

# **The Community Needs Driven Research Network**

A project to engage direct care providers in identifying issues facing continuing care that require additional research and knowledge translation

**Submitted to Alberta Innovates Health Solutions**

**February, 2014**





## TABLE OF CONTENTS

Acknowledgement.....	ii
Research Team.....	ii
Background.....	1
Methods.....	1
Ethics Approval.....	1
Reference Groups .....	1
Development of the model.....	3
Data Collection .....	5
Data Analysis.....	7
Results .....	8
Description and Status of Themes .....	1
1. Mental Health related issues:.....	1
2. Education related issues .....	3
3. System navigation and transition of care .....	5
4. Technology for adult learning and point of care .....	7
5. Role definition within the CC sector .....	8
6. Staff Retention and Recruitment .....	9
7. Working with families.....	10
8. Caregiving .....	12
9. Intercultural issues.....	14
10. Need for rehabilitation and recreation staff .....	15
Location dependent themes .....	16
11. Palliative, End-of-Life and Hospice .....	16
12. RAI Research .....	18
13. AHS Policy Inconsistencies .....	19
14. First Nations Issues .....	19
Pilot Projects .....	20
1. Challenging Behaviours - Steps to the development of a Behavioural Supports Alberta .....	20
2. Learning Circles Implementation and Evaluation (Adult learning) .....	20
Knowledge Translation Activities .....	21
Oral presentations and poster presentations related to CNDRN .....	21
Social Media activities .....	23
Future plans for Knowledge Transfer .....	23
Lessons Learned from the CNDRN .....	24
Next Steps.....	25
Appendix 1 - Focus Group Tools .....	26

## ACKNOWLEDGEMENT

The Institute for Continuing Care Education and Research (ICCER) would like to thank Alberta Innovates Health Solutions for the financial support given to the Community Needs Driven Research Network.

## RESEARCH TEAM

<b>Principal Investigators</b>
Dr. Alberta Cook, University of Alberta
Ms. Iris Neumann, CEO, CapitalCare
<b>Project Management</b>
Ms. Sandra Woodhead Lyons, Executive Director, ICCER
Ms. Lisa Allen, Program Assistant, ICCER
<b>Research Assistants</b>
Ms. Liliana Alvarez
Ms. Adriana Rios Rincon

## BACKGROUND

In early 2012 Alberta Innovates Health Solutions provided the Institute for Continuing Care Education and Research (ICCER) with an Innovation Grant evaluate the development and implementation of a Community Needs Driven Research Network (CNDRN). The purpose was to identify from the perspective of direct care providers in the continuing care sector what the outstanding needs were that could be addressed through increased research and knowledge translation. This was to be done by:

- a) creating a Needs Reference Group and a Research Reference Group consisting of interested and knowledgeable individuals from academic and provider organizations;
- b) developing a process for identifying needs and researchable questions;
- c) developing a framework to facilitate needs identification and knowledge brokering fundamental to the CNDRN research agenda in continuing care; and
- d) working with two teams of researchers/practitioners to develop a pilot project process that can further the development of activities around key issues identified by direct care providers.

The rationale behind the development of the CNDRN was that in continuing care, as in many areas of health research, much of the current research activity is driven by the interests of the researchers. While this can be relevant to clinical service delivery and address clinical needs, the clinical partners are often relegated to playing the role of sources of data rather than being full partners in the research. More significantly, clinical needs that require research study are often identified by clinical providers, but there is no vehicle for those needs to be formulated as research questions suitable for the identification of research teams. Even if questions can be appropriately identified, it is often difficult to develop interdisciplinary research teams to pursue the research questions collaboratively. A major barrier to the development of such collaborative research teams is that the teams are often cobbled together only when a research proposal is to be developed or a source of funding has been identified. There is not a cohesive brokering system available to link researchers to front-line collaborators.

## METHODS

### Ethics Approval

Ethics approval was received from the University of Alberta in July 2012.

### Reference Groups

In April 2012 two Reference Groups were established:

- a) **Needs Reference Group** - the main role was the identification of issues, challenges, practices with insufficient formal evidence, and areas that need information to inform practice in continuing care.

The primary activities of the Needs Reference Group were to:

- establish working relationships with continuing care providers throughout Alberta,
- consult with provider organizations regarding needs at the front-line worker, clinician and management levels,

- provide a forum to identify issues facing continuing care,
- aggregate, characterize and prioritize input from consultations,
- recommend a prioritized set of issues judged to be appropriate for further investigation to the CNDRN Research Reference Group,
- evaluate and monitor outcomes and results,
- evaluate best practices in KT and the most appropriate methods for each of the target audiences (e.g. front line workers, management, clinicians, etc.),
- oversee Knowledge Translation from the Research Reference Group to the providers of the province, and
- act as an advocate and champion for providers in the Network.

Table 1: Needs Reference Group Participants

Organization	Name	Duration
University of Alberta	Kyle Whitfield	April 2012 - April 2013
	Christie Schultz	April 2012 - April 2013
	Lars Hallstrom	April 2012 - April 2013
NorQuest College	Erin Bampton	April 2012 - June 2012
	Kim Campbell	July 2012 - April 2013
Bow Valley College	Bill DuPerron	April 2012 - December 2012
Bethany Care Society	Don McLeod*	April 2012 - April 2013
Excel Society	Sharon Read	April 2012
CapitalCare	Doris Milke	April 2012
AHS	Duncan Robertson	
Keyano College	Guy Harmer	April 2012
Bayshore Home Health	Donalda Farwell	April 2012 - June 2012
We Care Home Health Services	Kimberly Fraser	July 2012 - April 2013

\*Chair

b) **Research Reference Group** - the main role was to evaluate issues raised by the Needs Reference group to identify researchable questions in the identified items and the coordination of the conduct of research related to such questions.

The primary activities of the Research Reference Group were to:

- vet issues provided by the Needs Reference Group to identify researchable questions that arise from them,
- determine what evidence currently exists for questions so identified,
- review the existing literature in areas relevant to identified needs,

- summarize existing evidence from the literature and provide it to the Needs Reference group for knowledge transfer back to the providers,
- formulate appropriate research question(s) and develop a request for proposals to solicit research participation, if further research is warranted, and
- establish liaison with researchers in continuing care throughout the province.

Table 2: Research Reference Group Participants

Organization	Name	Contact information
University of Alberta	Douglas Wilson*	April 2012 - April 2013
	Janet Fast	April 2012 - April 2013
NorQuest College	Erin Bampton	April 2012 - June 2012
	Kim Campbell	July 2012 - April 2013
Bow Valley College	Bill DuPerron	April 2012 - December 2012
Bethany Care Society	Don McLeod	April 2012 - April 2013
CapitalCare	Doris Milke	April 2012 - April 2013
AHS	Duncan Robertson	April 2012 - April 2013
Red Deer College	Greg Wells	April 2012 - April 2013
Keyano College	Bev Maron	April 2012 - April 2013
	Donna Herald	April 2012 - April 2013

\*Chair

By September 2012 the activities of the Reference Groups had basically blended and the two groups were collapsed into "The Reference Group", which was chaired by Dr. Douglas Wilson, University of Alberta.

### Development of the model

Figure 1 shows the model developed to identify needs from continuing care providers, develop researchable questions, and encourage the uptake of these questions from researchers. The model was developed through discussion with members of the Reference Group.

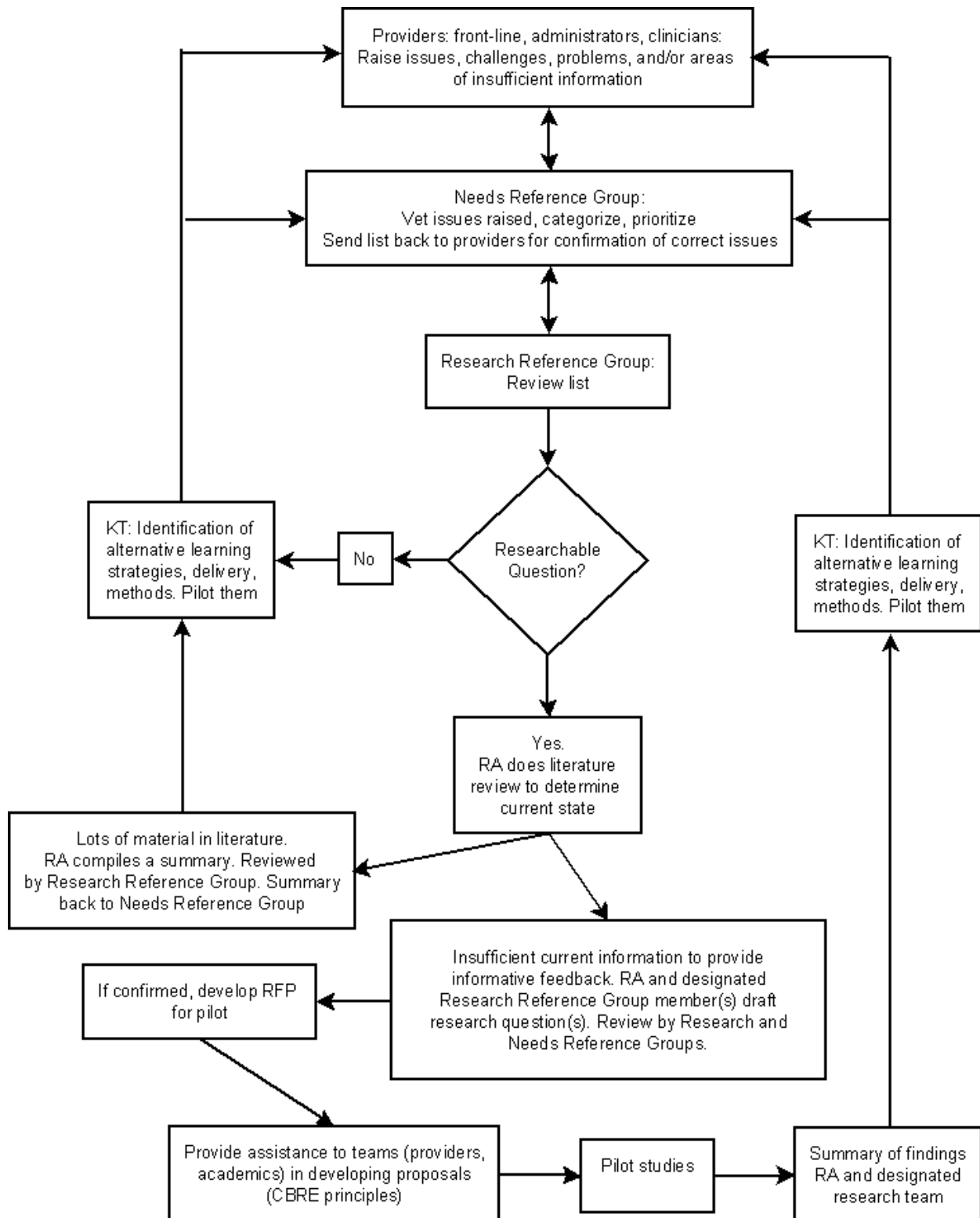


Figure 1 - Community Needs Driven Research Network model



## Data Collection



Focus groups and interviews were used to collect data from continuing care front-line staff across central and southern Alberta. In addition, four community network events in Northern Alberta, previously conducted by ICCER, were separately analyzed: one each in Grande Prairie and Slave Lake, and two in the Regional Municipality of Wood Buffalo. Even though the events included other topics, the data analysis focused on two particular topics discussed by participants during the event: 1) gaps and issues in CC; and 2) how research could improve practice and care in CC.

