PaCER REPORTS

Meaningful Results from Meaningful Engagement: Enabling Patient and Family Participation in the AHS Seniors Health SCN
A PaCER Study

Research conducted by: Sylvia Teare MEd, & Jean Miller PhD PaCER Researchers

Primary Investigator: Dr. Heather Hanson, Assistant Scientific Director, Seniors Health SCN

PaCER Supervisors: Nancy Marlett & Svetlana Shklarov

Patient and Community Engagement Research (PaCER) Program
O'Brien Institute for Public Health, University of Calgary

April 5, 2015
Calgary, AB

Contact: Sylvia Teare, MEd: teares@shaw.ca
Jean Miller, PhD: jeanleighton@shaw.ca
Nancy Marlett, PhD: Marlett@calgary.ca
Svetlana Sklarov, PhD: Shklarov@calgary.ca

Contents **Page**

Introduction and Background

This is a report of the PaCER (Patient and Community Engagement Research) study that engaged seniors in a dialogue to gain a better understanding of the issues they see affecting seniors' health in Alberta. The report also examines whether the platform areas and priorities of the Seniors Health SCN resonate with seniors' views. Ultimately, this work will address the larger objective of improving health service delivery and practices for older Albertans. The research was carried out by two trained PaCER researchers who are seniors: Sylvia Teare and Jean Miller.

Patient and community engagement researchers (PaCERs) are people with various health conditions who are trained to design and conduct health research using an established protocol of qualitative inquiry. The protocol was originally developed by Dr. Marlett and Dr. Emes (Marlett & Emes, 2010) in a seniors' resiliency project and further refined in an innovative collaborative project between Alberta Health Services and the University of Calgary, supported by Vecova Centre for Disability Services and Research and the Arthritis Society, and funded by the Canadian Foundation for Healthcare Improvement (2011 – 2013). The purpose of this collaborative project was to bring a strong patient voice to healthcare change (Marlett, Shklarov, Marshall, Santana, & Wasylak, 2014).

The PaCER research has 3 phases: SET, COLLECT and REFLECT. (See Figure 1) The SET phase clarifies the scope and direction of the study. Data is then collected (COLLECT phase) from patients using focus groups; narrative interviews; observation; or questionnaires. In the REFLECT phase patients participate in another focus group where they come to a common understanding of the findings and make suggestions on future research directions and knowledge dissemination. This iterative approach, driven by patients working with patients, brings a clearly patient voice to health system transformation. It results in a shared collective understanding of the issue, one that is solidly grounded in patient experience. The PaCER office (Institute for Public Health, University of Caglary) provides mentorship, support, and oversight throughout the research process. (For more information on PaCER: http://www.pacerinnovates.ca/)

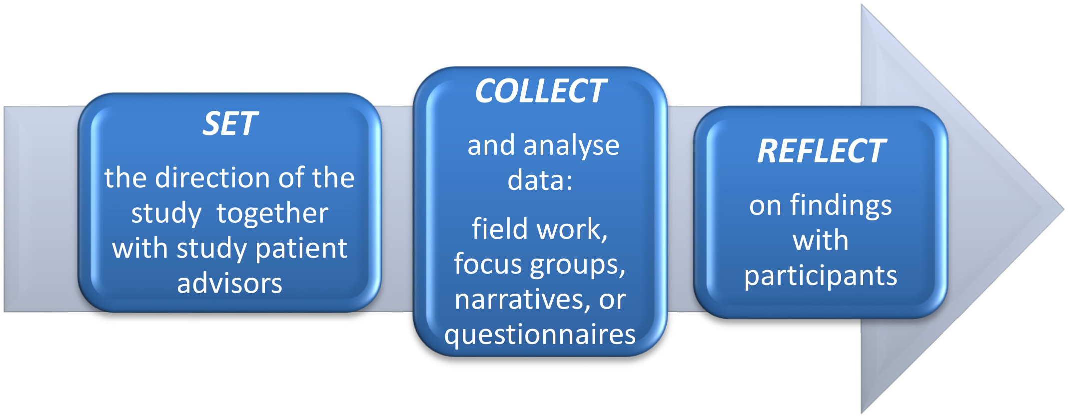

Figure 1: PaCER Research Methodology

Method: The PaCER Process for the MRME Study

This section begins with information about the participants followed by a description of the PaCER process used in this study.

