

REPORT of the ANNUAL WORKSHOP – MAY 26, 27, 2017

THEME:

Engaging people living with diabetes and their health care teams to improve patient experience and outcomes

GOALS:

- Acknowledge First Nations land and the example Indigenous ways of knowing provide for effective engagement of people living with diabetes
- Provide networking opportunities among members of our Patient Circles and with all participants in Diabetes Action Canada
- Establish a new understanding of patient engagement from the perspective of people living with diabetes that includes cultural sensitivity and social determinants
- Address the request from the Patient Circles to better understand how ongoing and future projects provide value for people living with diabetes
- Enable people living with diabetes and Diabetes Action Canada investigators to co-design patient related experience and outcome measures
- Assist Investigators to include people living with diabetes as meaningful partners in the co-design of ongoing and new projects
- Assist investigators in understanding the importance of scaling up projects to provide evidence for improved self-management and practice-based solutions

PLANNING COMMITTEE

1. Adriana Freitas
2. Alex McComber (Representative from Patient Council)
3. Aurel Schofield
4. Catharine Whiteside
5. Christopher Sargent
6. Debbie Sissmore
7. France Légaré
8. Holly Witteman
9. Jonathan McGavock
10. Maman Joyce Dogba
11. Mildred Lim
12. Neil Drummond
13. Olivia Drescher
14. Pusha Sadi

LOCATION: Hilton Hotel, Pearson International Airport, Toronto, Ontario.

PARTICIPANTS

- Patient Council (Circle) Members - 20
- Steering Council Members - 8
- Principal and Co-Investigators - 33
- Administrative Staff (Diabetes Action Canada) - 9
- Representatives from CIHR, Diabetes Canada, Juvenile Diabetes Research Foundation and other sponsors - 7

BIOSKETCHES OF THE SPEAKERS – see *Appendix 1*

SUMMARY OF EVENTS

May 27, 2017

The Workshop was opened with a traditional acknowledgment and welcome to the land by **Malcolm King**, member of the Mississauga of the New Credit First Nation, and Chair of the Diabetes Action Canada Steering Council. Catharine Whiteside, Executive Director of Diabetes Action Canada, and Jean-Pierre Després followed with an overview of the workshop goals and format. Most of the presentations were provided in both English and French, to accommodate all participants.

Keynote Address “*Welcoming Indigenous Ways of Knowing*”

Elder Roberta Price, a member of Coast Salish - Snuneymuxw and Cowichan Nations, and member of the Diabetes Action Canada Indigenous Circle, gave an inspiring and moving presentation on *Indigenous Ways of Knowing*. She focused on her own family’s experience and the multi-generational impact of colonization and the residential school system on Indigenous Peoples’ health (physical, mental and spiritual). She spoke about the importance of her Grandmother’s and Elders’ teachings on her life and the strength she has acquired now to support others as an Elder. Her work among Indigenous Peoples in the health care and education systems enables better understanding of Indigenous Ways to promote wellness and resilience. Elder Roberta Price emphasized the importance of engaging individuals in a circle, inviting each participant to share their views and their stories with respectful attentiveness and without interruption. Her message to the workshop participants was clearly “***Nothing about us, without us***”. Genuine respect for Indigenous culture, community-engagement and leadership of the Elders are necessary next steps for members of Diabetes Action Canada.

Reflection on Indigenous Health Challenges - Gary Lewis

Gary Lewis, Nominated Principal Investigator for Diabetes Action Canada, shared his personal reflection on how working with our Indigenous leaders (Malcolm King, Alex McComber) has enabled him to examine his thinking about the issues that face Indigenous Canadians. He related his narrative of being profoundly impacted by participating in the Aboriginal Youth Mentorship Program (AYMP) meeting in Winnipeg in August 2016, listening to the personal stories of individuals who have benefited from their engagement in the AYMP in their communities. He also attended the inaugural meeting of the Diabetes Action Canada Indigenous Peoples Circle in Kahnawake, in Quebec last Fall where he experienced first-hand the generosity, openness and welcome of this community. He witnessed the very effective PATH method of hearing all viewpoints and building consensus. Dr. Lewis does not pretend to have in depth knowledge of the many complex issues facing Canada’s Indigenous communities and has only started to scratch the surface of his understanding, but it has grown enormously over the past year. He urged all the participants at the Workshop to commit to bridging the gap of their understanding by

listening, participating, reading, engaging and all the time learning from our Indigenous Circle advisors.

Q&A – Group Discussion – Moderated by Jon McGavock (Goal Group Co-Lead for Indigenous People’s Health – Diabetes Action Canada)

Jon McGavock invited the Patient Council (now termed Circle) members to speak first and share their thoughts and questions (in English and French). Of note is that the Patient Circles had met for a day and half prior to the Workshop, in face-to-face conversation about their roles and potential work plans for Diabetes Action Canada. Jon emphasized the importance of genuine respect for listening and hearing all individuals and used an example from his own experience. When a group of individuals form a circle and sequentially present their views without interruption, the path to understanding and developing consensus is easily created. By contrast, when a group is dominated by a few voices or with interruption of individuals speaking, the process lacks respect and recognition that every individual and their view matters. Without the circle concept and ensuing respect for each individual, the outcome lacks consensus and true engagement of the group. The comments during the Q&A strongly supported the messages and learnings articulated by Elder Roberta Price not only for networking and engagement with Indigenous colleagues and communities, but for all Diabetes Action Canada activities.

WORKSHOP DISCUSSION GROUPS

The participants were assigned to seven small discussion groups (6 English speaking, 1 French speaking) that mixed Patient Circles members, Steering Council members, Investigators and sponsor representatives. Three facilitators were assigned to each group (1 Patient Circle members, 1 Steering Council or Goal Group Lead) as well as a recorder. Two discussion sessions were held in which all participants were invited to speak sequentially, un-interrupted, in a circle format enabling all to have an equal voice. The first discussion session focused on **“Building the Path for Meaningful Patient Engagement”** and the second was entitled **“Patient Reported Outcomes and Experience – What matters most to people living with diabetes?”**

Each small group session was preceded by an introduction by the relevant Goal Group leads on the Workshop Planning Committee who had prepared the objectives and questions for discussion. The Patient-Engagement Goal Group Leads (Joyce Dogba and Holly Witteman) were further informed by the outcomes of the Patient Circle meetings prior to the Workshop. The Goal Group Leads for the patient-reported outcomes and experience (Michelle Greiver, France Légaré) had previously worked with colleagues who conducted patient focus groups to obtain a list of patient-reported outcomes (PROMS) and experiences (PREMS) relevant to diabetes complications. A key objective of the second

session was to determine if this list was complete or required further input from the Patient Advisors and other stakeholders.

The details for the workshop process are found in *Appendix 2*.

Prior to the second session, **Jenny Ploeg**, Co-Director of the Aging, Community and Health Innovation Research Unit, School of Nursing, McMaster University, presented an example of an effective community-based intervention entitled “*Engaging older adults and their caregivers in a community-based program*”. This project engaged people over - 65 years with diabetes and multiple chronic conditions and their caregivers, including their inter-professional team. The interventions focused on promoting improved activity, nutrition and community-engagement to facilitate improved self-management, better compliance with treatment and early intervention with the right care at the right time. PROMS and PREMS were used as key indicators along with health economic measures. Reduced use of emergency room services and hospital admissions were important outcomes. To view the presentation, see *Appendix 3*.

Report of the Small Discussion Groups – moderated by Jean-Pierre Després

At the end of the second session, Jean-Pierre Després moderated the report back by one of the Facilitators from each of the groups and provided a French or English translation of the key points. The recordings of the discussion groups were analyzed and are summarized in the next section. For more detailed analytics refer to *Appendix 4*.

“Building the Path for Meaningful Patient Engagement”

Overarching Theme: Build trust of people living with diabetes by understanding and valuing their individual needs.