Figure 2 shows the distribution of both community networking events, and the CNDRN focus groups/interviews.

Figure 1 – Map of Alberta showing sites of focus group/interview and community networking events

A total of seven focus groups and three interviews (four participants) were facilitated in five cities across the province (Figures 2 and 3).

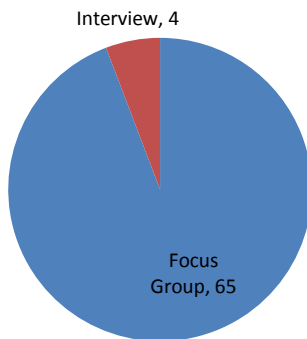


Figure 2: Participants per data collection technique

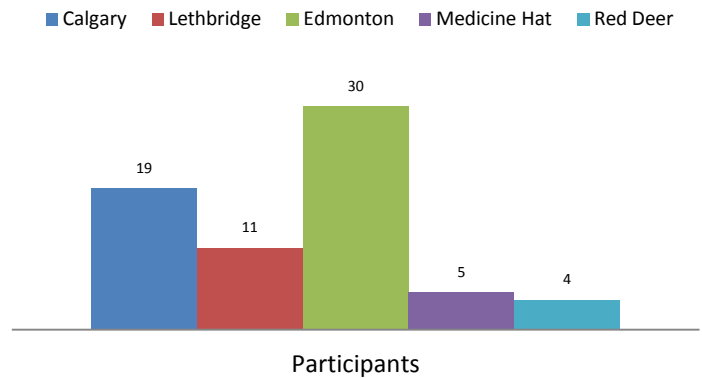


Figure 3: Participants per data collection site

Sixty-nine front-line workers from nine cities/ towns of the province participated in the consultation process (see Figure 4).

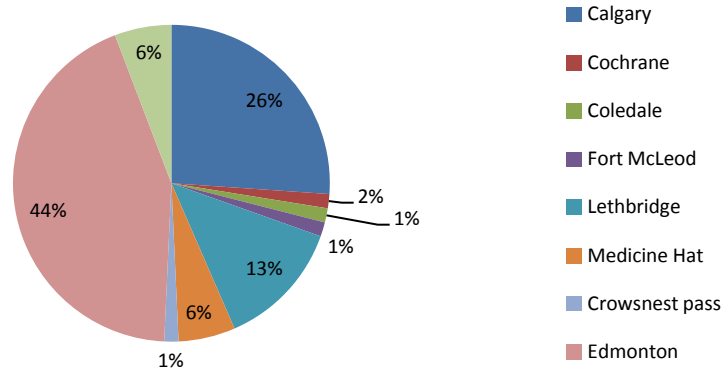


Figure4: Location of Participants Work Location

The percentage of participants from private, not-for-profit, and AHS provider organizations were roughly equal (See Figure 5).

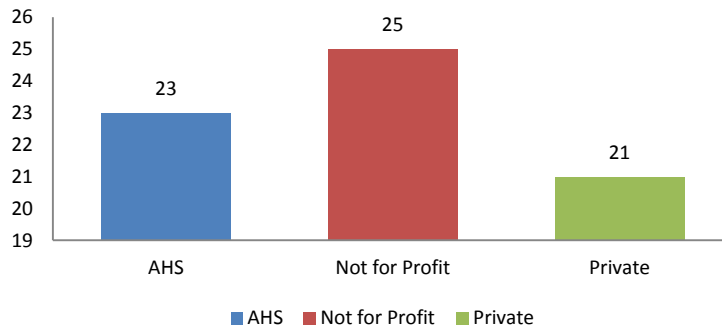


Figure 5: Type of provider organizations

Participants in this consultation process represented a wide range of disciplines, licensed and non-licensed professionals working in the continuum of care (Table 3).

**Table 3: Participants' Roles**

Major Role	Number of Participants
Administrator/Manager/ Director of care	22
Professional practice leads	12
Education (Examples learning consultant)	7
HCA	7
Nursing staff (NP/RN/LPN/)	6
Non- direct care staff (housekeeping/dining room)	6
Rehabilitation Staff	4
Recreation Staff	3
Physician	2
<b>Grand Total</b>	<b>69</b>

More than 75 participants took part in the four community networking events held in Grande Prairie, Slave Lake, and Ft. McMurray. Participants included local health care providers, municipal representatives, local citizens, colleges, professional associations, and Alberta government and health representatives. The purpose of the networking events was to examine continuing care issues in Northern Alberta and how education and research could help address them. Although the questions were not exactly what was asked in the focus groups, they were similar enough that the results were included in the CNDRN project in order to cover northern Alberta. These events were analyzed separately due to the difference in nature and session facilitation.

## Data Analysis

QSR NVivo 10<sup>®</sup> software was used for data analysis tasks. A coding scheme was developed according to the emerging data and was then used across sessions. This coding scheme served as the initial node structure in NVivo 10<sup>®</sup>.

Data analysis was conducted in two phases. In the first phase a manifest content analysis of interviews and focus groups transcripts was performed in order to determine the frequency with which each particular theme emerged in the data. The themes were used as initial coding categories (nodes) and were then applied to all interviews and focus groups (sources) by one coder. New emerging themes identified by coder and by the session facilitator and project manager were added, leading to refinement of themes. This first phase was then discussed with the session's facilitator to corroborate the data explore themes according to the session's notes. In a second phase, a latent content analysis was performed in order to explore the meaning of these themes and the issues related to each one of them, according to participants.

The Northern Alberta community networking events were separately analyzed. The same initial coding scheme was used and emergent themes were added to refine the node structure.

## RESULTS

Figure 6 highlights the main results from the consultation process



Figure 6 - Word Cloud highlighting the results of the CNDRN consultation

Table 4 presents the top ten themes identified by participants in the CNDRN pilot project (including results from both the consultation process and the community networking events).

**Table 4: Top Ten Themes Identified in the CNDRN Consultation Process**

Theme
Mental Health related issues
Education related issues
System navigation and transition of care
Technology for adult learning and point of care
Role definition within the CC sector
Staff retention and recruitment
Working with families

Caregiving
Intercultural issues
Need for Recreation and Rehabilitation staff

In addition to the top ten themes, four additional themes emerged as being highly important in certain areas of the province. Table 5 shows this themes and the area in which they were most frequently identified.

**Table 5: Four special themes, location-dependent**

Theme	Province Area
Palliative Care, end of life and hospice	Edmonton
RAI Research	Calgary and Edmonton
AHS Policy Inconsistencies	Southern Alberta
First Nations issues	Northern Alberta

## DESCRIPTION AND STATUS OF THEMES

This section describes each of the top themes, how the theme was defined by participants, and the issues related to it. Also included is the current status of the theme in Alberta, i.e. what is known about the current state of research and/or knowledge translation.

### 1. Mental Health related issues:

Mental health related issues were the most frequently identified issues by all participants regardless of role or organization. They fell within three major overlapping categories:

1.1 Challenging or responsive behaviours, and how to handle them, is the most representative issue around mental health. Responsive behaviours exhibited by individuals with dementia, mental illness, addictions, brain injury, developmental disabilities and other neurological conditions (intentionally or unintentionally), are understood to be forms of communication expressed in actions, sounds, words and gestures. Such behaviours may be a reaction or response to something important to them regarding their personal, social, or physical environment, state or experience. Participants reported little education of staff in terms of management, lack of strategies for adequate caregiving of people with challenging behaviours, and poor community education and knowledge that results in stigma of people with challenging behaviours. Participants also reflected on the relation between challenging behaviours and other contextual factors such as: i) continuous moving of the client between facilities; ii) lack of rehabilitation and recreation activities; and iii) language barriers with staff. These may cause the client to become anxious and to be “labeled as having challenging behaviours” but perhaps what is required, is a different approach to care. These factors impact care and the navigation of these clients throughout the system. For example, participants proposed questions related to: i) how to develop a care plan; ii) what strategies can be used to manage challenging behaviours; iii) what is the most adequate assessment that can reliably and consistently reflect their functioning; and iv) what resources can staff have at the bedside or in the home in order to manage these behaviours.

“The staff haven’t got the training in mental health so they don’t know how to recognize signs that maybe they are becoming acute again and maybe they need to have admission to acute psychiatry or how to manage these behaviours.”

“The staff are having to make pretty complicated decisions around what to do when they run into situations in the home and they don’t have any immediate backup. It’s not like they can run down the hall and say, “What do I do now with this person who’s acting out?”

“I think sometimes there’s a disconnect in the training that we provide, somehow is a small portion. How does it get sort of - how does education move with individuals as they move through the system.”

“We have what we label “behaviours” because we haven’t engaged them in anything meaningful, so care delivery tells me is a very passive “I do to you” already in the label, as opposed to a relationship with this client, with their family.”

Two additional issues were identified as strongly related to challenging behaviours (1.2 and 1.3).

“And I find that I have 111 clients, and I would say 85 percent of them have schizophrenia and the staff knowledge of that is very minimal...And we have staff coming in who don't have the first idea about schizophrenia or what it's about or what it's like.”

“We live in a culture where people with mental health issues aren't really recognized as having mental health issues, and even if they are, there's a large stigma around it. People aren't valued when they're seen to be crazy.”

“So when you have a dependency on an existing instrument now for assessment [MDS-RAI tools], are we adequately looking at those additional needs some of these clients have, and care-planning around them accordingly.”

behaviours for the staff to handle.

**1.3 Client mix:** The issue of clients/residents with diverse needs and age ranges was highlighted. Because of the mental health issues and needs (including depression episodes of the young residents), participants perceived that research is needed in terms of best clinical practice and in standards of care.

This issue was particularly strong in rural communities where there are fewer alternatives for individuals needing long term care or supportive living. In urban communities, such as Edmonton and Calgary, where there are more options, it is possible to separate individuals with different types of dementia. For instance, individuals with frontal lobe dementia and Alzheimer's disease display very different behaviours and are not necessarily compatible within the same facility. In smaller communities it is not always possible to separate the individuals.

