Ten years ago, our small group of researchers and sector stakeholders began a deliberate journey to improve residential long-term care. As I think about the past ten years, Churchill’s words float in—*the first quality that is needed is audacity*. We started with a big idea—a 20-year horizon and a wide ranging scope—and with lofty aspirations for better care and quality of life. That idea was more than a little audacious. It did not occur to us that we might not succeed or that our goal was not shared by the majority or that we could not create a unique space for both improvements in care and exciting ideas to flourish. Neither did we appreciate the size of the task or the capacity building that would be needed. A decade later and perhaps half way—at least some way—into the journey, I am proud of what we have accomplished but more, I am eager to see us realize the significant potential that is there, ready to be tapped.

TREC’s core is a strong set of partnerships and relationships built with people from and responsible for the long-term care system. Those partnerships have matured and expanded to include our advisory groups of residents and family/friend caregivers, trainees, and international science experts. We now actively navigate between traditional science (ensuring our science is blue ribbon) and an arguably more socially responsible fully partnered science. The *democratization of knowledge* is a core value—the belief that research knowledge belongs to everyone, can be made useful, and can and will lead to change and improvements. We believe that in partnership this is achievable: that quality can be affordable and that solutions can be spread and scaled. In our shared work space, researcher and decision maker worlds overlap with common goals. We invest a lot of energy into this shared space as the key to our success—and we know that more energy will be required to grow and sustain those partnerships and that shared space as we go forward.

The hard evidence that we were and are on the right track will be ongoing measurable improvements in the lives of highly vulnerable and complex older adults, living their last stage of life in long-term care. We must mobilize the courage to continue being audacious.

*Don’t say the old lady screamed. Bring her on and let her scream.* (Mark Twain)
**VISION**
To contribute to quality of care and quality of life for older adults and quality of work life for care providers in transformed residential settings.

**MISSION**
Develop sustainable practical solutions and tools that improve the quality of care provided to older adults, enrich the work life of their caregivers, and enhance effectiveness in residential long-term care.

**TRANSLATING RESEARCH IN ELDER CARE (TREC)**
is a pan-Canadian health services research program concentrated in Alberta, British Columbia, Manitoba and the Atlantic provinces, with limited participation from Saskatchewan, Ontario and the Territories.

TREC aims to produce knowledge that improves elder care through a partnership of researchers, knowledge users, policy makers and those most affected—residents and their families. This partnership ensures that the research meets the needs of everyone in the residential long-term care sector. TREC currently includes 33 researchers, 19 core decision makers and 14 trainees (see Appendix 2). TREC comprises a multi-committee governance structure to meet its mission and goals, including an International Scientific Advisory Committee (see side bar), a Research Management Committee, a Data Management Committee, a Training Committee and our newest addition—the VOICES advisory committee.

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**ISAC MEMBERS**
Dorothy Pringle (Chair), Board of Directors, Associated Medical Services Inc., Toronto, Canada
Sube Banerjee, Professor and Director, Brighton and Sussex Medical School, UK
Francine Ducharme, Desjardins Research Chair, Nursing Care for Seniors and their Families, Université de Montréal, Canada
Jean-Louis Denis, Professeur titulaire, Chaire de recherche du Canada, DGEPS - École de santé publique, Université de Montréal, Canada
Julienne Meyer, Professor, City University, UK
Carole Estabrooks, Scientific Director, TREC

**NEW MEMBER**
Susan Mitchell, Professor, Harvard Medical School, USA

**FORMER MEMBERS**
Adalsteinn Brown, Professor and Chair, Public Health Policy, Dalla Lana School of Public Health, University of Toronto, Canada
Mary Ann Scheirer, Consultant, Scheirer Consulting, Princeton, USA

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**TABLE OF CONTENTS**

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Voices</td>
</tr>
<tr>
<td>4</td>
<td>TREC’s Beginnings</td>
</tr>
<tr>
<td>6</td>
<td>TREC Today</td>
</tr>
<tr>
<td>9</td>
<td>Advancing Affordable Quality of Care</td>
</tr>
<tr>
<td>12</td>
<td>Accelerating Spread of Quality Care</td>
</tr>
<tr>
<td>14</td>
<td>Supporting Evidence-Informed Policy</td>
</tr>
<tr>
<td>18</td>
<td>Improving Workforce Health and Well-Being</td>
</tr>
<tr>
<td>20</td>
<td>Improving Work Environment</td>
</tr>
<tr>
<td>23</td>
<td>Creating Legacy</td>
</tr>
<tr>
<td>26</td>
<td>Appendix 1: TREC Timeline: 2007-2017</td>
</tr>
<tr>
<td>28</td>
<td>Appendix 2: The TREC Team</td>
</tr>
<tr>
<td>30</td>
<td>Funders</td>
</tr>
</tbody>
</table>

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“The TREC team wants to leave a legacy. They want to see their research make a difference, to see a change happen. It’s not research for the sake of research. TREC has always been framed to make the system better.”

**CORINNE SCHALM, EXECUTIVE DIRECTOR**
CONTINUING CARE, ALBERTA HEALTH
VOICES OF INDIVIDUALS, FAMILY AND FRIEND CARE GIVERS EDUCATING US: INNOVATING RESEARCH GOVERNANCE

The VOICES (Voices of Individuals, Family and Friend Care Givers Educating Us) committee is composed of persons living with dementia and family or friend caregivers of residents in long-term care settings. This advisory committee gives input and feedback to TREC researchers, shaping the research agenda through new lenses.

“Engaging with every facet of the long-term care sector is critical to our research,” says TREC researcher Janice Keefe, co-chair of the VOICES committee. “VOICES provides really important insight that we’re often missing—this isn’t a lab; these are real people and these are real families. We’re very proud of this committee and we value their contributions and the different perspectives they bring to the table. It’s like walking in another’s shoes.”

One pair of shoes belongs to VOICES member Faye Forbes. A resident of Nova Scotia, Forbes was diagnosed with dementia seven years ago. Far from slowing her down, the news lit a new spark within her and Forbes has become a tireless advocate for people with dementia. “For me it’s really important to get the word out to people to dispel the stigma, to say that life goes on,” she explains.

THE IMPORTANCE OF PATIENT ENGAGEMENT

Engaging patients (or residents in long-term care) and family members in health research is increasingly vital in our society. This is the central principle of Canada’s Strategy for Patient-Oriented Research.