Promote Effective and Meaningful Communication

- Researchers and health professionals must learn to listen more effectively and understand what matters most to people living with diabetes.
- Diverse communities require communication adapted to their specific backgrounds, cultures and circumstances – a single approach will not be relevant to all.
- People living with diabetes and its complications want to learn from researchers how evaluation of access to care, and new approaches to prevention and treatment can provide evidence for health system change including improved practice by health professionals.
- Diversify methods of communication to include more social platforms (including face-to-face) and enhance connectivity across Canada.
- Create more programs that involve the public. This will create awareness about the urgent need for improved outcomes for people living with diabetes through improved access to and follow-up within the health care system.

Create a Learning Environment for People Living with Diabetes and Researchers

- Training researchers should involve patients from the outset to change the culture enabling effective patient-oriented research.
- Educate researchers, educators and knowledge translators to understand how to engage people living with diabetes at both the individual level and through community-engagement.
- Empower people living with diabetes by improving their knowledge and understanding of the disease and its complications through customized learning opportunities that take into account barriers such as language and cultural preferences.
- Empower communities to establish priority education programs for their constituents making diabetes and complications a major priority.

Research Activities – “Nothing about us, without us”

- Engage people living with diabetes and their care givers (including members of the health professional team) in research activities from start to finish of a project, making it obvious that their involvement is needed and appreciated.
- Provide a menu of opportunities for engagement that will provide value to individuals recognizing their interest, skills and knowledge.
- Survey people living with diabetes to understand their top 10 concerns and address these with relevant research projects.
- Include risk analytics that reflect specific social determinants of health taking into account geography and access to care, socio-economic and cultural factors, language, community priorities.
- Focus research on access to care, including the circle of care that aligns primary and specialist services, and how to overcome the current silos and barriers experienced by people living with diabetes.

Patient Councils (renamed “Circles”)

- Ensure national reach of representation on Circles.
- Provide more funding for enhanced engagement of the Circles as the interface between Canadians living with diabetes and the Diabetes Action Canada investigators.

“Patient-Reported Outcomes and Experience” – What matters most to people living with diabetes?”

Overarching Theme: The value of PREMS and PROMS must be based on the needs articulated by people living with diabetes.

Perspectives of People Living with Diabetes

- Health professionals and researchers must recognize that PREMS and PROMS must reflect the holistic individuality of each person living with diabetes.

- Capture the “why” individuals engage in certain behaviors that modify (both positively and negatively) reported outcomes and experience.
- Train health professionals to engage people living with diabetes to facilitate the co-design of care paths using meaningful PREMS and PROMS. This will create mutual value and respect.
- Researchers, health care providers and people living with diabetes must work together to establish the value of PREMS and PROMS for research, quality improvement and promotion of self-management.
- Access to effective and timely health care for people living in remote regions of Canada remains one of the most important barriers to improving health - this is an urgent need requiring solutions that are customized to these communities.

Improve the Tools to Collect PREMS and PROMS

- Develop and implement simple and effective methods to collect PREMS and PROMS without redundant activity.
- Incorporate PREMS and PROMS into health care and shared decision-making between health professionals and people living with diabetes not just for research project outcome measures.
- Enable access to the Internet in remote areas so that people living with diabetes in these communities to improve access to care, promote better self-management and report their PREMS and PROMS.
- Use collected PREMS and PROMS to advocate for health policy change and improved practice.

END OF DAY SIMULTANEOUS EVENTS

- Steering Council Meeting with the Standing Committee for Strategic Partnering and Innovation
- Steering Council Meeting – attended by Nancy Mason-McLellan, SPOR Director, CIHR
- Goal Group meetings of Principal and Co-Investigators

RECEPTION – all invited to an evening social gathering

May 27, 2017

Keynote Address: “Community Mobilization & Engagement in Health Promotion Research: Empowering Individuals and Community”

Alex M. Otsehtokon McComber, is a member of the Kanien’kehá:ka community of Kahnawake. He presented his journey from growing up in New York where his father worked, to immigrating to his Indigenous community where he learned the language and customs of his Haudenosaunee people. In his address, Alex talked about the history of his people and the effects of colonization. Trained in education, he became a leader in the school system where he became engaged in a number of projects, including the AYMP, that

promote health and wellness. He has worked with a number of Indigenous Health leaders and others over the years who have dedicated their careers to improving the wellness of the Kahnawake Indigenous community. He believes strongly that health promotion, community mobilization, and personal empowerment for healthy lifestyles are key to healing the multi-generational trauma experienced by Canadian Indigenous Peoples. He now Co-Leads the Indigenous Health Goal Group for Diabetes Action Canada along with Jon McGavock and was instrumental in its organization and now leads our Indigenous Circle.

Knowledge Translation: Scaling up interventions with measures meaningful to people living with diabetes and the health system.

France Légaré, is the Goal Group Lead for Knowledge Translation and is developing a network of experts in scaling up successful community-based interventions focused on the Quadruple Aim (improved population health outcomes, improved experience and health outcomes for individuals, improved experience for health professionals, and reduced cost to the health system). All of the Diabetes Action Canada projects are about building capacity for patient-oriented research and scaling up effective interventions to prevent diabetes complications and improve the health of those living with diabetes. The science of scaling up is now recognized as a discipline that requires expertise in understanding the context in which the intervention is undertaken. Identifying the key barriers to scaling up interventions requires a deep understanding of the social determinants of health and mechanisms necessary to identify and successfully engage the most vulnerable populations in shared decision-making. See the full presentation in *Appendix 5*.

Q&A and GROUP DISCUSSION – moderated by Holly Witteman

The Workshop participants engaged in discussion (in English and French) focusing on the presentations by Alex McComber and France Légaré and community-engagement for scaling up successful interventions that promote wellness. The full engagement of Indigenous Communities in the development and rippling out of programs such as AYMP, customized within each community with Indigenous youth and Elders, was emphasized. The importance of technology-assisted information linkage and sharing to achieve scale-up, particularly in the context of primary care leadership in chronic conditions management, was emphasized. Access to timely and sustained interventions for individuals who experience barriers related to geography, socio-economic status, age or other chronic conditions (mobility and family support) must all be considered when designing scale up.

Announcements of Capacity Building Awards – Training and Mentoring, and Knowledge Translation

André Carpentier, Goal Group Lead for Training and Mentoring announced the successful inaugural competition for the Diabetes Action Canada – Diabetes Canada postdoctoral fellowships that will commence July 1, 2017. In addition, competitive Mentorship awards

for new investigators working in patient-oriented research related to the goals of Diabetes Action Canada who are in their first 3 years of appointment to faculty positions will be offered as of July 1, 2017. The Training and Mentoring Goal Group have established short immersion courses in patient-oriented research methods in English and French that will continue to be offered to trainees of Diabetes Action Canada investigators. The next course will be held in conjunction with the Annual Diabetes Canada meeting in Edmonton in early November.

France Légaré, Goal Group Lead for Knowledge Translation, announced new postdoctoral fellowship Knowledge Translation awards for individuals who are supervised by Diabetes Action Canada investigators. The applications are due in June and will be adjudicated immediately. Successful candidates will be notified for a start date of July 1, 2017. Awardees will be expected to participate in the summer institute provided by KT-Canada.

Panel of Diabetes Action Canada Goal Group Leads: Presentation of Next Steps and Advice from Workshop Participants

- **Moderated by Gary Lewis (English) and Jean-Pierre Després (French)**

Each of the 8 Goal Groups (see <http://diabetesaction.ca/category/research-profiles/projects/>) presented a synopsis of their work plans for the coming year that focused particularly on patient-engagement. It was recommended that by next year, patient advisors be invited to present along with the Goal Group leads. It was deemed that this year was too early in the evolving relationships between patient advisors and Goal Group leads to have invited the patient advisors to contribute meaningfully to this session. Each Goal Group Lead committed to more effective interaction with the Patient Circles and recruitment of patient advisors.