**1.2 Care of non-dementia clients:** Participants identified this as another priority issue around mental health. Emphasis was placed on the fact that the CC sector provides services not only to seniors and clients with dementia, but also to clients with mental health-related diagnoses and disabilities such as clients with brain injuries or severe physical disabilities. Clients with a diagnosis other than dementia often present challenging behaviours as well and the staff are not properly trained to handle these behaviours. Participants expressed that not enough attention is given in research to the assessment and care planning for these clients/residents, or into how to educate people to decrease stigma placed on mental health issues.

To complicate the issue even further, as the population ages, there are an increasing number of individuals with mental health issues who are now developing dementias. This adds another layer of

“I think oftentimes, we also have with the young adult unit, THEY refuse to accept the fact that they are here and they are going to stay here and that their condition is, in all honesty, probably not going to improve.”

“... sometimes the mix of clients isn't a fit because sometimes the new clients have different types of diagnoses than the other clients have and different specific needs.”

**CNDRN/ICCER related activities in Mental Health Related Issues:**

1. 21 November 2012 - Challenging Behaviours Symposium held.
2. CNDRN funding of Suzette Brémault-Phillips to do further work with Symposium data in order to develop an action plan for creating Behavioural Supports Alberta network. More details are provided in "Pilot Projects" section. The final report is available at [http://www.iccer.ca/cndrn\\_crb.html](http://www.iccer.ca/cndrn_crb.html)

3. Establishment of the Behavioural Supports Alberta website ([www.bsa.ualberta.ca](http://www.bsa.ualberta.ca)).
4. Grant proposals developed by Dr. Brémault-Phillips to Network of Excellence for Seniors Health & Wellness, Alberta Health, Alberta Health (Workforce Planning) and Technology Evaluation in the Elderly Network.
4. Advancing Behavioral Supports Alberta Symposium held on 20 February 2014. More information on it available from <http://www.iccer.ca/bsa.html>.
5. Behavioural Supports Alberta involved on a national level to create a pan-Canadian strategy.

“How do you effectively share the information with the staff in a way that they are going to understand and retain, and be able to use it, instead of overwhelm them with ‘here is a stack of reading’.”

## 2. Education related issues

2.1 Adult learning: Participants perceived a lack of effective strategies to promote learning and facilitate transfer of knowledge into the different situations that the staff face daily. Traditional in-

service methods are used in most organizations. There needs to be a more comprehensive approach using adult education theories and more innovative ways of transferring knowledge to health care providers. Learning opportunities need to be readily available (e.g. just-in-time learning), meet the current needs of the staff, and be reinforced by practice.

2.2 Effectiveness and outcomes: There is a need to assess the effectiveness and short- and long-term outcomes of education strategies. This includes assessing how performance and practice is affected by in-service strategies, and their impact on care.

Currently, strategies are commonly associated with in-service training. However, there is poor transfer of this knowledge into care, and staff are not able to use that knowledge in other CC settings. Knowledge seems to be compartmentalized. Staff feel that sometimes the

“How do I see the outcome that my education is effective and then that I am able to get them to transition that knowledge faster?”

“Is that outcome piece to say you are now not only tracking how many hours someone goes to education services, but what’s their performance like on the floor, and how does that reflect that they’re actually taking the knowledge into their practice and how are they able to actually transition it, no matter what the client looks like.”

knowledge is not available to them when they need it, that is, when they are facing a particular situation or client. Time invested in education is often not perceived by the system as being productive time and that imposes additional challenges in terms of motivation of staff and managerial support.



"I had the opportunity to kind of work with a new HCA program and it's very evident that there's knowledge lacking... it's get them out, get them a job no matter what the standard is...so then your outcomes become very poor, because that knowledge retention isn't there."

"They don't know what home care is and once they get to the houses where they are supposed to work they just say "oh this is hard" and they quit and they go to facilities."

"... it's about HCAs having the training, about cleaning the facilities, because every assisted living facility the health care aides have to do the cleaning, and dietary, too... So that stuff isn't being taught in the health care aide program. And like P4 said, so then we get students to come here [referring to assisted living] or people come here from school and they're, like, 'This isn't what I was taught'."

2.3 Health Care Aide (HCA) Training: Participants reported a critical issue in the lack of standards for HCA base training, which is not conducive to good quality care. The HCAs' competencies provided by base training are compromising the quality of care and the team development in the different streams.

There seemed to be differences around the province, depending on whether the education provider was a larger post-secondary institution, or a smaller, private education facility.

In supportive living environments the HCAs typically provide a broad range of services, including housekeeping, meal support, even cooking food.

#### **CNDRN/ICCER related activities in Education Related Issues:**

1. CNDRN pilot project funding of a Learning Circles project with Excel Society and Bethany Care Society with Barrington Research evaluating the Bethany Care Society part. More details are provided in "Pilot Projects" section. The interim evaluation reports are available at [http://www.iccer.ca/cndrn\\_lc.html](http://www.iccer.ca/cndrn_lc.html)
2. Two one-day forums hosted by ICCER with guest speaker Sienna Caspar on "Creating Cultures of Care: How Responsive Leadership Enables Responsive Care". These were held 7 October 2013 in Calgary and 8 October 2013 in Edmonton. The Edmonton session included video/teleconferencing across Canada.
3. Grant proposal related to adult education in continuing care are being developed:
  - a) expansion of the Learning Circle project submitted to the Network of Excellence for Seniors Health & Wellness (NESHW) - PI Dr. Sharla King, UofA, Co-PI Steve Freisen, Bethany Care Society
  - b) Responsive Leadership Interventions project submitted to NESHW - PI Sienna Caspar and Co-PI Don McLeod, both from Bethany Care Society
4. In follow-up to a related ICCER/AHS study (Optimizing Workforce Utilization to Inform Care Delivery in Continuing Care Facilities), a working group (AHS and provider organizations) is examining strategies that could address inconsistencies in HCA utilization in continuing care. A second working group is examining strategies related to collaborative leadership. These are part of a CIHR planning grant project.

### 3. System navigation and transition of care

**3.1 Information and education:** The most critical issue identified around system navigation was that of information and education for staff, families and clients, and the general public. Participants expressed that the lack of adequate information about the roles and services provided by the different levels of care in the continuum causes great confusion, adds time spent navigating, and ultimately impacts care for both the staff and the client. Front-line workers don't feel that they know how to adequately navigate the system. This then becomes a bigger issue for families who lack the resources and education to navigate the system effectively.

There are many levels of transition to be made and the paths for each individual vary. In Alberta the continuing care system has three main streams: i) home living; ii) supportive living; and iii) facility living (LTC). Palliative care can be provided in all of the streams. Not only are there transitions between the streams, there are transitions, backwards and forwards, and between acute care and primary care. It is a complex system that families and clients/residents do not understand well enough to navigate effectively or to find the best solution for an individual. The problem is increased by the lack of knowledge of the continuing care system by many health care workers, particularly in primary care and acute care.

"What they do is they hand you a list and you start phoning and you hope that somebody at the end of the line will take that, and will know what to do."

"It's very confusing for me as a new manager. I cannot imagine having a family member-- and we ran into this with transition all the time where the doctor doesn't really understand that world of navigation either so we are in the middle of trying to sort it out. They need a navigator to navigate them through the whole system: level of care, wherever they are going, and it doesn't end with their first placement, which might be assisted living but might go to long term care. This is very, very confusing for families."

"It's hard for US to keep track of who does what, let alone families. As you said, sometimes there's overlap, there's grey."

"My goal in my life is to have a system navigator position somewhere in our health care system; this is my number one."

"I think that there is more investigation that needs to be looked into regarding family knowledge and expectations pre-admission to long term care; in comparison to the reality of the services and the resources we have to offer."

"To have more of that transition area and some research to show what is the best time frames, like how long is that assessment period, [be]cause if we were able to better place individuals in the right environment, we might be able to support it."

"When at first we do assessments every three months and between the first two assessments a large proportion of our residents are much, much better, so we are thinking well is this the best place for them?"

**3.2 Assessment:** The time frame in which clients/residents are assessed is an important issue, as well as the details of that assessment. Participants discussed the fact that clients are not thoroughly and adequately assessed and this causes them to be placed at a facility that may not be the best fit or even the level of care that they require.

3.3 Impact of system navigation and transition of care on clients and families: Participants discussed that the impact of this process is often overlooked. Transition may potentially cause behaviours to increase, or the client's functioning to deteriorate. Participants brought up potentially useful research topics such as: i) the impact of relocation syndrome on clients; and ii) tracking the experiences of clients and families as they move across the system.

"I would like to see research on relocation stress syndrome and the impact of that pre-admission visit, 'cause I know most don't traditionally do a pre-admission visit...and then you wonder why, if they're moving them, particularly to a dementia unit, where the behaviours increase - 'cause I relate it to kind of like a woman wouldn't give birth at a maternity ward without touring it first, yet it seems to be okay to move these residents to a place, and where they live for the rest of their life, but they don't even get to see it."

"Has anyone ever looked at tracking an experience of a person in the system? So from the time that someone is, I mean they are still, at home, they are using home care services, then they need to progress to the next step in the system, and actually following people through the system to try to identify experiences, inefficiencies, and to look at it from a system perspective?"

**CNDRN/ICCER related activities in Systems Navigation and Transitions of Care:**

1. Alberta Health Services has various initiatives underway to try and streamline and improve systems transitions. For example, documentation and process changes are being made to ensure that Calgary and Edmonton zones are the same.
2. Two grant proposals have been submitted related to transitions:
  - a) systems transitions between acute care and supportive living - grant application submitted to AIHS KTA fund, PI Dr. Lars Hallstrom
  - b) evidence-informed tools to inform care - grant application to NESHW, PI Dr. Lars Hallstrom

#### 4. Technology for adult learning and point of care

Some of the participants described having had interactions with technology for training, communication, or care provision. In general, participants see this as a critical area in which research and evidence could support the implementation of technology in the CC sector. Participants identified technology as a much needed potential source through which the following issues could be addressed: i) training; ii) point-of-care learning; iii) communication between disciplines and team members (team development); iv) communication between staff and families and education regarding client's current state and needs ; v) better use of human resources (rehab staff or physicians that are not available 24/7 could have access to daily updated information on client's progress); and vi) literacy of staff (using picture-based or user-friendly technology interfaces could facilitate performance).

"It would also be interesting to see if there's a difference between organizations that are more paper-based flow vs. you know, Point Click Care actually has pictures and things like that that the individuals—so is there a better understanding by the HCAs staff or the, being able to use a picture vs. having to put in words and trying to interpret."

"Technology can also help us communicate to the family because we have a case care conference and we project all our data and the trend and it helps the family understand that so and so has not been eating and that's why she has weight loss and that's why all this is happening."

"I think we need research on technology and the impact on care because we do everything so manually, we could use ways to do it electronically and this could impact our data that we collect to inform decision making."

