



WHEATLAND & AREA
Hospice Society



UNIVERSITY OF CALGARY
CUMMING SCHOOL OF MEDICINE
COMMUNITY ENGAGEMENT LOCAL



Alberta Health
Services

Wheatland County Palliative & End of Life Care Community Engagement Report

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I. Project Overview

The aim of this project was to establish a partnership between the Wheatland and Area Hospice Society, the Cumming School of Medicine (CSM) and Alberta Health Services (AHS) – Calgary Zone Palliative and End of Life Care Services, in order to identify community members’ perceptions surrounding palliative and end of life care (PEOLC). This knowledge will help communities to learn how to better support further community development surrounding PEOLC. Caresland, Rockyford, Gleichen, Standard and Hussar each hosted one community conversation and Strathmore hosted two. All residents in Wheatland County were invited to all the conversations (not just the one located closest to their community). The focus of these events was to learn from community members’ experiences and knowledge. Collectively, between the seven events, there were 142 participants. Figure 1. summarizes the percentage of participants from each community.

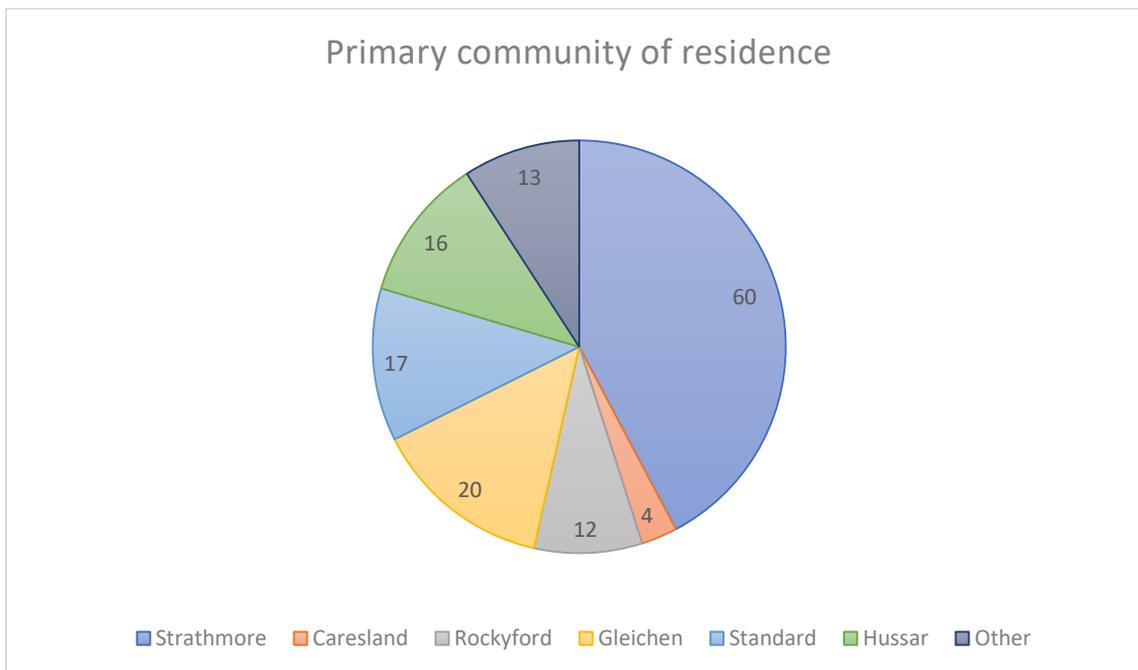


Figure 1. Breakdown of participants reported primary community of residence.

Overall, most participants attended an event located within their community. Table 1. Outlines attendance numbers for all seven events and identifies how many participants resided in a different community.

Community event	Number of participants	Number of individuals from other primary communities
Carseland 1	6	3
Gleichen 1	25	4
Hussar 1	16	1
Rockyford 1	16	4
Standard 1	17	0
Strathmore 1	40	3
Strathmore 2	22	3

Table 1. Attendance of each community event, identifying individuals from other primary communities

II. Demographics

Strathmore

Standard had a population increase of 11.8% between 2011 and 2016 (Statistics Canada, 2016 Census). In 2016, the total population of Standard was 13,756. The median age of the population is 38.4 compared to the provincial median age of 36.7, with a 64.1% distribution between 15 to 64 years of age. The age range of the Standard residents who attended a community conversation was 34 to 86 years of age, with a median age of 68. A large majority of individuals who attended the events in Strathmore were female (79%). Seven participants reported a community of residence outside of Strathmore, with individuals from Mossleigh, Hillview, Caresland, Chestermere and Airdrie. Figure 2. outlines the median age of participants per community compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

