ALLIANCE BREAKFAST MEETING HIGHLIGHTS

DATE: October 21st, 2018
TIME: 7:30 am EDT
LOCATION: Delta Hotel, Toronto
ATTENDEES

SECRETARIAT

Dr. Thais Coutinho (Chair)
Dr. Robert Reid
Dr. Malia Murphy
Ms. Sabrina Pillay, MSc

PATIENT ADVISORY COMMITTEE

Ms. Jackie Ratz (Co-Chair)
Ms. Donna Hart (Health Systems and Policy)

WORKING GROUPS

ADVOCACY

Ms. Wendy Wray, MScN
Dr. Lorraine Avery
Dr. Olga Toleva
Dr. Kelsey McLaughlin
Dr. Rajni Nijhawan

TRAINING AND EDUCATION

Dr. Beth Abramson
Dr. Carolyn Baer
Dr. Judy Luu
Dr. Martha Mackay

HEALTH SYSTEMS AND POLICY

Dr. Colleen Norris
Dr. Marie-Annick Clavel
Ms. Donna Hart

KNOWLEDGE TRANSLATION AND MOBILIZATION

Dr. Sharon Mulvagh
Dr. Christine Pacheco
OVERVIEW
On October 21, 2018 the Canadian Women’s Heart Health Centre hosted a breakfast meeting to allow newly established Alliance members attending the Canadian Cardiovascular Congress or living in the Toronto area to meet face-to-face, obtain highlights from the Working Group meetings underway and to discuss strategies to ensure the Alliance Working Groups have a coordinated, cohesive, and impactful approach to moving forward.

BACKGROUND
The Secretariat initiated the meeting and introduced themselves. Dr. Coutinho provided members with background, context, and rationale behind the formation of the Canadian Women’s Heart Health Alliance, a need which was identified through the Canadian Women’s Heart Health 2016 Summit Call to Action meeting, key informant interviews, and a pre-event survey. Outputs from these activities were discussed at an Alliance kick-off meeting held in April 2018 and four key areas of focus were identified, by which the Alliance Working Groups were defined.

The Alliance governance structure has been established and includes the four Working Groups, a Patient Advisory Committee, an International Advisory Committee, a Steering Committee and a Secretariat.

MEMBERSHIP
Since April 2018, four Working Group Chairs and two patient partner Co-Chairs for the Patient Advisory Committee have been appointed. Out of 70 applicants, 55 members have been recruited for the Alliance Working Groups and Committees, 14 of whom are patient partners.

The Alliance has pan-Canadian representation and is comprised of clinicians, scientists, allied health, and program managers, and patient partners with various professional and personal experiences in advocacy, education, knowledge translation, law, telecommunications, engineering, human resources, and psychology. Steering Committee membership recruitment is underway and will be solidified for the first meeting on November 22nd, 2018.

PERSPECTIVES FROM A PATIENT PARTNER
Ms. Hart, a member of the Health Systems and Policy Working Group and Patient Advisory Committee shared her experience as a woman who was diagnosed with heart failure and who subsequently received a heart transplant. Having been vigorously active and healthy up until 2014, Ms. Hart reflected on the signs and symptoms leading up to her diagnosis that went unrecognized, and what she and her health providers could have done differently.

Key messages from Ms. Hart included a need to educate health care providers about signs and symptoms of heart disease in women to prevent women from being “stopped at the gate”, and to refer more women to cardiac rehabilitation programs. Ms. Hart also spoke to the importance of enhancing the quality of communication with patients to prevent misunderstandings, and include them in research to ‘level the playing field’ and help save women’s lives.
WORKING GROUP KICK-OFF MEETINGS

Between October 9th and 12th 2018, the Health Systems and Policy, Advocacy, and Training and Education Working Groups conducted their first meetings, held virtually over WebEx. Chairs co-facilitated meetings with Dr. Lisa Petermann, an external consultant who also facilitated the April 2018 Alliance kick-off meeting. Attendance at each of the working group sessions was high and there was much participation and enthusiasm from all members. The Knowledge Translation and Mobilization Working Group, and Patient Advisory Committee will have their meetings on November 6th, 2018 and November 13th, 2018, respectively. Working Group Chairs briefly discussed their meeting highlights.

1. Health Systems and Policy Working Group (HSPWG) | Chaired by Dr. Norris

Nine initial priority areas for the HSPWG were identified from the synthesis of responses to the Expressions of Interest, the Alliance kick-off meetings and the HSPWG discussion. Among these priorities was the creation of a women’s specific version of the Framingham Risk Score. A survey was sent out to the HSPWG members to help further prioritize deliverables. Dr. Norris suggested that it might be more impactful if the four Working Groups could collaborate to identify and work towards common deliverables.

2. Advocacy Working Group (AWG) | Chaired by Dr. Sedlak

Dr. Sedlak was unable to attend the meeting so the highlights were provided by Dr. McLaughlin. The AWG identified specific deliverables: a social march, movement or awareness event to be implemented for February 13th, 2019; and the development of an advocacy toolkit.

