10-13-2017

SWAHN Southwestern Academic Health Network Conference 2017 : the Patient Voice & Experience in Southwestern Ontario

Schulich School of Medicine & Dentistry

SWAHN SouthWestern Academic Health Network

SWAHN Conference 2017:
The Patient Voice & Experience in Southwestern Ontario

Friday, October 13, 2017

Arthur & Sonia Labatt Health Sciences Building
Western University
London, Ontario

Conference Proceedings

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ISBN Print Version: 978-0-7714-3161-6
ISBN Online Version: 978-0-7714-3162-3

Published by the SouthWestern Academic Health Network (SWAHN), December 2017.
(c/o Schulich School of Medicine & Dentistry, Western University
Clinical Skills Building, Room 3720, London, ON N6A 5C1)

OVERVIEW:

The SouthWestern Academic Health Network (SWAHN) engages health care, academic, research, and community organizations in the South West and Erie St. Clair Local Health Integration Network regions, as well as the School of Pharmacy at the University of Waterloo (located within the Waterloo-Wellington Local Health Integration Network region). Together, these organizations work towards fulfilling SWAHN's vision to transform health in Southwestern Ontario through integrated excellence in research, education, and clinical practice. SWAHN's mission is to improve population health and to become a national leader in health care, education, and research.

Since the beginning of 2017, SWAHN's leadership, with recommendations from Network contributors and volunteers, has worked toward revising the Network's structure in order to make changes that are in alignment with both current and future needs while addressing various challenges to ensure continued advancement and value creation as the organization matures. A new organizational structure, approved by the Steering Committee in September 2017, is based on the tenets of SWAHN's value proposition: interprofessional collaboration, networking, and knowledge sharing.

As part of the Network reorganization, a new leadership structure was created. The former Steering Committee has now become the Network Contributors' Roundtable (NCR), thereby ensuring that all of SWAHN's financial contributors have an opportunity to participate equally in priority setting and strategic planning rather than being bound by particular Committee terms. Annual networking events (like the October 13, 2017 conference) will be planned for the NCR starting in 2018.

SWAHN's new organizational structure was shared at the SWAHN Conference on October 13, 2017. In addition to serving as a venue to share information about the restructuring process and to highlight various Network activities and successes, the SWAHN Conference was designed to provide an opportunity for SWAHN's contributors and volunteers to participate in knowledge sharing and networking.

The conference, held at Western University in London, Ontario, was a full-day event that included presentations based on its theme: *The Patient Voice and Experience in Southwestern Ontario.* The day began with a two-part presentation featuring Health Quality Ontario's patient partnership framework, delivered by Jennifer Schipper, Health Quality Ontario's Chief of Communication and Patient Engagement. Dr. Gillian Kernaghan, President and CEO of St. Joseph's Health Care London (and Co-Chair of SWAHN) then shared her organization's care partnership that has involved the contributions of patients, residents, families, and caregivers.

Other presentations included a personal story shared by Mr. Wayne Kristoff who was engaged as a patient in a research study for diabetics at the Lawson Health Research Institute. This was followed by Dr. Shannon Arntfield's presentation on the value that practicing narrative medicine offers to both health care providers and their patients. The morning session concluded with a special theatrical production that explored the Indigenous patient experience.

In the afternoon, breakout sessions on patient partnerships and the Indigenous patient experience were held, sparking discussion among participants. Following the conference, various themes were identified based on an analysis of the various breakout group discussion notes and participant evaluations. The following key learning points were identified by participants both during the group discussions and through the conference evaluation forms.

Indigenous patient experience:

- The SWAHN Conference discussion was just a starting point. There is a long way to go due to historical and deeply rooted challenges and barriers.
- The Indigenous voice remains underrepresented in all aspects of healthcare. Representation needs to be improved across health care structures.
- Institutions should play a role in promoting Indigenous cultural training among faculty/staff.
- Partnerships between health care institutions and Indigenous communities are necessary to enhance mutual learning and to build trust and mutual respect.
- The use of tangible artifacts within institutions (e.g., hospital waiting areas) will help to create safe and welcoming environments for Indigenous patients and staff.
- Meetings with Indigenous community representatives should be arranged in a circle to reduce power imbalances (i.e., deconstructing hierarchies).
- Face-to-face meetings are preferable than telephone/video meetings.
- Start the process to address the incorporation of the Indigenous world and whole person view into overall health care.
- Share information.

Patient partnerships:

- The concept of “health literacy” is important.
- Patients and their caregivers need to be empowered and engaged in all aspects of health care system design/planning, research, and clinical decision making.
- Practical information and practitioner resources are needed regarding how to meaningfully engage patients/the patient voice for example:
    - best practices in patient engagement
    - how to implement patient partnership frameworks
    - how to recruit patients as volunteers and/or as speakers

Other:

- The concept of narrative medicine was also referenced several times in the conference evaluation forms as was learning about the Indigenous patient experience.

The themes noted above will be shared with the Network Contributors’ Roundtable (NCR) at its spring 2018 meeting for discussion. The Secretariat has also determined the following next steps:

- A shared learning opportunity will be developed for the NCR’s spring meeting where leading initiatives, strategies, practices, and/or research concerning Indigenous patient engagement in the health / health care sector are presented by SWAHN members.
- An update concerning the Change Foundation’s “Changing Care” initiative will be shared at the NCR table and will be highlighted on SWAHN’s website.
- The NCR and the Secretariat will explore how to apply narrative medicine to health care settings across the region.

CONFERENCE HIGHLIGHTS:

- SWAHN was pleased to hold its October 2017 conference the Arthur & Sonia Labatt Building at Western University through the assistance of the Faculty of Health Sciences – one of SWAHN's financial contributors. In addition to the conference planning team chaired by Dr. Doug Jones, SWAHN would like to extend thanks to the many volunteers from Western Health Sciences who helped to make the conference a success by serving in various different ways throughout the day for set-up, registration, troubleshooting, and tear-down. This assistance was greatly appreciated!

- Dr. Kathryn Nicholson, a former SWAHN Committee member while a graduate student in Epidemiology & Biostatistics at Western University, provided assistance in compiling this document. We thank Kathryn for her efforts to record the information shared by presenters.