Participants

Thirty-four seniors living in Calgary and a small rural Alberta community self-identified to participate in this research. Calgary participants were recruited using posters at Seniors Centres, a notice in the Canadian Association of Retired Persons Calgary newsletter, as well as referrals and links to acquaintances and friends. Each Calgary contact received an invitation letter/email leaving them free to accept or decline participation. Participants in the rural community were recruited by contacting the Manager of a rural senior’s housing development who posted an invitation to a SET focus group in their facility. In the group of 34, 30 participants were women and four were men. The age range of the participants was from 61 to 101. All but 4 of the participants were 65 and older. The majority of the participants were retired; two were semi-retired and one participant was on medical leave from full-time work.

Table 1: Participants by age groups

Age Groups	**Number of Participants**	**Number of Males**	**Number of Females**
60s	9	1	8
70s	5		5
80s	11	3	8
90s	7		6
100s	2		3
Total	34	4	30

Table 2: Rural/Urban participants by age groups

Age Groups	**Rural**	**Urban**
60s	1	8
70s	3	2
80s	6	5
90s	5	2
100s	2	
Total	17	17

For the SET activity, seven participants, including one male, were from Calgary and area, and a group of 16, including two males, were from a small Alberta community. The COLLECT interviews were done with 11 participants, including one male and one participant from a rural setting. For the REFLECT activity there were 13 participants. All participants in REFLECT had also taken part in a SET or COLLECT.

Data Collection Process and Analysis

This section of the report describes the process used for data collection in this particular PaCER study. Because of the iterative nature of PaCER research, where what is learned in each phase (SET, COLECT, REFLECT) informs the next, this section also includes data analysis.

The SET activity was held in two locations (Calgary and a small rural town) where a total of 23 seniors participated in one of two focus groups where they identified the issues they see affecting seniors' health in Alberta. The consent form was reviewed in the group and signed before the SET activity began. Participants began the discussion by talking about how they manage their own health, accessing information as they need it. They identified the need to keep or find a family physician to turn to should health problems arise. Finding appropriate housing is important as they age, and they saw a need for more facilities for various levels of senior care. They also need a better understanding of the path for seniors from home to hospital to long term care. The detailed discussion of each point was documented on flip charts. We used this information to adjust and solidify the telephone interview guide for the COLLECT phase.

For COLLECT, 11 seniors were interviewed by the PaCER researchers, five in person and six by telephone. Participants received the consent form by mail or email prior to their interviews. Those interviewed face to face signed the form in person. Those interviewed by telephone gave verbal consent. All interviews were recorded. The interviewer/researcher used the audiotape and her notes to create a descriptive document for each interview. Each researcher independently analyzed all of these descriptive documents, highlighting what she saw as the important points. Together the researchers reviewed the documents building a comprehensive list of issues, themes and other points. They also assigned codes and numbers to participants according to their participation in the SET focus groups (FG), the COLLECT (C), or the

REFLECT (R), thus protecting participants identify and confidentiality. The researchers then grouped this data in light of the project goal: *issues seniors see affecting their health in Alberta*, which led to these categories: 1) managing your health on a day-to-day basis; 2) finding a family physician 3) moving through the health care system (physician's appointment, referrals, hospital, transitions); and 4) identifying what seniors need from the health care system. The researchers continually went back into the COLLECT data, aligning specific points and validating the categories.

The 4 categories of data were taken to the REFLECT focus group where participants considered the fit between what they had said and what was reported, exploring the information in some detail. The REFLECT focus group ended with each participant identifying the system elements they thought were most important for seniors. Together the researchers analyzed the data from the REFLECT session and this collaborative, iterative process led to the final set of issues and elements of an effective health care system.

Findings: Seniors Perspectives on Issues Affecting the Health of Seniors in Alberta

As this is a patient-to-patient research, the findings are described using the first person plural, where "we" stands for the participants and researchers as one voice. We begin by describing how we as seniors manage our own health and go on to describe the health issues we as Albertans face.