"And there's also some old-school thoughts on—by some of the administrators in the care centers that they don't want their staff to be searching the web, they don't want—we have sites that there's no Google, there's no access to the internet outside of what's posted on ... So that's frowned upon, that's ... you don't sit, you don't do the—that investigation, then, isn't being reinforced, it's being (chuckles) suspended, basically, from the top down; you don't spend work time doing that kind of stuff. So how do you get research information out to that front line user, then, is the question."

##### **CNDRN/ICCER related activities in technology for adult learning and point of care:**

1. There are no targeted ICCER-based projects at this time related to point of care learning. However, ICCER continues to encourage researchers around Alberta to do more research into issues related to this.

## 5. Role definition within the CC sector

“And when you go from one model of care that is an LPN focused model of care to another model of care which is an HCA [led] model of care, and these people need to be superstars in their organizations, how can we have that within our scopes of practice?”

“To have some research around competencies of the LPN vs. the RN, around scope of practice and you know, um, as the assessment leads.”

This issue was discussed mainly as a result of the overlap that exists among the tasks assigned to RNs, LPNs and HCAs across facilities. This relates to the increasing demands that are being placed on LPNs and HCAs in settings where they are leading the care without the appropriate critical thinking tools to do so. It is unclear whether LPNs have certain competencies that can allow them to lead and drive some care settings, or whether they are being asked to do so without providing them the necessary educational tools. Participants mentioned research ideas that could

benefit this area such as; i) comparing outcomes of care between RN and LPN driven tasks in certain key areas (Examples RAI assessment); and ii) exploring which competencies RNs, LPNs, and HCAs perceive to be within their role and competencies in the CC sector, and compare that with the actual care models.

### **CNDRN/ICCER related activities in role definition with the CC sector:**

1. The one-day symposium held in Calgary and Edmonton, October 7 and 8, 2014, Creating Cultures of Care: How Responsive Leadership Creates Responsive Care, was related to the issue of role definition and team work between the various levels of nursing.
2. A grant, which also relates to adult education, called the Responsive Leadership Interventions project submitted to NESHW - PI Sienna Caspar and Co-PI Don McLeod, both from Bethany Care Society
3. In follow-up to a related ICCER/AHS study (Optimizing Workforce Utilization to Inform Care Delivery in Continuing Care Facilities), a working group (AHS, AH, and provider organizations) is examining strategies to address issues related to role clarity of nursing staff in continuing care. This is part of a CIHR planning grant project.

## 6. Staff Retention and Recruitment

Staff retention and recruitment was considered an issue with very unique characteristics in the context of CC. Participants identified this issue in terms of the initial recruitment of staff, and the retention and work environment:

**6.1 Recruitment:** Staff expressed frustration and confusion regarding the difficulties of attracting nursing and rehabilitation staff to the CC sector. They describe the emphasis that is given to acute care and recovery settings during the formal training of these professionals. Their expectations are often related to those settings in which the goal of interventions is that of improvement and recovery. The CC sector cares for a population that is often severely disabled, or experiencing a compromised aging process, and the goal is not so much to improve, but to maintain independence as much as possible and to promote quality of life.

“People aren’t valued when they’re seen to be “crazy,” and therefore, anybody who works in an industry that’s caring for people with these mental health issues, their work isn’t really valued either. Outsiders aren’t real advocates of giving these people raises.”

“... you want the long term dedicated staff. So what is it that we need to do to keep it that way? and that impacts knowledge translation because you are always trying to keep everybody up to speed.”

“Once we get the right people in the door, what do we need to do as an organization to help them realize like ‘oh this is good place I want to stay at in the long term’ instead of ‘oh god this is just insane. I might as well apply for the next open job that comes up at Wal-Mart.”

“They would hire a health care aide and they [the HCA] would just work for two weeks and be gone. And I think clients and residents are suffering from this.”

“And others even quit before starting. They don’t know what home care is and once they get to the houses where they are supposed to work they just say “oh this is hard.”

“It’s not a sexy area to go and work. It just isn’t. But part of that is lack of knowledge and understanding of the benefits of having those disciplines and the impact of some of the quality of care.”

“What are we missing? Why are we not attracting the experienced or the eager nurses and health care aides and occupational therapists into continuing care settings? Or why are they leaving?”

“How do we ensure that the people that we are hiring and training for these programs are gonna be the best fit? Because we all know that unless you’ve got the right temperament for working with this group, doesn’t matter how smart you are, it doesn’t matter how much you know, you are not gonna be good at it”.

“... because if they come from school (I don’t know what they teach them in school) it’s different from what they’re coming into.”

Additional challenges that can make the CC sector unattractive for young graduates are the stigmas associated with mental health issues and the challenging behaviors that staff deal with across the continuum.

Participants also expressed the challenges in recruiting HCAs who have the interpersonal skills necessary to care for the clients and to deal with the job demands. They often referred to the unrealistic expectations of HCAs that leads them to frustration and burden when faced with the job expectations. This is potentially related to the training they are getting, and the competences being developed in those training programs.

**6.2 Retention:** Once staff are recruited and hired, the issue of staff retention emerged as a critical issue that has a direct impact on quality of care. For example, HCAs often quit within few months of starting in the position. This in turns impacts the in-service training, the team development, and the costs related with additional hiring processes. These sudden resignations cause organizations to rely

heavily on temporary staff, which increases the confusion of the client and the families and impacts the procedures and routines of the site. Issues with retention also place additional demands on the rest of the staff and increases the likelihood that they may also feel inclined to leave the job, or experience health related issues. Other factors related to retention are associated with pay, which participants feel does not correspond with the huge amount and type of work that these providers are asked to do.

**CNDRN/ICCER related activities in staff retention and recruitment:**

1. ICCER is facilitating a continuing care stream of the University of Alberta's interdisciplinary team based course for health professionals (IntD410) for the third year. One aim of the course is to encourage young professionals to look at continuing care as a potential career opportunity.
2. In follow-up to a related ICCER/AHS study (Optimizing Workforce Utilization to Inform Care Delivery in Continuing Care Facilities), a working group (AHS and ICCER) is examining strategies to address issues related to communications and casual staff. These are part of a CIHR planning grant project.

## 7. Working with families

Participants reflected on working with families as an important and often overlooked issue in continuing care. They defined this category in terms of five broad elements that require researchers' and clinician's attention:

**7.1 Family's role:** The diversity of the population served by the CC sector in Alberta is also reflected in the diversity of the families and their unique journeys supporting a loved one. Sometimes families can be very involved. Others are informed and only actively involved when requested and some are not involved at all. The role the family plays has the potential of improving the quality of life of the client while

allowing the staff to concentrate on their work and programs with the client as planned. Participants illustrated this point by reflecting on clients with involved families who, from their perspective, show better disposition for recreational activities, more stable moods, higher levels of engagement, and better personal hygiene. As well, these families tend to organize more care activities both in-facility (e.g. hairdressing appointments) and external to the facility (e.g. dentist or specialist physician appointments). Participants commented on the level of involvement of these families as being appropriate and as reflecting that these families trust the staff. This level of trust allows them to monitor and give feedback to staff while also being willing to receive education and information. When levels of trust are not adequately developed, families can put pressure on staff and cause unnecessary setbacks on the clients' progress. On the other hand, families who are not involved not only impact the client, but place additional demands on the staff that can cause staff members to assume responsibilities outside of their competence and mandates.

Research on this issue could provide evidence and a better understanding of: i) the impact of family's involvement in client outcomes; and ii) strategies that can positively encourage family participation and

“Some of them say that the staff are their family because they are the only people they see.”

“I think we have to really work at including them; I don't think it comes natural to us. So they often play a huge part of that individual's life, but they are just being treated as outsiders coming in, as opposed to part of the care team.”

“... but kind of the overarching idea should be that you ask families, you collaborate with families to come up with mutual goals to find out what their values and priorities are.”

family-staff team development. Research could also inform the CC sector by providing insight into the expectations of families and their perceptions of their roles in the CC sector.

“Work with family caregivers, they are so burdened with the information, there’s so much information coming at them that they are scared of the diagnosis, they are scared of what it means, we can provide lots of education, all of us can, but it is how it gets coordinated and repeated in the same way.”

“We don’t know because it’s also that we get a “Do I want to hear this little piece on the diagnosis” piece, and then at what point can we give them more about long term care, then at what point can we introduce end-of-life care.”

“I’ll talk to families in the hallways, or wherever, and I’ve got them in tears, not meaning to, but it’s because I’m trying to explain to them that this is normal process, they don’t understand it. It’s horrible that families don’t get more education.”

“What I would like to know about that topic is what families need from us.”

“The family is kind of the client, you really can’t separate them.”

7.2 Families as CC clients: Participants commented on the amount of time and resources devoted to educate families in terms of the disability or aging process of their loved one. Several factors such as cultural background, stages of grief, coping strategies, and unrealistic expectations make this process more complex. As a result, front-line workers feel that the CC sector is not only caring for a client that comes into a long term care or supportive living facility, but it’s actually caring for a family, and research needs to be done to explore the dynamics of family-centered practice as well as client-centered practice. Staff feel that society is demanding that the CC sector redefine who the client is, and to develop strategies to support families in the process. This could also impact the burden on staff and the quality of life of the client. Another way in which research can support workers in this area, is in the development of knowledge translation models for families and tools that can provide staff with a framework for communication with families in stressful situations.

### 7.3 The overlooked value of family’s knowledge:

Participants expressed a growing awareness related to the knowledge that families have as previous and primary caregivers of the client. Their past experiences and knowledge of the client’s personal history and background equip them to deal with or contribute to the management of critical issues such as challenging behaviors, non-verbal communication strategies, and preferences or dislikes. Participants feel that the CC sector often relies on the academic knowledge and training of staff, establishing a dynamic in which personal knowledge of the clients is not as relevant or even acknowledged, considering that most families have no formal training in health care. Research is needed in order to explore and understand more about this family-based knowledge and how it can be incorporated to team development practices in which families become part of the caregiving team.

“... so family would be a key link to sharing their knowledge of what works with their loved ones and how I can work with them.”

“...we aren’t giving credit to families with NO education, with NO base knowledge, and they have a vast knowledge that we haven’t respected.”

“... but have we respected what the knowledge is of the family as a caregiver coming into the care center, or we haven’t because we are nurses and we know it all?”



The issue of working with families was found to be strongly related with that of system navigation and transition of care. Participants reported this issue as being one that has a large impact on staff time and efficiency due to the amount of time that is currently being spent in family education, information and advocacy.

**CNDRN/ICCER related activities in working with families:**

1. There are no targeted ICCER-based projects at this time other than the systems transition projects mentioned previously. However, ICCER continues to encourage researchers around Alberta to do more research into issues related to families in continuing care.