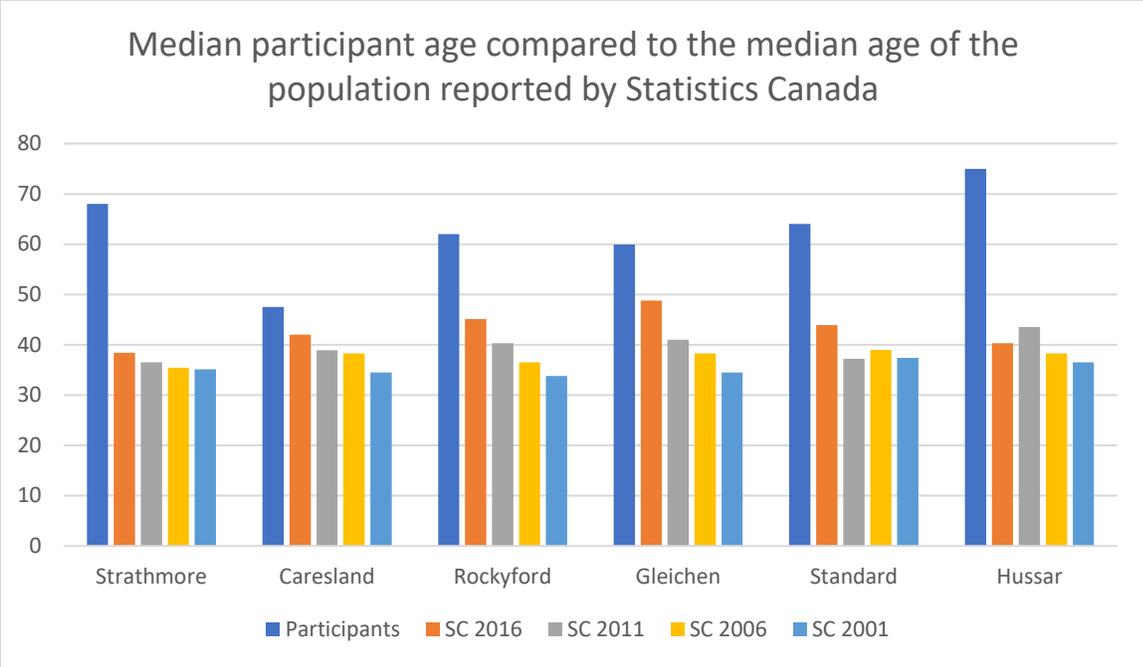


Figure 2. Median age of participants compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

* SC= Statistics Canada

Carseland

Carseland’s population has decreased between 2011 and 2016 by 7.6% (Statistics Canada, 2016 Census). In 2016, the total population of Carseland was 525. The median age of the population is 42. Compared to the provincial median of 36.7, with 69.2% of the distribution between 15 to 64 years of age. The age range of Carseland residents who attended a community conversation was 34 to 73 years of age, with a median age of 47.5. A significant majority of participants from the Carseland event were female (80%). Two participants reported a community of residence outside of Caresland, with one in Langdon, one in Strathmore. Additionally, one participant did not report which community they resided in. Figure 2. outlines the median age of participants per community compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

Rockford

Rockford's population decreased by 2.8% between 2011 and 2016 (Statistics Canada, 2016 Census). In 2016, the total population of Rockford was 316. The median age of the population is 45.1 compared to the provincial median age of 36.7, with a 67.2% distribution between 15 to 64 years of age. The age range of the Rockyford residents who attended a community conversation was 33 to 87 years of age, with a median age of 62. A significant majority of participants from the Rockyford community were female (75%). Four participants from the Rockyford event reported a community of residence outside of Rockyford, three of which resided in Strathmore and one resided in Namaka. Figure 2. outlines the median age of participants per community compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

Gleichen

Gleichen's population decreased by 3.6% between 2011 and 2016 (Statistics Canada, 2016 Census). In 2016, the total population of Gleichen was 324. The median age of the population is 48.8 compared to the provincial median of 36.7, with a 67.2% distribution between 15 to 64 years of age. The age range of the Gleichen residents who attended a community conversation was 54 to 91 years of age, with a median age of 59.5. A slight majority of participants from the Gleichen community were female (52%). Three participants from the Gleichen event reported a community of residence outside of Gleichen, with two individuals residing in Cluny. Additionally, one participant did not report which community they resided in. Figure 2. outlines the median age of participants per community compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

Standard

Standard's population decreased by 6.9% between 2011 and 2016 (Statistics Canada, 2016 Census). In 2016, the total population of Standard was 353. The median age of the population is 43.9 compared to the provincial median age of 36.7, with a 63.4% distribution between 15 to 64 years of age. The age range of the Standard residents who attended a community conversation was 32 to 79 years of age, with a median age of 64. A slight majority of participants from the Rockyford community were female (59%). All participants reported residing in Standard. Figure 2. outlines the median age of participants

per community compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

Hussar

Hussar experienced a population increase of 8% between 2011 and 2016 (Statistics Canada, 2016 Census). In 2016, the total population of Hussar was 190. The median age of the population is 40.3 compared to the provincial median age of 36.7, with a 63.2% distribution between 15 to 64 years of age.