Managing our own health

As seniors we actively manage our health by using resources readily available in our communities, for example, pharmacists with specialized knowledge; foot care at seniors' centres; blood pressure machines at drugstores; exercise classes; and yoga at community and seniors' centres. We consider it important to stay active, develop networks of friends, join groups, and be interested in what is happening in the world. We use the Internet and we self-advocate. Self-management of our health is made possible through the support of family and friends with whom we consult prior to taking our concerns to the health system. Some of us without family find self-managing more difficult: for example, one participant noted that "people with family get help from them to file all these forms (OAS, CPP ...) but I have no one." (CR1)

When we go to our family physicians we write our concerns down, often bringing potential solutions that we research ahead of time. We ask our physicians to write down their instructions and we don't leave their offices until we have a complete understanding of what to do now, and what to do next. One participant shared a guide she had developed that helps her decide whether she should go to her physician. (CR5) (Appendix A) She will go to her doctor when:

a. She has a cough that lasts longer than 1 month,
b. She has a suddenly enlarging lump,
c. Her shoes become too tight,
d. She has unusual bruising or bleeding.

When we run into health problems we turn to the healthcare system, and where we turn depends on the urgency of our need; who we think will be best able to help us; and how far we have to go to reach that person or service. We go to neighborhood drop-in-clinics when we don't want to drive to our physicians' offices or the Primary Care Network after-hours clinics. One senior said she goes to a near-by drop-in clinic to get ears cleaned because, "I can go, and then it is done." (C4) Some of us go to urgent care clinics when we want to be seen right away but do not feel the problem is an emergency. When we encounter long waits for tests or surgery we seek alternate solutions, for example paying for private MRIs. We advocate for ourselves and as one participant put it, we are "happy to go out and find the help when we need it". (C1) Another participant approaches this by "looking for minimal treatments for the best outcomes in a segmented system." (CR4) Although we think we manage our health quite well we do worry about whether the healthcare system will to be there when we need it.

Accessing the Health Care System

When our health is such that we need the health care system we face issues in finding a family physician, and moving through the healthcare system.

Finding a family physician

Having a family physician (FP) is very important to accessing healthcare services, so when our physicians retire or move it is important to replace them. For the most part this isn't too difficult. We find it easier to get a new physician if our former FP worked in a group practice, for example, Associate Clinic, or a Primary Clinical Network. However some face challenges in accessing a new physician: even in group practices you need to be re-interviewed to become a patient of one of the other physicians. Some of us are fortunate enough to live in a seniors' residence where a family physician comes on a regular basis. One participant goes to a private physician and pays a steep fee because no physician in her area is taking new patients. "I found a physician in our neighborhood who looks after patients privately, at a cost of $450 per hour, so I write down my questions for him and talk very fast when I go in to see him." (CR5) One older senior said that "50 years ago there was no problem finding a physician – just difficulty getting to one as travel was so hard". (FGO3)

Moving through the healthcare system

When we encounter health issues that require medical attention, we go to our Family Physician. Sometimes our physicians refer us to specialists which leads to worries about how long we will have to wait for these appointments. Some of us have found it can take some time for our referrals to leave our physicians' offices. After referral, we sit and wait to be contacted, and never know when the call is going to come. At times it seems that the only option for care is Emergency which is often not the right place. One senior was told by her FP to "go to Emergency to see an orthopedic surgeon faster." (CR2) That same senior had an experience where she was unable to get admitted to the appropriate Emergency:

> This senior told a story of a recent event where she called an ambulance and the EMTs thought she might be having a stroke. The paramedics wanted to take her to the FHH as it's good for stroke care, but their Emergency was backed up. They sat in her driveway for 15 min while they tried to find room for her in an Emergency unit. She was very anxious with this wait as she had read that when you suspect a stroke you should get to emergency quickly as there are drugs that can dissolve the clot preventing stroke damage. When she got to an Emergency that was accepting patients she still waited 3 ½ hours. Luckily, she was not having a stroke. (CR2)