Some of the highlights of the projects described included (but were not limited to):

- Advancing diabetic retinopathy screening using tele-ophthalmology to full scale province-wide programs (starting in Ontario). Analysis of new screening sites serving the most vulnerable and under-screened populations, e.g., East-Side Vancouver, First Nations communities in BC.
- Implementing a proof-of-concept diabetes repository using primary care and other data sources for the purpose of improved patient care and patient-oriented research. The first data download from the Canadian Primary Care Sentinel Surveillance Network is planned for the Fall of 2017. Phase 2 will be the development of a national diabetes repository.
- The Clinical Trials Goal Group envisions developing the infrastructure to support patient-oriented research in diabetes and its complications. The announcement of the new JDRF/CIHR clinical trials funding will assist in establishing a national network of clinical investigators in Type 1 diabetes and its complications.

EVALUATION

The feedback from the Workshop was as follows. Over 90% of those who responded to the evaluation questionnaire (~40%) indicated that they strongly agreed or agreed with these comments.

- The duration of the Workshop was just right.
- The Workshop addressed the themes of “Meaningful Patient Engagement” and “Patient-reported outcomes and experience”.
- The Small Discussion Group sessions were helpful.
- There was opportunity for me to express my views and/or have my questions addressed.
- On the whole, the presentations and discussion items were informative.

Which segment of the Workshop did you like most/least?

Some of the “liked most” comments included;

- Keynote speakers were fantastic and inspiring
- Small group discussions were great
- Speakers who shared personal experiences
- Workshops – in circles
- Learning from Indigenous and patient perspectives

Some of the “liked least” comments included;

- Little recognition that patients have gender and other characteristics limiting/restraining access to resources and capacity to deal with health issues
- The language around KT is always full of jargon that is not necessarily known to patients that can be frustrating
- Small work group members were not informed of the context of the questions as Diabetes Action Canada had already done much of the work (PREMS and PROMS)
- Indigenous way far overdone

What would you like to see added or removed from the future Workshop?

Some of the “add” comments included;

- General overview of programs and progress at the beginning of the Workshop
- Systematic recognition of gender issues
- More clarification on the Network’s vision and a clear, concise update on progress made towards achieving that vision
- Be ready to include patient partners as part of the panel presentations
- Add more preparatory/context of what Diabetes Action Canada has done
- Add simultaneous translation
- Keynote addresses should be on informative and interesting subjects

- More time for interaction between patient advisors and researchers that would help “level the playing field” and improve relationships and future communication
- Add students and trainees to the participants
- Add front-line health care to learn from their communities of practice

Some of the “remove” comments included:

- Excessive focus on patient experience at expense of other issues
- Remove some content for a “shorter workday”

Diabetes Action Canada Workshop Speaker and Moderator Biographies

Malcolm King, PhD, a member of Mississaugas of the New Credit First Nation, and Professor, Faculty of Health Sciences, Simon Fraser University. In his career in pulmonary research, Dr. King has developed new approaches to treat mucus clearance dysfunction in chronic lung disease, and is now working on addressing issues in airborne disease transmission. At the University of Alberta, he served as Chair of the Aboriginal Healthcare Careers Committee from 1993 to 2009; this training program has graduated more than 70 health professionals. He has been recognized for his achievements by the Alberta Lung Association (1999), the National Aboriginal Achievement Foundation (1999) and the University Of Alberta Board Of Governors (2003). From 2009-16, he led the CIHR Institute of Aboriginal Peoples' Health as its Scientific Director. In this role, he was responsible for developing a health research agenda aimed at improving wellness and achieving health equity for First Nations, Inuit, and Métis Peoples. He serves as the Chair of the Steering Council of Diabetes Action Canada, the highest governance body for this national research consortium.

Jean-Pierre Després, PhD, Dr. Després is Professor in the Department of Social and Preventive Medicine, and Scientific Director of the International Chair on Cardiometabolic Risk at Laval University and is the Director of Research of the Québec Heart Institute, Québec City. His expertise covers the assessment and management of obesity and body fat distribution, lipid metabolism, diabetes, metabolic syndrome, exercise, nutrition and the prevention and the treatment of congestive heart disease risk factors. In 2014, he became the inaugural Director of Science and Innovation for Alliance santé Québec, a new collaboration between Laval University and Québec City to address the myriad of health determinants including the social, economic, geographic and public health issues to develop new models of integrated health care. Diabetes and its complications figure prominently as a complex chronic disease that requires community-engagement and coordination of health and social services. Dr. Després is the Co-Scientific Lead of Diabetes Action Canada.

France Légaré, MD PhD, FCFPC, Professor, Department of Family Medicine and Emergency Medicine, Université Laval and holds a Tier 1 Canada Research Chair in Shared Decision-Making and Knowledge Translation and director of the Health systems research, implementation research and knowledge translation health systems research component of the Quebec SPOR Support Unit (QSSU). She is the Co-Lead of the Diabetes Action Canada Goal Group on Knowledge Translation. The patient-oriented research focus of this Goal Group is to contribute to sustaining health and well-being in society by supporting high-quality diabetes care. It will provide diabetes patients and their health professionals with the necessary skills to promote shared decision-making throughout the healthcare continuum and embedded within an interprofessional approach. This research is expected to harmonize patients' expectations with respect to professional practices within the Canadian healthcare system using the best knowledge and evidence available as well as what matters most to them with the aim of improving patients' outcomes while ensuring their safety.

Gary Lewis, MD MSc FRCPSC, Professor of Medicine and Physiology, and Director of the Banting and Best Diabetes Centre, University of Toronto. He is the Named Principal Investigator and Co-Scientific Lead of Diabetes Action Canada. The Lewis lab has had a long interest in the mechanisms of various aspects of diabetic dyslipidemia, including postprandial lipemia, HDL lowering and hypertriglyceridemia. We have also had a long standing interest in the mechanisms of Type 2 diabetes. He has previously performed both animal and human mechanistic studies but currently focuses exclusively on human Type 2 diabetes and complications risk. He now performs integrative, physiological studies in humans, to determine the regulation of intestinal and hepatic lipoprotein particle production by hormones, nutrients and pharmacological agents. He has have received funding to study the central nervous system regulation of metabolism related to cardiac disease in Type 2 diabetes.

Alex M. Otsehtokon McComber, MEd, is a member of the Kanien'kehá:ka community of Kahnawake, in Quebec near Montreal. He has extensive experience working with the Kahnawake School Diabetes Prevention Project as a Diabetes Prevention Intervention Facilitator, Training Coordinator and Executive Director. He is the recipient of an Honorary Degree of Doctor of Science from Queen's University recognized for his exemplary work with a number of national diabetes organizations including Health Canada's Aboriginal Diabetes Initiative. He strives to integrate the traditional knowledge of the Rotinonsonni (The People of the Longhouse) into his daily life and share traditional teachings through community support mechanisms. Alex's holds close ties to Indigenous communities and believes strongly that health promotion, community mobilization, and personal empowerment for healthy lifestyles are key to healing multi-generational trauma. He serves as Co-Lead of the Diabetes Action Canada Goal Group on Indigenous Peoples' Health.

Jon McGavock, PhD, Associate Professor, Department of Pediatric and Child Health, CIHR Applied Health Chair, University of Manitoba. Dr. McGavock established his lab at the Children's Hospital Institute of Manitoba in 2006 to study the treatment and prevention of type 2 diabetes in youth. He is a CIHR Applied Health Chair (2014-2019) and the lead for the DREAM and DEVOTION research teams that have secured over \$22M in external funding to reduce the burden of Type 2 diabetes in youth in Canada. He currently is the PI for a CIHR Pathways team grant that assembled Canada's largest network of scientists and Indigenous communities focused on the prevention of Type 2 diabetes among Indigenous youth. He is the Co-Lead of the Diabetes Action Canada Goal Group in Indigenous Peoples' Health.

Jenny Ploeg, PhD, Professor of Nursing, Director of the Aging- Community and Health Research Unit, Faculty of Health Sciences, McMaster University. Her primary research interests include evaluation of community health services for older adults and their caregivers; best practice guideline implementation, sustainability and spread; and qualitative, quantitative and mixed methods research. She has led numerous studies involving the design, evaluation and translation of innovative health promotion programs. In 2013, Dr. Ploeg, Dr. Markle-Reid and an interdisciplinary research team of investigators, clinicians, trainees and collaborators from across Canada, were awarded a combined \$5.8 million to fund the new Aging, Community and Health Research Unit. Their research program is funded by the Canadian Institutes of Health Research Signature Initiative in Community Based Primary Health Care and the Ontario Ministry of Health and Long-Term Care to develop and evaluate innovative, community-based primary health care interventions to promote optimal aging at home for older adults with multiple chronic conditions, including Type 2 diabetes, and to support their family caregivers.