- The conference engaged more than 50 attendees from 20 organizations/divisions across the SWAHN region as well as from Toronto.

- During the morning, the conference was devoted to thematic presentations on the patient voice and experience. The topics included patient partnership frameworks, a patient's engagement in research, and narrative medicine. These presentations were followed by a special theatrical performance featuring a play written by an Indigenous playwright, Mr. John Boc, entitled "*How the Circus Vanished*." This award-winning production, set in a mental health facility in the 1970's, explored the experiences of two Indigenous patients from their own perspectives.

- The afternoon agenda focused on a presentation related to SWAHN's reorganization project in 2017 and also highlighted two SWAHN projects: IPE Day and a community pharmacists' workshop focused on malnutrition in seniors.

- Two participant breakout sessions also took place in the afternoon. These discussions included a presentation on patient partnerships as well as on the Indigenous patient experience. These sessions were designed to encourage networking and knowledge sharing opportunities. Participants were also asked to share their suggestions regarding SWAHN's next steps concerning the conference theme: the patient voice and experience in Southwestern Ontario.

- Slide-deck presentations from the conference can be found on SWAHN's website: http://www.swahn.ca/41/Resources/

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APPENDICES:

CONFERENCE AGENDA: Friday, October 13, 2017

9:45 a.m. – 10:00a.m.	**REGISTRATION / NETWORKING – South Lobby**	
10:00a.m. – 10:05a.m. Rm.35	Greetings / Conference Overview / Introduction of theme speakers	Dr. Ken Blanchette, Co-Chair, SWAHN; Associate Vice President, Academic, St. Clair College
10:05a.m. – 10:50a.m. Rm.35	Theme presentation – Patient Partnership Framework	Ms. Jennifer Schipper, Chief, Communication and Patient Engagement, Health Quality Ontario / Dr. Gillian Kernaghan, President & CEO, St. Joseph's Health Care London (Co-Chair, SWAHN)
10:50a.m. – 11:30a.m. Rm.35	Patient Engagement in Research and Narrative Medicine	Mr. Wayne Kristoff (10 min.) / Dr. Shannon Arntfield, London Health Science Centre (30 min.)
11:30a.m. – 11:40a.m.	**Introductions and transition to Rm.40**	
11:40a.m. – 12:25p.m. Rm.40	The Indigenous Mental Health Patient Experience: *How the Circus Vanished* – a play by Mr. John Boc	Mr. Bill Hill, St. Joseph's Health Care London / Ms. Kathy Quayle-Pinkerton
12:25p.m. – 1:15p.m.	**LUNCH / NETWORKING – South Lobby**	
1:15p.m. – 1:30p.m. Rm.35	SWAHN's value proposition / updates on the restructuring process	Dr. Gillian Kernaghan, Co-Chair, SWAHN
1:30p.m. – 1:35p.m. Rm.35	SWAHN Project Showcase - Introduction of speakers from Interprofessional Education and Nutrition Working Groups	Dr. Robin Walker, SWAHN Lead; Integrated Vice President, Medical Affairs & Medical Education, St. Joseph's Health Care London & London Health Sciences Centre
1:35p.m. – 1:50p.m. Rm.35	Interprofessional Education Project Team – IPE Day analysis	Ms. Elaine Lillie, Co-Chair, SWAHN IPE Project Team; Director of Interprofessional Education & Curriculum Development, School of Pharmacy, University of Waterloo / Dr. Kevin Fung, Co-Chair, SWAHN IPE Project Team; Chair/Chief, Dept. of Otolaryngology, Schulich School of Medicine & Dentistry and London Health Sciences Centre and St. Joseph's Health Care London
1:50p.m. – 2:05p.m. Rm.35	Nutrition Project Team -- Assessing Nutrition Risk in Seniors in the Community Pharmacy	Ms. Catherine Joyes, SWAHN Manager

2:05p.m. – 2:15p.m. Rm.35	Q&A	Dr. Robin Walker
2:15p.m. – 2:25p.m. Rm.35	Introduction of breakout sessions and transition to breakout rooms	Dr. Robin Walker
2:25p.m. – 3:25p.m. ***(Concurrent breakout sessions – pick one)***	Patient partnerships – **Rm.#9**	Facilitators: Dr. Jacobi Elliott, CARE Partnership Lead; Ms. Jody Glover and Ms. Dana Borrie, QI/KT Facilitators, St. Joseph's Health Care London
	Indigenous patient experience – **Rm.#35**	Facilitators: Dr. Samantha Boshart, London Health Sciences Centre; Mr. Bill Hill, St. Joseph's Health Care London; Mr. John Boc, Playwright; Ms. Kathy Quayle-Pinkerton
3:25p.m. – 3:40p.m.	**BREAK / NETWORKING**	
3:40p.m. – 4:20p.m. Rm.35	Breakout group reports to all attendees *(Synopsis from the breakout sessions)*	Dr. Ken Blanchette
4:20p.m. – 4:30p.m. Rm.35	**Closing remarks** *(Please submit your completed evaluations!)*	Dr. Gillian Kernaghan

THEME PRESENTATION #1 – Patient Partnership Frameworks

Speakers: Ms. Jennifer Schipper, Chief, Communication & Patient Engagement, Health Quality Ontario / Dr. Gillian Kernaghan, President/CEO, St. Joseph's Health Care London (and Co-Chair, SWAHN)

This presentation began with a video produced by the Cleveland Clinic as part of its 'Empathy Series' called "*Patients: Afraid and Vulnerable*" (https://tinyurl.com/ycczk7ke), highlighting the importance of listening to what matters to the patient and walking in his/her shoes to improve health care quality. In efforts to improve the quality of health care, patients' perspectives, beliefs, needs, and backgrounds need to be considered by health care professionals.

Health Quality Ontario is the provincial advisor on health care quality and they engage with patients and caregivers on everything they do – from reporting to the public on how the system is performing, developing standards for what quality care looks like, evaluating the effectiveness of new health care technologies and services, and promoting quality improvement aimed at sustainable positive change.