There was discussion as to whether a march would be feasible during the winter, or if an event promoting woman’s cardiovascular health awareness through community, workplace or organizational efforts (e.g. wearing red) would be more feasible. The members at large identified the importance of capitalizing on existing successful events and hash tags. Collaboration with Heart & Stroke was determined to be essential.

Development of a Women’s Heart Health slide deck which compiles patient experiences, current data and gaps in knowledge and practice, was suggested as way for Alliance members raise awareness in their own institutional networks. The AWG also discussed development of an advocacy toolkit but further discussion is required to determine whether the toolkit users should be community advocates or health providers.

3. Training and Education Working Group (TEWG) | Chaired by Dr. Abramson

The TEWG discussed developing training modules, establishing women’s heart health sessions for trainees at future CCC events, and podcasts as possible working group deliverables. Still to be determined is whether patients or health providers should be the focus for the first project, as well the process to deciding on content (e.g. disease-focused). A survey will be sent to the TEWG membership help prioritize.

Dr. Abramson observed that some of the other Working Groups deliverables overlapped with those of the TEWG and identified a need to avoid duplication. She asked the attendees how they felt about each working group focusing on different priorities.

4. Knowledge Translation and Mobilization Working Group (KTMWG) | Chaired by Dr. Mulvagh

The KTMWG will be meeting on November 6th. Dr. Mulvagh spoke to the KTMWG deliverables that had been previously identified. These included creating new women-specific guidelines and integration of women specific content into existing resources. She also highlighted the importance of procuring funding to sustain
DISCUSSION AND QUESTIONS
Dr. Coutinho facilitated a discussion period during which time members were asked to identify strategies that could be employed to ensure that the working group priorities are aligned, and that the Alliance is impactful. **Key points from this discussion included:**

- Based on the comments regarding the gaps in health provider knowledge and practice as it pertains to women's heart health, causing women to be “stopped at the gate” the Alliance's initial efforts should focus on healthcare providers.

- There is a need to coordinate priorities and activities across Working Groups. It’s important that Working Groups share their deliverables with other groups to avoid redundancies. This will also allow Members to provide a 360-degree approach to the chosen area(s) of focus, thereby increasing chances of success.

- The Alliance should capitalize on the expertise of its various members. This may involve cross Working Group consultation as members in one Working Group may have expertise to lend on a project led by another Working Group.

- Prioritizing Working Group activities by disease process may not be the best way forward.

- The creation and publication of a position statement, which gathers all the evidence to date, was mentioned as a first step to guide alliance activities. The focus of such statement is still to be defined.

- Another important aspect to be addressed is the marginalization of women’s cardiovascular health in scientific documents and conferences (for example, by assigning lectures and manuscripts of this topic to “Special populations”, or perpetuating a concept that women are “atypical” when it comes to cardiovascular disease).

SCALING NATIONAL INITIATIVES
Dr. Reid, Deputy Chief of the Prevention and Wellness Centre who has experience in scaling initiatives such as the Ottawa Model for Smoking Cessation, spoke to the importance of creating value and responding to a business need in order to be successful. In order to select specific outputs from the Working Groups, Members must consider the overall need for each candidate output. Dr. Reid spoke to the importance of engaging decision makers and opinion leaders such as the Chiefs of Cardiology, and Cardiac Surgery - most of whom are men - in the development, implementation and dissemination of Alliance outputs.

GOING FORWARD
The following items were identified as key next steps for Alliance Members, in order to ensure progress:

- Each working Group will narrow down priorities for action within their respective mandates. This can be done with surveys within each Group.

- A meeting including the 4 Working Group Chairs and members of the Secretariat will be organized to help align Working Group priorities (i.e.: decide on a few critical priorities for action that will be approach by each Working Group from the perspective of their mandate).

- Once priorities have been solidified, Members will engage in writing the Vision and Strategic Priorities of the Alliance, which will then guide activities going forward.
NOVEMBER 2018

- NOVEMBER 6TH: KNOWLEDGE TRANSLATION WORKING GROUP MEETING 1
- NOVEMBER 13TH: PATIENT ADVISORY COMMITTEE MEETING 1
- NOVEMBER 16TH: FINALIZATION OF STEERING COMMITTEE WORKING GROUP CHAIR MEETING
- NOVEMBER 21ST: STEERING COMMITTEE MEETING 1
- NOVEMBER 22ND: CROSS-WORKING GROUP PRIORITIZATION SURVEY DUE
- NOVEMBER 30TH: CROSS-WORKING GROUP PRIORITIZATION SURVEY DUE

DECEMBER 2018

- DECEMBER 7TH: TRAINING AND EDUCATION WORKING GROUP MEETING 2
- DECEMBER 14TH: ADVOCACY WORKING GROUP MEETING 2

JANUARY 2019

- JANUARY 14TH: KNOWLEDGE TRANSLATION AND MOBILIZATION MEETING 2
- JANUARY 15TH: HEALTH SYSTEMS AND POLICY WORKING GROUP MEETING 2
- JANUARY 31ST: ADVOCACY WORKING GROUP MEETING 3