

Hospice Halifax

A PLACE LIKE HOME

Community Consultation Report

May 1st, 2018

www.hospicehalifax.ca

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Territorial Acknowledgement

We would like to begin by acknowledging traditional lands. We are in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq People. The Mi'kmaw are the traditional custodians of the land where Hospice Halifax resides and we would like to pay our respects to the elders, both past and present, of the Mi'kmaw Nation.

Introduction

As Hospice Halifax moves towards its goal of opening the doors of its hospice residence on October 1st, 2018, input from its community of supporters grows in importance. The following report explores a substantial part of the organization's community consultation process on March 26, 2018 about the services and supports the community feels Hospice Halifax should provide and offers a summary of the results. These results will be considered as part of our organizational planning and development.

Approach & Methodology

Background

Community Engagement is stated as one of Hospice Halifax's key organizational values – in fact, like many hospices, we embrace the description, 'in community, by community, for community.' Community engagement is considered a cornerstone to the organization's success as we strive to build a sense of community through trust, collaboration, and mutual respect.

Hospice Halifax (formerly called the Hospice Society of Greater Halifax) started in 2001. In 2002, we established our first working and administrative board of directors. We received our charitable registration status in 2003.

We signed a land lease agreement with the Atlantic School of Theology in 2015 which allowed the construction of Nova Scotia's first hospice residence to start. We plan to open on October 1, 2018.

Our membership includes community members, advocates, health care professionals, and families touched by hospice care. About 100 volunteers help create awareness about hospice care, offer support programs, and organize events. Each year, we host major annual fundraising initiatives like Feeling the Love Dinner and Dance Party, Hike for Hospice, Hats Off for Hospice, and Angel Tree.

Consultation

What supports and services does the community want Hospice Halifax to offer?

From January to March 2018, Hospice Halifax invited interested community members to share their perspectives on the organization's future supports and services through two avenues: an online survey hosted by Hospice Halifax's website and two in-person engagement sessions hosted at the Halifax Central Library.

To help answer the overarching research question, the community was asked to consider two areas:

- 1) If you or someone you love were in hospice, what would you want your experience to include? What would you find nurturing?
- 2) What do you think is important for hospice to be aware of and understand about the people in our community?

Hospice Halifax staff and board members have also met with (and continue to meet with), various key community stakeholders (i.e. faith-based groups, cultural groups, non-profit organizations, health care institutions, etc.). While that input is highly valuable to the community consultation process and development of the hospice residence, it is not included in this report as the conversations are still in progress.

Timeline

The community consultation process took place over the course of 3 months and included the following key dates:

January 2 nd to March 30 th , 2018	Anonymous online survey accessible via the Hospice Halifax website
March 26 th , 2018	Two community engagement sessions at the Halifax Central Library (1:30pm-3:00pm & 5:30pm-7:00pm)
April 30, 2018	Report back to community via website/social media/ email distribution

Confidentiality

Some identifying information was collected from attendees of the community engagement sessions for the purpose of illustrating representation. This was collected through the completion of registration forms. Completing the registration form was not a requirement of participating, resulting in this data being incomplete (i.e. 48 registration forms completed, approximately 60 people attended). All registration forms were destroyed post completion of this report.

Identifying information was not collected from online survey respondents. They were invited to provide their name, email address, and phone number if they were interested in talking further with Hospice Halifax about their responses. Providing this information was completely optional.