Health Quality Ontario's goal is to foster an empathetic culture in our health system that recognizes patient, family, and public engagement at its centre. To support this effort, the organization gathers and designs tools and resources that empower all people living in Ontario to participate in their care and to help facilitate engagement between patients, families, and health providers. Health Quality Ontario also created, in consultation with patients and health professionals, a Patient Engagement Framework for Ontario, to guide health care professionals and patients in planning for, implementing, and evaluating patient engagement activities. A Patient, Family, and Public Advisors Program was also created to root the work in the values and experiences of those who use Ontario's health system.

Concurrently with the development of the Ontario patient engagement framework, St. Joseph's Health Care London was developing its own patient partnership framework that establishes the importance of patient involvement and patient engagement in the organization's strategic plan. A component of the strategic plan is focused on patients in order to ensure that the organization is guided by patient voices. The strategic priorities include: ensuring patients and their families are full partners in their care and in the co-design and improvement of care delivery, embracing the relentless pursuit of safety, and optimizing transitions through the care system with and for patients, residents, and families. The outcome of both the provincial work and St. Joseph's showed alignment in the approach to patient partnership.

More specifically, St. Joseph's Health Care London developed a care partnership that involved the contributions of patients, residents, families, and caregivers. This involved caregiver engagement and a focus on dignity, reliability, and participation in the relationship. There was emphasis on informing, consulting, involving, collaborating, and then empowering the patients in health care initiatives, direct care, and in advocacy. The intent is to ensure that all patients are empowered.

Examples of patient engagement and patient co-design for St. Joseph's Health Care London included the redesign of the organization's cafeteria and palliative care unit. Another future issue to address is to consider implementing more inclusive visiting hours.

THEME PRESENTATION #2 – Patient Engagement in Research –

Speaker: Mr. Wayne Kristoff, Patient Participant

Mr. Wayne Kristoff shared his experiences as a patient engaged in the “Remit Study” at Lawson Health Research Institute in London, Ontario. Mr. Kristoff was diagnosed with Type II diabetes in 2014. At the time of his diagnosis, he was prescribed metformin, which caused discomfort and, as a result, he was not able to take the recommended dosage.

Mr. Kristoff became involved in the Remit Study after he saw a news story on the research project covered by CTV London. The study was focused on methods of placing diabetes in remission, allowing patients to manage diabetes without relying on medication. Based on his background in education, Mr. Kristoff was interested in how research can improve care delivery. Some of the expectations of study participants included meeting with a dietitian, tracking physical activity, and maintaining medication use.

Mr. Kristoff relayed his experience in the research project which involved weekly visits to the diabetes clinic where his food diaries were reviewed and where he received encouragement and counselling. He then began decreasing the dosage of medication with the help of clinicians and he eventually ceased all of his medication (something he was very pleased with). Eventually, his HbA1C levels increased and this required further medication, but he experienced great success over 18 months and his quality of life has improved. He reported having more energy and was excited about meeting great people for support. Mr. Kristoff shared his belief that these opportunities are important for patients and he will continue to look for other ways to be involved.

THEME PRESENTATION #3 – Narrative Medicine

Speaker: Dr. Shannon Arntfield, London Health Sciences Centre

Narrative medicine involves working with and sharing a narrative, conducting the practice of close reading, and conducting reflective writing. The principles that follow include the fact that this approach is experiential, relational, and embedded to follow the health care professional beyond the actual practice. In other words, narrative medicine is based on the belief that stories are important and are necessary to succeed in caring for others. Along this process, the health care provider must be moved to act on a patient's beliefs, to join with the person who suffers, to access the personal experience of another, to listen for a story, and to believe that this story is important.

This also requires the recognition of the difference between the concepts of both illness and disease. Illness is the uniquely innate human experience of symptoms and suffering, which refers to how the sick person (and members of the family) perceives himself or herself to be, and how he or she lives with and responds to symptoms and disabilities. Disease is what a practitioner creates in the recasting of illness into theories of the disorder and a reconfiguration of the patient's and family's problems as narrow technical issues and problems of altered structure or function. When illness is reduced to a disease, there is conflict that arises, something essential is lost, experience is not legitimized and key issues may not receive intervention (reference: Arthur Kleinman's The Illness Narratives: Suffering, Healing and the Human Condition).

It is important for the health care provider to listen for stories. Disease is an interruption of life and chronic disease is a perpetual interruption of life where the body or "self" has been made strange. As a result, the sick person is at risk for losing their destination or map, losing their sense of familiarity with their body and self, and losing their voice. Stories can be an approach to reclaiming the process and can serve practical, existential, and relational purposes (reference: Arthur Frank's The Wounded Storyteller).

Skills developed through the practices of narrative medicine include the capacity to recognize, absorb, interpret, and be moved by stories of illness. Narrative medicine allows health care providers to enter into the world of their patients, without the requirement of actually becoming sick themselves and allowing them to access the personal experience of another individual (reference: Rita Charon's Narrative Medicine).

Reading fosters inter-subjectivity based on a study from the journal Science published in 2013. This forces the reader to make inferences about the characters, be sensitive to emotional nuances, and be tolerant of complexity and ambiguity. Stories are important and some are absorbed better than others. There are different types of stories. Restitution stories are more easily accessible or valued in health care systems.

Narrative knowledge is a skill set that can be used to make sense of a story with its teller, time course, plot, and meanings. The purpose is to join with the person who is suffering, also known as co-suffering and co-constructing. This indicates that there is more than one expert in the room (i.e., the main expert is the patient) and there is a more equal distribution of power. This creates a therapeutic relationship that arises through the sharing of respective knowledge, identification of common goals, and collaboration on choosing strategies.

Implementation of narrative medicine means that the health care provider is moved to act on his/her patient's behalf. Narrative medicine is most useful – when the illness is not going to end,

when the problem is not neat and tidy, the provider must “stay with” the suffering patient, the provider must partner with “the difficult” patient or when we must acknowledge and navigate our own humanity, fallibility and mortality.

There numerous outcomes of practicing narrative medicine, including a patient’s formation of meaning and legitimizing their experience, enabling the patient-clinician “therapeutic alliance” for co-constructing, and for the health care provider to serve as therapeutic agent. As such, these outcomes can be particularly meaningful for the patient, for the patient-provider relationship, for the health care provider and for the society more broadly (such as through the birth of a storyteller, engagement of listeners, and recognition of others’ feelings and experiences via “me too, me too”).