Elder Roberta Price is Coast Salish from the Snuneymuxw/Cowichan Tribes. She is the mother of 4 and grandmother to 8. Elder Roberta has committed to professional and volunteer work in the Health, Social Services, and Education fields for most of her career. She is dedicated to building a strong base of knowledge from which to make improvements to the health care system, specifically for Indigenous people.

Over the past decade, Elder Roberta has worked in partnership with researchers at the UBC School of Nursing on a number of studies. In that role she has guided study activities around Indigenous approaches to health. Her role has been to ensure that the research is relevant and responsive to Indigenous contexts, and to assist in implementation of interventions within clinical settings. She oversees ceremonial and traditional aspects of research projects, including integration of traditional healing approaches with 'Western' approaches. The studies she has been involved with relate to structural and interpersonal violence and trauma – including colonialism, racism, and poverty – and their effects on health care access and quality for Indigenous people.

Elder Roberta also works directly within the education and health care systems. In the Education system, she is the District Elder in the Richmond, Delta and Burnaby School Districts. She has served as Cultural Knowledge Keeper/Elder in classrooms in Richmond, Delta, Burnaby, Surrey, Vancouver and North Vancouver School Districts for over 30 years. At the University of British Columbia, she is Elder Speaker for

UBC medical students in year 1, 2, in Psychiatry and in graduate classes; Elder speaker to School of Social Work Graduate students; Elder Speaker to UBC English Language Institute (International students for 6 years now); and Elder speaker to Education Professional Development Days for the School Districts.

In the health care system, Elder Roberta works as an Elder with Vancouver Coastal Health in the Aboriginal Patient Navigators Program and their 10 week Healing Circles and is Elder in Residence; She is also an Elder at BC Women and Children's Hospital in the Elders Visiting Program (for 6 years). She also serves as Elder for support circles for Indigenous people living with HIV/AIDS and Elder for Red Road HIV+ Society. Through this work she has directly supported hundreds of patients through some of the most difficult times of life, from birth to death and through many illness crises.

Elder Roberta is much sought after as a Coast Salish Elder, opening many conferences in Richmond, Vancouver, and throughout the lower mainland of greater Vancouver.

Catharine Whiteside, CM, MD, PhD, is Emerita Professor and former Dean of Medicine, Faculty of Medicine, University of Toronto. During her career as a clinician-scientist she studied the mechanisms causing diabetic kidney disease. Dr. Whiteside has been an enthusiastic supporter of students and trainees throughout her career. During her tenure as Dean of Medicine she established the Centre for Inter-Professional Education in collaboration with the University Health Network and the Center for Ambulatory Care Education with Women's College Hospital. She is the recipient of the Canadian Medical Association 2009 May Cohen Award for Women Mentors. In 2015 she was awarded an Honorary Fellowship in the College of Family Physicians of Canada. She now serves as the Executive Director of the Strategic Patient-Oriented Research Network in Diabetes and Related Complications.

Holly Witteman, PhD, is an Assistant Professor in the Department of Family & Emergency Medicine, Université Laval (Laval University). She directs the research unit within the Faculty of Medicine's Office of Education and Professional Development. She is also a scientist at the Research Centre of the CHU de Québec-Université Laval, at the new Institute of Primary Care Research. With an interdisciplinary background in human factors engineering, human-computer interaction, and decision sciences, her research is about the design and evaluation of digital media in health decision-making. She specializes in human-computer interaction in health education, risk communication and decision-making, including design methods to support broad, inclusive user-centeredness and patient-centeredness. She is the Co-Lead of the Diabetes Action Canada Goal Group in Patient-Engagement.

WORKSHOP SMALL GROUPS DISCUSSIONS

Goals, principles and process

1. WORKSHOP SMALL GROUP #1 – Patient Engagement in Research

❖ Goals

Establish a new understanding of patient engagement in research from the perspective of people living with diabetes that includes cultural sensitivity* and social determinants of health
Address the request from the Patient Councils to better understand how ongoing and future projects provide value for people living with diabetes

**Cultural sensitivity¹ is the recognition of the importance of respecting difference. Cultural safety² has been identified, by the Aboriginal Healing Foundation's (AHF) review of 140 plus projects, as critical to healing, and that relationships based on acceptance, trust and safety are the first step in the healing process.*

❖ Question(s) we will address during the session #1

- **Reflecting on the speakers' discussion and the sum of your experiences so far (inside Diabetes Action Canada and elsewhere), what things could Diabetes Action Canada do (what structures, processes and approaches could be implemented) to enable patient partners to make a full contribution to research?**

2. WORKSHOP SMALL GROUP #2 – Patient Reported Outcome Measures & Patient Reported Experience Measures

❖ Goals

Ensure that Patient-Reported Experience Measures and Patient-Reported Outcome Measures used in Diabetes Action Canada reflect the needs and priorities of patients, health professionals, researchers, and health systems.

❖ Question(s) we will address during session #2

- **1. What are important patient experiences that Diabetes Action Canada should collect? (for experiences groups only)**

¹ Indigenous Physicians Association of Canada. First Nations, Inuit, Métis Health Core Competencies. A Curriculum Framework for Undergraduate Medical Education. April 2009.

² Simon Brascoupé, Catherine Waters. Cultural Safety. Exploring the Applicability of the Concept of Cultural Safety to Aboriginal Health and Community Wellness. Journal de la santé autochtone, November 2009.

- **2. What are important outcomes and characteristics that Diabetes Action Canada should collect?** *(for outcomes groups only)*

3. FORMAT & PRINCIPLES

❖ Format of the Workshop

- The Large Workshop introductory comments from the Co-Leads will set the stage for the Small Group format including the circle model that respectfully engages each member in turn to speak about what matters most to them.
- At the end of the discussions, everyone in the group should agree on three essential points to report back.
- The Co-facilitators of each group will present the outcomes and recommendations of the group

❖ Helpful reminders for etiquette during group discussions

DO'S

- **Do introduce yourselves.**
- **Do respect all voices.**
- **Do be courteous and allow others an opportunity to speak if they haven't yet.**
- **Do respect people's right to not speak on a particular topic.**
- **Do listen when someone is speaking.**
- **Do have fun!**
- **Do help make other participants feel at ease so that they feel comfortable speaking**
- **Do use first names**
- **Do put away cell phones and them on vibrate or mute.**

DON'TS

- **Don't use acronyms or jargon.**
- **Don't interrupt or finish people's sentences.**

APPENDIX A– SUPPORT MATERIAL FOR WORKSHOP SMALL GROUP #2 EXPERIENCES GROUPS

What are important patient experiences that Diabetes Action Canada should collect?

Satisfaction with Quality of Life issues that might not arise during the typical patient provider encounter:

- Time for diabetes management
- Sport and Exercise
- Sex life
- Family Burden
- Knowledge about diabetes
- Work
- School
- Socializing, friends
- Leisure activity

Satisfaction with the delivery and organization of diabetes care:

- Individual's experiences with healthcare providers
- Individual's experiences with their healthcare system

Satisfaction with treatment:

- Use of diabetes medications in their everyday life
 - Blood sugar testing
 - Medication side effects
 - Insulin treatment
 - Hypoglycemia
 - Self-efficacy
 - Getting check ups

- 1. Are there ideas that are missing here?**
- 2. Which of these ideas matter most to you?**

APPENDIX B – SUPPORT MATERIAL FOR WORKSHOP SMALL GROUP #2 OUTCOMES GROUPS

What are important patient outcomes and characteristics that Diabetes Action Canada should collect?