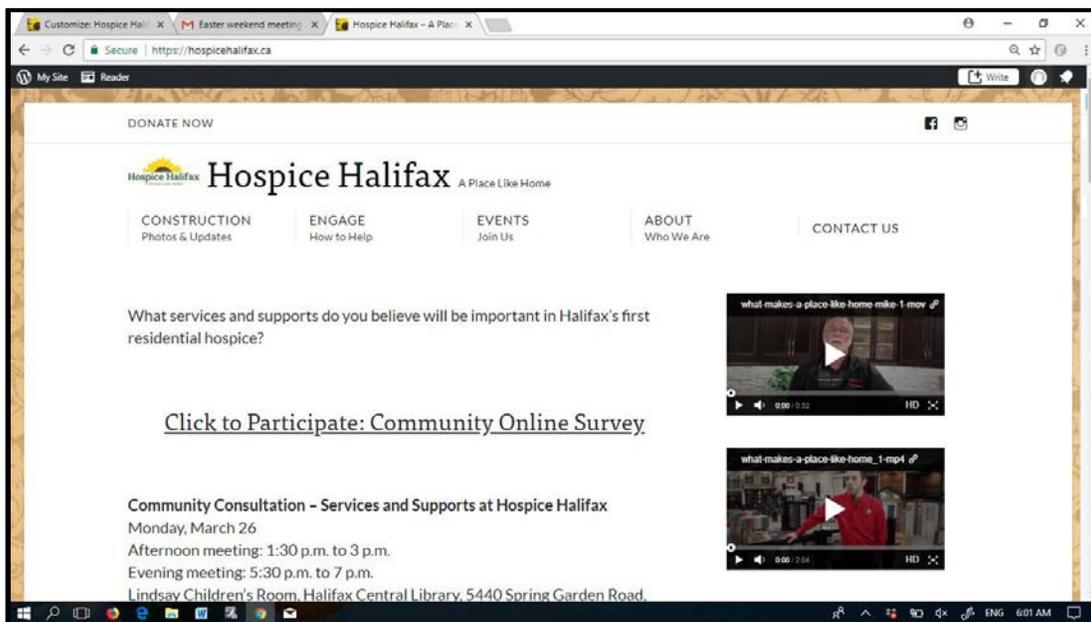
The results included in this report are displayed in aggregate form, unless noted as a direct participant quote. Any identifying information has been removed from the direct participant quotes. These quotes are included to reflect sub-themes that arose from the data during coding and analysis.

Survey

The online survey was hosted on the Hospice Halifax website from January 2nd to March 30th, 2018. It was highlighted on the home page and in selected menus and blog posts in preparation for the community engagement sessions. Individuals who had RSVP'd to a previously scheduled community engagement session were notified of the online survey when informed of the new date and times. It was offered as an alternative to those interested community members who were not able to attend the new date or times.

The online survey was also provided via email to key community stakeholders to distribute within their contacts and/or act as an alternative to attending the community engagement sessions. The online survey was promoted via Hospice Halifax's Facebook page in pre- and post-community engagement sessions.

The online survey received a total of 428 views and 74 respondents. Records of each completed survey were automatically forwarded via email to the author of this report (in addition to the Administrative Assistant, Operations Manager, and Manager of Programs and Services in order to address any immediate concerns).



Community Engagement Sessions

Two community engagement sessions were held on Monday, March 26th at the Halifax Central Library. To aid in accessibility, two time slots were offered to interested attendees: 1:30pm-3:00pm and 5:30pm-7:00pm.

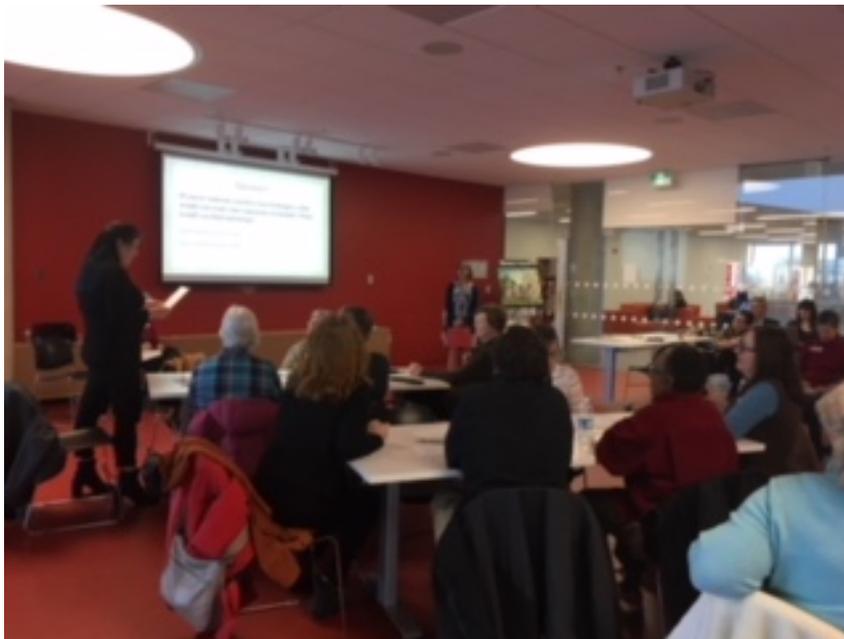
Attendees were asked to complete registration forms upon arrival. The registration forms asked attendees to provide their name, age range (options of 10 year spans provided), postal code, email address (explicitly stated as optional). The registration forms also included an area for attendees to respond to the following statement: "We want to make sure we are representative of our diverse community. If there is any part of your identity that is important to highlight for these purposes, please share." Attendees were seated in small groups of 4-6 people.