The most central task of a health care provider is to alleviate suffering. One of the most difficult duties as human beings is to listen to the voices of those who suffer and the health care practice will always be imbued with fallibility and uncertainty. Building a narrative practice is possible and if individuals are interested in doing more of this, there are options. For example, individuals can develop a community of practice, take time to read on the topic, practice writing reflectively, and start community storytelling.

THEME PRESENTATION #4 – *How the Circus Vanished* – A theatrical presentation written by Mr. John Boc

Cast: Mr. Bill Hill, Actor/Director; Ms. Kathy Quayle-Pinkerton, Actress

How the Circus Vanished, by John Boc was written in 1978. The play was almost deliberately destroyed by the playwright in 1984 when he threw most of his poetry and theatre scripts into a bonfire on his farm during an acute phase of his illness. His daughter Morgan, only 10 years old at the time, saved three plays in a box and gave them to the playwright in 2003. *How the Circus Vanished* was entered in the London (Ontario) One Act Festival that year and went on to win three of five major awards at the festival. From there it went on to win two Continuing Medical Education awards in 2006 and 2008. In 2010, it was invited to be performed in New York City as part of an international mental health conference and won Best Original Script. *How the Circus Vanished* is a play about a man and a women on a psychiatric ward in the 1970's who by experiencing their past, recognize each other's presence. The play delves into the lived experience; how people who are experiencing mental health issues feel they are viewed by healthcare workers, and society in general.

SWAHN PRESENTATION – Value Proposition / Leveraging Accomplishments / Updates on the Restructuring Process

Speaker: Dr. Gillian Kernaghan, Co-Chair, SWAHN Network Contributors' Roundtable; President & CEO, St. Joseph's Health Care London

Dr. Gillian Kernaghan shared an update on SWAHN's restructuring process in 2017. SWAHN's leadership, with recommendations from Network contributors and volunteers, has worked toward revising the Network's structure in order to make changes that are in alignment with both current and future needs while addressing various challenges to ensure continued advancement and value creation as the organization matures. A new organizational structure, approved by the Steering Committee in September 2017, based on the tenets of SWAHN's value proposition (see figure below), was shared with the Conference audience.

SWAHN facilitates interprofessional collaboration, networking, and knowledge-sharing opportunities across health-care related education, research, health service providers, and other stakeholders in Southwestern Ontario to identify gaps and to improve the health of individuals, families, communities, and systems.

SWAHN's reorganization was particularly suitable now because of the growth of the organizational framework, the volunteer base, and the projects that are under development.

This reorganization will reduce the layers to improve communications by streamlining the structure to make it more nimble as a value network, to facilitate operations based on capacity and resources, and align the organization to its value proposition, ensuring its continued advancement and value creation for its contributors.

SWAHN's former standing committees have been eliminated in favour of establishing improved two-way communication flow between the Working Groups (now Project Teams) and SWAHN's leadership. The Steering Committee has now become the Network Contributors' Roundtable (NCR), thereby ensuring that all of SWAHN's financial contributors have an opportunity to participate equally in priority setting and strategic planning in the future – rather than being bound by particular Committee terms. Annual networking events will be planned for the NCR starting in 2018.

New Terms of Reference documents and "Stream" descriptions are currently under development and will be released once finalized. Updates to SWAHN's website will take place over the next few months. Finally, SWAHN's strategic plan, developed in 2013 for a five year period (2013-2018) will be revisited and refreshed for the next stage in SWAHN's progress in 2018.

SWAHN PROJECT HIGHLIGHT #1 – INTERPROFESSIONAL EDUCATION PROJECT TEAM – IPE DAY ANALYSIS

Speakers: Ms. Elaine Lillie / Dr. Kevin Fung, IPEPT Co-Chairs

This presentation was focused on the Interprofessional Education (IPE) Day organized by members of SWAHN's IPE Project Team.

IPE is an important aspect of training for health care students as a means of impacting their future interactions with other service providers in different disciplines and professions. Having a solid understanding of the interprofessional nature of health care teams will positively impact the delivery of patient-centred care and will improve quality outcomes, wellness, prevention, integrated services, and coordinated care delivery.

Two "IPE Day" events have been held to date (one in 2016 and one in 2017). Both events involved more than 400 students gathering at venues in London and Windsor for presentations, stereotype discussions, activities, and case analysis in small groups led by facilitators from the various professions represented. These events began with a "real" patient case to set the stage for the day's conversations concerning the importance of the patient voice and interactions between the members of an interprofessional health care team.

IPE Day 2017- London venue - Althouse College auditorium at Western University.

The events have been evaluated using the Interprofessional Collaborative Competencies Attainment Survey and qualitative questions collected from each student participant. In both years, the survey indicated improvements in each of the IPE competencies, across the five disciplines. More specifically, "collaboration" was the topic that saw the most recurring improvement overall, followed by "team functioning." In their own survey, facilitators gave the event a high rating and indicated that it was a meaningful learning experience for students.

IPE Day 2017 – Windsor venue – CAW Centre, Ambassador Auditorium, University of Windsor.

Students indicated their appreciation for meeting fellow students in different professions, hearing a diversity of perspectives, the openness and approachability of health care professionals, the demonstration of the value of interprofessional collaboration, a learning environment that encouraged participation, and the learning that came from the small group sessions.

IPE Day has been a successful and tangible SWAHN initiative. In the future, the Co-Chairs would like to continue to advance the concept – building IPE into health care curricula and advancing such curricula for health care professionals in community practice within the SWAHN region. It was also noted that future expansion of the day would be ideal – including additional students from other health care disciplines as well as additional facilitators representing different professions. This growth will be dependent upon increased funding -- particularly to support the rental of a larger venue to accommodate an increase in participants. Integration with other SWAHN project teams (like palliative care) is also a goal for the future.

The next event will be held on the afternoon of March 26, 2018. The planning team welcomes requests from individuals who would like to participate as facilitators at the event.

SWAHN PROJECT HIGHLIGHT #2 – NUTRITION PROJECT TEAM – ASSESSING NUTRITION RISK IN SENIORS IN THE COMMUNITY PHARMACY (A COMMUNITY PHARMACIST WORKSHOP)

Speaker: Catherine Joyes, SWAHN Manager

On behalf of SWAHN's Nutrition Project Team Co-Chairs, Dr. Janet Madill and Ms. Christine Wellington, Catherine Joyes provided an overview of the "Community Pharmacist Workshop" project that is currently under development.