The age range of the Hussar residents who attended a community conversation was 57 to 81 years of age, with a median age of 75. A significant majority of participants who attended the Hussar event were female (81%). The majority of participants who attended the Hussar event, reported Hussar as their primary community; one participant identified Dalum as their primary community of residence. Figure 2. outlines the median age of participants per community compared to the median age of the population reported by Statistics Canada. Data taken from the 2016, 2011, 2006 and 2001 censuses.

III. Services

In the community events that were held, the conversation always began by talking about health services. While many positive experiences were shared, members of Wheatland County felt that the services that are currently available for Palliative and end of life care (PELOC) were inadequate. Many community members expressed that they were surprised Alberta Health Services (AHS) was engaging with rural communities to gain a better understanding of their experiences and needs. Community members thought that this was a positive sign of developing a sustainable partnership with AHS, where transparency and a bi-directional exchange of information was possible.



“It’s easier to help
when it’s your
community”

a. Access

“The last thing you want when you’re grieving is to get in a car and drive somewhere”

Barriers to accessing services was the largest frustration expressed when individuals were speaking about their experience with PELOC. When community members have to travel out of their community to access services, it makes an already difficult time more exhausting. Driving to appointments was described as a traumatic experience. *“When you’re looking after a loved one who is palliative, you’re in no condition to drive”*. The distance to access services made individuals more reluctant to access services and sometimes was the cause of delaying seeking medical supports. When an individual has to leave their community to access services, they often feel very isolated. Additionally, travel is not only emotionally stressful, but also a financial burden. When an individual is able to stay in their community, it fosters more patient centered care, with increased supports for the family.

“Distance is a barrier to providing emotional support to loved ones”

b. Delivery of Services

“I feel like when you have to go to the city to access care, you leave your community, you have to be separated from people you want to be close to, your family may be there, but your friends won’t be”

Community members were quick to identify gaps in the existing system and find inventive ways to address the gaps in a way that was unique to their specific community: from converting empty building to care facilities to repurposing and expanding existing services. Additionally, community members felt that communication needed to increase surrounding transitions of care. At the core of these services, individuals felt that it was crucial that they accommodate an individual’s culture and lifestyle, so that they would support the whole community.

Home Care was often used as an example of a service that needed to be expanded in the Wheatland County. Community members often stated that Home Care was the best support to keep individuals in their community on their palliative journey. While some individuals expressed uncertainty about having strangers come into their home, having a consistent care team made families more comfortable and was crucial in increasing the dignity of an individuals' care.

Individuals spoke about hospice as a comfortable environment that provided great supports when they were needed. Community members felt much more at home in a hospice than they did receiving care in a sterile hospital environment. Having a hospice close to home was something all the communities wanted, however individuals expressed it would be challenging for any location to meet everyone's needs in Wheatland County, due to the spread-out nature of rural communities. Many individuals thought the values and experiences surrounding hospice should be applied to envision a solution that would better meet all the rural communities needs.

“[Hospice] brings home to the patient. This is much different than a hospital room”

Due to the barriers accessing care in the communities, many individuals told stories of how their loved ones spent their last days in hospital. Community members found this experience to be uncomfortable as the care wasn't personalized and it was challenging to accommodate family and friend. The busy environment contributed to the experience not bring restful. One individual described providing palliative care in a hospital like *“trying to put a square peg in a round hole”*. Increasing the ability to provide care in the community was thought to be the best way to provide person centered care. If this type of care is going to be delivered in the hospital, community members felt it was very important for there to be a special room for palliative care in order to better support the individual and their family. Community members expressed that the palliative care rooms that exist provide amazing services, but that there are not nearly enough of them.

IV. Community Capacity

At the forefront of all the community conversations was examining “*what our community can do to help*”. Rural communities inherently have strong community networks that support one another. Community members suggested that the hospice society help increase cohesion between supports, services and health care professionals; this would allow for wrap around care for an individual and their family. Creating a community network of care would recognize the knowledge and experience of locals and enhance the community’s capacity to care for individuals in their community as they were approaching end of life.

