BeACCoN Advisory Committee Meeting – May 2nd, 2018

Notes and Action Items

Meeting Objectives

- Advice on Metrics and Infrastructure
  - Patient and Caregiver Generated Data
  - Relevance and Potential Partnerships
- Advice on Evaluation Framework
  - Patients First Learning Health System
  - Relevance and Potential Partnerships
- Advice on Innovations for Complex Needs
  - Segmentation/Playbook
  - Relevance and Potential Partnerships

Background

BeACCoN Research Priorities as Approved at April 2017 Advisory Committee Meeting

1. Community and self-management innovations for complex patients with multi-morbidity and their caregivers to support the goals of keeping them in the community as long as possible while providing them with the best care in the right setting and ensuring smooth transitions in care.
2. Cross-sector innovations to help support the smooth transition of youth to the “adult” primary, community and social care system, especially those with complex needs (complex health problems and/or technological dependence including mental health issues, developmental delays or congenital/acquired neurological or cognitive impairment).
3. Innovations that connect primary health care to provincial, municipal and community supports and/or social services that address upstream social determinants of health (housing, food, income, education) for complex needs individuals, including individuals with mental health and addictions issues.

MOHLTC Health System Research Fund and SPOR Renewal Updates

- CIHR’s Strategy for Patient-Oriented Research has contributed to an important shift in the way that health funders, work with patients, communities and services providers to improve the health care system. The ministry acknowledges the excellent work that has been undertaken to date by OSSU, the Research Centres, Networks and BeACCoN to create the supportive patient oriented research environment necessary for this paradigm shift. Ontario’s Health System Research Fund (HSRF) has also made the shift to patient oriented research creating significant opportunities for collaboration through two targeted calls:
  - HSRF Targeted Call for Patient Oriented Research in Mental Health and Addictions (launched in January 2018)
  - HSRF Targeted Call Program for Patient Oriented Research on Health system Integration and Performance (launched in March 2018).

  The ministry has adopted an innovative approach to its review process. An integrated panel of scientists, ministry knowledge users, and people with lived experience/patients contribute and participate in review and merit panel meetings

- SPOR renewal and HSRF provide a unique opportunity to broaden and deepen Ontario's commitment to patient-oriented research and innovation for a person-centred care that supports rapid learning and deeper health system improvement.

Advice on Metrics and Infrastructure

Discussion of Patient and Caregiver-Generated Data

Relevance

There was consensus that understanding the "patient story" is central to patient-oriented research. At a minimum, this story should include patient-reported outcomes (PROMs) and patient reported experience (PREMs). Ideally, the story would allow for a narrative from the patient or caregiver that provides a nuanced and personal description of their health and their experience with care. Inherent in the collection of these types of data, is the consent from the patient or caregiver. It was suggested that patient-generated data on outcomes and experience are essential elements in the evaluation of health care innovation.

Consent was identified as a key priority. Consent should involve agreement on who can have access to the data, if it can be linked to other data and if it can be used for research and evaluation. Patients and caregivers should have consent options around the specific types of data that will be used. To help provide a positive context for consent it was suggested that individuals who provide data for research or evaluation have the opportunity to know which specific studies used their data and to be acknowledged for providing their data for research and evaluation. Additionally, the importance of engaging with specific populations (i.e. Indigenous communities) about ownership and use of their data was also raised. There was agreement that collecting data using existing validated PREMs and PROMs was a first priority but that there were real opportunities to collect richer and more detailed data in the future. It was agreed that the data collection or capture process should be sensitive to patient and caregiver needs and abilities. It was also agreed that linkage of patient-generated data to other data sources would leverage the value of all data.

Partnerships

Patients and caregivers are the key partners in patient- and caregiver-generated data. It was agreed that they must be involved from the outset in any provincial effort to develop a strategy around collecting and using patient- or caregiver-generated data. This should include their involvement in developing the consent process around the use of the data, co-design of the any processes or tools to collect the data and developing a process to acknowledge to value of the data in research. Along with patients and caregivers it was felt that working with primary care physicians and linking patient-generated data to EMR provides an opportunity to develop a real-time system that could both improve care and provide data for research. It was recognized that other partners would include researchers and developers who were working on patient-generated data collection tools and research teams and policy makers (i.e. LHINs and PFACs) who could use these data to evaluate health system innovation.

Action Items – Key Agreements

- Person/caregiver-generated data should be a priority for BeACCoN.

- BeACCoN should play a convening role in bringing key stakeholders, most importantly patients and caregivers, and including researchers, policymakers and groups developing and studying tools, and the information from those tools, for data collection to better understand the issues and guiding principles around consent, collection and use of patient-generated data.

Advice on Evaluation Framework

Discussion of *Patients First Learning Health System Concept*

Relevance

There was discussion around the Learning Health System (LHS) concept as a way to support health system transformation at the provincial level. The OSSU renewal planning framework supports a patient-centered learning health system approach. The new national PIHCIN NCO provides an opportunity to build a useful system-level approach at a pan-Canadian level.

Patients and caregiver engagement is central to LHS concept. The requirement for patient engagement across the spectrum was recognized. This should include the resources and funding required to support this, such as training and support for patient and caregiver advisors. There was agreement that the SPOR National Data Platform (NDP) should support a LHS approach and that the platform should include a wide range of data including primary care EMR data and patient-generated data.