SWAHN's Nutrition Project Team's focus is to engage health/human service providers and academics from different professions in addition to students and service users from across Southwestern Ontario in the development and implementation of interdisciplinary initiatives for nutrition-related concerns in the region. At present, the Nutrition Project Team has three different projects under development. Its workshop entitled '*Assessing Nutrition Risk in Seniors in the Community Pharmacy*' was highlighted at the SWAHN Conference.

SWAHN's pilot workshop will focus on building awareness of nutrition screening and assessment tools among community pharmacists. The rationale for this project is based upon a 2015 report from the Canadian Malnutrition Task Force (CMTF) which indicates that 45% of patients admitted to medical and surgical units in Canadian hospitals are malnourished. *(A news release on the CMTF study can be found here: http://www.newswire.ca/news-releases/landmark-study-reveals-that-malnutrition-is-a-serious-yet-avoidable-emergency-in-canadian-hospitals-529755861.html)*

Given this statistic, it is important to ensure that health care professionals are informed about the impact of malnutrition on a patient's length of stay, morbidity, and hospital readmission rates. Community pharmacists are often one of the first points of contact upon discharge from the hospital. As a result, SWAHN's Project Team has chosen to target community pharmacists in Waterloo for the workshop. While the workshop will introduce participants to various screening and assessment tools, the *SCREEN IIAB* will be the primary focus given that it has been validated for use in community health care settings for use with senior patients.

In addition to learning about the *SCREEN IIAB*, participants will learn about available community resources for patient nutrition support (post screening) from registered dietitians who will also be engaged in the workshop. The ultimate goal of the workshop is to create a model of knowledge translation that, once proven, can be transferred across the SWAHN region.

A submission for research ethics approval for this project is currently underway at the University of Waterloo to permit project evaluation which will inform modifications for future workshops. Participant surveys will also allow the project team to determine if the screening tool was actually implemented in community pharmacies – and if not, the data will advise the team about barriers to delivery.

This will be the first SWAHN event held at the University of Waterloo's School of Pharmacy. The event, scheduled for March 2018, aligns with both "Nutrition Month" and "Pharmacist Awareness Month."

CONFERENCE THEMES & NEXT STEPS

Based on feedback gathered from the breakout session notes and conference participant evaluation forms, various themes and points for future action were identified.

Indigenous patient experience:

- The SWAHN Conference discussion was just a starting point. There is a long way to go due to historical and deeply rooted challenges and barriers.
- The Indigenous voice remains underrepresented in all aspects of healthcare. Representation needs to be improved across health care structures.
- Institutions should play a role in promoting Indigenous cultural training among faculty/staff.
- Partnerships between health care institutions and Indigenous communities are necessary to enhance mutual learning and to build trust and mutual respect.
- The use of tangible artifacts within institutions (e.g., hospital waiting areas) will help to create safe and welcoming environments for Indigenous patients and staff.
- Meetings with Indigenous community representatives should be arranged in a circle to reduce power imbalances (i.e., deconstructing hierarchies).
- Face to face meetings are preferable than telephone/video meetings.
- Start the process to address the incorporation of the Indigenous world and whole person view into overall health care.
- Share information.

Patient partnerships:

- The concept of “health literacy” is important.
- Patients and their caregivers need to be empowered and engaged in all aspects of health care system design/planning, research, and clinical decision making.
- Practical information and practitioner resources are needed regarding how to meaningfully engage patients/the patient voice for example:
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    - how to implement patient partnership frameworks
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Other:

- The concept of narrative medicine was also referenced several times in the conference evaluation forms as was learning about the Indigenous patient experience.

The themes noted above will be shared with the Network Contributors’ Roundtable (NCR) at its spring 2018 meeting for discussion. The Secretariat has also determined the following next steps:

- A shared learning opportunity will be developed for the NCR’s spring meeting where leading initiatives, strategies, leading practices, and/or research concerning Indigenous patient engagement in the health / health care sector are presented by SWAHN members.
- An update concerning the Change Foundation’s “Changing Care” initiative will be shared at the NCR table and will be highlighted on SWAHN’s website.
- The NCR and the Secretariat will explore how to apply narrative medicine to health care settings across the region.

APPENDICES

APPENDIX 1: OVERVIEW OF THE SOUTHWESTERN ACADEMIC HEALTH NETWORK (SWAHN)

The SouthWestern Academic Health Network's vision is to transform health in Southwestern Ontario through integrated excellence in research, education, and clinical practice. Its mission is to improve population health and be a national leader in health care, education, and research by:

- Leading the development of innovative and value-added education, research, evaluation, and knowledge;
- Accelerating the dissemination of research-based evidence and leading practices into clinical practice to enhance patient and population health outcomes, quality, accessibility and affordability of health care;
- Integrate innovative collaborative models of education within health care delivery and research;
- Engaging community partners, patients and families to inform the academic service integration;
- Identifying appropriate performance measures to monitor progress and performance;
- Enhancing and advancing synergy and the sharing of resources between our organizations for mutual benefit in integrated patient care, education and research.

In the fall of 2017, a newly developed organizational chart was approved by what is now SWAHN's former Steering Committee which was comprised of a subset of leaders from the Network's various funders. In the newly restructured SWAHN, the Steering Committee has become the Network Contributors' Roundtable (NCR) which is Co-Chaired by Dr. Gillian Kernaghan, President and Chief Executive Officer of St. Joseph's Health Care London, and Dr. Ken Blanchette, Associate Vice President, Academic at St. Clair College in Windsor. The NCR now includes representation from all of SWAHN's financial contributors, ensuring that they have an opportunity to participate equally in priority setting and strategic planning for the future – rather than being bound by particular Committee terms.

St. Joseph's Health Care London, St. Clair College, and other organizations provide financial support to the Network and include area hospitals in London, Windsor, Sarnia, Stratford and Owen Sound; universities and colleges (including Western University, University of Windsor, University of Waterloo, Fanshawe College, St. Clair College, and Lambton College); community and research organizations (Erie St. Clair Hospice Palliative Care Network and Lawson Health Research Institute); and Local Health Integration Networks (LHINs) in the South West and Erie St. Clair regions.