“It’s not the brick and mortar... it’s the heart”

a. Community Connections

Many people don’t know what hospice is or what PELOC services are available. Community members strongly expressed that this should be part of every hospice society’s mission is. Even among individuals attending the community events there was confusion surrounding what palliative care was. At many tables, individuals took the opportunity to learn from one another and share their knowledge. Many community members said that they learned a lot through their personal experience and would have been far less overwhelmed if they could have talked

“We think of a building, but it goes beyond that; supports may be something we can’t physically see”

to someone else who had already gone through supporting someone through the palliative process. Individuals suggested that the hospice society could build a community network for this type of peer support and knowledge translation. It was suggested that having individuals share their stories could be a powerful tool in educating the community. The stigma surrounding death and dying could be addressed through educational nights, as well as other awareness campaigns led by the hospice society.

b. Education

The importance of education surrounding death and dying was considered crucial in order to increase awareness and address stigma. Often people don't talk end of life care until they are

"I think if you're exposed to death young, you're just more comfortable. When there's a funeral, kids get involved and get a sense of community"

actively dealing with it in some way; individuals said that this made the process far more overwhelming.

Having including education and awareness strategies has the potential to strengthen communities to come together and own PELOC in their communities.

Community members felt that better educating medical professionals on palliative care was important, especially family doctors, as they are often the first point of contact and have preexisting relationships. Many individuals felt that family doctors could be a great resource to increase awareness and help people navigate end of life, as they hold a respected role in the community. It was suggested that educational campaigns should be talking about advanced care planning.

V. Supports

Community members felt that supports needed to be in place before they were required. Many people felt lost and overwhelmed when a loved one was approaching the end of their life and did not know where to find guidance. Often individuals felt uncomfortable asking for help because they did not want to burden their community.

"In a community everyone pitches in, in the ways they know how, whether it's shoveling, cooking or looking after the garden"

Caregivers also expressed guilt in reaching out for support, as they felt that were letting down the loved one they were looking after. It was suggested that having caregiver support groups

would help individuals be more comfortable reaching out and feel more connected to their community.

Family and Community Support Services (FCSS) was the only central place people knew they could get information from¹. Communities with FCSS consider it a very invaluable support. Community members wanted to see something like FCSS in all the rural communities specific to PELOC so that getting information and support would be an easy process. It was suggested that type of support should extend to other areas such as helping people prepare their wills and advanced care planning.

Often, individuals weren't aware of the services available to them. By having a central hub, it is hoped that the available services will be better communicated and utilized. Community members also hoped that having a central hub for resources would help provide supports to individuals who are less connected to the community. It was suggested that this could

“Wheatland Hospice Society should have mentors and networks so that people can get the support they need”

potentially extend to a website, resource booklet and a phone-line. If a resource guide was developed, community members wanted it to be available all over town, and not just in health care settings; this could be a means of raising the awareness surrounding PELOC.

a. Caregiver Supports

Having more accessible respite care options would provide much needed help for caregivers. While the experience of caring for someone as they approach end of life is very rewarding, it can also be very stressful and cause significant anxiety for the caregiver. Community members suggested having supports like helping with crops and doing errands would support caregivers

¹ Rural sites include Villages of Hussar, Rockyford, Standard; hamlets of Gleichen and Carseland; and entire Wheatland County.

immensely. It was suggested that the hospice society could play an organizing role in coordinating community support.

b. Cultural Supports

Having accessible supports that were barrier free was very important to the community. When working towards building a network of volunteers and increasing networks between community members, individuals felt inclusivity should be core to all planning and outreach. Many community members suggested this could be encouraged by having a diverse group of people on boards and committees. Not only would this make PELOC supports more holistic, but it would also present an opportunity to learn from different cultures and groups within the community. The inclusion of supports specific to Indigenous cultures was considered very important to community members. Conversations surrounding Indigenous supports was very prevalent at the Gleichen event, but was discussed at all the events.

c. Grief and Bereavement

A prominent discussion point in all the community conversations, was where individuals received support from. Many individuals felt that religious groups were the strongest form of support within the community and felt it was important that people who did not belong to a specific religious community received the same level of support. Community members identified that the available grief and bereavement services are often not convenient to access and are primarily advertised solely to the individual's close family. Community members suggested having open peer support groups in the community would help them work through their grief, and help them feel more connected to the community. Individuals expressed feeling isolated after losing a loved one and expressed that talking to someone going through something similar would be very comforting. Having the community come together to respond to the need for grief and bereavement support was suggested as a means to foster more culturally appropriate supports for all members of the community.

IV. Conclusion

“We need to appreciate the commonality of rural communities, not just the differences”

All five communities across Wheatland County felt they needed increased supports surrounding PELOC. Often the conversation began with discussions surrounding services, but always shifted to the importance of community together as a community to support each other. Community leaders will have to continue to develop collaborative relationships with other stakeholders. Developing and nurturing these relationships should facilitate the identification of the supports and services required to support equitable PELOC in rural communities.