Hospice Halifax's CEO, Gordon Neal, commenced each community engagement session by introducing the facilitator, Medical Director Stephanie Connidis, and presenter, Interim Nurse Manager Glenna Thornhill. The agenda for each community engagement session was as follows:

- Introduction
- Large group discussion: What brought you to this meeting?
- Construction update re: freestanding hospice residence
- Process explanation for session
- Small group discussion: If you or someone you love were in hospice, what would you want to your experience to include? What would you find nurturing?
- Large group discussion: Small groups reporting key discussion points to the larger group

- Small group discussion: What do you think is most important for hospice to be aware of about the people in our community?
- Large group discussion: Small groups reporting key discussion points to the larger group
- Upcoming events and thank-yous
- Conclusion

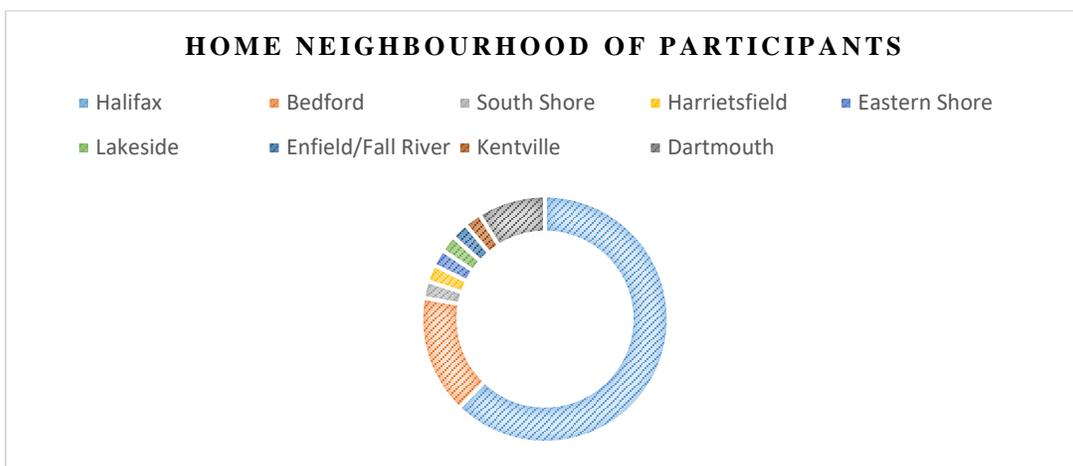
Volunteer note-takers were seated at each table, responsible for recording the comments of each small group member during small group and large group discussions. Guidelines, templates, and a short orientation were provided for note-taking volunteers. All records were collected by the author of this report. Attendees were invited to contact staff or board members if they had outstanding questions or concerns.