Members of the VOICES committee meet in Edmonton in March 2017.
TREC’s research and the VOICES committee were avenues where she felt she could contribute. “TREC’s work is probably not going to affect me but it will benefit those coming behind me. And my perspective is different than that of the researchers and the care givers. It’s important to get all those perspectives together and work collaboratively. I might feel something, see something, understand something differently than they do.”

TREC is leading the way with this advisory structure—Alberta Health Services and the government of Ontario both plan to set up similar advisory groups of seniors and long-term care residents. TREC also hopes to add two more advisory groups, as resources and capacity permit: front line workers and operators of nursing homes.

**VOICES**
- Graham Bond, Alberta
- Roberta Bishop, Manitoba
- Ken Chipeniuk, Alberta
- Phyllis Fehr, Ontario
- Heather Fifield, Nova Scotia
- Faye Forbes, Nova Scotia
- Barbara Kieloch, Manitoba
- Jim Mann, British Columbia
- Ruth Murphy, Alberta
- Alvin Schrader, Alberta
- Linda Young, British Columbia

**NAMING RESIDENTIAL FACILITIES FOR LONG-TERM CARE**
Numerous terms are used to describe facilities that provide 24-hour residential care for older adults, including “long-term care facilities,” “(personal) care homes” and “nursing homes.” In this impact report we mainly use “nursing homes.”
TREC’S BEGINNINGS
FINDING

Quality is made in “clinical Microsystems” or care units in nursing homes. In TREC we showed that if you look at resident outcomes or indicators only at the facility level you miss important unit-to-unit variances. TREC researchers work to report results at the microsystem level.


FRIENDS NO LONGER WITH US

TREC gratefully acknowledges the contributions of former TREC supporters who have passed away.

Sandy Cobban’s research on oral health in long-term care residents has left a legacy that continues today in TREC’s work.

Phyllis Hempel was an early TREC champion whose tireless work helped set the program on its path.

Christine Newburn-Cook fostered the development of the secure data repository within the Faculty of Nursing.

We honour their memories.

“The seeds for TREC were planted in 2005 while TREC researchers Carole Estabrooks and Peter Norton were studying the use of research in acute care. They were frustrated by the lack of data on patient outcomes, needing data that had been systematically collected over multiple years to measure their work against. They began to realize that their efforts could be more valuable elsewhere.

At the same time, rapid shifts in population aging and the dramatic increases in chronic health challenges such as dementia moved closer to centre stage. A small group of researchers and decision makers decided to refocus all efforts on a frail and highly vulnerable population that received little attention—the frail elderly living in nursing homes. With a $4.7 million grant from CIHR in 2007, TREC launched with the prairie provinces as its initial “laboratory.”

“We felt long-term care was an area where we could make a difference. And that belief is the glue that has kept us on this path for ten years.”

CAROLE ESTABROOKS
SCIENTIFIC DIRECTOR, TREC

The Greying Nation

By 2036 the number of Canadians over 65 is expected to double to 10.4 million and one third of seniors over 85 will have some form of age-related dementia. Up to 70% of people living with dementia will die in long-term care.

1 Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis (2014). Age Aging. Badrakalimuthu V, Barclay S.
TREC approaches improving the lives of nursing home residents from multiple directions:

- strategies to improve quality of care and quality of end of life care
- strategies to enrich the daily lives of residents
- strategies to improve quality of work life for staff
- strategies to assist managers, administrators, owners and policy makers with evidence-informed decision-making

Many TREC research studies identify specific targets that could yield significant improvements from relatively small changes at ground zero—directly for residents and the staff who care for them. Other studies target strategies to spread innovative and effective practices throughout the nursing home sector.

The platform for all TREC’s work is the longitudinal TREC Measurement System (TMS). The TMS has matured into a research technology that has been collecting resident, staff, care unit and facility data for 10 years now. It contains standardized observations on resident clinical and functional outcomes. In addition, it includes data on factors that influence their quality of care and quality of life and end of life. The TMS also captures data on characteristics of the front line workforce including indicators of health, and quality of work life for staff, gathered regularly through surveys and interviews. TMS data are from residents and all levels of staff in nearly 100 participating nursing homes in British Columbia, Alberta and Manitoba (and previously Saskatchewan).

From this TMS platform, TREC researchers develop and carry out smaller, short-term projects to create change on many fronts.

**BURNOUT AMONG CARE AIDES**

**HEALTH OF CARE AIDES**
Examines the physical and mental health of care aides. Does the workplace influence health? Are these health measures linked to modifiable resident outcomes, such as pain, behavioural problems, depression or use of physical restraints? Led by Matthias Hoben, University of Alberta.

**RESIDENT LENGTH OF STAY**
Examines how long residents live in nursing homes. Has this changed over time? How does it vary between different health regions? This project is also an opportunity to explore the effects of policies that aim to keep older adults living in the community longer. Led by Matthias Hoben, University of Alberta.

**PAIN**
Determines pain trajectories of residents six months before death. Understanding the extent of pain as residents near end-of-life is the first step toward solving it. Next steps are focusing on best practices in managing pain once it is identified. Led by Malcolm Doupe, University of Manitoba.
RESPONSIVE BEHAVIOURS OF PERSONS OR RESIDENTS WITH DEMENTIA

Examines aspects of nursing home work environments that contribute to aggressive behaviours among residents. Led by Liane Ginsburg, York University.

VARYING CLINICAL PROFILES OF RESIDENTS BY REGION

Investigates effects of different numbers of nursing home beds per capita in each province. Are differences associated with clinical complexity of newly admitted residents and consequences of varying admission practices? Led by Malcolm Doupe, University of Manitoba.

REGULATED STAFF

Analyzes demographic characteristics and health and work-related outcomes for regulated staff (nurses, occupational therapists, physiotherapists, etc.) in Western Canadian nursing homes. Led by Janet Squires, University of Ottawa.

ASSESSING WORK ENVIRONMENT (CONTEXT)

Simplifies our Alberta Context Tool into fewer categories for ease of use and interpretation, allowing us to assess nursing home work environment at the unit and facility level. How does context relate to quality of resident care and quality of work life for staff? Led by Peter Norton, University of Calgary.

CLINICAL TRIALS

Improving nursing home care through feedback on performance data (INFORM)

A randomized real world clinical trial. How does tailoring feedback to unit managers on the measured work environment build and accelerate their use of TREC research findings to influence change? Specifically, how does feedback influence work environment? How do cost and effectiveness differ with different levels of feedback? Led by Matthias Hoben, University of Alberta; Liane Ginsburg, York University; Peter Norton, University of Calgary and Carole Estabrooks (PI), University of Alberta.