1. Physical health

- Mobility
- Self-care
- Restricted usual activities
- Pain/discomfort
- Vitality (e.g. being active and waking up rested)
- Health habits and diabetes self-management

2. Mental health

- Anxiety
- Depression
- Mood
- Cognitive and emotional health
 - effect on life
 - duration of illness
 - control over illness
 - beliefs about effectiveness of treatment
 - coping style

3. Social health

- Social support
- Sex life
- Days of restricted activity
- Days of social restriction
- Social participation


4. Environmental health

- Access to health services
- Access to transport
- Living conditions
- Food security
- Housing status


5. Personal

- Household income
- Ethnicity
- Valued activity
- Quality of life

- 1. Are there ideas that are missing here?**
 - 2. Which of these ideas matter most to you?**
-



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and Health
RESEARCH UNIT



McMaster
University


Engaging Older Adults with Diabetes and Their Caregivers in a Community-Based Program

Jenny Ploeg, RN PhD
Maureen Markle-Reid, RN, PhD

Diabetes Action Canada Annual Workshop
May 26, 2017

Outline

- Introduction to the Aging, Community and Health Research Unit Community Partnership Program for Older Adults with Type 2 Diabetes
- Engaging with older adults and caregivers
- PREMs and PROMs
- Description of the Aging, Community and Health Research Unit
- Next steps



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Community Partnership Program

Developed from the grassroots:

- Patient and caregiver engagement in a national workshop related to needs of older adults with diabetes and potential ways to address those needs
- Patient, caregiver and provider input into design of the intervention



A Six-Month Intervention



HOME VISITS

MONTHLY
GROUP
SESSIONS



MONTHLY
NURSE-LED
CASE
CONFERENCES

NURSE-LED
CARE
COORDINATION



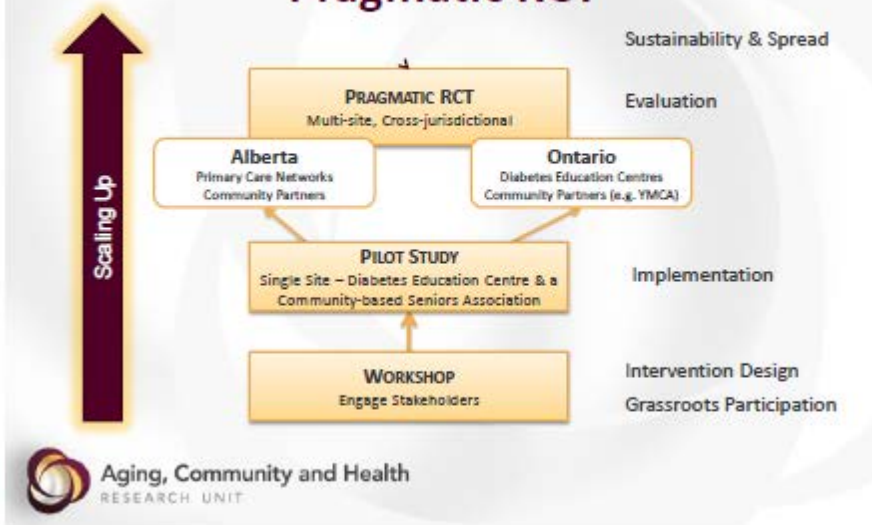
Source: CDC #12726



CARE
COORDINATION



From Feasibility Study to Pragmatic RCT



A Community Partnership

A Diabetes Education Centre (DEC)



A Senior's Centre



Feasibility Study Results (n=36)

- CPP was viewed as acceptable and feasible by participants and providers
- Participants had higher physical functioning at 6 months compared with baseline
- Participants, volunteers and providers provided valuable feedback regarding suggested changes to the program



RCT Study Partners

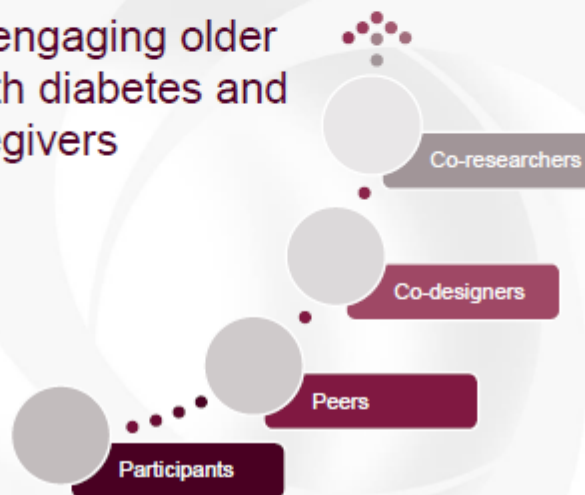


Results of Ontario RCT (n=159)

- Intervention group had better mental health, lower depressive symptoms, better diabetes self care compared to control group
- Improvements achieved at no additional cost to society as a whole
- Results from AB expected soon



Ways of engaging older adults with diabetes and their caregivers



Patient & Caregiver Engagement in Community Partnership Program thus far...

- Study participants
- Peers at community sites: sharing experiences, support
- Co-design: input into the design of the intervention
- Interpretation of findings
- Patient and caregiver advisory committee



PREMs and PROMs

- PREMs: patient-reported experience measures: e.g., satisfaction with health services
- PROMs: patient-reported outcome measures: e.g., health-related quality of life



PROMs Assessed in Community Partnership Program

- Health-related quality of life:
 - Physical functioning (Pt, CG)
 - Mental functioning (Pt, CG)
 - Depressive symptoms (Pt, CG)
 - Anxiety (Pt)
 - Self-management (Pt)
 - Self-efficacy (Pt)
 - Caregiver strain (CG)
- (Note: Pt=patient, CG=caregiver)



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Patient Perspective

- I wanted to learn more about diabetes and its relationship to my age. I will be 85 next June. Having been a diabetic for 16 years, and surviving well, I was interested in learning anything new about the treatment and developments. My wife had always managed by medications and when I lost her to cancer eight years ago it was obvious I had to accept the responsibility.
- I was interested in the study participation because it helped me re-focus on my own personal requirements. This led to more exercise and a better diet. I also enjoyed meeting new people and was surprised at the wide variance in the ages and physical condition, appearance and attitudes of co-members.



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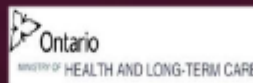


Introduction to the Aging, Community and Health Research Unit

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The Aging, Community and Health Research Unit (ACHRU) – An Overview

Goals:

- To promote optimal aging at home for older adults with multiple chronic conditions and to support family caregivers
- To design, evaluate and translate new and innovative interprofessional community-based interventions to improve quality of life and care



Aging, Community and Health
RESEARCH UNIT

Stakeholder Network



48 Agencies



5 Government Representatives



43 Researchers



17 Research Trainees:
Post Doctoral Fellows,
graduate students (PhD &
Masters), undergraduates



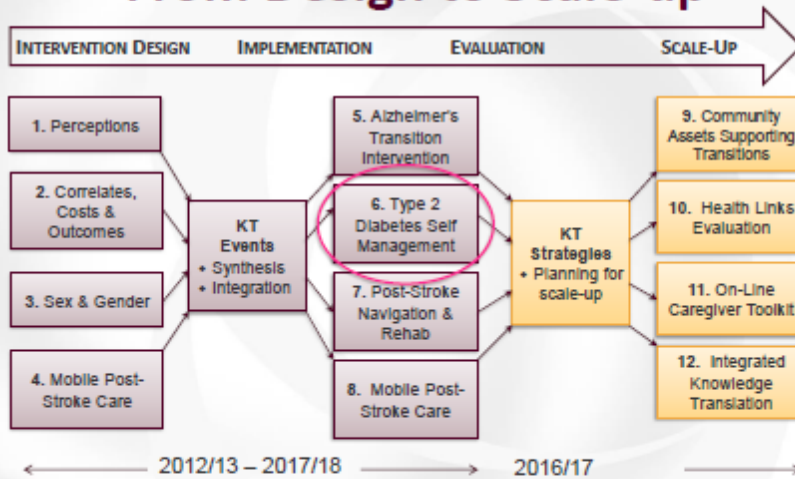
8 Patients & Family Caregivers



5 Provinces



From Design to Scale-up



Older Adult & Caregiver Engagement integrated throughout ACHRU

- Intervention co-design
- Grant development
- Study implementation
 - Adapting and tailoring
- Interpreting results
- Patient and public engagement workshop
- KT events, presentations
- Co-presenting at Ministry meetings