Dr. Robin Walker, Integrated Vice President Medical Affairs and Medical Education, London Health Sciences Centre and St. Joseph's Health Care London, and Dr. Davy Cheng, Vice Dean, Faculty Affairs, Schulich School of Medicine & Dentistry at Western University are SWAHN's Co-Leads in the areas of Interprofessional Collaboration and Knowledge Generation & Translation. Projects in these two streams align to SWAHN's focus on research, education and clinical practice. These projects address priorities for the region including palliative care, interprofessional education, Choosing Wisely, research ethics, and nutrition.

SWAHN's value proposition focuses on facilitating interprofessional collaboration, networking, and knowledge-sharing opportunities across health-care related education, research, health service providers, and other stakeholders in Southwestern Ontario to identify gaps and to improve the health of individuals, families, communities, and systems.

APPENDIX 2: SWAHN CONFERENCE PLANNING TEAM

The following individuals contributed their expertise, ideas, and efforts in the preparations leading up to the October 13, 2017 conference and at the event itself. SWAHN is grateful for their ongoing support and commitment.

- Dr. Doug Jones, SWAHN Conference Planning Team Chair; Vice Dean, Basic Medical Sciences, Schulich School of Medicine & Dentistry, Western University;

- Ms. Vanessa Ambtman-Smith, Indigenous Health Lead, South West Local Health Integration Network

- Dr. Davy Cheng, SWAHN Co-Lead; Vice Dean, Faculty Affairs, Schulich School of Medicine & Dentistry, Western University

- Dr. Karen Danylchuk, Committee Member, Associate Dean, Undergraduate Programs, Faculty of Health Sciences, Western University

- Dr. Robin Walker, SWAHN Co-Lead; Integrated Vice President, Medical Affairs & Medical Education, London Health Sciences Centre & St. Joseph's Health Care London

- Ms. Catherine Joyes, SWAHN Manager

SWAHN would also like to extend thanks to the many volunteers from Western Health Sciences, Schulich School of Medicine & Dentistry, and other Western University staff who helped to make the conference a success by serving in various ways throughout the day for set-up, registration, troubleshooting, and tear-down. This assistance was greatly appreciated!

- Mr. Jess Bechard, Faculty of Health Sciences
- Ms. Vicki Douvalis, Schulich School of Medicine & Dentistry
- Ms. Ronnine Elston, Schulich School of Medicine & Dentistry
- Mr. Neil Fulford, Faculty of Health Sciences
- Ms. Debra Hawthorne, Faculty of Health Sciences
- Dr. Kathryn Nicholson, Postdoctoral Fellow, McMaster University
- Mr. Greg Postma, Faculty of Health Sciences
- Mr. Zak Zia, SWAHN Assistant
- Western Great Hall Catering
- Western Parking Office
- Western Room Booking Office

A special thank you is extended to Mr. Michael Barrett, CEO, South West Local Health Integration Network for facilitating the involvement of the actors/playwright in presenting *How the Circus Vanished*.

Finally, SWAHN would like to acknowledge the many conference speakers and facilitators for their significant efforts to inform and lead discussion based on the patient voice and experience theme through thoughtful presentations and interactive sessions.

APPENDIX 3: BREAKOUT SESSION QUESTIONS

SWAHN Conference 2017
Theme: "The Patient Voice & Experience in Southwestern Ontario"
Friday, October 13, 2017

BREAKOUT DISCUSSIONS

We have arranged for two concurrent one-hour breakout sessions this afternoon to further explore patient partnership frameworks and the Indigenous patient experience based on the information shared during the morning presentations. Before the discussion begins, each breakout group will need to elect a note taker. A synopsis of the discussion points will be shared with all conference participants once we reassemble after the breakout sessions have concluded.

Considering the presentations that we have heard today, please discuss the following questions and record your discussion points on the poster paper provided.

Breakout session: Patient Partnerships

1. What specific recommendations/information did you learn from the Health Quality Ontario and St. Joseph's Health Care London experiences that will help you to consider implementing a similar project in your institution?

2. What additional information, resources, and support are needed to enhance engagement of patients/families in projects?

3. What are your recommendations for SWAHN's next steps concerning the advancement and/or implementation of patient partnership framework initiatives in the region?

Breakout session: Indigenous Patient Experience

1. What did you learn from today's presentation of *How the Circus Vanished* as well as from what Dr. Samantha Boshart has shared that will help guide your organization in improving the experience and engagement of Indigenous patients?

2. What additional information, resources, and support are needed to enhance this work?

3. What are your recommendations for SWAHN's next steps concerning the advancement of improved Indigenous patient care engagement and experience initiatives in the region?