## 8. Caregiving

This issue was one that emerged initially as a very broad category. Participants used the term caregiving to refer to many and different care related situations including care delivery models and staff cultural backgrounds. However, these very distinct categories, such as care delivery models, emerged as separate phenomena in the analysis process and were therefore considered as separate. During the sessions, participants were also prompted to explain in more detail what they meant by caregiving issues. As a result of pulling out separate distinct categories and of analyzing participant's response, caregiving was often and particularly related with three consistent issues across sources: i) attitudes and attributes of caregivers that impact caregiving; ii) the issue of caregiving for couples in the CC sector; and iii) the impact of clients' habits and addictions on caregiving.

"And also remembering that we are providing care for people that there's still so much of their lives that we don't impact. Just like you said, we take care of the physical things, but we miss a lot of what gives you quality."

"I think that there's lots of work to be done with all levels of staff regarding boundaries, professional boundaries; you know, to be engaged and attentive and kind to the residents that we look after, but also keeping that—that you're there as a caregiver, that is your purpose."

"Well, and how do you teach compassion? Those interpersonal skills, how do you develop those among your staff?"

### 8.1 Attitudes and attributes of caregivers:

Participants expressed that the attitudes and inter-personal skills required to successfully provide care, are often overlooked in training, recruitment and team development. Such skills and attributes are considered to be fundamental for providing quality of care. Research could help understand more which of these skills, attitudes, and attributes are important, and formulate strategies that could help staff develop and use them effectively.

8.2 Caregiving and couples in the CC sector: An emergent issue of increasing importance to staff is that of providing care for couples in the CC sector. More often, staff are seeing aging couples who require different levels of care. Because there are no current strategies, and few facilities, to accommodate couples with diverse care needs, the couples are usually separated. Staff expressed the impacts they perceive that this has on care for the couples. Research is needed in order to identify the characteristics and demographics of couples in this situation, and the impact that the different accommodation options may have in terms of costs and care for the family members.

“It is quite problematic when one spouse needs long term care maybe the other spouse needs level four and because they don’t fit exactly. It is hard to keep them together.”

“... you know for people who have been married for maybe 60 or more years, where one spouse could provide a little bit of support for the other one, they are separated and it’s quite traumatic for them.”

“I saw a man in the community who has been separated from his wife who has dementia. He is in a different facility and when he goes to visit and the wife is engaged in a relationship with another male on the dementia unit after he lived for 50, 60 years with this one woman and that’s all we are able to provide?”

“But there’s one addiction out there that they totally ignore and just banned totally and it’s cigarettes. And that is a huge issue.”

“And from a health promotion standpoint, smoke free is great but yet this is also these people’s home and from a quality of life issue that’s a huge deterrent for them. So how do we balance the two?”

“And these people are 80, 90 years old, they’ve smoked their entire lives, and it’s an addiction. It’s not like they can just quit.”

### 8.3 Caregiving and the impact of habits and

addictions: When discussing caregiving issues, participants commented on the huge impact caused by the clients’ lifelong habits and addictions. Many of the current CC clients have tobacco or alcohol addictions. Since smoking and alcohol consumption is prohibited in most facilities, staff need to deal with the additional demands imposed by addiction related behaviors and symptoms. Participants feel that the impact of these addictions, specifically tobacco, hasn’t been adequately addressed and that care staff lack the necessary tools and resources to support clients and provide care when considering these additional issues.

#### **CNDRN/ICCER related activities in caregiving:**

1. There are no targeted ICCER-based projects at this time related to caregiving. However, ICCER continues to encourage researchers around Alberta to do more research into issues related to caregiving in continuing care.

## 9. Intercultural issues

When reflecting on intercultural issues, participants described issues related with the cultural backgrounds of both staff and clients. Both perspectives impact care and team development.

“We have generational types of issues and understandings, beliefs, practices, and then we also have cultural, and how does that affect the family and the clients’ perception of their care and happiness with their care?”

“...is a very important area and understanding what the various backgrounds bring. Like Jewish, what’s important to them. And understanding what’s important with the various Islamic groups, and the Buddhists, and the Sikhs. And understanding and being able to be supportive in an appropriate way to the various cultures.”

“So we have a fair number of residents, who are of a different cultural and religious background and I think it’s becoming more and more difficult to help them to meet their cultural and spiritual needs.”

9.2 Staff’s cultural backgrounds: The cultural diversity of the Canadian population is becoming increasingly evident amongst the CC staff. HCAs and non-direct care staff (Examples dining room staff and housekeeping) are often new Canadians. This creates additional challenges to the caregiving dynamic that participants felt are related to having English as a second language. Participants reported several similar experiences in which staff used their native language in the work setting to increase efficiency and to overcome communication challenges. The use of languages other than that of the client’s is perceived as increasing clients’ confusion and disorientation, and potentially increasing challenging behaviors.

Participants also commented on the fact that immigrants with professional medical or nursing backgrounds, and other graduate education, find it hard to meet the requirements to practice in Canada. Therefore, they often seek HCA training

9.1 Clients’ cultural backgrounds: On one hand, the increasingly multicultural background of the Canadian population is reflected on the CC sector. With an aging population, more and more clients with diverse cultural backgrounds are coming into the CC settings and programs, demanding intercultural competencies from care staff. This raises questions regarding the impact of cultural differences in the dementia population and in those with mental health issues. Clients with diverse cultural backgrounds and their families have differing expectations and needs in terms of care, as well as certain boundaries important to them in their interactions with their caregivers. These cultural and spiritual needs, as well as their impact on the clients’ and families’ experiences of care and expectations, are not well understood. Also strategies are required to help staff deal with, and be prepared to support, clients with differing cultural backgrounds, such as developing intercultural competences.

“... as a resident you can have different cultural languages being spoken... caregivers would speak in their own language and I don’t know if there’s actually education that it’s important to speak in the language if you can, I mean they already are confused and having dementia problems and then all the people around them are speaking in another language, um, it not only isolates them, but it also confuses them.”

“I’m not sure of what education or research has been done to show the impact on the residents when staff speak other languages in front of them. Specially, for people to be able to take that information into a study it would show to them this is what happens to this particular resident when you are talking in a different language.”

“The majority of the health care aides are new Canadians, maybe more nurses and so how do you help them deal with us. And communication in cross-cultural or transcultural nursing, communication patterns.”

and positions. The fact that they have this base knowledge can also cause them to feel frustrated and seek responsibilities more like they would have had in their home country.

**CNDRN/ICCER related activities in Intercultural Issues:**

1. A team of researchers and knowledge users (led by AHS, including University of Alberta, ICCER, CapitalCare, Excel Society, NorQuest College, and McMaster University) are developing a grant proposal to study intercultural issues amongst staff in continuing care.

## 10. Need for rehabilitation and recreation staff

“I think another great research project might be to look at the effect, both within the dementia population and within the cognitively intact population, of the effects of a substantial well run therapeutic and leisure activity programs within the sites and its effect on antipsychotic and antidepressant use. Because I think sometimes people are depressed because they are bored and haven’t got anything else to do.”

“...we need to look at what effect rehab has not only on their progress or their maintenance of independent function but also on their mental affect and their perception of quality of life. I think those are huge areas because those are areas that are much underfunded.”

“...and it seems that doing things to maintain a quality of life is not an extra it should be just as important as the physical care that we give but how do we get to the point where that IS considered just another normal part of the service that we provide?”

Front-line staff across the province expressed the need for research that documents and identifies the benefits and impact of rehabilitation and recreation services and interventions for CC clients. Participants reported that the clients, families, and front line staff see the benefits from these interventions, but the way funding is provided makes it harder for providers to justify hiring more rehabilitation and recreation professionals. From the participants’ perspective, engagement in therapeutic and recreational interventions and programs increases motivation, independence, functional capacity and quality of life. It also appears to decrease the need for certain types of medications and reduces challenging behaviors. Though participants recognize that there is research available in this area, they point out that it is often international and therefore not culturally or contextually relevant; also it is often conducted in specific sites that do not represent the rural and urban sites, which in turn makes it non-generalizable.

**What’s happening with the need for rehabilitation and recreation staff:**

1. Alberta Health asked ICCER to put together a research team and submit a proposal to look at Quality of Life and recreation therapy. A grant was submitted October 31, 2013 to Alberta Health and approved in January 2014. PI Dr. Gordon Walker, University of Alberta.

## Location dependent themes

### 11. Palliative, End-of-Life and Hospice

The issue of palliative and end-of-life in CC was especially relevant for professionals in the Edmonton area. They reflected on these issues as being emergent ones that will continue to impact other areas of the province in a larger scale as the CC clients with chronic conditions start requiring these types of services. They expressed a concern related with the current understanding of health care professionals regarding end-of-life care, which is often related to cancer patients. Health care professionals often overlook the role of end-of-life care when working with populations with non-cancer related chronic conditions, such as dementia. Two main research needs were identified by participants in this area: i) staff education; and ii) end-of-life care in CC facilities across the continuum.

#### 11.1 Staff education in palliative care:

Participants identified the education of staff as one of the pressing issues. Frontline workers are ill prepared to face and deal with end-of-life issues and are often not able to cope with these situations. This impacts care since staff cannot accurately inform or support the families or the client in the last days. Research is needed in order to: i) explore the current perspectives of staff and families regarding end-of-life issues in CC; and ii) develop strategies to handle these situations in the most humane and healthy way possible. Also, if staff were trained, they could more effectively identify clients in need of these services and get the palliative care teams involved sooner, so that their quality of life is increased and the cost to the health care system is reduced in the long term.

“It’s really hard for staff who haven’t been in this situation, so they’re so sad. So they need to be more educated about palliative, about how to look after these palliative needs.”

“... and I think some people maybe had the feeling that “Why isn’t he in the hospital?” So we did have meetings and talked about why it is that he’s allowed to be here and pass away here, and I think that really helped the staff to understand that.”

“We just want to have more education for the staff in the continuing care, trying to help them to identify the patients sooner than later, ‘cause that is going to affect patient’s care, their quality of life, and also a huge cost for the system. We are assuming that there would be cost effectiveness to our involvement as well.”

“I think people are familiar with the concept of palliative care in urban areas, but majority of the time, they have that concept associated with cancer. So our aim is to get people to think outside that box and look at non-cancer population. Because majority of the times, the term “palliative care” goes hand-in-hand with prognostication and how long is the patient’s survival. And because for the majority of non-cancer patients, you cannot prognosticate as clearly as for cancer, or not as well as you do for cancer, people have difficulty identifying patients who need palliative care services.”

“and we just had - like, our resident that was palliative that passed away. It was really nice. His sister, she did the funeral service, arranged for the funeral home to come here and do the funeral service here, because here was where his friends were, ‘cause our residents wouldn’t go to his funeral if it was at another place. So it was really nice that we had these classrooms to use so we had space to do that in. I don’t know that—we don’t have that space at other places.”

“So it’s people with chronic disease, but it’s also the frail elderly and dementia populations, where if they had earlier management of some of their symptoms, that advanced care planning, so they’re not ending up in acute care to spend some or most of their days. So we have some numbers in our program about the numbers of people that do have Emergency visits and acute care admissions, but is so unknown!”