Safer care for older persons in residential environments (SCOPE)

A randomized real world clinical trial of a model for bottom-up change. How can we best support care aides as leaders of unit-based quality improvement initiatives? How can we best train managers in supporting front line quality initiatives? SCOPE is based on a modified model of the IHI Collaborative Breakthrough Series. Led by Adrian Wagg, University of Alberta.

(continued next page)
NETWORKS AMONG NURSING HOMES IN CANADA
Advice-seeking networks in long-term care—a social network analysis

Identified informal advice-seeking networks among nursing homes. Who are opinion leaders within networks and who “bridge” between networks? Both are key to accelerating successful spread of innovations and new knowledge. Led by Janice Keefe, Mount Saint Vincent University; Carole Estabrooks, University of Alberta; Jim Dearing, Michigan State University.

SYSTEM PROJECTS
Canary
Created a single indicator of the quality of the nursing homes in a region or province, assessed quarterly. Comprises 12 carefully chosen quality indicators such as resident falls, pressure ulcers, pain and use of antipsychotics. Led by Peter Norton, University of Calgary.

Trajectories
Identified modifiable and burdensome symptoms and potentially inappropriate care practices experienced by residents in Canadian nursing homes in their last 12 months of life. This is a precursor to a larger study. Led by Carole Estabrooks and Matthias Hoben, University of Alberta.

MAJOR LEVERAGED STUDIES
Older persons’ transitions in care (OPTIC)
Investigates care transitions for residents between nursing homes and emergency departments. What factors make transitions successful and improve quality of care for frail older adults? Findings have led to three more OPTIC studies: IMPACT (Improving communication during aged care transitions), EXACT (Examining aged care transitions decision making), and OPTIC QI (Quality indicators for transitions). Led by Greta Cummings, University of Alberta.

Seniors adding life to years (SALTY)
A major Canadian Institutes of Health Research (CIHR) team, led by TREC researcher Janice Keefe at Mount Saint Vincent University in Nova Scotia. How can we improve end of life for older adults living in nursing homes, their families and caregivers? TREC researchers lead one of four streams in this team, identifying burdensome symptoms and inappropriate care practices. TREC stream led by Carole Estabrooks and Matthias Hoben, University of Alberta.

STUDIES DONE/LED BY TREC TRAINEES
Projects carried out by TREC trainees include:

- oral health of nursing home residents
- un-befriended residents
- end of life care
- communication in social networks, particularly how knowledge is communicated and diffused in health organizations
- improving the lives of vulnerable populations
“All teams involved in the SCOPE pilot have been involved in innovation. From creating mobility logo cards, to initiating tea and coffee service to reduce noise, to removing the noisy doors in a dining room, to instituting back rubs and touch therapy to relieve pain. But SCOPE is not just about improving resident care. It shows what care aides can do when they put their minds to it and have the right tools and support—and it proves their potential as leaders in quality.”

ADRIAN WAGG
TREC RESEARCHER, UNIVERSITY OF ALBERTA

EVIDENCE FOR A FRONT LINE APPROACH TO IMPROVING QUALITY: SCOPE

What happens if you give front line care providers the tools to make change? What happens when the people who provide more than 80% of the direct care in nursing homes lead changes?

Safer care for older persons in residential environments (SCOPE) examines the effects of empowering care aides to take the lead on quality improvement strategies within their units—a bottom-up model for change. SCOPE was motivated by patterns identified in TREC’s first phase TMS data. Care aides reported high levels of emotional exhaustion and cynicism, but also reported high levels of a sense of meaning and purpose in their work. This triggered the idea that empowering care aides to participate in change and
quality initiatives, and in fact lead them, might access significant untapped care aide potential. In 2010, TREC launched a feasibility study in seven nursing homes in BC’s Interior region and in two larger Alberta homes. That study brought measurable improvements in resident pain, behaviours and skin health, and improvements in care aide quality of work life.

In February 2017 a full SCOPE pilot study (phase 1 of a larger trial) wrapped up in Manitoba. Teams of care aides from seven different nursing homes focused on quality improvement in pain, mobility or responsive behaviours of dementia.

For example, the team from the Salvation Army-Golden West Centennial Lodge “set out to get residents moving and keep them moving.” They worked with 29 residents at varying stages of mobility. Among the team’s strategies: charts and picture reminders outside each resident’s room to communicate the mobility program to staff on other shifts, and a Sunday evening mobility program for residents.

Residents who needed staff to push their wheelchairs are now self-propelling. One resident needed help to walk but now ventures on her own with her walker to visit the facility’s pet birds every day. “We saw such improvement firsthand with the residents— they moved better, slept better and their moods were better,” says Rosanette Mintac, a care aide for 17 years and part of the Golden West SCOPE team. “We felt such a sense of accomplishment. Our efforts were recognized by the facility and by families, and our opinions were valued and listened to by the management team.” Mintac now feels confident voicing her opinion, a new confidence despite her years of experience.

“The biggest impact is probably the growth that I’ve seen in the care aides. Their overall engagement and commitment to the goals they are working to accomplish to benefit residents is incredible.”

HANA FORBES, EXECUTIVE DIRECTOR OF LONG-TERM CARE
WINNIPEG HEALTH REGION

“TREC tells us more about long-term care than any other source in the country right now and it can provide more direction in terms of how we spend money in that sector than what we are currently getting.”

“TREC has demonstrated a pretty direct correlation between the quality of life of people who deliver care and the quality of care that is delivered. People spend a long time in long-term care—it is a vulnerable population and it is critical we understand how to make their last years on earth as comfortable and enjoyable as possible.”

“Long-term care is a difficult environment and it asks a lot of the people who work there. Most have little preparation for the work they’re asked to do. We understand very little about how to support people in these roles. Because of TREC we understand more.”

DOT PRINGLE, CHAIR
TREC INTERNATIONAL SCIENTIFIC ADVISORY COMMITTEE

“The biggest impact is probably the growth that I’ve seen in the care aides. Their overall engagement and commitment to the goals they are working to accomplish to benefit residents is incredible.”

HANA FORBES, EXECUTIVE DIRECTOR OF LONG-TERM CARE
WINNIPEG HEALTH REGION
“The long-term care sector for decades was forgotten as far as robust research into quality of care. TREC put the quality agenda on the map for researchers and clinical staff. Many quality improvement initiatives developed within the TREC framework can apply more broadly in health care than just in the residential care sector.”