Partnerships

There was widespread agreement that a LHS approach should be a collaborative effort between BeACCoN and the other SPOR networks based on a SPOR NDP. The chronic disease networks are working to consolidate SPOR projects with strategies from across the country and Ontario is the leader in many of these areas. It was also emphasized that patients and frontline care providers must be actively engaged in order for the LHS approach to be successful.

Action Items - Key Agreements

- BeACCoN to work with OSSU and the national SPOR enterprise in supporting the notion of a LHS and a comprehensive SPOR NDP
- BeACCoN should focus its efforts provincially around a well-defined and specific demonstration of the LHS approach
- The MOHLTC efforts to create a governance structure and framework around data access is an important aspect of the LHS approach and should be supported by BeACCoN.

Advice on Innovations for Complex Needs

Discussion of the Segmentation/Playbook Strategy

Relevance

Research led by the Commonwealth Fund has shown that segmenting complex needs populations into groups with similar health and social care needs and then targeting delivery system innovations that provide integrated patient-centered care appropriate for that group – the segmentation/playbook strategy - can improve outcomes and control costs. BeACCoN has worked with Diabetes Action Canada

(DAC) and the TC LHIN on the implementation of this strategy for diabetes care. There was agreement that LHIN sub-regions would be a good target for this strategy and that diabetes is a good use case. This work builds nicely on the provincial SPOR investment.

Partnerships

There was discussion about using TC-LHIN/DAC/BeACCoN partnership as an example and moving it forward, while leveraging resources from across the province. It was suggested that BeACCoN could consider approaching other academic sites across the province (such as London and Hamilton) and partnering with institutions such as the Population Health Solutions Lab on the segmentation/playbook strategy. It was also recognized that there might be opportunities to partner with Saint Elizabeth who have a new innovation arm, MaRS, and private insurers (i.e. Sunlife), etc.

There was also discussion around the importance of cross-sectoral work. BeACCoN should continue finding connections and looking for opportunities to link people together beyond healthcare. BeACCoN could help connect where people know there are others doing good work but may not have the time to find the commonality between their work.

Action Items – Key Agreements

- BeACCoN to continue partnership with DAC and TC LHIN with a focus on diabetes
- BeACCoN to look for opportunities beyond TC LHIN and to broaden the partnership
- Build on the work with the Commonwealth Fund and link to MOHLTC and national efforts

Appendix 1 – List of Attendees

Adalsteinn Brown – Interim Dean, Dalla Lana School of Public Health, University of Toronto

Erika Runions MacNeil – Manager, Research Planning and Management Unit, Ministry of Health and Long-Term Care (MOHLTC)

Onil Bhattacharyya – Associate Professor, Department of Family and Community Medicine, University of Toronto; Frigon Blau Chair in Family Medicine Research, Women's College Hospital

Geoff Anderson – Research Lead, BeACCoN; Professor, Institute of Health Policy, Management and Evaluation, University of Toronto; Adjunct Scientist, Institute for Clinical Evaluative Sciences (ICES); Adjunct Scientist Women's College Hospital Research Institute

Ivy Wong – Network Director, BeACCoN

Kristen Pitzul – Manager, Data & Analytics, BeACCoN; Funding and Performance Advisor, Ontario Hospital Association

Julie Dunning – Network Manager, BeACCoN

Dara Gordon – Policy Research Coordinator, Institute for Health Systems Solutions and Virtual Care (WIHV), Women's College Hospital

Aileen Chan – Director, Health Data Branch, MOHLTC

Sherif Kaldas – Director, Health Sectors Model Branch, MOHLTC

Fredrika Scarth – Director, HQO Liaison and Program Development Branch, MOHLTC

Debra Bell – Manager, Strategic Policy Unit, Home and Community Care Branch, MOHLTC

Victor Castellino – Health System Planning Lead, Office of the Chief Health Innovation Strategist, MOHLTC

Jennifer Moloney – Team Lead, Policy Development and Implementation, MOHLTC

Deborah VanOosten – Senior Research/Planning Advisor, Research Planning and Management Unit, MOHLTC

Cindy Perry – Manager, Research and Evaluation Unit, Ministry of Community and Social Services

Eddy Nason – Assistant Director, Ontario SPOR SUPPORT Unit

Susan Fitzpatrick – Chief Executive Officer, Toronto Central Local Health Integration Network (LHIN)

Alvin Cheng – Director of Health Analytics and Innovation, Toronto Central LHIN

Miin Alikhan – Special Executive Advisor, Ministries of Health, Government of Ontario and Government of Alberta

Andrew Pinto – Public Health and Preventive Medicine specialist, Family Physician, St. Michael's Hospital; Scientist, Li Ka Shing Knowledge Institute; Assistant Professor, University of Toronto

Michelle Greiver – Family Physician, North York General Hospital; Deputy Director, UTOPIAN; Clinical Scientist at Department of Family and Community Medicine, University of Toronto; Scientist, North York General Hospital; Adjunct Scientist, ICES Central

Cathy Whiteside – Executive Director, Diabetes Action Canada (DAC) – A SPOR Network in Diabetes and its Related Complications

Alies Maybee – Patient Advisor, Patient Advisors Network (PAN)

Patrick Feng – Research Project Manager, Institute of Health Policy, Management & Evaluation, University of Toronto