

# Community Needs Driven Research Network

CNDRN

## Pilot Project for the Development of a Community Needs Driven Research Network for Continuing Care in Alberta

Data Analysis and Results Report



INSTITUTE FOR CONTINUING CARE EDUCATION & RESEARCH

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## **ACKNOWLEDGEMENTS**

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## BACKGROUND

In 2012, as part of the development of a Community Needs Driven Research Network (CNDRN), ICCER conducted a consultation process across Alberta using qualitative research methods. The purpose was to identify priority themes and issues for research to improve practice, from the perspective of front-line workers in the continuing care (CC) sector.

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.

## METHODS

A total of seven focus groups and three interviews (four participants) were facilitated in five cities across the province (Figures 1 and 2).

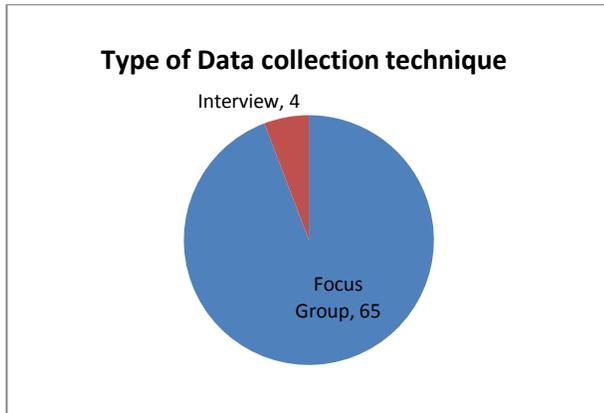


Figure 1: Participants per data collection technique

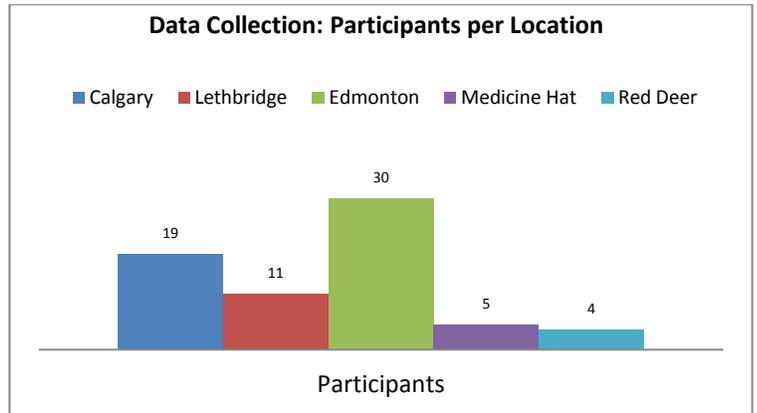


Figure 2: Participants per data collection site

Sixty-nine front-line workers from nine cities/ towns of the province participated in the consultation process (see Figure 3).

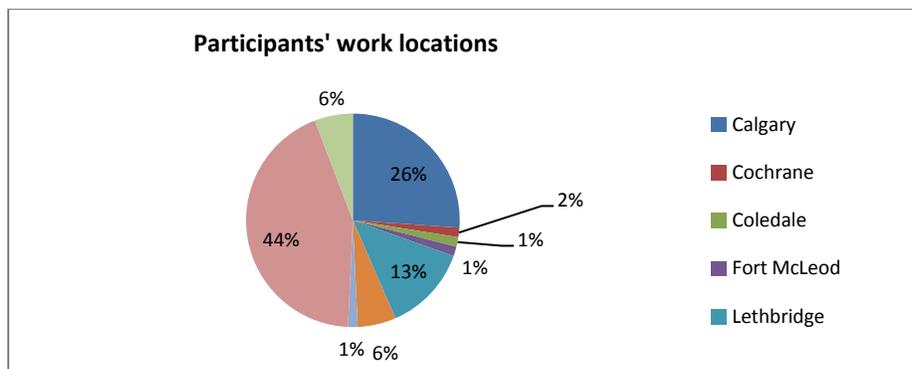


Figure 3

The percentage of participants from private, not-for-profit, and AHS provider organizations were roughly equal (See Figure 4).