“So stuff like, we have the primary prevention, but we don’t have a lot of the secondary prevention. My background and my practice background from many years was critical care, and we knew for 34 years that people coming from long-term care to spend their last 10 days in an ICU is not an appropriate place for them to spend their last moments with their family. But it’s still occurring!”

11.2 End-of-life care in CC facilities: The other element identified by participants relates to the special situations of CC clients, who identify the CC facility as home, when they need end-of-life care. Clients are more frequently asking to die in the facilities and the CC facilities are not always prepared to deal with this issue. Also, when getting near to the end-of-life, clients are often referred to the emergency room, and this causes them to spend their last days in the ICU instead of hospice. Participants expressed that this results from the lack of interdisciplinary work between palliative care teams and CC, and the lack of resources to assess clients in an end-of-life situation. Research would allow exploring the costs that ICU stays at the end-of-life represent to the system, as well as impact of caring for a client in the facility at the end of life.

## 12. RAI Research

The RAI instrument was mentioned across the province. However, the comments were more frequent in Edmonton and Calgary. The questions around RAI assessments were frequently related to many of the other issues raised. Participants expressed the need for research to assess the impact of using the RAI instrument in care planning and client outcomes.

In general, they felt that RAI is a useful tool but not enough to provide an accurate picture of the client and his/ her needs. Also, the short and long term process and complex needs of the client are not easily captured with RAI. In addition, participants indicated that using RAI with certain specific populations, such as clients with mental health issues, is not appropriate as it does not capture the complexity.

The limitations of the RAI for capturing the complexity extends to the use of the RAI Home care instrument in supported living, where participants feel is not appropriate for the specific context. For this reason, some facilities complement the use of RAI with their own instruments.

Research is needed in order to identify the missing aspects of the assessment and standardize a complementary tool. Since RAI impacts funding, the RAI instrument a critical part of the continuing care system and participants feel more research needs to be done regarding this element.

Participants also discussed the need to identify the required professional competencies of the clinician, to ensure reliability of the RAI assessment. They expressed the need for research that looks at the inter-rater reliability and outcome differences when the assessment is conducted by an RN or an LPN.

“Because RAI doesn’t capture the complex range of behaviors, my program is actually the result from that funding so, but I know speaking to our other secure dementia units who also are dealing with some pretty serious complex behaviors, RAI is not capturing it for funding purposes.”

“I find it interesting that the RAI instrument has a mental health module and has a home care module but... some of the questions that are in those modules are not in the long term care module, although they would be appropriate, given some of the challenges of the day to day.”

“... maybe this is the foundation but what additional assessments are added on that becomes sort of the standard to say “when you have this kind of a population you can add these elements and get a broader, you know, more complex, comprehensive assessment to help you with those populations”. So RAI plus? What could the plus be to help pull out the additional information for care plan.”

“I think is recognizing that the RAI gives minimum data. Like it seems like a lot of assessment but is still minimal. So what’s a next step?”

“I would challenge another research project, is the RAI-HC, the home care instrument. Is it the right instrument to be used in Alberta’s SL3-4-4D environments?”

“... we have sort of a mix model where some sites have RNs and some have LPNs that do RAI assessments, is there a difference in the outcome? Is it related to the training the individuals get when they first start that whole assessment piece or is it related to the basic education that they receive as part of their degree? Because I know there’s a lot of discussion from different care centers, is there a difference between an RN or an LPN doing the baseline assessment which leads to the care plan which leads to everything that we do?”

“They have to get it all together so that we are on that same page so that everybody is getting the same services because we are not.... So that if you go into a facility it looks the same whether you are here, or here, or there.”

“They keep changing the words and the levels and everything, so it’s hard for ... and they don’t really inform you when these things are changed, necessarily, so it’s hard to know.”

### 13. AHS Policy Inconsistencies

This theme was both identified as critical and frequently explored in Southern Alberta. There is a common perception that AHS policies seem to be inconsistent across the province with information and service gaps in areas. Participants said that this situation causes confusion among the clients and staff, and that it impacts care particularly in rural or more remote sites. Several inconsistencies were mentioned such as terminology, and service access, with clients in the southern part of the province being

at a disadvantage compared with those in Edmonton or Calgary. This has also caused policies and service planning to respond to the needs of the major cities but not consider the particular situations faced by the CC sector in remote and rural areas. These concerns were supported by discussion from the northern community networking events, where service gaps were highlighted frequently.

### 14. First Nations Issues

This theme was the top issue in Northern Alberta. It was defined by participants as the issues in continuing care related to the unique and particular characteristics of First Nations communities in the province. Several elements make the care for seniors and people with disabilities particularly hard. On one hand the geographical location causes isolation, making it hard to attract staff that can commit and are interested in moving to these isolated areas. This impacts staff retention and recruitment. The geographical isolation also makes it hard to arrange transportation for CC clients when they happen to need acute care services. Clients often have to wait longer and this can even complicate their health issues. Jurisdictional issues create difficulties as facilities and professionals often struggle to identify what agency or institution is responsible for funding a certain part of the care process for the senior and this delays the access to services.

Issues include:

Confusion arising from inconsistencies in geographic divisions (where you live, who funds your care, hierarchies of care, etc...)

Jurisdictional issues for aboriginal communities prevent collaboration

Not economically viable for health professionals to move to the outlying communities.

No reliable transportation for outlying communities



## PILOT PROJECTS

As part of the CNDRN funding, we committed to supporting two groups of researchers to further the development of research capabilities around key issues identified by the CNDRN consultation process. After review of the data, and discussion with the Reference Group, two projects were selected to partially address the top two issues: Mental Health Related issues and Adult Education issues.

### 1. Challenging Behaviours - Steps to the development of a Behavioural Supports Alberta

We approached this in a multi-step process. The first step was to support a symposium on November 21, 2012 - "Challenging/Responsive Behaviours: Developing an Alberta Action Plan" co-led by ICCER and the Alberta Challenging Behaviours Interest & Research Group (now known as Behavioural Supports Alberta [BSA]). The aim of the symposium was to explore and discuss the development of an Alberta Action Plan to: i) manage challenging/responsive behaviours exhibited by individuals across the continuum of care with mental illness, addictions, cognitive impairment, brain injury, developmental disabilities and other neurological conditions; and ii) support those caring for, or supporting them.

Based on the groundswell of support from provider organizations to have more work done to establish a Behavioural Supports Alberta, similar to the Behavioural Supports Ontario, we funded Dr. Suzette Brémault-Phillips and her research team to take the next steps in the development of a plan to develop BSA.

Her work took the results of the one-day symposium and further analyzed the data from the day's working discussions. She verified the recommendations proposed at the symposium, and formulated a report of the symposium findings, identifying next steps. She was able to develop a website ([www.bsa.ualberta.ca](http://www.bsa.ualberta.ca)) and encourage practitioners to join communities of practice. Her final report can be found at [http://www.iccer.ca/cndrn\\_crb.html](http://www.iccer.ca/cndrn_crb.html).

Dr. Brémault-Phillips and her research team are actively seeking additional grant funding and have written and submitted several proposals already.

The next step in the process was a second joint ICCER/BSA symposium, Advancing Behavioural Supports Alberta, held February 20, 2014. More detailed information on the symposium can be found at [www.bsa.ualberta.ca](http://www.bsa.ualberta.ca) and [www.iccer.ca](http://www.iccer.ca).

### 2. Learning Circles Implementation and Evaluation (Adult learning)

Since knowledge transfer and increasing the capacity of health providers to integrate best practices into care continues to be one of the most urgent challenges *and* opportunities for quality improvement in health care, the CNDRN funded the evaluation of the development and implementation of learning circles at Bethany Care Society. A learning circle is a form of cooperative learning that brings together experienced practitioners in structured collaborative learning groups to discuss topics of mutual interest. Bethany and Excel Society participated in the pilot project, but only Bethany's process was formally evaluated with an external evaluator.

Barrington Research Group from Calgary was contracted to develop an evaluation framework, including an evaluation logic model and data collection matrix. The project at Bethany ran from about June 2013 to December 2013. Given the short time frame of the project, there are still many questions from the logic model that remain unanswered. The next steps are to enhance the pilot project at both Bethany and Excel, and to expand to other care provider organizations. A grant application to the Network of

Excellence in Seniors Health & Wellness has been submitted. If funded, the project will develop an implementation tool kit for learning circles, and further test the evaluation model.

The interim reports from the learning circle pilot project can be found at [http://www.iccer.ca/cndrn\\_lc.html](http://www.iccer.ca/cndrn_lc.html). The final report will be posted once it is completed.

## KNOWLEDGE TRANSLATION ACTIVITIES

### Oral presentations and poster presentations related to CNDRN

The following is a summary of posters and presentations made that are related to the development and implementation of the CNDRN.

Event	Audience	Approximate Numbers
Challenging Behaviours Symposium, Building Capacity and Sustainability for Behavioural Supports Alberta. February 20, 2014	Health care professionals, front line workers, academics, researchers, policy makers – included national exposure	In-person – 80+ One main video-conference site in Calgary for 30. Video-conference and teleconference across Alberta, Saskatchewan, Manitoba, Ontario, and New Brunswick
Canadian Home Care Association Home Care Summit, October 28 - 30, 2013 <i>Needs driven research in continuing care: Research priorities and needs in the Home Care sector</i> (Alvarez L, Woodhead Lyons S, Fraser K)	Home care professionals – national exposure	40
Alberta Association on Gerontology. October 23, 2013 <i>Institute for Continuing Care Education and Research – Provider Perspectives on the Community Needs Driven Research Network</i> (Woodhead Lyons S, Neumann I, Read S)	Health care professionals, researchers, policy makers	28
42 <sup>nd</sup> Annual Scientific and Educational Meeting of the Canadian Association on Gerontology -Aging...from Cells to Society. 17-19 October 2013 <i>Lessons Learned from Developing a Community Needs Driven Network for Continuing Care</i> (Woodhead Lyons S, Alvarez L, Cook A)	Health care professionals, academics, researchers – national exposure	~25

Event	Audience	Approximate Numbers
<p>Inspiring Quality in Continuing Care Conference. 9 October 2013. <i>Behavioral Supports Panel</i> (Woodhead Lyons S, Brémault-Phillips S, Cole M) (invited presentation)</p>	<p>Health care professionals, front line providers, policy makers</p>	<p>~50</p>
<p>Creating Cultures of Care – October 7 (Calgary) and October 8 (Edmonton and beyond) ICCER’s first 5 years and the results of the Community Needs Driven Research Network</p>	<p>Calgary - Health care professionals, front line providers, academics Edmonton - Health care professionals, front line providers, academics, researchers, policy makers - national exposure.  Note: all individuals who participated in the CNDRN focus groups and interviews were invited.</p>	<p>30  In-person – 43 Video-conference – Calgary: 3 sites; St. Albert: 1 site; Ft. McMurray: 1 site; St. Paul: 1 site; Lethbridge: 1 site; Morley: 1 Site; Onion Lk, Sask:1 site. Telephone – 18 lines (known to be as far away as St. John, New Brunswick)</p>
<p>Advances in Qualitative Methods Conference. 21-23 June 2013. <i>Community needs driven qualitative research: Evidence based practice from within</i> (Alvarez L, Woodhead-Lyons S)</p>	<p>Academics, researchers</p>	<p>~20</p>
<p>Covenant Health Research Day 2013 – 7 February 2013 The Beginnings of Behavioural Supports Alberta (BSA): A Provincial Initiative (Brémault-Phillips S, Parmar J, Woodhead-Lyons S, Friesen S, Lee J) (poster presentation)</p>	<p>Health care professionals, front line providers, policy makers</p>	<p>~100</p>
<p>Challenging Behaviours Symposium, November 21, 2012</p>	<p>Health care professionals, front line workers, academics, researchers, policy makers – included national exposure</p>	<p>In-person – 80+ Video-conference and teleconference across Alberta, Manitoba, and Ontario</p>

## Social Media activities

As of June 2013 ICCER embarked on a social media campaign to raise ICCER's exposure and to help disseminate the results of the CNDRN.