In these situations we find ourselves going from making our own healthcare decisions to having very little say in what happens to us as we move through the healthcare system. We find the path through the system a mystery. We need to know how transition through acute care works and what information determines where we go. One participant's mother went to Emergency where the physician immediately started talking about her needing to find somewhere to live with more care, at the same time adding that he really did not know how to go about that. The family went into a panic scouting out different facilities, and worrying about how they would pay for it, only to be told that they could only access long term care (LTC) through transition services. (FG1) Participants noted that families need to be involved when they move through the system, and personal circumstances need to be considered. If we end up in emergency care we may find there is no room for us in the hospital so we wait on a gurney or a bed in the hallway. We may then move to a room on a unit. From the unit we may go home perhaps with some homecare support, or wait for long term care or other care facility. One participant related a story of an elderly aunt who, when she was in hospital, was told that her bed was needed and she was discharged home at 2 am. The participant said, “It is wrong to hear of 80-90 year old patients being discharged at 2am to the care of another 80-90 year old or being sent home by taxi.” (FGR6) When we are ready to leave acute care, we find the system is blocked up and we can’t move on. Through no fault of our own, our need for 24 hour assistance means we can’t return home but the system does not have anywhere else for us to go. The shortage of long term care beds creates a backed up system so we don’t get the right care in the right place and that impacts our self-management.

The process of determining where we go should be based on our needs instead of where we do or don’t fit into a slot. (C4) These should be done in a partnership between us and the system.

We are thankful to go home with help from Homecare but find we still have little control over our health. One participant’s experience with Homecare services seemed uncoordinated with different care providers and nurses each time. (FGR3) She found it difficult to determine who to collaborate with for care. She has been waiting 6 months for her husband with dementia to get admitted into a day program once a week: “I don’t know what the proactive process is to arrange for some help.” (FGR3)

One participant said, “The current ‘stay in own home’ approach is not all that successful as many of us cannot keep up own home and our major asset deteriorates. We get into a ‘hole’: where we can’t keep up own home; can’t afford a fancy seniors’ residence; and lose consecutiveness with others. Our independence is traded off for safety. A house can become an anchor.” (C5)

Seniors’ Advice for Improving the Healthcare System

Our advice for improving the health care system includes: improved communication; better information about levels of care across the system; better access to the care we need; health professionals who know how to care for older adults; and more innovative housing options;.

There needs to be improved communication throughout the system. In an improved system professionals would communicate **with** rather than **to** patients: they would listen more, care more, and provide more explanations. At the system level electronic records would facilitate easy access to test results, and treatments to staff, specialists and patients.

There would also be greater dissemination of information about seniors’ housing and the care facilities that are available. The services to expect from each of these facility types would to be clear, specific and communicated to the wider community, for example in grocery stores, coffee shops, and community newsletters.

In a fixed system we would be able to access the care we need when we need it, be it a family physician, diagnostic tests, specialists, and surgery or alternate levels of care. We would not have to worry about whether our health needs would be met met, there would be care when and where we needed it, and support to help us maintain our health as we age. With respect to waiting for diagnostic tests, one senior said, “If I can get in (for an MRI) the next day when paying, perhaps the system needs to fund more MRI times - 24/7 if need be.” (CR2) This senior was told the MRI wait was 1 year so she paid to have it done privately. The test was done within a week and her surgery done in the time it would have taken to get the publically funded MRI. With respect to moving through the system, one senior identified a need for “more Social Workers trained to guide us through the system especially for those without family help.” (CR1) She also identified a need for greater mental health resources specifically for seniors.

We think it is important that all healthcare staff have more training for working with seniors. This is particularly true for those working with people with dementia: one participant noted “some do not seem to know how to work with those with dementia.” (FGR2) Professionals working with seniors also need care for “whole person not to just body parts.” (CR4)

An improved healthcare system would encourage and facilitate housing innovation. If we have housing choices where others are around 24/7 we may not need as many ‘care’ facilities. New models of community living could include support for the development of villages within neighborhoods where those joining the village could share house cleaning and repair; yard care and snow removal services; cook together; and help each other out. Healthcare could provide clinic hours for these villagers. (C1) In considering the development of affordable housing choices, one participant said: “What ever happened to good old fashioned boarding houses?” (CR5) Boarding houses used to provide affordable homes for singles allowing them to live together, paying for a room in a home with nominal charges inclusive of bedroom, food and laundry facilities, generally sharing the domestic duties of the house.