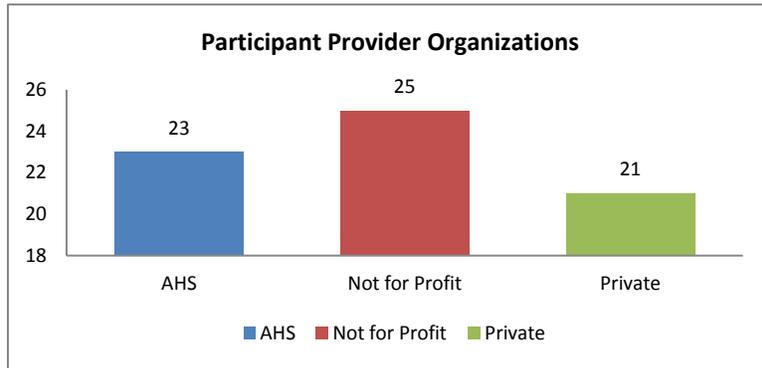


Figure 4

Participants in this consultation process represented a wide range of disciplines, licensed and non-licensed professionals working in the continuum of care (Table 1).

Participants' Roles	
Row Labels	Count of Overall Role
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>

Table 1: Participant roles

Also, 75 participants took part in the community networking events in Northern Alberta, including local health care providers, municipal representatives, local citizens, colleges, professional associations and Alberta government and health representatives. 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 the 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 and to 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

Table 2 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) The sources column represents the number of data collection sessions (interviews, focus groups, and community events) in which the themes were identified as important. The references column represents the number of quotes in the text that make reference to these issues as being important.

Theme	Sources (n=14)	References
Mental Health related issues	11	105
Education related issues	13	95
System navigation and transition of care	11	80
Technology for adult learning and point of care	10	64
Role definition within the CC sector	10	61
Staff retention and recruitment	10	51
Working with families	8	51
Caregiving	11	39
Intercultural issues	6	33
Need for Recreation and Rehabilitation staff	5	27

Table 2: CNDRN consultation, Top ten themes

In addition to the top ten themes, four additional themes emerged as being highly important in certain areas of the province. Table 3 shows these themes and the area in which they were most frequently identified.

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

Table 3: Four special themes, location-dependent

## Top ten themes

The following is a description of each of the top five themes, how the theme was defined by participants, and the issues related to it.

### 1. Mental Health related issues:

1.1 Challenging behaviours is considered the most representative issue around mental health. Participants reported little education of staff in terms of management, lack of strategies for adequate care giving 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 such as: 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. It is worth noting that the other two issues were identified as strongly related to challenging behaviours (1.2 and 1.3).

Examples:

- “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?”
- “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.”

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.

Examples:

- “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.”

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.

Examples:

- “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.”

## 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. 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 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.

Examples:

- “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’.”
- “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.”
- “I think it would be really great and my goal would be that we could look at for the facility to have online orientation and ongoing education and access.”

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 impacted by in-service strategies and their impact on care.

Examples:

- “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.”

2.3 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.

Examples:

- “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’.”

### 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.

Examples:

- “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.”

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.

Examples:

- “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?”

3.3 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.

Examples:

- “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?”

#### 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).

Examples:

- “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.”

## 5. Role definition within the CC sector

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.

Examples:

- “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.”

## 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. 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.

Examples:

- “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.”

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.

Examples:

- “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.”

## 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 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.

Examples:

- “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.”

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 and not only client-centered. 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.

Examples:

- “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.”

7.3 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 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.

Examples:

- “... 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.

## 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 care giving; ii) the issue of caregiving for couples in the CC sector; and iii) the impact of clients’ habits and addictions on caregiving.

**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.

Examples:

- “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?”

**8.2 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.

Examples:

- “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?"

**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 are having 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.

Examples:

- "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."

## 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.

**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 inter-cultural competences.

Examples:

- "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 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.

Examples:

- "... 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, um, in cross-cultural or transcultural nursing, communication patterns."

## **10. Need for rehabilitation and recreation staff**

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 Rehab and Rec 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.

Examples:

- "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?"

## 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.

Examples:

- “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.”

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.

Examples:

- “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!”

## 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. This impact on funding makes 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.

Examples:

- “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?"

### **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.

Examples:

- "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."

### **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.

Examples:

- 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

### **The community needs driven process**

In addition to the themes, 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:

- "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!"

## **DISSEMINATION ACTIVITIES**

The research team will be developing a series of dissemination activities in order to widely broadcast the findings from the consultation process. Now that the front-line staff in continuing care have identified their top issues, researchers will be encouraged to do research in these areas. Where research has already been done, front-line staff need to be made aware of the results and how to apply the results to their practice.