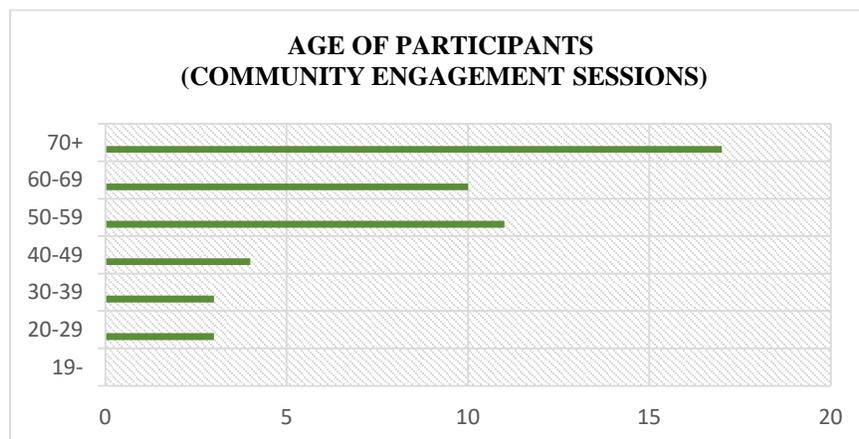
Who Participated?

Approximately 60 people attended one of the two community engagement sessions, while 48 completed the registration forms. The following stats are a representation of those 48 people:

The majority of attendees live in Halifax proper (North, South, West, and Central), making up more than half of the attendees (28). The remaining 20 are varied, living in communities like: Harrietsfield, Lakeside, Kentville, Bedford, Enfield/Fall River, the Eastern Shore, and the South Shore.



People in their 50s, 60s, 70s and older represented 80% of attendees, while the remaining 20% were composed of people in their 20s, 30s and 40s.



Only 11 individuals shared aspects of their identity on their registration forms. 6 of these individuals reported identities that are commonly underrepresented in community consultation processes (i.e. visible minorities, members of the LGBTQ+ community, persons with disabilities, religious minorities), as evidenced by several authors identified through a cursory literature review (Burns et al., 2004; Catt & Murphy, 2003; Holder, 2015; Strega & Brown, 2015).

Data regarding age range, postal code, and other identifying characteristics was not collected for online survey respondents.

Report to Community

The following report summarizes key themes from the amalgamation of the online survey responses and notes taken during the community engagement sessions. The responses were reviewed, coded, collated, and analyzed by the author in advance of preparing this report.

The report is available to the community via www.hospicehalifax.ca.

Results

All of online survey responses and recorded notes from the community engagement sessions were reviewed, coded, and collated. Four overarching themes emerged as a result of the codes assigned and their collation. Each overarching theme has 6-14 sub-themes.

In reviewing the material, four major themes developed when respondents considered what supports and services they want Hospice Halifax to offer: ATMOSPHERE, VALUES, APPROACH, and ACCESS.

Each sub-theme is accompanied by a quote from a participant to help illustrate what it captures. While participant and respondent input was varied and detailed, the major themes and sub-themes identify the common threads throughout the individual perspectives. The raw data, which includes the excerpts from the online surveys and community engagement session notes used in the coding phase, is available on request by contacting Hospice Halifax.

Atmosphere

This theme refers to the setting, feel, and design of the hospice residence. It includes the following sub-themes:

Home-like

“A non-sterile environment with colour, or a window, or a view of nature, and artwork.”

Sense of Community

“We are always going to rely on the potential for others around us to provide a sense of home and a sense of community, regardless of the situation.”

Personalized Space

“The ability to bring in your own comforters, pillows, whatever makes the room comfortable for your loved one.”

Celebrations

“When death occurs, how do you let the whole community know? Bonds will be formed – a ceremony, memorial, some way to let other people know the death has occurred.”

Privacy

“Unfortunately, in hospital or other assisted living facilities at end of life, it is not always possible to allow people the privacy they would like. I think that would be one of the MANY advantages to a hospice.”

Welcoming

“A welcoming spirit for all types of families and relationships.”

Quiet

“Quiet, peaceful environment.”

Scent-Free

“Sensitive environment for some.”

Variable Lighting

“Proper lighting of all levels: low, medium, and high – depending on activity or care required – amount of lighting varies.”

Values

This theme refers to the considerations, influences, and key philosophies that would shape the operation of the hospice residence. It includes the following sub-themes:

Choice

“If people do not want to eat, allow this.”