APPENDIX 4: BREAKOUT SESSION DISCUSSIONS - V*erbatim transcription of notes*

Breakout Session #1: The Indigenous Patient Experience

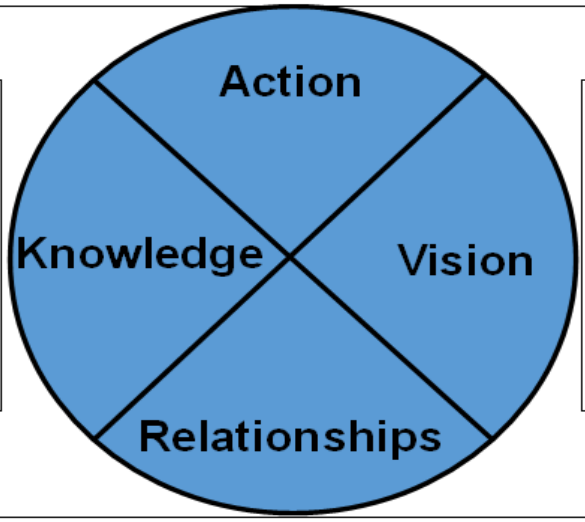
- How can we "live in the question"?
    - What can we/I do for your care?
- How can we make the patient environment safe to be in?
    - What are the differences between the "Indigenous experience" and other patient experiences
- What tools exist/tangibles to promote an inclusive environment/reconciliation?
    - Indigenous cultural safety training foundation—now what?
    - Tolerance scale
- How can we demonstrate that out healthcare 'spaces' are for Indigenous peoples?
- Connect w/local Indigenous communities
- How are we going to change the dynamic – Indigenous/non-Indigenous relationships
- Sharing stories = healing
- Silencing experiences = suffering
- How can we start talking about bias?
- Ceremony = primary care; good patient care
- How to better support Indigenous chronic disease/diabetes population?
    - Can't separate disease from everything else in life → Far beyond clinical
- Roots/barriers to illness
    - Much deeper than conditions/disease
- Profound structural barriers
    - Structures we live under powerful, and they can be changed
- Address social determinants of health; systemic approach
- Approach → needs to be altered
    - Incorporate Indigenous worldview
- Change "I can't" to "I can"
- How do you address structural barriers?
    - Reciprocity & inclusion – learning from one another
    - Self-determination
    - How do people see help can be offered
- Create bridges
    - Model of care built on western worldview
- Indigenous advisory that can re-design structures/programs
    - Who informs care matters
- Indigenous voices underrepresented in all aspects
    - healthcare
    - municipalities
    - governance
- How is 'power' shared in the Indigenous community?
    - deconstruct hierarchy
    - engage in conversation
    - mutual agreements
    - develop trust → validate knowledge
- Keep asking questions
    - e.g. how can we improve the Indigenous patient experience (the Bluewater Health example)

APPENDIX 4: BREAKOUT SESSION DISCUSSIONS - *Verbatim transcription of notes* – (continued)

Breakout Session #1: The Indigenous Patient Experience (continued)

Discussion Summary:

- How can we make the (Indigenous) environment safe for Indigenous patients ongoing education
- keep asking questions --> live in the question: what can I/we do for you care?
- share stories/stop silencing Indigenous voices
- change "I can't" to "I can"
- address root causes (distal/structural determinants)



- What tools exist?
- understand colonization -- power imbalances; implicit bias
- understand that there is an Indigenous worldview
- Indigenous cultural safety/ tolerance scale
- mutual learning from one another
- trauma/violence informed

- To improve the Indigenous patient experience:
- develop trust
- follow self-determined actions
- look beyond physical health/ illness
- whole person
- reciprocity
- respect

- create new relationships on an equal footing
- sit in a circle (deconstruct hierarchy)
- engage in conversation (inclusion)
- create an agreement (validate knowledge)
- build new structures (Indigenous led/specific)
- create inclusive environment
- don't be scared to show vulnerability

APPENDIX 4: BREAKOUT SESSION DISCUSSIONS - *Verbatim transcription of notes* – (continued)

Breakout Session #2: Patient Partnerships

1. **What specific recommendations/information did you learn from the Health Quality Ontario and St. Joseph's Health Care London experiences that will help you to consider implementing a similar project in your institution?**
   - concept of Health Literacy is important
   - engage patients in design of webpages

2. **What additional information, resources, and support are needed to enhance engagement of patients/families in projects?**
   - opening video from Cleveland clinic was very valuable
   - straightforward guidelines
   - practical information on how to meaningfully engage patient voice
   - information on what not to do
   - how to use patients effectively on committees
   - closing the loop – people see that their input was used, they are making a difference
   - what are other organizations doing to recruit Patient Advisors
   - education/orientation to P.A. role
   - meaningful work for P.A.
   - recruitment allows for diversity

3. **What are your recommendations for SWAHN's next steps concerning the advancement and/or implementation of patient partnership framework initiatives in the region?**
   - implementing patient partnership frameworks and sharing information with other hospitals
   - get patients to come to faculties and speak to students (we talked about patients speaking at conferences + meetings)
   - Ensure patient advisors participate on Workplace Violence work.

APPENDIX 5: CONFERENCE EVALUATION FORM

SWAHN SouthWestern Academic Health Network

~SWAHN 2017 Conference~
Friday, October 13, 2017
The Patient Voice & Experience
CONFERENCE EVALUATION

SWAHN would like to receive direct feedback and constructive recommendations from you in order to improve events like this one in the future. Please be as specific as possible in your ratings and comments. Thank you.

Conference objectives:

1. To engage SWAHN's contributors in knowledge sharing
2. To provide an opportunity for SWAHN volunteers to network
3. To highlight SWAHN's recent activities and successes
4. To provide an update on SWAHN's restructuring process

In your opinion how would you rate this event on the following factors? (Please circle the appropriate number)

Please use the scale: 5 = strongly agree to 1 = strongly disagree					
a) The event's contents were relevant to me.	5	4	3	2	1
b) The event satisfied my personal expectations.	5	4	3	2	1
c) The event allowed me to network with people from other organizations.	5	4	3	2	1
d) The event has motivated me to connect with peers from different organizations to potentially collaborate on projects.	5	4	3	2	1
e) The event increased my awareness and understanding of SWAHN's function, activities and successes.	5	4	3	2	1
f) The event increased my understanding of the value of SWAHN.	5	4	3	2	1
g) The content delivered by the morning speakers enabled me to have a greater understanding of the importance of engaging the patient voice and experience in academia, research, and clinical practice.	5	4	3	2	1
h) I was able to make a meaningful/significant contribution to today's breakout group discussions.	5	4	3	2	1
i) Overall, the event was an effective learning experience.	5	4	3	2	1
j) I hope to attend future SWAHN events based on my experience today.	5	4	3	2	1
k) Commercial influence did not bias today's event.	5	4	3	2	1

1. Which breakout group session did you attend?

A. Patient partnerships

B. Indigenous patient experience

APPENDIX 5: CONFERENCE EVALUATION FORM (continued)

2. **What was the most important thing that you learned today?**

_____
_____
_____

3. **Describe at least one thing that you will do differently based on what you learned today.**

_____
_____
_____

4. **Specify any changes that you think would have made this SWAHN event more effective.**

_____
_____
_____

5. **What advice do you have for SWAHN regarding its role in helping to increase awareness on the patient voice and experience across Southwestern Ontario to provide value to its stakeholders?**

_____
_____
_____

6. **What topics would you like addressed at future SWAHN events?**

_____
_____
_____

7. **Please provide any additional comments about today's program.**

_____
_____
_____
_____

Thank you for completing this evaluation form.
If you would like to be involved with SWAHN in its work, please let us know!