HEATHER COOK, EXECUTIVE DIRECTOR
HOSPITALS AND COMMUNITIES, INTERIOR HEALTH (BC)

“The biggest thing we gained from SCOPE was the voice it gave to care aides,” affirms Kyla Gilmour, director of resident services at Concordia Place, another participating facility. “It was so amazing to see the growth in team members and their passion for quality improvement, and for them to see what a vital role they play in that quality improvement.”

The greatest early improvements from SCOPE are in indicators of staff health and work life, particularly when managers are engaged at participating sites. Improvements in resident outcomes follow. SCOPE is an affordable approach to improving quality, making use of nursing homes’ existing staff and resources.

TREC launches the full pragmatic randomized trial of SCOPE in Alberta and British Columbia later in 2017.
TREC’s study of advice-seeking networks in long-term care included 958 nursing homes across Atlantic, Western and Northern Canada. Ontario and Quebec are not yet part of TREC’s data collection.

**CONNECTING THE DOTS:**
Advice-seeking networks in long-term care

How do you spread innovation in the long-term care sector? One way is to engage the people who are asked for advice by others.

Social network analysis is a technique used to map networks of people and the ties that connect them. The TREC study of advice-seeking networks in long-term care used this approach to identify informal advice-seeking networks. The study mapped networks among Canada’s nursing home leaders and networks among nursing homes themselves.

This study identified a nation-wide network structure in long-term care, tied together through informal advice-seeking relationships—a single advice-seeking network that spans the country, plus highly developed regional networks.

It also identified people and nursing homes that bridge networks—boundary spanners. Both network opinion leaders and boundary spanners can be targeted as early adopters to successfully spread initiatives, to innovate and to implement new health knowledge in resident care.

This study was a Partnership for Health System Improvement project study funded by CIHR and our provincial health funders. Decision makers and knowledge users from across the country, including government department officials, health system administrators and nursing home directors, were heavily involved from conception right through extensive dissemination activities.
SHARING RESEARCH RESULTS

TREC shared the results of the network study with a variety of stakeholders, through a variety of strategies:

- Creating information packages with survey feedback for the 482 survey participants
- Hosting six webinars for survey participants
- Hosting eight regional webinars for knowledge users and decision makers in the nursing home sector and in government agencies
- Completing 39 interviews with advice seekers, opinion leaders and boundary spanners
- Presenting results to Alberta’s Seniors Health Strategic Clinical Network
- Presenting results at the Nova Scotia Centre on Aging conference
- Hosting three knowledge translation summits (Edmonton, Winnipeg, Halifax) attended by 77 knowledge users in total
- Presenting a nationally broadcast webinar for the Alzheimer’s Society of Canada

IMPACT

TREC identified a nation-wide advice-seeking network among Canada’s nursing homes. This pan-Canadian network is a potential tool to spread innovation more efficiently and cost-effectively throughout the sector.

IMPACT

The advice-seeking networks in long-term care study is the first of its kind to identify professional advice networks in Canadian long-term care and to analyze how provincial differences in geography, public policy, and market dynamics influence these networks and in turn, the diffusion of innovations.
TREC’s research is valuable in setting policy—applying data from TMS to analyze and modify a facility’s work environment, its staffing and services, staff’s use of best healthcare practices, and staff health and well-being. Examples include TREC projects on how and why care aides are rushed in their daily tasks, on burnout among staff, and on length of stay by residents.

In addition, TREC’s System Projects are smaller “proof of concept” studies. Stakeholders and TREC researchers jointly identify a problem to analyze, and results often influence policy. The early years of TREC saw three preliminary system projects:

- the role of life stories in helping care aides learn about residents
- coaching for managers in long-term care
- supportive supervision for registered nurses in long-term care

System projects continue to evolve and are now conducted in partnership with decision makers.

“...the TREC partnership is incredibly valuable for decision makers because it provides relevant local evidence. We need to stop doing a last minute scramble or having people who don’t understand operational needs moving forward without data. There is huge value in this research and zero value in implementing things in healthcare with no evidence.”

BARBRA LEMARQUAND-UNICH, EXECUTIVE DIRECTOR
SENIORS, PALLIATIVE AND CONTINUING CARE, CALGARY ZONE, ALBERTA HEALTH SERVICES

“We wanted to look at the system level and not individual nursing homes. We decided we weren’t just going to look for the canary dying but whether it was singing a better song than it had been for a while—an indicator that would tell us whether the system is getting better, worse or staying the same.”

PETER NORTON
TREC RESEARCHER,
UNIVERSITY OF CALGARY

CAN WE MONITOR QUALITY AT THE SYSTEM LEVEL?
The Trajectories and Canary projects

The Trajectories project studied modifiable symptoms and potentially inappropriate care practices experienced by residents in Canadian nursing homes near the end of life. The project was conceived after conversations with people working in the nursing home system, partnering TREC researchers with care providers and decision makers. It used TMS data to determine which symptoms and practices place the most burden on residents, and to develop and evaluate ways to measure and monitor burden. In all sites, the burden of modifiable symptoms worsens as the end of life approaches. However, nursing homes with better work environments have lower rates of burdensome resident symptoms. This is significant because work environment is modifiable.

When a provincial health minister asked if TREC could use TMS data to detect shifts in nursing home quality at the system level, the Canary project was born (named for the birds that miners carried into tunnels to warn of dangerous gases—an early detection system).

SHARING DATA TO INFORM POLICY

TREC is committed to supporting people working within the long-term care sector and to informing policy, with significant feedback from its research. After every wave of data collection, nursing homes in the TMS database receive feedback reports individualized for their sites and for different levels of staff. This gives them access to a rich source of information that links work environment, staff and resident data. TREC has now begun feeding results back to decision makers midway through studies to encourage input and information sharing.

TREC’s commitment to feedback is pivotal in its partnerships with decision makers and knowledge users at all levels. Making a difference in long-term care requires getting research findings to the front line and to people who can use the information.

IMPACT

TREC’s *Dying in a Nursing Home* paper describes modifiable symptom burden in three TREC provinces. The paper had strong media impact, with TREC scientific director Carole Estabrooks interviewed on three Alberta radio programs, an Edmonton television current affairs show and the national CBC Radio program *Cross Country Checkup*.


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FINDING
TREC found that length of stay for residents in nursing homes significantly decreased in the Edmonton and Calgary zones from 2008 to 2014. The decrease may be due to a policy change in Alberta that aims to keep older adults at home or in assisted living settings as long as possible.

- Publication in preparation (Hoben M et al.)

IMPACT
TREC research in policy papers:
- A March 2017 review paper from the BC Ministry of Health, on residential care staffing, cited TREC research on building practice-sensitive quality indicators.