Dementia and End of Life Care

Two topics that are part of the work of the Seniors Health Strategic Clinical Network were not raised until brought to the participants by the researchers: dementia and end of life care. When asked, these were the findings.

Seniors said there are no medical fixes for dementia and end of life care; we just need a system that is working (professionals giving good care) and the system will be fine. They said that dementia is considered the ‘elephant in the room’. It is not talked about, is kept in the family as “attitudes and relationships towards those with dementia change when people know.” (FGR3) The big concern is that family caregiver health be attended to with respite offered routinely. Some admit to being worried as there is dementia in their families but they do not know how the system can address their concerns. As seniors we expect the system to be there for us if dementia happens to us or our family members.

With regard to end of life care, participants made these points: a) there needs to be ‘death with dignity’ programs where people are allowed to die with and controlled pain both mental and physical; b) provide comfort; c) do not use machines to prolong life if patient does not want that; and d) when tough personal directive decisions have been made, honor them. (CR4)

Alignment of the MRME Project with Seniors Health Strategic Clinical Network Platforms

The Seniors Health Strategic Clinical Network (SH SCN) is part of Alberta Health Services health transformation process. Its objective is to develop and implement strategies to address the health care needs of Alberta’s aging population and thereby contribute to AHS goals of bringing appropriate care to community, better health outcomes and healthy system sustainability. The SH SCN has identified ‘Platforms’ or key strategy areas to moving towards achieving that objective:

1) Healthy Aging and Seniors Care,
2) Aging Brain Care, and
3) Anticipating an Aging Alberta.

The researchers analyzed what was learned through the PaCER process and aligned that information with the SH SCN platforms. (See Table 3) Although it appears that there is good alignment there is a distinct difference between the system voice and the senior voice. The Seniors Health Network platforms are broad in nature, addressing the health needs of older Albertans from a system perspective. In contrast, the senior voice is one of worry that the system won’t be there for them when they need it. This is a gap that needs attention. Although there are SH SCN initiatives that are likely to address seniors’ issues, for example the Dementia Help Line and the MOVE initiative directed at seniors in care facilities, the system access issues identified by the seniors in this study need to be addressed.

Table 3. Aligning PaCER Findings with the SH SCN Platforms

Aging Brain Care	
• Improve diagnosis, treatment and management of dementia and cognitive disorders	○ Dementia is not talked about – kept in family as attitudes and relationships towards those with dementia change when people know. ○ Need more services like GARP – reduce wait time ○ There are no system fixes for dementia and end of life care; we just need a system that is working
• Promote best possible care and services for seniors and their caregivers	○ One person has been waiting 6 months for her husband with dementia to get admitted into a day program where he would go once a week. “I don’t know what the proactive process is.” (FGR3) ○ Have SW or navigators to guide through system ○ Support for seniors caring for other seniors ○ Family caregiver health needs to be attended to with respite offered routinely.

• Address and correct myths about how the brain ages	
Healthy Aging and Seniors Care	
• Promote healthy aging and the prevention of frailty	o Want help to be there when we need it. o Care needs to be directed to whole person not to just body parts: support not just for physical needs but also for mental and emotional needs. o There are issues in accessing acute care, specialists, test, and long term care. o Provide system guides to seniors' self-management of their health. o Need new models of community living for seniors e.g., virtual village with health supported by Nurse Practitioner.
• Ensure seniors receive quality care at end of life	o There's no system fixes for dementia and end of life care; we just need a system that is working (professionals giving good care) and the system would be fine. o What is needed is 'death with dignity' programs: people allowed to die with controlled pain both mental and physical. Comfort and 'no machines' are important. o When tough personal directives have been made, health care system must honor them.
• Adopt elder-friendly approaches to care across the system	o Coordinated home care services, seniors need to know who is in charge of their care. o Fix transitions for seniors across system and make sure that all staff including family physicians have same information. o Close the loop: need follow-up in home care and referrals. o Choices – don't stereotype all seniors – a variety of programs and housing alternatives are needed, staff need to work with families and seniors to find solutions.
Anticipating an Aging Alberta	
o Influence health policies	
o Provide input on health and social planning	o Innovative housing o Electronic records
o Ensure that students who will care for seniors receive appropriate education	o Good listeners – the patient (even those with dementia) and family need to be listened to and choices offered so choice can be made based on what patient wants and believes. o All healthcare professionals need education on working with seniors.

