

BACKGROUND

- Healthcare systems are engaging public and patients to help identify priorities for research and quality improvement.
- Evidence suggests that patients and families are more open to sharing their experiences with those who have had a similar experience.
- Patient and Community Engagement Research (PaCER) is a novel approach to patient and family engagement, in which:
 - PaCER learners are community members who have lived experience with a health condition, and who have undertaken participatory, qualitative health research training to create a new collective patient-informed research voice.
 - Collaborative research is conducted by, with, and for, patients from Alberta communities.
 - People share their wisdom and experiences as patients and caregivers with the goal of incorporating research-informed patient voices into heath system research, planning and policy.

RESEARCH QUESTION

To understand what matters most to patients who live in rural, remote, or isolated communities in Alberta when they transition from hospital back to their home.

The purpose of the research study was:

- To learn about the unique challenges and stressors that rural patients experience in Alberta, as well as what worked well for them as they transitioned home from the hospital; and
- To identify specific needs, new patient resources and potential solutions to the Alberta health system/providers that could help improve patient experiences and rural patients' health outcomes.

METHODS

This qualitative research project used the innovative PaCER three phase engagement process:

SET	 To help define, confirm, and refine the focus and direction of our study N = 7 patient partners
	 To capture patient experiences and perspectives
	 Study design: qualitative inquiry; conducted focus groups and interview
COLLECT	 Population: adult Albertans discharged from hospitals; live in rural or re N = 10 participants
REFLECT	 To validate our findings with the participants from COLLECT; come to a c understanding of our thematically analyzed data; explore suggestions ar recommendations
	 N = 7 participants

Participant Recruitment

Participants recruited for the study were residents of Alberta who were 18 years of age or older and had been discharged from hospital within the last five years to their rural home. A poster advertising the opportunity was issued to ten organized groups.

Data Collection

Data was collected through two focus groups and four individual interviews. Six semistructured questions framed the data collection discussions.

Qualitative Analysis

- Researchers examined and articulated biases prior to research
- Text data collected through focus groups and interviews was thematically analyzed • Narrative analysis conducted from individual interviews
- Iterative researcher discussions regarding emerging data, coding and thematic categories
- Data was collated from 32 codes into themes
- Frequency was analyzed by manually counting to ensure accuracy and consistency
- Iterative process to sort the data codes into overarching thematic groups

ACKNOWLEDGEMENTS

This study was conducted by the Patient & Community Engagement Research (PaCER) team in support of the Home to Hospital to Home Transitions Project, in partnership with the Strategic Clinical NetworksTM, Primary Health Care Integration Network, the University of Calgary Patient & Community Engagement Research Program (PaCER), and the Alberta SPOR (Strategy for Patient Oriented Research) Unit. Our team would like to acknowledge the time and candid contributions from our volunteer patient partners and participants. Without their insights and experience, this study would not have been possible.

What matters most to Albertans from rural, remote, or isolated communities when returning home after being hospitalized.

Duquette, D., Ganton, J., Giroux, K., Jiang, K., Semeniuk, G., Trifaux, J. On behalf of the Strategic Clinical NetworksTM, Primary Health Care Integration Network, and the Patient & Community Engagement Research Program (PaCER), University of Calgary Ethics ID: REB22-0771

remote areas

common and

Participant Characteristics

Characteristics

Alberta Health Services (AHS) (Five Health Zones)

Date of Birth (year)

Gender

Distance from hospital to home in driving time (hours)

What We Heard

A code frequency table was used to create a word cloud. Larger words reflect a higher frequency of use of the code.



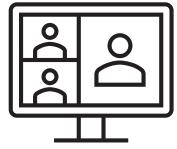
RESULTS

Exemplar Quotes

"It's (follow-up consultation) something that could have been done by telehealth, it could have been done, you know remotely. That's a long trip for something you could have done over the phone.

"The bottom line is it has to be something that's prepared ahead of time. You can't just dump a patient back in their rural community and *expect to have the supports* there. You have to build those supports ahead of time."

"I would suggest that there be a patient manager...right from the start...so that there is some continuity. And I think that's part of the problem. Continuity is missing."



Number of Participants		
N=9		
North = 1		
Central = 4		
South = 4		
Before 1957 = 7		
1957 to 1972 = 1		
1973 to 1988 = 1		
Men = 1		
Women = 8		
0 to 1 = 3		
1 to 2 = 1		
2 to 4 = 4		
> 4 = 1		

"They said that they would transfer my records... I kept waiting for Homecare and I finally phoned them... They'd never heard of me... Fortunately, I have a very good friend here who is a trained veterinary assistant, and she knew about wound care."

'I don't think that the doctors in the city hospital were familiar with the Homecare problems in the rural areas... If daily Homecare is not an option in the rural community, it shouldn't be a recommendation that's made by the doctor."

What We Learned

There is a perceived gap in equitable access to healthcare between urban and rural settings which needs to be better recognized, understood and addressed. As PaCER students, we wanted to help fill this gap by engaging rural patients to help understand what unique healthcare needs they have and what solutions could help address those needs.

The key gaps identified by the patient participants tended to fall into four broad categories: Information, Transportation, Support, and Processes. None of these gaps exist in isolation, they overlap, and we have fit them into three overarching themes.

- **1. Needs unique to rural/remote Albertans:** Some needs are unique to or amplified for Albertans living in rural, remote or isolated communities when they return home after being hospitalized, due to their geographic location.
- **2.** Gaps identified by rural/remote Albertans: Gaps in the healthcare system were experienced at many points along patients' transitions home which affected their patient experience and their path to a positive recovery. Participants identified several areas where their needs were not met.
- 3. Supports that were most helpful: Participants shared what supports were most helpful in their discharge and recovery. Where the healthcare system didn't provide what they needed, people described the community and personal support they turned to for effectively navigating their transition home and recovery.

RECOMMENDATIONS FOR IMPROVEMENTS

- rural residents.
- resources to reduce any gaps in the rural community.

What matters most to patients was continuity of care across the system from urban hospitals back to their rural communities, for a seamless patient experience/service. Gaps in processes such as transferring information from urban to rural/remote care providers were noted throughout the study. Patient participants are eager to see Alberta Health Services act on the findings and recommendations in this study.

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THEMES



. Set rural patients, families and their caregivers up for success with appropriate information, education, skills training and resources well in advance of their discharge. This could include a 'Rural Addendum' to the Patient Pathway Template that is being developed by the Alberta Health Services Provincial Pathway Unit for patients, with specific resources for the rural communities including questions specific to the unique needs of

2. Set rural healthcare providers up for success by facilitating a "warm handover" when patients transition from an urban to a rural facility or their primary care Medical Home. This would include calling ahead to speak with personnel at the receiving site and ensuring all information is input into, or forwarded to, all appropriate systems and community

3. Reduce the travel burden and costs for rural patients for follow-up care after discharge by using virtual care and better utilizing rural healthcare resources.

4. Assign a transition-navigator who will be available and easily accessible to help rural patients post discharge. The case management can be virtual or in-person. This role does not need to be filled by a medical professional; however, they should have expert knowledge on how and where patient resources can be sourced.

CONCLUSION