Canary is a “proof of concept” project, using TREC data to build an indicator that measures the overall health of the system. The goal was a single composite indicator that could be monitored every three months to signal quality at the system level. It is based on 12 carefully chosen quality indicators from standardized resident assessment data that is collected by all Canadian nursing homes.

The Canary team has completed stage 1 of this work, showing that watching this score over time can show how changes affect the system. For instance, in 2010 Alberta began using funding for long-term care that is based on patient and health needs. The Canary score changed, with some indicators getting better and some worsening. One key take-home message is that quality indicators need to be monitored when changes are implemented as often when one improves in response to a change, another will worsen (because there are finite resources in the system).

Early application of the Canary score to seasonal flu data has been promising, showing a predictable pattern of lagged quality worsening after each flu outbreak. The Canary team will assess the score’s validity with data from the Canadian Institute for Health Information. TREC’s goal is to hand the scoring technique over to decision makers in health ministries and regions, allowing them to generate their own reports and readily monitor quality of care at a system level.

“In healthcare there is a steadily increasing appetite for evidence and evidence-based decision making. In a health system where budgets are tight or tough decisions need to be made what gets attention and funding? You can’t manage what you can’t measure. Measurement is at the heart of TREC. Ten years of TREC has created a huge infrastructure based on a big investment but the payoff is also very large.”

JEFF POSS
TREC RESEARCHER, UNIVERSITY OF WATERLOO
DEVELOPING ENERGY FOR EVIDENCE-BASED DECISION MAKING

Marian Anderson has been involved with TREC since 2007, when she was director of care for the Shepherd’s Care Foundation. She remembers the early days as a real driver for the nursing home’s use of data and evidence-based change.

For Anderson, TREC’s impact extends far beyond the day-to-day operations of the two Shepherd’s Care facilities in Edmonton. “Personally, I never believed I would have the opportunity to be involved with research the way I was with TREC,” she explains. “Through that involvement I have developed a real passion for evidence-based care which made me start questioning how people make decisions. And I know I have passed that passion on to managers and practice leads at Shepherd’s Care because I hear them say those very words. I really feel like the benefit was amazing for me. I became more confident in my leadership and I wouldn’t be where I am today if not for involvement with TREC.”

“Through that involvement I have developed a real passion for evidence-based care which made me start questioning how people make decisions. And I know I have passed that passion on to managers and practice leads at Shepherd’s Care because I hear them say those very words. I really feel like the benefit was amazing for me. I became more confident in my leadership and I wouldn’t be where I am today if not for involvement with TREC.”

MARIAN ANDERSON
SHEPHERD’S CARE FOUNDATION, EDMONTON

“We continue to have a need and desire to extend research to the front lines in long-term care. TREC is the only research being done with care aides in the driver’s seat and leading research at the front lines. It’s also a robust means to provide jurisdictional comparisons in long-term care outcomes across Canada—the ability for us to see how we compare against other regional health authorities.”

GINA TRINIDAD, CHIEF OPERATING OFFICER LONG-TERM CARE, WINNIPEG HEALTH REGION

Marian Anderson was identified as an opinion leader in TREC’s study of advice-seeking networks in long-term care. She is now semi-retired but still involved with Shepherd’s Care as a nurse consultant who leads special projects.
FINDING
TREC data show that both physical and mental health of care aides in nursing homes are worse than the general population. However, the health of care aides working in nursing homes with more positive work environments is notably better.

1 Publication in preparation (Hoben M et al.)

With long-term data from the TMS platform, TREC measures staff job satisfaction, work engagement, empowerment, burnout, physical and mental health, tasks left undone or rushed for lack of time, and use of best practices in healthcare. By monitoring over time how these and other indicators change, we develop a picture of the health and well-being of the long-term care workforce.

IMPACT
Care aides report high levels of emotional exhaustion and cynicism in our TREC data, which worsens over time. This often leads to burnout, with significant impact on staff turnover and retention, and poorer care for residents. TREC researchers are exploring factors in these high levels of exhaustion and cynicism and whether the factors are modifiable. This could support healthier front line staff and improve quality of care, while saving costs from reduced staff turnover.
“These small things can make a big difference. Nobody wants to think of our staff feeling undervalued, stressed or burnt out. TREC data made us look at care aides a little differently. TREC gives the site information we wouldn’t normally have access to and gives staff a safe outlet where they feel they can speak openly and confidentially.”

Alanna Kull, Director of Care
Saul & Claribel Simkin Centre, Winnipeg

FINDING
Care aides are under considerable stress yet remain highly committed to their work. Care aides in 2014 reported even higher levels of cynicism than in 2010.


FINDING
TREC published the first profile of Canada’s front line long-term care workforce, captured in the paper Who is looking after mom and dad? Unregulated workers in Canadian nursing homes. More than 60% of the 1,381 care aides in Saskatchewan, Manitoba and Alberta who took part in the TREC survey were born outside Canada. Just under 50% spoke a first language other than English. Most were middle-aged and older women, with high school diplomas. More than 83% had care aide certificate-level education. A 2014 follow-up study showed an increase to more than 60% of staff whose first language is not English (4,057 care aides interviewed).


IMPACT
The Who is looking after mom and dad? paper that profiled care aides in prairie nursing homes generated significant media coverage. Articles appeared in five daily newspapers across Canada and TREC scientific director Carole Estabrooks was interviewed on CBC Radio’s The Current.

- Alanna Kull was identified as a boundary spanner in TREC’s study of advice-seeking networks in long-term care.
IMPROVING WORK ENVIRONMENT

FEEDING TREC DATA BACK TO MANAGERS TO IMPROVE WORK ENVIRONMENT: INFORM

Uptake of research is slow, estimated at around 19 years from discovery to use. Uptake is likely even slower in the long-term care sector, which was neglected for longer by researchers and others. Meanwhile we have more reports on harmful effects of not applying the best research evidence on quality, safety, effectiveness and efficiency.

The INFORM study (Improving nursing home care through feedback on performance data) develops strategies to effectively tailor and feed back research data to long-term care managers, using a goal-directed approach. Determining the best methods to feed back data will be a major advance in applying research more easily, for better quality in long-term care.

INFORM aims to improve performance by supporting managers as they use TREC research findings. TREC data are applied to improving work environments and making positive changes on care units.

The Bow View Manor in Calgary, a long-term care facility operated by The Brenda Strafford Foundation, was already part of the TMS when the opportunity arose to participate in INFORM. Unit-level data from the TMS showed that care aides at the manor felt they had little opportunity to participate in formal meetings about resident care. Management saw INFORM as a tool to address this concern.