Next Steps

- Collaboration with Diabetes Action Canada and *Better Access and Care for Complex Needs [BeACCoN]*
- Working with administrative data bases such as UTOPIAN
- Partnership with YMCA
- Partnership with Diabetes Education Programs and Primary Care
- Patient and caregiver involvement in PREM and PROM development



Analysis of the small groups discussions Workshop 1

1. Goals of the Workshop

- Establish a new understanding of patient engagement in research from the perspective of people living with diabetes that includes cultural sensitivity* and social determinants of health
- Address the request from the Patient Councils to better understand how ongoing and future projects provide value for people living with diabetes

2. Steps of the analysis

- Gather a team (Olivia, Catherine, Mary and Joyce)
- Use an adapted intervention mapping method
- Starting from the summary analytic document sent by Cathy, we extracted the 4 objectives (see table 1).
- Then we suggested activities to be implemented to achieve those objectives. To do so, we performed the analysis in two subgroups of 2 team members (hereafter referred to as pairs). Each member individually suggested activities then the pair discussed and agreed on a list of activities. The two pairs then met together to compare their activities and consensually agreed on a list of activities (see table 1)
- Members of the analytic team each then read two of the seven Small-Group discussion reports extracted a list of activities. (We wanted to make sure every suggestion was considered)
- Activities were categorized under each of the four main objectives. They were then grouped by a likeness and incorporated in table 1. The activities were classified into 3 categories: i) activities already planned; ii) planned but needed some modifications and iii) new activities.
- The groups responsible for the implementation of the activities were also identified in table 1. This will be discussed during the post workshop meeting as well as an implementation plan (including metrics).

3. Next Steps

- Meeting of the Patient Engagement Goal Group (with Holly) to adjust our initial plan and define new targets and metrics for meaningful Patient Engagement
- Consult with Patient Circles about questions that remain unclear after the analysis (see page 6)

Table 1: List of activities to provide meaningful patient engagement activities (post Toronto meeting)

Objectives	Activities	Type of activities*	Group responsible
1. Promote Effective and Meaningful Communication	1.1. Create webinars, infographics, web-based resources to disseminate research results that are easily consumable by the public	M	Knowledge Translation/Training and Mentoring/Patient Engagement goal groups
	1.2. Co-develop curriculum and professional development with patient partners to orient researchers and health care professionals in utilizing and incorporating the patient voice and participation	N	Training & Mentoring Goal Group
	1.3. Reach out to media outlets (newspapers, radio...) to promote and foster patient engagement.	N	DAC management
	1.4. Facilitate and foster a sense of community among patient partners (Ex: Create an online forum and continue face-to-face meetings (increase frequency if possible).	AP	Patient Engagement Goal Group / DAC management
	1.5. Diversify DAC communications to broaden our reach. Create a public Facebook page. Optimize website usability by establishing the web portal and increasing website traffic	M	Patient Engagement Goal Group / DAC management
	1.6. Revise French content of website	N	Patient Engagement Goal Group
	1.7. Adapt and improve all communications strategies. Use community-based organizations and patient-partners (citizen participation). Use more visual means of communications, ensure accessibility of language for the general public, ensure all publications produced by DAC use accessible language (ie: reduced jargon) and use multifaceted methods of communications (phone, email, etc...).	N	Patient Engagement Goal Group / DAC management
	1.8. Adapt and improve all communications strategies by making everything bilingual and explore possibility of other languages such as languages spoken by First Nations.	AP	DAC management
	1.9. Reduce stigmatization and patient blame, by focusing on improvements and active listening.	AP	All Goal groups and DAC management

* P = Already planned; N = New activity; M = planned but to be adjusted (modifications required)

Table 1 (continued)

Objectives	Activities	Type of activities*	Group responsible
2. Create a Learning Environment for People Living with Diabetes and Researchers	2.1. Patient partner mentorship of new patient partners	AP	Training and Mentoring/Patient Engagement goal groups
	2.2. Render health information accessible to patients by making high quality health information available on the internet, by creating health information sessions at the CDA meeting or other events, by connecting with other patient education groups (Think Tank Type 1).	N	Knowledge Translation / Training & Mentoring Goal Groups and partnership with Diabetes Canada
	2.3. Create a learning activity in the form of a webinar or forum. Structured Q&A session with a health care professional and a patient partner who has extended experience (living or caring). They are asked to answer the same set of established questions. It is a collaborative attempt to create a more comprehensive picture of diabetes care, 1) empowering patients and 2) educate the audience (seeing the patient perspective and the clinical aspect of diabetes care). It is customizable to different audiences	N	Knowledge Translation/Training & Mentoring/Patient Engagement Goal Groups
	2.4. Develop tailored/adapted training activities on patient-oriented research according to stakeholders' specific needs (patients, researchers, health care professionals...).	M	Training & Mentoring Goal Group
	2.5. Create opportunities and tools to empower patient partners to disseminate messages (ex: role reversal exercises and public speaking).	N	Training & Mentoring / Patient Engagement Goal Groups
	2.6. Create strategic interdisciplinary partnerships to improve uptake of research findings (ex: engage with primary care researchers, frontline health workers and other SPOR Networks).	AP	Knowledge Translation Goal Group / DAC management

* P = Already planned; N = New activity; M = planned but to be adjusted (modifications required)

Table 1 (continued)

Objectives	Activities	Type of activities*	Group responsible
3. Research Activities – “Nothing about us, without us”	3.1. Consult with the Knowledge Translation team about whether to go ahead with using the James Lind Alliance priority setting activity	M	Knowledge Translation/ Patient Engagement goal groups
	3.2. Diversify ways that patient partners can engage in DAC research activities. Create menu of opportunities, for example: patient partners can be ambassadors at scientific conferences/ presentations/ workshops with decision makers.	M	Patient Engagement Goal Group / DAC management
	3.3. Invite Patient Partners to scientific conferences	M	Patient Engagement Goal Group
	3.4. List all ongoing DAC research projects and make available on website.	N	All Goal Groups / DAC management
	3.5. Identify other researchers (outside of DAC) whose research is focus on socio-economic determinants and other determinants of healthcare.	N	All Goal Groups
	3.6. Identify and use a Patient Engagement framework that is valid, inclusive, interdisciplinary and holistic that will lead to practical outcomes (Can-SOLVE, AYMP, IPERC). And co-develop a patient engagement definition.	N	Patient Engagement / Indigenous Peoples Health / Sex & Gender Goal Group
	3.7. Establish effective knowledge translation practices to convey research results (ex: gathering testimonials from patients and frontline workers).	M	Knowledge Translation Goal Group

* P = Already planned; N = New activity; M = planned but to be adjusted (modifications required)

Table 1 (continued)

Objectives	Activities	Type of activities*	Group responsible
3. Research Activities – “Nothing about us, without us”	3.9. Establish relationship trust between patients, communities and the healthcare system (ex: welcome elders, include ceremonies (even small gestures), invest time and resources).	AP	All Goal Groups / DAC management
	3.10. Involve patient partners as early as possible (ex: grant writing for researchers, and patient CVs).	M	Patient Engagement and all Goal Groups
4. Patient Councils (renamed “Circles”)	4.1. Recruit more caregivers as patient partners and patient circle members	M	Patient Engagement Goal Group
	4.2. Develop strategies to reach out to ‘hard-to-reach’ communities using more proactive recruitment methods (i.e. CDA, Edmonton; or presentations/booths at targeted/relevant events)	M	Patient Engagement Goal Group / DAC management
	4.3. Work with DAC sponsors to increase visibility of DAC patient engagement activities (using varied marketing, communication activities)	N	Patient Engagement Goal Group / DAC management
	4.4. Develop strategies to reach out to ‘hard-to-reach’ communities partnering with community organizations	M	Patient Engagement Goal Group
	4.5. Survey patient partners about ways the patient voice could be more present in DAC	AP	Patient Engagement Goal Group
	4.6. Invite researchers to Patient Council meetings.	AP	Patient Engagement Goal Group
	4.7. Develop strategies to reach out to hard-to-reach communities (geographically, socio-economically, and culturally) and vulnerable groups, using more proactive methods (ex: CDA Edmonton; Presentations/booth at targeted/relevant events).	M	Patient Engagement / Indigenous Peoples Health Goal Groups
	4.8. Create a model/portal to engage patients in research (ex: videos of patients who have engaged in research and web portal with bios of patient partners).	N	Patient Engagement / Indigenous Peoples Health / Knowledge Translation Goal Groups

* P = Already planned; N = New activity; M = planned but to be adjusted (modifications required)

Questions for the Patient Circles:

- How can we measure the impact of participatory research on meaningful changes to the health care system?
- What programs could we create to prompt more public involvement in research projects to ultimately improve outcomes for people living with diabetes?
- How can we involve partners in research when some basic needs are not met?
- How can we make it easier for people to get involved?
- How can we create more direct lines of communications between patients and researchers?
- How can we anticipate patient needs and raise awareness?
- How would patient partners like to be helped and supported to fulfill their life plan through the Network?

