Research

Participants identified the following key barriers to communities being active research partners:

- Lack of provider time to participate in program research, development and evaluation;
- Need for knowledge and research translation so that providers see the direct, visible, constructive benefit for themselves and their clients

### Moving Research into Practice

When participants commented on translating research findings into their practice they often highlighted a macro-level approach that calls on the utilization and enhancement of existing networks and tools. Their recommendations also include:

- Translate quantitative data into stories, narratives and conversations using everyday language (specifically, develop practice applications of current research such as findings presented at the workshop by Drs. Gucciardi and Hyman)
- Create a resource research position dedicated to developing and evaluating diabetes programs and providing support for providers who collect and analyze program data, (e.g., program analyst attached to diabetes programs)
- Adapt foreign service models in order to create locally responsive programming
- Balance research knowledge with practice knowledge in research and knowledge translation. Research practice partnerships should inform research questions and approaches
- Strengthen partnerships between communities and hospitals to ensure research-practice partnerships are used
- Engage with regional Local Health Integration Networks (LHINs) to foster central communication hubs and regional coordinators (note the new micro-level of community engagement of the Diabetes Steering Committee in its work building an inventory of resources)
- Evaluate strategies for working with women of colour from the practitioners perspective

## Policy Recommendations

### Policy Directions

Participants noted that the new Ontario Diabetes Strategy is an important milestone in health policy that supports equitable diabetes programming. More specifically, they noted that free glucose test strips for low-income women who have diabetes would be an effective change; and that the conflict between funding hospital versus community-based diabetes provider positions reflects the ongoing larger conflict between these two sectors.



### Funding and Community Development

- Increase/secure funding for the non-insured and ensure cost of non-OHIP services reflect the socio-economic realities of people who need them
- Develop a compensation policy that retains diabetes nurse and dietitian educators
- Build capacity by funding an "Analyst" position at each community health centre to evaluate programs (note possible use of Purkinje system)
- Include research resources in funding allocations (i.e., funding plus in-kind resources)

### Community Involvement in Policy

- Include diverse people whom policy affects in policymaking (i.e., women of colour with diabetes, families, and health and social service providers)

- Move away from working in silos and approach issues from a combination of policy, research and practice perspectives
- Partner with practitioners on data collection (i.e., e-health, diabetes registry, provider client data bases) on immigration and racialized group status to better plan, monitor and evaluate strategies to reduce diabetes inequities

### Systemic Changes

- Revise accreditation standards to reflect anti-oppression primary healthcare reform and renewal practices for health service providers
- Move "beyond empowerment" to structural changes like open networking of Community Health Centres, centralized communication/case management, and creation of "one-stop shopping," for improved client accessibility
- Recognize that system expectations often compromise best practices, (e.g., heavy focus on quantitative approaches and data, too many funding models)
- Find more humanistic language for identifying individuals who are currently classified as "non-status"
- Create accountability measures for service gatekeepers
- Go beyond the individual to look at the community as well as systematic and structural barriers to inequities.
- Make intersectoral collaboration concrete through stakeholder analysis and mapping services across sectors

### Other Policy Priorities

- Analyze cost of "no change" to current policy, practice, research approaches
- Continue to address SDoH, especially income, that contribute to diabetes inequities in newcomer communities
- Recognize unique needs of racialized newcomer communities as a priority population

## Service Delivery & Practice Recommendations

### Service Delivery and Practice Changes

Participants highlighted the critical importance of change management as an organizational and structural issue that needs to address and improve how future research, practice, and policy is developed, implemented, evaluated and communicated.

Although our participants were not clear as to which practice models they preferred, they collectively asked “where is the balance between personalized and generalized care?”. Further exploration of this topic found that participants had questions on the appropriate balance between an individualized approach versus a community approach to self management of diabetes. Additionally, it was noted that cultural responses are part of the larger practice imperative of building provider capacity and skills in providing culturally competent care.

### Staff and Resources

- Increase, broaden, and intensify resourcing and provider training
- Include peer learning (roles and responsibilities are a significant issue)
- Recruit provider staff that reflect clients served to build community capacity

### Education and Programming Considerations

- Consider community-specific cultural responses to diabetes and learning (e.g., stigma of diabetes, permission to participate in learning forums outside the home, trust issues, group work vs. one-on-one practice settings, differences in belief systems)
- Develop mainstream diabetes prevention services that are culturally competent and accessible
- Move away from didactic, one size fits all and structured approaches to client-centred care