Diversity of Needs

“Everyone’s needs are going to be different.”

Diversity of Identities

“Require richness in diversity and explore opportunities for education and cultural awareness.”

Inclusion

“Reach out to various cultural communities to ask what they would want in a hospice – would they access hospice?”

Public Education

“Hospice has a role to play in increasing community awareness of palliative care and in engaging people in conversations around normalizing end of life. The public needs to know they have the option to “die well” in a setting where they will be cared for and fully respected.”

Beliefs re: Death & Dying

“Death can be a celebration – we in Western culture have shifted it to this low, silent event.”

Approach

This theme refers to the functioning, style, skills, and engagement of staff and volunteers associated with Hospice Halifax. It includes the following sub-themes:

Patient/Family-Centered Care

“Person in hospice and their family being listened to. Person’s goals of care honoured.”

Pain Management

“Access to medical professionals that can manage symptoms.”

Staff/Volunteer Characteristics

“Empathy, compassion, friendliness, patience – all the obvious things, but I think they cannot be stressed enough.”

Companionship

“Having others around just to take your mind off the current situation or to talk about what was happening can be literally all you need to push through the moment to moment situations that arise.”

Multi-Dimensional Support

“Multi-disciplinary team to look after the physical, mental, emotional, and spiritual needs and supports for the family.”

Service Coordination

“How hospice works with [the] health system, palliative care, ED [emergency department], paramedics, nursing homes, pharmacies, alternative health practices, social services, as well as religious and spiritual organizations, lawyers and ethicists access, funeral homes, crematoriums...”

Access

This theme refers to the availability, facilitation, and provision of specific services, amenities, and supports. It includes the following sub-themes:

Resources/Information

“Educations needs are high – families need to understand what’s happening and how to cope. Connecting families with community resources nearest to them is vital for the long term. Let them know of options that exist.”

Food Options

“Make sure people can eat the food they like.”

Music

“To be able to play their favourite music.”

Visitors Access

“To visit any time our loved one wants us to.”

Transportation

“Public transportation access? How can that be helped with loved ones who cannot drive and need to get there?”

Medical Assistance in Dying

“A willingness to provide the full spectrum of end of life care (including palliative care and medical assistance in dying).”

Admissions

“If access is limited, who gets priority and what happens to those not prioritized? Will there be restrictions, if so, what are they?”

Outdoors Access

“A place to walk, a place to push a wheelchair. A place to sit outdoors in the rain or snow (covered bench).”

Wishes Granted

“I would hope hospice would do their best to accommodate a person’s wishes within reason.”

Animals

“Pets in rooms, own pets, and therapy pets.”

Respite

“Respite for family members.”

Complementary Therapies

“Alternate types of care i.e. massage, acupuncture, osteopathy, pets, etc.”

Programming

“Therapeutic groups and recreation as well.”

Amenities Access

“The technology and aids to make a stay comfortable.”

Conclusion

In conclusion, we revisit the research question that inspired the community engagement process: What supports and services does the community want Hospice Halifax to offer?

Drawing from the four major themes and thirty-five sub-themes, it is apparent that the community wants Hospice Halifax to offer supports and services that:

- Create and maintain a welcoming, peaceful, comfortable, and flexible **ATMOSPHERE** that reflects the positive aspects of home.
- Embody **VALUES** surrounding diversity, inclusion, choice, and community awareness.
- Are shaped by a holistic, individualized, compassionate, and resourceful **APPROACH** to care.
- Reduce barriers to **ACCESS**, meeting the diverse needs and wishes of the community it serves.

As a result of the complete community engagement process represented by both the online surveys and community engagement sessions, the four major themes have been identified as key priorities for consideration in the continued development of Hospice Halifax and its hospice residence. This report, in addition to the raw data, is under review by the organization's Staff and Board of Directors.

Thank You!

Hospice Halifax gives its sincere thanks to all those who contributed to this process: survey respondents, engagement session attendees, community partners, supporters, and volunteers. Your contributions are appreciated!

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