How does DAC plan to address translating new knowledge into practice...

Listen to patients' needs



How does DAC plan to address translating new knowledge into practice...



Listen to patients' needs



Look for evidence-based solutions that meet patients' needs



Develop solutions to meet patients needs

How does DAC plan to address translating new knowledge into practice...



Listen to patients' needs



Look for evidence-based solutions that meet patients' needs



Develop solutions to meet patients needs



A measure of what is important to patients



New treatment



Patient/clinician education



Ways for achieving a better quality of life

How does DAC plan to address translating new knowledge into practice...



Listen to patients' needs



Look for evidence-based solutions that meet patients' needs



Develop solutions to meet patients needs

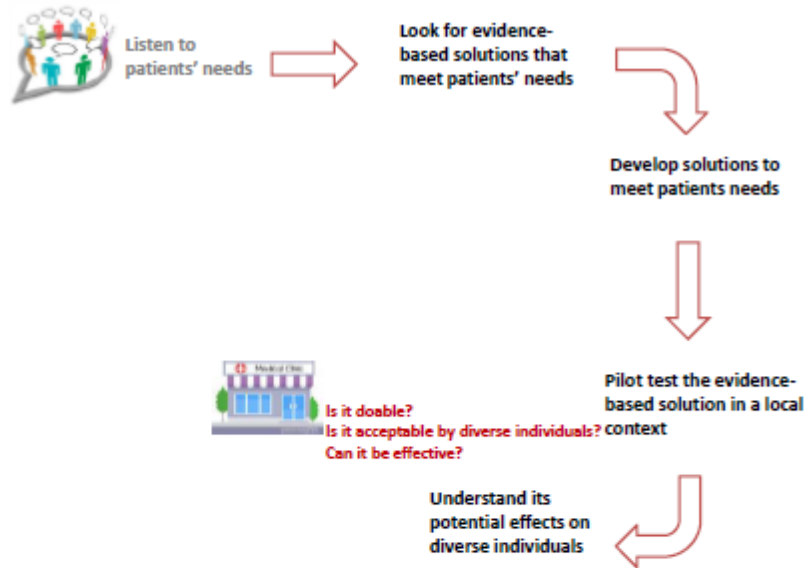


Pilot test the evidence-based solution in a local context

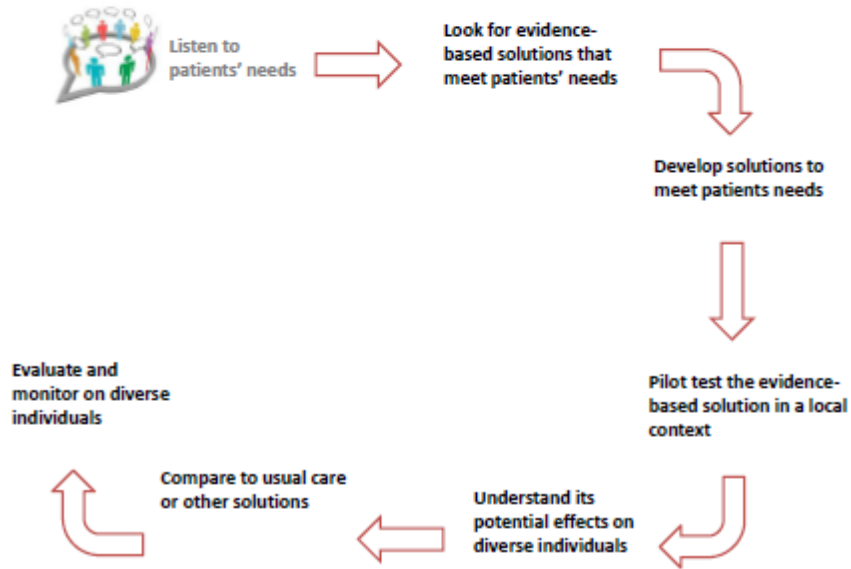


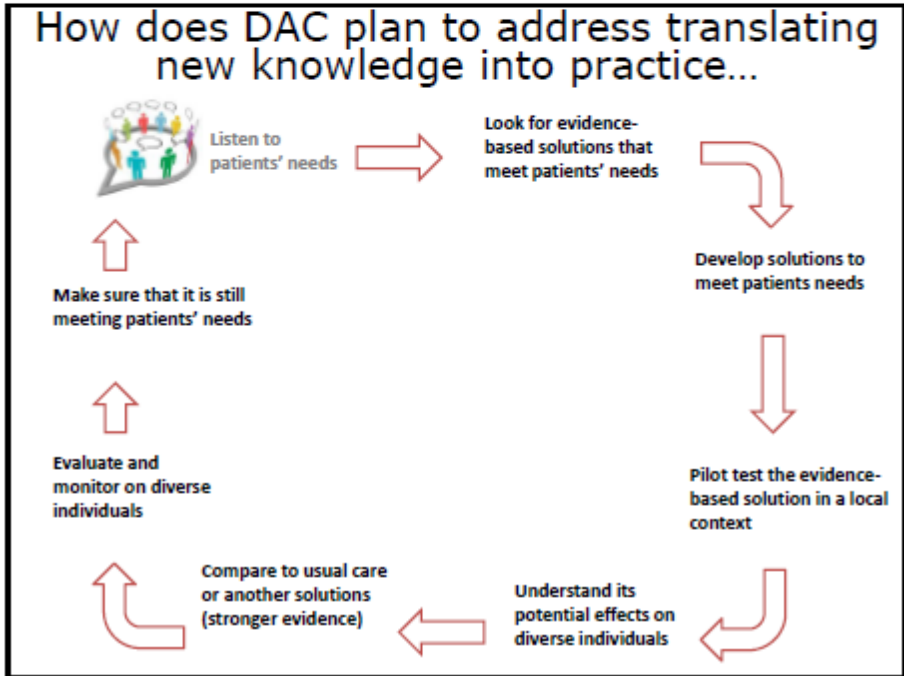
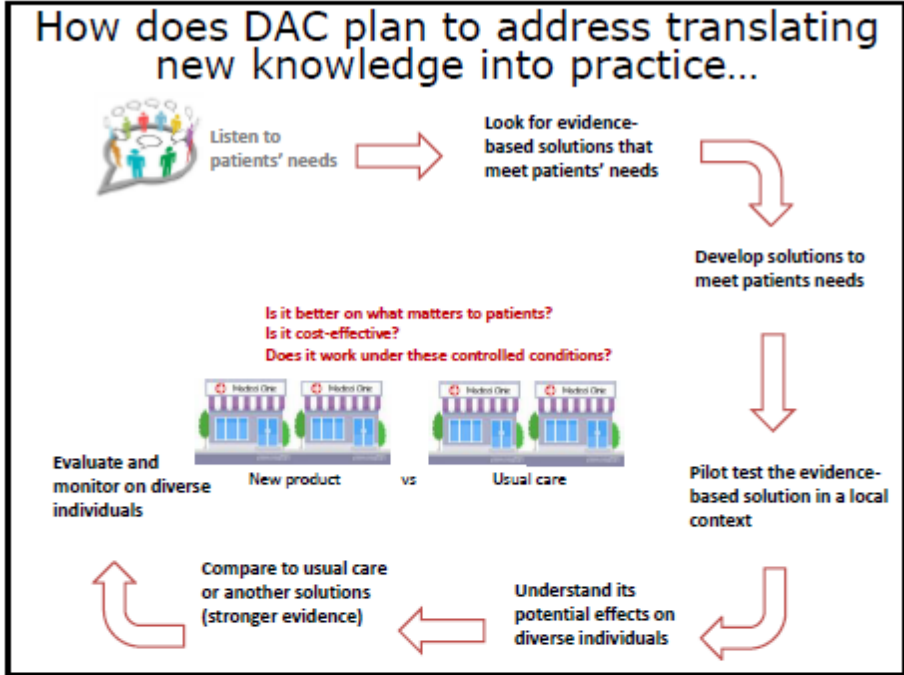
Understand its effects on diverse individuals (in a local context)

How does DAC plan to address translating new knowledge into practice...