- Develop culturally sensitive programs that are grounded in reality of women’s transnational experiences and provider capacity to deliver
- Develop “one-stop shopping” for diabetes care (e.g., umbrella care, holistic care, service mapping across 14 LHINs)
- Look at diverse education approaches, (e.g., storytelling, dance, music, conversation, walking breaks, women’s only programs)
- Consider what will happen after the client leaves the Community Health Centre (i.e., is there a good match between the health advice or treatment and the client’s values, beliefs and resources?)
- Map key initiatives for diabetes self management education to demonstrate the gaps
- Strengthen funder awareness and acknowledgement that fee-for-service does not reflect the increased time providers need to spend with clients due to language and culture barriers



## Workshop Feedback

### Workshop Feedback

The topic of diabetes self management through a health equity lens was timely and relevant for participants. The presentations and discussion were very relevant to practitioners who are creatively addressing the real issues women of colour face in self managing their diabetes. The participating researchers are currently addressing identified gaps in the literature. Its content was relevant for policy makers as evident by the diabetes health policies currently being implemented. A representative from the Ontario Ministry of Health and Long Term Care congratulated the workshop developers for tackling health equity in diabetes self management by linking the issue with available evidence and promising practices. This kind of ongoing dialogue needs to be taken back to the organizations of practitioners and researchers.

Workshop evaluations showed that 62% of participants “very much” and 32% “somewhat” gained increased understanding of the issues faced by women of colour in self management of diabetes. Knowledge of research increased “very much” for 43% of participants and “somewhat” for 57% of participants. As a result of this workshop, 54% “very much” increased their knowledge of promising programming for the target population with 41% “somewhat” increasing their knowledge. Participants of the workshop expressed their appreciation and enthusiastically participated in the forum.

### POST WORKSHOP FEEDBACK

Qualitative data from the workshop evaluation survey and discussion at the followup session showed these key learnings from participants:

- Importance of culturally appropriate programming for women with diabetes
- Different approaches to culturally competent diabetes management education

- Need for individualized and unique programs for different communities
- Importance of understanding the barriers women of colour face in accessing appropriate diabetes services
- Importance of tackling issues from policy, research & practice perspectives and going beyond the individual to look at community, systemic and structural factors.
- Importance of social determinants of health perspective when addressing diabetes and inequities
- Currently, gaps exist in Canadian research and there is need for further Canadian research on diabetes education programming for women of colour with diabetes

The evaluation survey data also indicated that participants wanted to learn more about current strategies and programs being used and have more opportunities to brainstorm amongst themselves. Some people commented that what interested them most was “hearing stories” from the educators. As participants were primarily practitioners in various work settings, they were also looking for more workshop “take-aways” such as key concepts, points and messages that highlighted practical advice and applications of the research presented in the morning plenary session. A frequent comment was that inviting women of colour with diabetes to the workshop to hear stories and experiences in accessing and receiving services would have been helpful (eg.. what strategies work and why as well as what doesn’t work). Also inviting more policy stakeholders and involving physicians at these types of workshops would be important.

Participants commented favourably on the efforts to balance knowledge translation on research versus practice knowledge. Participants indicated that the research presented at the workshop needed to be translated further

## Workshop Feedback cont...

into practice language for easier application. Circulation of presentations or summaries of research prior to the workshop may have facilitated discussions and key learnings. These findings can be used to inform future knowledge exchange forums, particularly those developed for practitioners.

Being able to maintain networks and connections made at this workshop was a huge point for many participants. Ideas included a newsletter with compiled works of participants to keep everyone informed about each other's work; e-mailing a contact list to maintain or initiate contact with participants; a list-serv with relevant information on diabetes management/prevention and opportunities to continue discussions initiated at this workshop; and follow up workshops where participants have the opportunity to talk about how they have or would implement learnings.

Evaluations indicate that the workshop met its first five objectives and mobilized efforts towards its sixth objective. This report will be shared with Canadian practitioners, researchers and policy makers to inform further work in the development of best practice guidelines for the delivery of diabetes self management women of colour.

## NEXT STEPS

Looking ahead, these workshop findings combined with other reports and contributions by organizations and researchers can be used to influence and support further work in diabetes programming for women of colour:

- Determine which of the mainly non-Canadian results found in the systematic literature reviews will help in designing a diabetes education programs in urban Canadian settings
- Use the workshop forum as an incubator for the design of new approaches to service delivery with the target population
- Provide information to Canadian researchers, practitioners and policy makers to either develop or make changes to program guidelines for urban Canadian women of colour with diabetes
- Support development of new multi-disciplinary and inter-sector collaborations among researchers and users of research
- Create virtual space (eg. website, listserv or wiki) where practitioners can go to find the latest research, policy and practice information
- Create further opportunities for networking amongst researchers, practitioners and policy makers on diabetes education programming for women of colour



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