A team of two program managers, a care aide, a nurse and the director of nursing worked with the TREC team to develop a goal: at least one care aide would attend 100% of multidisciplinary care plan reviews. This goal was achieved. Follow-up showed that care aides attending the reviews felt that their opinions were valued and they wanted to continue attending.

"[INFORM] gave care aides a chance to discuss what they think is important. Care aides are the majority of the work force in long-term care and it is really important that they are empowered to make a difference. They are essential to improving quality of care for residents."

NAVJOT VIRK, RESEARCH & INNOVATIVE PRACTICE COORDINATOR
THE BRENDA STRAFFORD FOUNDATION, CALGARY

TREC: TRANSLATING RESEARCH IN ELDER CARE
20
“The field of organizational behaviour suggests that relationships between work environment, work attitudes and work outcomes—where you work and how you feel about or perceive your work—influence how you feel about yourself and how you perform. The extent to which you perceive that you receive support influences work attitudes like organizational commitment, which can influence job satisfaction, which can influence work performance and the things that you do that go above and beyond your job. Long-term care really relies on people to perform above and beyond. TREC measures these perceptions of work environment.”

WHITNEY BERTA
TREC RESEARCHER, UNIVERSITY OF TORONTO

“This was not just about involving the care aides; it was about making sure they were actively engaged,” says Navjot Virk, research and innovative practice coordinator with The Brenda Strafford Foundation. The Foundation is now interested in finding new ways to integrate care aides in everyday care and in other initiatives to recognize the great work they do. “There is an absolute commitment organizationally and we are talking of expanding this initiative to our other sites.”

INFORM recently wrapped up in 35 nursing homes in British Columbia and Alberta. It will follow these sites to assess if outcomes change or stay steady after a year.

FINDING
TREC research shows that residents have lower levels of symptoms such as pain and shortness of breath in nursing homes with more positive work environments. This connection has never before been measured over the long term in Canada.


FINDING
The work environment in long-term care is important. A positive work environment can increase the use of best practices in resident care and improve staff and resident well-being. The work environment can be changed and improved.

“In Alberta approximately one-third of long-term care providers are private operators. The...data shows that there is little difference in quality of care between the public, voluntary and private operators in Alberta. This is different than in the US. But assumptions are often made based on evidence from the US because there is a dearth of evidence on long-term care in Canada. TREC fills that void.”

CAROL ANDERSON, EXECUTIVE DIRECTOR
CONTINUING CARE, EDMONTON ZONE, ALBERTA HEALTH SERVICES

STARTING A CONVERSATION:
Using TREC data on tasks and interactions

Wendy Calhoun is director of operations at Kaigo Senior Living Group in Interior Health, BC. Her organization has been a TREC nursing home for five years.

Calhoun saw immediate impact after TREC came to Kaigo for data collection: staff thanked her for allowing them to be involved. “It meant a lot that TREC involved all staff and took the time to sit down and talk to them,” she remembers. “The staff really appreciated that people wanted to hear what they had to say.”

TREC’s data are invaluable as far as Calhoun is concerned. When Kaigo received its facility feedback report she was most interested in the data about tasks and interactions. “What we saw is that tasks get done but there was never enough time for interactions with residents. It shows how task oriented we are.” The information has started an important conversation that includes ideas on transferring some of the care aides’ tasks to housekeeping, allowing the aides to give more care.

“How can we, as an organization, shift our culture so that staff feel ok if they didn’t get everything done but had time to spend with the residents?”

WENDY CALHOUN, DIRECTOR OF OPERATIONS
KAIGO SENIOR LIVING, RICHMOND

IMPACT
TREC researchers developed the Alberta Context Tool (ACT) to assess organizational context (work environment). We collect the ACT data from care aides who are closest to the residents and use their scores to produce resident care unit and facility scores of context. The ACT is now available in English, French, Swedish, Dutch, German and Chinese, and is used in 11 countries. Awareness of the ACT is increasing steadily in healthcare sectors beyond TREC. We are currently exploring a version of the ACT for mobile device use.
Over ten years we have built assets and a lasting legacy with impact far beyond TREC research.

THE LONGITUDINAL TREC MEASUREMENT SYSTEM
The longitudinal TMS was built from the ground up during TREC’s first five years and developed as a sophisticated data platform and research technology. It holds data collected regularly over time on:

- nursing home staff outcomes
- health and daily living outcomes for nursing home residents
- structural data on care units and entire nursing homes

Its unit-level (clinical microsystem) data and its collection of context (work environment) data make it unique in Canada and internationally. This valuable information is not otherwise available.

IMPACT
TREC has supported managers and ministry staff in long-term care to measure quality of care and use TREC data to improve care. We have held workshops on statistical process control methods in measuring quality and on using the resident assessment instrument data to improve quality.

“The knowledge coming out of TREC research is incredibly useful. It is knowledge that reflects the current state and gives information beyond the [standard resident assessment] indicators. TREC gives regions excellent data about their own performance, right down to the unit. It is incredibly specific, important information. And the integration of knowledge users, researchers and decision makers is invaluable.”

DEE TAYLOR, DIRECTOR
RESEARCH DEPARTMENT, INTERIOR HEALTH (BC)
A MODEL FOR MANAGING RESEARCH DATA

TREC’s unique, comprehensive policies on data management and intellectual property are borrowed by other research entities. TREC developed the Health Research Data Repository as a secure and confidential virtual research environment. Now integrated into the Faculty of Nursing at the University of Alberta, it supports health-related research projects and collaboration across research disciplines. It houses health research data and promotes secondary use and re-purposing. TREC researchers and trainees outside Edmonton also have vital remote access to data.

TREC TRAINEES:
building capacity in long-term care

One of TREC’s greatest legacies may be its training of highly qualified personnel. TREC has built capacity in applied health research and in long-term care through formal and informal training. To date, TREC researchers have mentored:

• 15 postdoctoral fellows
• 5 PhD
• 12 MSc
• 26 undergraduates, the majority in our summer program.

Of these, six postdoctoral fellows, three PhD students and five MSC are current TREC trainees (see appendix). These trainees have brought incredible diversity to TREC, coming from around the world with various backgrounds and specialties. They receive mentorship from a team of leading scholars in long-term care and knowledge translation research and work with a comprehensive longitudinal database that is unique in Canada. They publish in high impact journals and build professional relationships with a successful multidisciplinary, pan-Canadian and international team. They contribute meaningfully to research that advances long-term care and informs policy and gain experience in data collection and analysis, teaching, grant writing, writing and reviewing journal papers, managing research studies and supervising students and staff. TREC also runs an active summer program for undergraduate students and plans to link with other agencies to hold joint summer institutes going forward.