Type	Target Audience	Exposure if known
Website upgrade including: <ol style="list-style-type: none"> <li>1. CNDRN section                             <ol style="list-style-type: none"> <li>a. Summary report</li> <li>b. 2-pagers for overview and each of the 14 identified issues</li> </ol> </li> <li>2. Partnership stories highlighting successful programs, research and other activities</li> </ol>	Health care professionals, front-line workers, policy makers, public	All materials available for download
LinkedIn Company page	Health care professionals, academics, policy makers, public	Variable, some postings have over 200 impressions
LinkedIn Discussion group	Health care professionals, academics, policy makers	As of February 2014 – 39 members
Twitter	Public	As of February 2014 – 43 followers
Facebook	Health care professionals, academics, policy makers, public	

## Future plans for Knowledge Transfer

Activity	Target Audience	Status
Webinars	Health care professionals, front-line workers	Dependent upon future funding
Videos	Health care professionals, front-line workers, public	Dependent upon future funding
Annual province-wide symposia	Health care professionals, front-line workers	Dependent upon future funding

## LESSONS LEARNED FROM THE CNDRN

1. **Language can be a barrier** - We discovered that even after going through ethics approval, where information letters and consent forms are written to no more than a grade 6 level – it is not necessarily appropriate for a workforce (health care aides, dietary aides, etc) who have a low level of education and where English is frequently the second language. We need to be adaptable and creative to engage all HCAs and other providers who may have lower comprehension levels.

2. **Interdisciplinary focus groups are preferable** - During the ethics process we were asked by one person to separate the HCAs out from other providers. We declined saying that HCAs already felt neglected and not part of the team as it was. To separate them would be to say that they weren't good enough to join the other providers. While this is very true, we discovered the importance of having a multi- or interdisciplinary focus group. We found that often the HCAs would be quiet until they heard what others were saying and felt comfortable with the process, but then they became quite vocal. The one focus group that was made up exclusively of "low level" personnel, there was very little

"Can I ask you a question? Is there going to be some research on the difference the outcome will make in the end because you did consult, vs. the research driven derived project? Because this is more expensive way to do things probably to start with when you have a certain period of time to do this community consultation sort of piece but it's so relevant to us, so good, it will be good to see if there's a difference."

"Yeah, we want to engage the researcher, engage with him. 'Cause he wants—I mean, he wants access to our data, we want his knowledge, and I mean, we can only learn from each other, so we need to collaborate, we want to."

"And I think for research in all long-term care across the province, we have to all do something differently in terms of knowledge translation and knowledge application. So... collaboration, being consulted, I just think that's a ... I think it's a critical point; I think it's going to be phenomenal!"

conversation. They had difficulty understanding what we were looking for without being able to follow the example of the regulated providers.

3. **New methods for getting home care involvement are needed** - The Home Care personnel who were participated in the focus groups tended to be in non-direct care positions. The few Home Care Aides who participated were facility-based, not community-based. In Edmonton we tried, with the help of a private home care provider organization, to get Home Care Aides to one focus group. We had no responses. The way community based home care is set up, Home Care Aides do not have the flexibility or time to participate in such activities. We will be looking at more innovative and creative ways of including home care for future activities.

4. **There are difficulties in organizing focus groups outside of urban areas** - In rural areas there are greater communications, scheduling, and transportation barriers when trying to bring people together for focus groups. These issues are not dissimilar to what their clients/residents face in trying to obtain services.

5. **There is a great deal of interest from direct care providers in participating in such activities** - Participants often commented on the needs driven research process that was being carried out. They provided positive feedback and expressed their desire and need to be involved. The following are some examples of references made in regards to the process throughout the sessions:

## NEXT STEPS

The need for a CNDRN remains. ICCER continues to seek additional funding in order to sustain the CNDRN. We will continue to:

1. Disseminate our findings:
  - [www.iccer.ca](http://www.iccer.ca)
  - [twitter \(@ICCER\\_AB\)](#)
  - [facebook \(http://tinyurl.com/oq7cz36\)](http://tinyurl.com/oq7cz36), and
  - [LinkedIn \(http://tinyurl.com/p9eabah—Group\)](http://tinyurl.com/p9eabah) or [http://tinyurl.com/oo6kjmd—Company page](http://tinyurl.com/oo6kjmd)
2. Actively encourage researchers to conduct research in these high priority issues.
3. Work with provider organizations to initiate innovate programming, based on best practices, to address the issues.

## APPENDIX 1 - FOCUS GROUP TOOLS

1. Focus group recruitment poster
2. Focus Group Information letter and consent form
3. Focus group guide
4. Themes and issue document to support focus groups



## How can research inform your practice? What gaps or needs do you believe research should address?

### What is this about?

We are a research team from the Institute for Continuing Care Education & Research and we are looking forward to working with you on a project about identifying the needs and priorities of continuing care workers that can drive research projects in this area. We would like to invite you to be a part of the more than 50 workers across the province that are telling us what research could do to improve their work and the quality of care.



### We know that

... you are the experts when it comes to providing continuing care services. You are the ones that know which gaps in information and evidence exists, what the challenges and priority issues are. You can help us identify what research should be done in continuing care that will have an impact for you and the users. Your experiences and insights will be very helpful to us.

### We would like to find out

... which topics are important to health care workers and others in the community. We want to know what research could be done that would have a direct impact on improving continuing care. Continuing care includes a range of activities and supports. These include home and health supports for those living in their own homes or in lodges, supportive living, long term care, and end of life issues in all venues.



### We want to listen

... as you tell us what you think the priorities and issues in your practice are.  
... as to how can research projects impact your work and the quality of care.  
... to your information needs in any aspect of continuing care.  
We would like to invite you to a group session to discuss continuing care.



### A bit more about the research

Much of the current research activity in continuing care is driven by the interests of the researchers. While this can be relevant to your practice, the needs that require research study are often identified by continuing care providers and front line workers, but there is no vehicle for those needs to be formulated as research questions suitable for the identification of research teams. Our project is promoting the development of needs driven research questions and projects through the identification of issues, challenges, practices with insufficient formal evidence, and areas in which research can further inform practice within the continuing care sector in Alberta.

This project is funded by Alberta Innovates - Health Solutions

Initiative: Community needs driven research network in continuing care. For more information contact Sandra Woodhead Lyons: [sandra@iccer.ca](mailto:sandra@iccer.ca) (Study coordinator).



## INFORMATION LETTER FOR FOCUS GROUPS

**TITLE:** Development of a Community Needs Driven Research Network for Continuing Care in Alberta

**SPONSOR:** Alberta Innovates Health Solutions

**PRINCIPAL INVESTIGATORS:**

Dr. Al Cook, Professor Rehabilitation Medicine, University of Alberta ([al.cook@ualberta.ca](mailto:al.cook@ualberta.ca), 780-492-5001)

Ms. Iris Neumann, CEO, CapitalCare ([iris.neumann@capitalcare.net](mailto:iris.neumann@capitalcare.net), 780-448-2422)

**CO-INVESTIGATORS:**

Don McLeod, Bethany Care Society	Donna Herald, Keyano College
Doug Wilson, University of Alberta	Bev Maron, Keyano College
Erin Bampton, NorQuest College	Doris Milke, CapitalCare
Bill DuPerron, Bow Valley College	Sharon Read, Excel Society
Janet Fast, University of Alberta	Duncan Robertson, Alberta Health Services
Lars Hallstrom, University of Alberta	Greg Wells, Red Deer College
Guy Harmer, Keyano College	Kyle Whitfield, University of Alberta

**PROJECT COORDINATOR:**

Sandra Woodhead Lyons, Executive Director, Institute for Continuing Care Education and Research (ICcer) (780-248-1504).

This information letter is only part of the process of informed consent. It should give you the basic idea of what this research is about and what your participation will involve. If you would like more details, please ask. Take the time to read this letter carefully and to understand any accompanying information. You will receive a copy of this letter.

## **BACKGROUND**

The goal of this study is to improve continuing care in Alberta. We want to know which topics are important to health care workers, family and others in the community. We are studying what research could be done that would have a direct impact on improving continuing care. Continuing care includes a range of activities and supports. These include home and health supports for those living in their own homes or in lodges, supportive living, long-term care, and end of life issues in all venues.

## **WHAT IS THE PURPOSE OF THE STUDY?**

To consult with provider organizations, care providers, and others in the community involved in the area of continuing care.

To find out which issues in continuing care need to be researched.

To place those issues in priority order based on front line needs.

## **WHAT WOULD I HAVE TO DO?**

You have been asked to participate in a focus group. The focus group will last approximately two hours. During the focus group, the researcher will ask a series of guiding questions on some issues that have been identified by the research team as needs or gaps in continuing care. You will be asked to freely share your opinions about those issues, and comment on any other issues or needs that you think the researchers need to know or be aware of.

We would like to get your permission to audio-record the sessions to provide an accurate record of our conversation. Notes will also be taken.

## **WHAT ARE THE RISKS?**

There are no known risks to participating in this study. Your job will not be affected in any way by your participation in this study or by the information you provide.

## **WILL I BENEFIT IF I TAKE PART?**

There is no direct benefit to participating in this study although information collected may be used to develop research in continuing care so that it can adequately inform your professional practice and needs. This in turn may change how you do your job in the future.

## **DO I HAVE TO PARTICIPATE?**

Your participation in the study is voluntary. You may decline to answer any of the questions and end your part in the study at any time. Should you wish to withdraw from the study, please inform the researcher or contact the individual listed below. If you decide to withdraw, please

be aware that your recorded comments and answers will not be coded in the transcriptions but can not be removed from the data up to that point.

You also have the right to ask questions and ask for more information whenever you like.