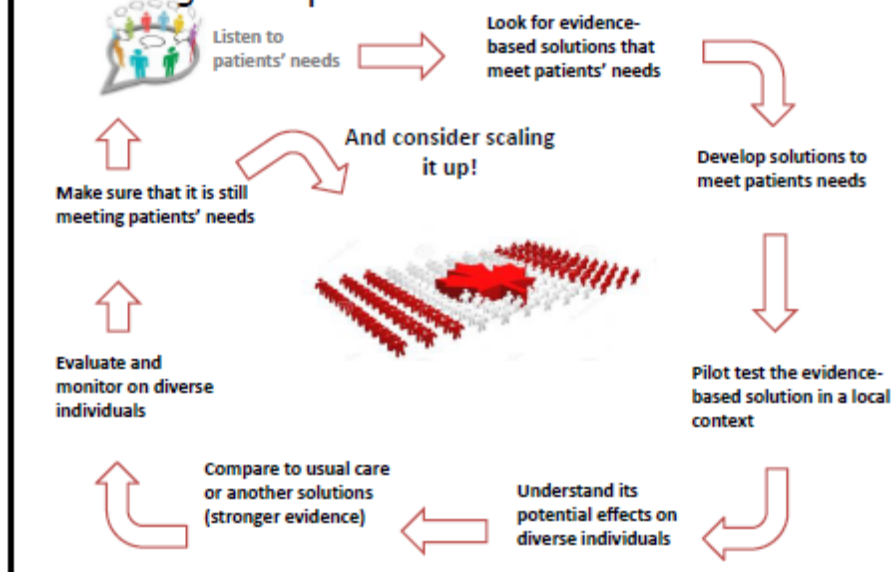


How does DAC plan to address translating new knowledge into practice...





How does DAC plan to address translating new knowledge into practice so all Canadians benefit!



A country of perpetual pilot projects

CMAJ 180 (12) 2009



What is Scaling up?

- «*Deliberative efforts to increase the impact of successfully tested health innovations so as to benefit more people and to foster policy and programme development on a lasting basis.*»
 - «*successful*» means that innovation is realistic to carry out, relevant and worthwhile, and the interventions have real and beneficial impact on the health concern they are designed to address

- Fixsen DL et al. 2009
- Ovreteit 2010
- Fixsen DL et al. 2013
- WHO

A framework for scaling up an evidence-based solution



What do we know about effective scaled up strategies?

- Few trials assessed the impact of strategies to scale up (I) evidence based solutions in primary care settings (P) :
 - P: participants
 - I: scale up intervention (of an evidence based solution)
 - C: comparator
 - O: a measure of scale up (needs a denominator and a numerator)
- A lot of confusion between assessing the impact of the evidence based solution that is being scaled up and the scaling up intervention itself
- Most trials were conducted in low- and middle-income countries, with most having focused on infectious diseases (communicable diseases)
- It is uncertain whether any of those strategies are effective given the poor reporting

Ali Ben Charif et al. 2017

How do we know we've scaled up?

- Very few scale up studies measure– Reach Effectiveness Adoption Implementation Maintenance
- Very few studies inform us about a denominator and a numerator
- Very few studies inform us on what they will consider successful scale up



• <http://re-aim.org/>

Can scaling-up be a bad idea?

Presented by
France Légaré, BSc Arch, MD, PhD
Hervé Tchala Vignon Zomahoun, PhD

1- Not ethical



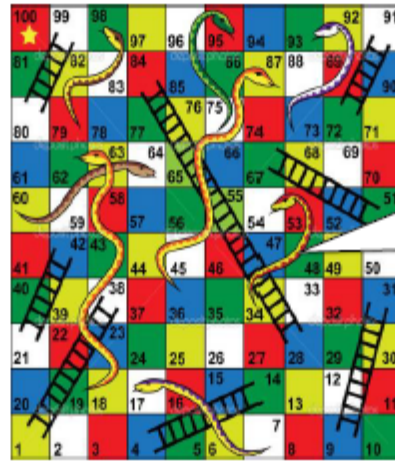
- Not all EB practices should be scaled up
- Scaling up HIV testing “must remain voluntary, be accompanied by adequate counselling, and be linked to existing or promised treatment and prevention programs”

Macklin Health and Human Rights 8 (2) 2005

- Implementing circumcision in some cultural groups

Mavhu and al. AIDS Behav 18 2014

2 - Potential collateral damage



3 – It's a “top down” approach

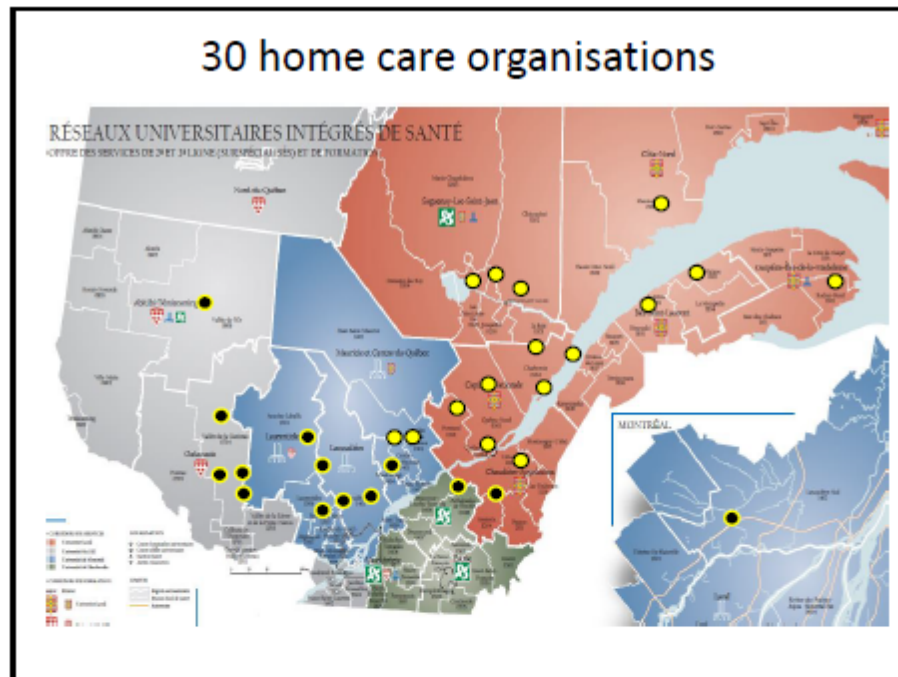


- Top down approaches may reduce local collective action and undermine communities' existing networks

Nayak and Berkes Environmental management 41 2008



30 home care organisations



Where next?

- **Not everything is scalable or should be scaled up as it requires specific attributes and will require competing resources !**
- **Successful scaling up requires strong partnerships among patients, policy-makers, researchers, clinicians and communities.**
- **As a network, we may want to discuss what kind of evidence-based solutions we should invest in and scale up.**