Trainees are the future for TREC’s sustainability and succession planning. They go on to work, study and do research in long-term care, bringing new insights to the sector. Many former TREC trainees now have faculty appointments, are career scientists and are creating their own enduring legacies through their work.

“TREC is a national network with some international stakeholders; it is a cross-jurisdictional and interdisciplinary collaboration. It is a hub of scientifically engaged people where decision makers in government and in care facilities can go for evidence and advice to make organized, informed decisions. It is where questions meet expertise and that is very powerful. TREC is committed to producing tangible impacts in long-term care facilities and informing policies for improving the lives of the elderly and, in doing so, is committed to setting the scientific bar at its very highest.”

BILL GHALI, SCIENTIFIC DIRECTOR
O’BRIEN INSTITUTE FOR PUBLIC HEALTH, UNIVERSITY OF CALGARY
THE INTANGIBLES:
TREC’s unique space

Through research, TREC has built leadership capacity in long-term care. It has empowered care aides and has taught managers to use feedback from data to improve performance on their units to make positive change.

But TREC is more than simply a research program. It is an umbrella, an opportunity, an idea and a transactional space. That space is shared. Researchers and knowledge users have built partnerships and relationships of trust over the past ten years and now work closely together toward shared goals. They improve the quality of care provided to older adults, enrich the work life of care providers and strengthen the effectiveness of residential long-term care.

TREC has brought people across Canada (and from the United States and Sweden) together in a focused network—people who would otherwise have worked separately on issues in long-term care without the benefit of broader perspectives. This network has had significant impact and has the potential to bring lasting change to long-term care.

Researchers, system decision makers and knowledge users have driven TREC’s agenda. They demonstrate remarkable commitment to TREC’s goals and its potential for positive change. These relationships were nascent ten years ago—no one envisioned today’s partnership. TREC built that partnership carefully over time with participation, insight, wisdom and willingness to step up from key people. All have the best interests at heart of residents in long-term care. That successful partnership also paved the way for new, innovative relationships like TREC’s VOICES committee.

Creating these unique partnerships and special relationships—this “transactional space”—was not a formal objective. Yet it may be the most enduring effect in the long-term care system. Frail seniors in residential care and those who look after them can only benefit from this shared commitment, collegiality, collaborative learning and willingness to risk that TREC gave form.

“\[This space between research and practice, doing research with people and not doing research to people is really important. This constant interaction among staff about what works and what doesn’t, what’s the best way to do something—all of these things have a tremendous impact on care environments, which makes things better for residents. This is the reason everyone is here.\]

MALCOLM DOUPE, TREC RESEARCHER
UNIVERSITY OF MANITOBA

IMPACT

TREC scientific director Carole Estabrooks recently co-chaired a national forum on dementia (sponsored by the Canadian Academy of Health Sciences) with University of British Columbia neurology professor Howard Feldman. They also authored a paper on the Canadian Dementia Challenge for the Canadian Journal of Public Health.

APPENDIX 1: TREC TIMELINE: 2007-2017

2007
- TREC established
- $4.7 million grant from CIHR
- First ISAC meeting

2008
- TREC 1.0 Wave 1 data collection begins in June

2009
- TREC 1.0 Wave 1 data collection concludes in June

2010
- TREC 1.0 Wave 2 data collection concludes in June
- Health Canada provides funding for SCOPE study
- SCOPE begins in BC (feasibility of quality improvement by front line staff)

2011
- SCOPE feasibility study wraps up
- Feedback from data collected is provided to staff of nursing homes

2012
- Alberta Health Services commits funding to TREC

2013
- TREC ends

Canada Foundation for Innovation provides funding for TMS
- Alberta Health Services commits additional funding to TREC
- TREC 1.0 ends
Alberta Health commits funding to TREC

Winnipeg Regional Health Authority commits funding to TREC

TREC 2.0 begins in September

TREC 2.0 Wave 1 data collection begins

Study of advice-seeking networks in long-term care begins

2014

TREC 2.0 Wave 1 data collection concludes in April

INFORM clinical trial begins (Improving nursing home care through feedback on performance data)

Study results published: Who is looking after Mom and Dad? — the first profile of the care aide workforce in Canada

Study results published: Dying in a nursing home — the first profile of symptom burden at the end of life

2016

SCOPE pilot study wraps up in February

TREC 2.0 Wave 2 data collection begins in May

TREC celebrates 10 years of impact in June

2017

BC Ministry of Health commits funding to TREC

BC’s Fraser Health Authority commits funding to TREC

Study results published: A profile of residents in Prairie nursing homes

2013

SCOPE pilot study (a precursor to a full clinical trial) launches in Winnipeg in February

Carole Estabrooks named to Order of Canada in October for her contributions to translating research into health-care improvements for older Canadians

Summits held across Canada and other extensive activities conducted to share results of study of advice-seeking networks in long-term care

SALTY project launches in Alberta, BC, Ontario, Nova Scotia

Advisory committee of friends and family members of persons in long-term care (VOICES) established
APPENDIX 2: THE TREC TEAM

THE TREC TEAM BY THE NUMBERS

11 DISCIPLINES
17 UNIVERSITIES & RESEARCH CENTRES
33 RESEARCHERS
19 CORE KNOWLEDGE USERS

DATA COLLECTORS
29

STAFF MEMBERS
11

IN THE TREC COORDINATING CENTRE
IN EDMONTON

REGIONAL PROJECT COORDINATORS
5

IN THE HEALTH REGIONS

THE TREC TEAM

RESEARCHERS

ALBERTA
Fiona Clement University of Calgary
Greta Cummings University of Alberta
Carole Estabrooks University of Alberta
Zahra Goodarzi University of Calgary
Andrea Gruneir University of Alberta
Leslie Hayduk University of Alberta
Jayna Holroyd-Leduc University of Calgary
Jennifer Knopp-Sihota Athabasca University
Peter Norton University of Calgary
Simon Palfreyman University of Alberta
Joanne Profetto-McGrath University of Alberta
Sentil Senthilselvan University of Alberta
Adrian Wagg University of Alberta

BRITISH COLUMBIA
Elizabeth Andersen University of British Columbia Okanagan
Jennifer Baumbusch University of British Columbia
Colin Reid University of British Columbia Okanagan
Jason Sutherland University of British Columbia