### **WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

You may be asked to participate in a follow-up interview if we have more questions for you. An electronic survey may be distributed after all interviews/focus groups are completed. You may be asked to complete the survey.

### **WILL MY RECORDS BE KEPT PRIVATE?**

During the focus group there may be individuals who know and recognize you. Although we request focus group participants respect the confidentiality of others in the group, we cannot guarantee it. Outside the group, your anonymity and confidentiality will be ensured in the transcribed data. You will not be identified by name in the transcription process.

The Project Coordinator, the research assistant, and any of the research team participating in the focus group are aware that you are participating in this study and therefore it may not be possible for you to take part in the study anonymously. The information that you provide, however, will be kept confidential. Code numbers will be used on transcripts and notes. Lists of participants along with the code number and consent forms will be stored separately from the data. All information from the study will be reported at a high level only meaning that your name will not be identified. Only principal and co-investigators, project coordinator, and research assistant will review transcripts and notes. All data collected will be stored in a locked cupboard at the Institute for Continuing Care Education and Research for a period of five years.

Ideas and quotes from focus groups and notes will be used for interim and final reports, publications and presentations of research information, but at no time will you be known by your name or in any other way. Anonymity and privacy will be assured as much as possible. You may have a copy of interim and final reports.

This study has been approved by the Health Research Ethics Board, University of Alberta.

### **CONTACTS**

If you have further questions concerning matters related to this research, please contact Sandra Woodhead Lyons, Executive Director, Institute for Continuing Care Education and Research (ICCER), 4-023 Edmonton Clinic Health Academy, University of Alberta, 11405 - 87 Avenue NW, Edmonton AB T6G 1C9 (780-248-1504 or [sandra@iccer.ca](mailto:sandra@iccer.ca)).

If you have any questions concerning your rights as a possible participant in this research, please contact the Research Ethics Office, University of Alberta at 780-492-2615.

## **FOCUS GROUP PROTOCOL**

### **1. INTRODUCTION**

[approx. 5 minutes]

Welcome Everyone! I want to start by thanking all of you for coming today. My name is Sandra Woodhead Lyons and I will be facilitating the group today. I would like to introduce my colleague (X) who will be observing the session and taking notes.

I hope each of you have received information about the purpose of this meeting today. However, I will go over the purpose of this study and give you an overview of what we will be doing during this session.

First, I would like to cover some housekeeping issues.

I assume that you have all filled out the consent form already. If you arrived late and have not filled out the consent form, I will have to ask that you do so now before we continue.

Just a reminder that this session will be recorded on audiotape. One reason we do this is so we can identify key themes from the focus groups. However, I want to assure you that everything you say here will be kept anonymous. Your name will not be associated with anything that you say. Sometimes however one of you may say something that concisely captures a point that has been raised frequently. In that case, we may use your exact words as a quote. But we would NOT identify WHO had said these words.

Because we are taping the session, I have to ask you to speak one at a time. If several people are talking at once, the tape recorder cannot pick up what is being said and I might miss something important. As well, I do want to hear from everyone. And so I would ask that all of you be respectful of the thoughts and opinions expressed during the session; thus, allowing for an equal opportunity for everyone to speak and participate. I may try to draw some people into the discussion. But I don't want to make you uncomfortable. Hopefully you will feel free to participate – sharing as little or as much as you are comfortable with. Also, I would like to ask that what is said here stays here. Just as we will be respecting your confidentiality, we ask that you respect the confidentiality of others in the group. Please do not discuss what others in the group have shared.

#### **How long will all this take?**

Today, our session should last approximately an hour and a half.

During the discussion today, we would like to hear YOUR opinion. When we have discussions, we would like you to speak up and voice your opinion especially if it is different from the opinions already raised. We do NOT want everyone to agree with each other - rather we would like to hear all the varying viewpoints. In other words, it is certainly all right to disagree with something that someone else has said.

#### **Purpose**

The purpose of this focus group is to determine your perspectives on what research could be done in the continuing care sector that could make a difference to practice and to the care of people using continuing care.

Tonight we want to identify the needs, priorities, issues, challenges, practices with insufficient formal evidence, and areas in which you, as continuing care provider, believe that research and information is needed to inform practice within the Continuing Care sector in Alberta. This information will be used to inform the development of research questions and the identification of gaps in the literature and potential for research projects.

## 2. PARTICIPANT INTRODUCTIONS

[approx. 5-10 minutes]

We would like to start with introductions. We would like to introduce ourselves and we will ask you to do the same. Knowing each other will allow us all to feel comfortable in this enriching discussion.

## 3. QUESTIONS

[approx. 40-60 minutes]

After the introductions, the team will share the “Themes and issues document” list (attached to ethics application form in documentation section), to encourage discussion and as a starting point.

➤ *In order to start our conversation we have prepared a list of areas in continuing care where research may inform practice and development of innovative practice and care provision strategies. This list has been compiled from different written sources and official reports. We would like to share this with you and we would like to hear what your thoughts are on this. Under each theme you find the definition of the theme and some examples of the kind of issues or gaps that might be related to each. Please use these as a starting point, and feel free to tell us if you relate to them or if you want to bring up any other related or non-related areas in the field of continuing care. We now want to start by asking your opinion on some questions and we can discuss about them:*

- *In your practice, what are your top three issues that affect how you provide care? (Everyone gives top issues and RA writes them down on flip chart)*
- *Let’s talk about these issues (approach will depend on what issues and how many issues have been identified by group. If many issues given, try to come to some consensus on what the top five or so are) how do they affect your practice?*
- *How do these relate to the themes we have identified (refer to sheet)?*
- *Which of these themes could have the biggest impact on your practice, if best practices were identified through more research?*

The Themes and issues list document is shared with the participants in advanced but copies are also provided during the session. Discussion is encouraged around how the group feels it reflects their perceptions. The themes documents are only meant to serve as a guide for the focus group and to give participants an idea of the breadth and scope of areas they might want to discuss.

## 4. CONCLUSION AND WRAP UP

[5 minutes]

***Facilitator will summarize some of the key issues or features of the discussion and will ask if any participants have any final comments or feedback in regards to the focus group.***

***Final thank you, wrap-up, and discussion of any further housekeeping issues.***

**ICcer – Community Needs Driven Research Network – Consultation Process  
 Themes and Issues for discussion with Focus Group/Interview Participants**

These 20 theme areas are for discussion purposes. You might group some of the issues differently. You might not consider some themes to be problematic in continuing care. You might have other themes that you think are more important. That's fine, this list is not meant to be inclusive, but rather a starting point for identifying the major issues that you feel affect practice in continuing care.

When reviewing this list, consider what would be the most powerful levers to influence practice. If answered, what questions could improve your practice?

**THEME: Care Delivery Model**

How the care delivery model is set up so that is responsive to the care needs and experiences of residents/clients, reflects inter-professional practice, and is based on data and evidence.

**THEME: Caregiving**

Caregiving refers to the provision of assistance to another person who is ill, disabled, or needs help with daily activities. It often requires attention to the physical, mental, social, and psychological needs and well-being of both the caregivers and the elderly person requiring care.

**THEME: Dementia Care**

Dementia care is for residents with dementia or Alzheimer's disease. Dementia care can be offered in specialized units within supportive living and long term care facilities. These units are secure and provide special stimulation for residents who are in many cases physically able but lacking mental capacity.

**THEME: Development of options for adult learning**

Health care aides and other front-line workers have limited time for education and upgrading. Improved options for providing new learnings and best practices are necessary.

**THEME: Education related**

Appropriate education and training of care providers at all levels is important to care.

**THEME: First Nations Issues**

Providing continuing care to First Nations groups has challenges and barriers, in part due to remoteness and lack of population, but also due to barriers between levels of government.

<p><b>THEME: Intercultural Issues</b></p> <p>There are intercultural issues that can affect continuing care both from the perspective of specific cultural groups needing care (i.e. Chinese population in both Edmonton and Calgary have opened long term care centres) and from the perspective of many front line workers coming from other countries with different cultural attitudes towards seniors and aging than Canada has.</p>
<p><b>THEME: Knowledge Translation</b></p> <p>How to transfer good ideas, research results, and skills between researchers, educators, and health care providers in order to improve care.</p>
<p><b>THEME: Leadership Skills Development</b></p> <p>Leadership in continuing care takes place at both formal and informal levels. It is important that care providers are trained, educated, and supported in order to provide appropriate leadership.</p>
<p><b>THEME: Lifestyle Induced Dementia</b></p> <p>People with lifestyle induced dementia (such as from alcohol or drug use) display different behaviours from people with some of the other types of dementia (such as Alzheimer's). There is an increase in the numbers of lifestyle induced dementias and the system needs to prepare for this.</p>
<p><b>THEME: Mental Health related issues</b></p> <p>Mental health issues are increasing. Some research indicates that between 60-90% of residents in the continuing care sector have at least one disturbing behaviour. Managing challenging behaviours in the client/resident population is an increasing concern throughout the continuing care sector.</p>
<p><b>THEME: Palliative/ End of Life Issues /Hospice</b></p> <p>With an ageing population increased numbers of older people live and die in long term care and other continuing care settings. There needs to be a common understanding of palliative care, end-of-life care, and care planning for staff, residents, and family members.</p>
<p><b>THEME: Physical Environment</b></p> <p>The physical environment can have an impact on the health and well-being of both residents/clients and caregivers. Not only has the natural environment many proven benefits, the built environment, using evidence-based features, is as effective for persons with Alzheimer's related dementia as current medications.</p>
<p><b>THEME: Quality of Care - Intervention Studies/Clinical Practice Issues</b></p> <p>Quality health care is about delivering the best possible care and achieving the best possible outcomes</p>

for people needing continuing care services. Basically it means doing the best possible job with the resources available.

**THEME: Role Definition within the CC Sector**

The continuing care sector is still evolving. It is important to define current and future roles of health care workers, in particular RNs and LPNs in the continuing care sector and how scope of practice for their disciplines will affect future role definition.

**THEME: Staff Retention and Recruitment**

The continuing care sector relies on front line staff to care for residents and clients. It can be difficult to recruit people to the sector. Once they are hired, it is important to retain staff.

**THEME: System Navigators and Transition of care**

Alberta's continuing care system provides Albertans with the health, personal care and accommodation services they need to support their independence and quality of life. Individuals need to transition from level to level (i.e. supportive living to long term care) and from the acute care system to the continuing care system. This can be confusing and difficult at times. Support is needed by residents and families to navigate through these systems.

**THEME: Team Development**

Team work is important in the continuing care sector. Individuals need to know how to work in an interdisciplinary team and teams need to be supported to maintain optimal functionality.

**THEME: Technology**

Technology can be used to support clients and residents in continuing care and to help individuals maintain independence longer.

**THEME: Working with Families**

Regardless of where an individual lives within the continuing care sector (home, supportive living, long term care), families play an important part in supporting and caring for their loved ones.