APPENDIX 6: CONFERENCE EVALUATION FORM RESPONSES

Responses to Likert Scale Questions: Using the following scale (5=strongly agree to 1=strongly disagree), participants responded as follows.

In your opinion how would you rate this event on the following factors?

Please use the scale: 5 = strongly agree to 1 = strongly disagree	
a) The event's contents were relevant to me.	4.82 (22 Responses) 96.4%
b) The event satisfied my personal expectations.	4.68 (22 Responses) 93.6%
c) The event allowed me to network with people from other organizations.	4.50 (22 Responses) 90%
d) The event has motivated me to connect with peers from different organizations to potentially collaborate on projects.	4.50 (22 Responses) 90%
e) The event increased my awareness and understanding of SWAHN's function, activities and successes.	4.68 (22 Responses) 93.6%
f) The event increased my understanding of the value of SWAHN.	4.60 (20 Responses) 92%
g) The content delivered by the morning speakers enabled me to have a greater understanding of the importance of engaging the patient voice and experience in academia, research, and clinical practice.	4.77 (22 Responses) 95.5%
h) I was able to make a meaningful/significant contribution to today's breakout group discussions.	4.14 (21 Responses) 82.9%
i) Overall, the event was an effective learning experience.	4.68 (22 Responses) 93.6%
j) I hope to attend future SWAHN events based on my experience today.	4.64 (22 Responses) 92.7%
k) Commercial influence did not bias today's event.	4.86 (22 Responses) 97.3%

1. Which breakout group session did you attend?

A. Patient partnerships → 8/19 (42.11% of respondents).
B. Indigenous patient experience → 11/19 (57.89% of respondents).

APPENDIX 6: CONFERENCE EVALUATION FORM RESPONSES (continued)

Verbatim narrative responses:

2. What was the most important thing that you learned today?

- Narrative medicine, the indigenous experience.
- Narrative studies.
- Narrative medicine.
- Patient voice strategies such as narratives, are important & should be incorporated into training of health care professionals.
- Narrative medicine.
- Narratives, indigenous.
- Patient experience – gives voice to people's story → "why" & opportunity to live fully.
- The importance of listening and meeting with Indigenous people face to face.
- Building relationships to support the indigenous patient experience.
- IPE.
- Great day – loved the play! Pts/caregivers as partners.
- That SWAHN exists, its terms of reference and networking.
- Narrative medicine.
- Need for healthcare literacy for patient portal.
- Narrative Medicine – wow!!! Amazing account.
- Major separation between academia & actual practice at Parkwood Hospital levels
- Learning about SWAHN
- Narrative & Listening
- Different research projects engaging patient care

3. Describe at least one thing that you will do differently based on what you learned today.

- Consult indigenous elders for hospital policies.
- Involving indigenous people in the conversation.
- IPC for teams as well as students.
- Affirmed values & priorities I already had but gave me new purpose & resolve.
- Narratives.
- Ask and show me.
- Not email my Indigenous contact but sit and meet with her and gain more knowledge about the communities we serve.
- Learn from Indigenous groups.
- Loved reminder about narrative medicine.
- Team up with other patient/caregiver committees in Southwestern Ontario.
- I will take the pt-engagement learnings back + put that knowledge into our practice.
- Connect with other hospitals patient advisorys [*sic*].
- Narrative medicine considerations.
- MORE
- Nothing.

APPENDIX 6: CONFERENCE EVALUATION FORM RESPONSES (continued)

Verbatim narrative responses:

4. **Specify any changes that you think would have made this SWAHN event more effective.**
   - More time for Q + A with presenters.
   - Add membership contact list for future networking. Thanks.
   - Introduction or mention of constituencies present.
   - WIFI provided for guests.
   - Introduce representative orgs.
   - None.
   - NONE.
   - It was a very good event – really meaningful play – glad it was included.
   - I would have liked to have seen more emphasis on patient advisory groups not just CARE
   - None.

5. **What advice do you have for SWAHN regarding its role in helping to increase awareness on the patient voice and experience across Southwestern Ontario to provide value to its stakeholders?**
   - Reach out to more frontline staff, more social media.
   - Not promoted enough.
   - Involve more patient voices on design team.
   - N/A.
   - Champion and use influences @ every level to drive change.
   - NONE.
   - Communicate.
   - Spreading existing knowledge – learn from one another if practices already in place in other hospitals. Practical tips of engagement.
   - Continue work with students, follow them through as they start their clinical and are influenced by other providers.
   - Broader network.
   - Focus on patient's caregiver (partner in care) as part of the patient healthcare team. Embrace designated family member.
   - Support for effectiveness of patient advisory councils in health care facilities. How patients can effectively collaborate with health care.

6. **What topics would you like addressed at future SWAHN events?**
   - Youth mental health, addiction vs. disease model.
   - What new + relevant topics should be incorporated in health care prof'l training. Navigating the healthcare system from a patient perspective.
   - Case study methods – grant proposals. Lobbying political action.
   - Ageing?
   - Thanks for making ppt available. PC group + other (project teams) to present where they are.
   - Emphasis on POVERTY + its effect on healthcare. It's role in malnutrition? Availability of medication? etc.

APPENDIX 6: CONFERENCE EVALUATION FORM RESPONSES (continued)

Verbatim narrative responses:

7. Please provide any additional comments about today's program.

- This was a wonderful conference. I wish it was longer (2 days?) It was so eye opening and I'm leaving here with so much more to think about and some wonderful contacts. GREAT JOB.
- Discussion of "meaning" of the play would have helped. Some did not see value in the play.
- I was disappointed there was no free WIFI available.
- Awesome day, great speakers.
- Incredible day! Thanks!
- Thank you so much. Great day!
- Great networking experience.
- Excellent day!
- It was great, I wish I could have attended both breakouts.
- Great day.
- Enjoyed the play + its message
- THANK YOU

APPENDIX 7: CONFERENCE ATTENDEE LIST

SWAHN would like to thank the following individuals who attended the conference. Any errors or omissions are unintended. In recognizing these individuals, please note that the content and analysis of these proceedings should in no way be interpreted as a reflection of their individual opinions or those of their organizations.

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