Discussion

The seniors who participated in this research project were generally healthy and represented the two ends of the spectrum of aging: the young-old (60-80) and the old-old (80-100). They typify the final third of the healthcare journey. The younger seniors were relatively healthy: they exercise, try to eat well, keep involved and attempt to stay as healthy as they in order to encounter the healthcare system as little as possible. They have developed a perspective of the healthcare system through older family member’s experiences. They are worried whether the system will be there to support them should they need it and have concerns about the problems encountered by their family members. Older seniors are more philosophical: the system has so far been there when they needed it and they expect that it will continue to be there. They have made the tough decisions about leaving their homes when their health failed and have made choices related to housing and medical care. They also try to manage their health with good nutrition, social involvement and activity. (CR3)

The underpinning concept which emerged in this PaCER study is one of maintaining control and managing health on a day-to-day basis. All seniors want more attention paid to what they see as their needs when in the system. When asked what the perfect journey through healthcare would look like, seniors indicated that they would like as little contact with the system as possible. One said “I just want the system to be there in case I need it, but at 90 I plan to go to sleep and not wake up.” (CR7) When we need acute care and then cannot go back home we would like the system to provide: good listeners – the patient (even those with dementia) and family need to be listened to and alternatives for care need to be offered so choice can be made based on what we want and believe.

The system needs alternatives – don't stereotype all seniors – a variety of programs and housing alternatives are needed, then staff to work with families and seniors to find what best meets not just their physical needs but also their mental and emotional needs. One rural senior said, "Truly listen to seniors – what their hopes are" (C4): she hopes that she will not be told she has to be in a room with no place for hobbies or for her kids to visit. She wants there to be enough 'inventory' appropriate for choices and hopes that the system remembers they are providing a home not just housing. (C4)

Conclusion

Seniors have developed effective strategies for self-managing their health and what they need is a health care system that supports their self-management. When they run into health problems that require medical management they need to be able to rely on the health care system being there: it is at this juncture where the issues arise. Older Albertans need a system that is more responsive to their needs, one that helps them emerge from the system as healthy as possible, and gives them confidence that the type of care that best suits their needs will be available. As they travel the last third of their health journey, they want to partner with health professionals and the system to ensure their journey is a successful one. To that end, there is a need for the system to partner with older Albertans to address the professional/patient perspective gap between the SH SCN Platforms and the access issues faced by older Albertans. This patient-to-patient research is one step in that direction.

Recommendations

Based on the findings of this PACER research we recommend that Seniors Health SCN:

1. Support seniors in their efforts to maintain their health, for example extending the MOVE initiative into the community.
2. Partner with those developing innovative housing initiatives to support seniors' self-management of their health.
3. Work in partnership with seniors to address their issues of accessing and moving through the health care system.
4. Work with seniors to produce clear information on how people move through the health care system, with guidance on who to contact and their role in transitioning.

Respectfully submitted

Jean Miller and Sylvia Teare on behalf of PACER

References

Marlett, N. & Emes, C. (2010). *Grey Matters: A guide to collaborative research for seniors.* Calgary: University of Calgary Press.

Marlett N, Shklarov S, Marshall D, Santana MJ, Wasylak T. (2014). Building new roles and relationships in research: A model of patient engagement research. *Quality of Life Research, November 2014.* DOI 10.1007/s11136-014-0845-y http://link.springer.com/article/10.1007/s11136-014-0845-y

Appendix A: Seniors Self-help Health Checklist:

1. Have you had tea and toast more than 2 x in week? – resource is nutrition information
2. Do you have trouble seeing at night?
3. Do you ever get dizzy when standing up?
4. Do you have someone who could help you on speed dial?
5. Do you have vegetables every day? - List of stores that deliver fresh produce.
6. Can you see the numbers on your phone?
7. Have you had any falls in your home?
8. Do you sleep more than a hour in the day?
9. Are you a safe driver: is your spouse or child afraid to get in the car with you?
10. Can you shoulder check?
11. Do you have a will?
12. Do you have a Personal Directive?