SASKATCHEWAN
Gary Teare Saskatchewan Health Quality Council

MANITOBA
Malcolm Doupe University of Manitoba
Malcolm Smith University of Manitoba
Genevieve Thompson University of Manitoba

ONTARIO
Whitney Berta University of Toronto
Lisa Cranley University of Toronto
Liane Ginsburg York University
Jeff Poss University of Waterloo
Janet Squires University of Ottawa

NOVA SCOTIA
Janice Keefe Mount Saint Vincent University
Lori Weeks Dalhousie University

INTERNATIONAL
Ruth Anderson University of North Carolina at Chapel Hill, USA
Anne-Marie Boström Karolinska Institute, Sweden
James Dearing Michigan State University, USA
Holly Lanham University of Texas Health Science Center at San Antonio, USA
Johan Thor Jönköping University, Sweden

KNOWLEDGE USERS

ALBERTA
Carol Anderson Alberta Health Services
Barbra Lemerquand-Unich Alberta Health Services
Eleanor Risling Alberta Health Services
Heather Hanson Alberta Health Services
Corinne Schalm Alberta Health

BRITISH COLUMBIA
Heather Cook Interior Health Authority
Laura Choroszewski Fraser Health Authority
Heather Davidson Ministry of Health
Cindy Kozak-Campbell Interior Health Authority
Keith Mc Bain Vancouver Coastal Health Authority
Cindy Regier Interior Health Authority
Ron Kelly Fraser Health Authority
Irene Sheppard Fraser Health Authority
Deanne (Dee) Taylor Interior Health Authority

MANITOBA
Lorraine Dacombe Dewar Manitoba Health
Roxie Eyer Manitoba Health
Hana Forbes Winnipeg Regional Health Authority
Gina Trinidad Winnipeg Regional Health Authority

NOVA SCOTIA
Susan Stevens Nova Scotia Health Authority

AFFILIATED MEMBERS
Mary Schultz Alzheimer’s Society of Canada
Leslee Thompson Accreditation Canada
TREC TRAINEES
Ten years of building capacity in applied health services and long-term care research (Names of supervisors in brackets)

CURRENT TREC TRAINEES
POSTDOCTORAL FELLOWS
Amanda Beacom University of Alberta; PhD from University of Southern California, USA (Carole Estabrooks)
Adam Easterbrook University of Alberta; PhD from University of British Columbia, Canada (Carole Estabrooks)
Matthews Hoben University of Alberta; PhD from University of Halle/Wittenberg, Germany (Carole Estabrooks)
Thomas Lo University of Alberta; PhD from University of Newcastle, Australia (Carole Estabrooks)
Maryam Nesari University of Alberta; PhD from University of Alberta, Canada (Carole Estabrooks)
Yuting Song University of Alberta; PhD from Duke University, USA (Carole Estabrooks)

DOCTORAL STUDENTS
Stephanie Chamberlain University of Alberta (Carole Estabrooks)
Ibo MacDonald University of Ottawa (Janet Squires)
Tim Rappon MD-PhD student, University of Toronto (Whitney Berta)

MASTER’S STUDENTS
Laura Aloisio University of Ottawa (Janet Squires)
Helen Doan University of Alberta (Carole Estabrooks)
Erin McAfee Mount Saint Vincent University (Janice Keefe)
Lauren MacEachern Mount Saint Vincent University (Janice Keefe)
Melissa Demery Varin University of Ottawa (Janet Squires)

UNDERGRADUATE STUDENTS
Muhammad Moola University of Alberta (Matthias Hoben)
Lily Lu University of Alberta (Matthias Hoben)
Kristy Kang University of Alberta (Stephanie Chamberlain)

Yi Zhang University of Alberta (Adam Easterbrook)
Yajing Hao University of Alberta (Matthias Hoben)
Lim Jingwei University of Alberta (Stephanie Chamberlain, Andrea Gruneir)
Abigail Heninger University of Calgary (Zahra Goodarzi, Jayna Holroyd-Leduc)

FORMER TREC TRAINEES
Supervised by Carole Estabrooks unless otherwise noted.

POSTDOCTORAL FELLOWS
Anne-Marie Boström University of Alberta (2008-2011); PhD from Karolinska Institutet, Stockholm, Sweden; now associate professor Karolinska Institutet, Stockholm, Sweden
Elizabeth Dogherty University of Alberta (2014-2015); PhD from Queen’s University, Canada; now registered nurse, Providence Health Care, Vancouver, Canada
Lisa Cranley University of Alberta (2009-2012); PhD from University of Toronto; now assistant professor, University of Toronto, Canada
Alison Hutchinson University of Alberta (2007-2009); PhD from University of Melbourne, Australia; now professor, Deakin University, Australia
Jennifer Knopp-Sihota University of Alberta (2013-2015); PhD from University of Alberta, Canada; now assistant professor, Athabasca University, Canada
Anastasia Mallidou University of Alberta (2008-2011); PhD from University of Alberta; now assistant professor, University of Victoria, Canada
Natalia Ricci University of Alberta (2014-2015); now postdoctoral fellow, City University of Sao Paolo, Brazil
Susan Slaughter University of Alberta (2008-2011); PhD from University of Calgary; now associate professor, University of Alberta, Canada
Karam Turk-Adawi York University (Liane Ginsburg, 2014-2015); now associate professor, Qatar University, Qatar

DOCTORAL STUDENTS
Sandy Cobban University of Alberta (2005-2012); deceased
Janet Squires University of Alberta (2006-2010); now associate professor and associate director, Nursing Best Practice Research Centre, University Research Chair in Health Evidence Implementation CIHR New Investigator in Knowledge Translation, University of Ottawa, Canada

UNDERGRADUATE STUDENTS
William Bambrick University of Alberta (2010-2012)
Heather Carleton University of Alberta (2012-2014)
Alison (Lucarotti) Connors University of Alberta (2006-2010)
Kaylie Hoglin University of Alberta (2012-2015)
Faith Ko University of Alberta (2013-2015)
Christina Manraj University of Alberta (2011-2015)
Shauna Zinnick University of Manitoba (Malcolm Doupe; 2012-2016)

SELECTED PUBLICATIONS
2007–2017: 10 YEARS OF IMPACT

10 YEARS OF IMPACT
2007-2017: 10 YEARS OF IMPACT

2007-2017: 10 YEARS OF IMPACT

2007-2017: 10 YEARS OF IMPACT

2007-2017: 10 YEARS OF IMPACT