

2022

## Engaging patients and families in developing, implementing, and evaluating hospital at home: A Canadian case study

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### Recommended Citation

Spina SP, Hainstock T, Haddadi R, Bourke B, Thompson L, Borycki E, Cartwright J, Forbes D, Harder CK, Kushniruk A, Mckelvey T, McMillan T, Menz S, Mukai K, Riddle M, Tierney S, Zeron Mullins M. Engaging patients and families in developing, implementing, and evaluating hospital at home: A Canadian case study. *Patient Experience Journal*. 2022; 9(1):217-226. doi: 10.35680/2372-0247.1660.

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### Cover Page Footnote

Acknowledgements: The authors would like to thank the Island Health Executive, BC Ministry of Health, Island Health Research and Capacity Building, BC SUPPORT Unit Vancouver Island Centre, and Delaney - The Engagement People for their support and commitment to this engagement initiative. A special thanks to our Patient Partners, Beth Bourke and Lisa Thompson and all the patient and family caregivers who responded to the survey and shared their perspective. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_PtFamComm](http://bit.ly/PX_PtFamComm)

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### Abstract

The Hospital at Home (HaH) care model is naturally patient-centred, with improved patient and family experiences and outcomes firmly anchoring the innovative approach to care. Existing literature focuses largely on the health care and patient care outcomes of HaH; however, to date, none of the identified literature has reported on engaging patients and families in the development, implementation, or evaluation of the HaH model of care. A multi-stakeholder, Patient-Oriented Research team in Victoria, British Columbia, Canada engaged patients and family/friend caregivers (PFCs) across all components of the HaH program. Guided by best practices in patient and public engagement, the team collaborated to 1) explore the potential impact of in-home acute care on PFCs' experiences; 2) identify health, social, and practice outcomes that matter to PFCs; 3) examine the social and environmental factors which may impact delivery of HaH; and 4) inform the HaH evaluation framework that includes PFC priority measures related to experience and outcomes. A public, online survey (n=543 PFC respondents) revealed both program-specific and evaluation-specific themes. These included a focus on patients achieving their own health goals and standard health outcomes, as well as patients and caregivers receiving training to support care at home. Engaging PFCs throughout HaH conception and implementation ensured the end program accurately reflected the priorities, concerns, and values of those that HaH is meant to serve.

### Keywords

Patient and public engagement, hospital at home, patient-oriented research

### Introduction

Hospital at Home (HaH) is an innovative care model that enables hospital-level care to be provided to patients in the comfort of their own home. Through in-person and virtual visits, patients can receive safe,

effective care from health care providers experienced in hospital medicine.

HaH is an established model in many regions of the world, including the United Kingdom (UK), Europe, Australia, and New Zealand. Studies have demonstrated high levels of patient satisfaction,

reduced length of stay, and equivalent or better clinical outcomes compared to standard hospitalization.<sup>1,2</sup> Initially conceived as a solution to relieve health system pressures (e.g., hospital bed overcapacity and budget constraints),<sup>1</sup> HaH has most recently assumed a promising role in the management of the COVID-19 pandemic in British Columbia by creating additional hospital capacity and reducing the risk of nosocomial infections.<sup>3</sup>

Existing HaH literature focuses largely on clinical outcomes, satisfaction and cost, and the benefits that the model brings to the health system from a patient and health care system outcomes perspective. However, to date, none of the identified HaH literature has engaged patients and family/friend caregivers (PFCs) in the development, implementation, or evaluation of the model.

The Alternatives to Traditional Hospital Care Offered in Monitored Environments (AT-HOME) research team in Victoria, British Columbia, Canada took a patient-led approach to engaging PFCs in supporting the development, implementation, and evaluation of the HaH program. Guided by best practices in patient and public engagement, the AT-HOME research team collaborated with PFCs at two distinct engagement levels: 1) as active members of the team (Patient Partners) and 2) as participants in the broader public engagement initiative. We wanted to hear from those who would be impacted by the HaH program to better understand measures of success and to learn about potential barriers or supports required to receive acute care at home.

By involving PFC voices and perspectives, we were able to better capture, understand, and implement patient-identified priorities in order to improve outcomes and experiences. In this case study, we describe our work in engaging PFCs to inform the HaH program, as well as our broader AT-HOME program of research. We also discuss the importance and value of including PFCs in health service research, planning, and improvement activities moving forward.

## Background

### *The Hospital at Home model of care*

Hospital stays can be associated with a range of hospital-acquired adverse events such as nosocomial infections,<sup>4</sup> decreased physical activity,<sup>5</sup> and delirium,<sup>6</sup> all of which come at a high cost to the health care system.<sup>7</sup> The Hospital at Home (HaH) model of care has been shown to generate high levels of patient satisfaction and a reduced length of hospital stay, while maintaining hospital-level quality and safety of care at home.<sup>1,2</sup> Some studies also report cost savings,<sup>5,8,9</sup> or

costs comparable with standard care,<sup>10</sup> and some have recognized the potential cost savings with expansion and long-term use of service.<sup>11</sup> However, more robust studies are needed to provide a more conclusive assessment of the cost comparisons.<sup>12</sup>

The HaH model has been in operation for more than 25 years and is well established in Australia,<sup>1</sup> New Zealand,<sup>13</sup> the UK, and parts of Europe.<sup>2</sup> Although evaluation frameworks developed by private and public health care systems to support their HaH programs exist, these frameworks are quantitative and focus primarily on standard clinical measures including clinical processes, standards of care, clinical complications, satisfaction with care, functional status, and costs of care.<sup>14,15</sup> There is a significant gap in current literature around evaluating PFC experiences within the Canadian context. Further, there is a scarcity of existing literature that illustrates the process of partnering with patients and families to inform program design and an evaluation framework that measures outcomes important to them. The AT-HOME research team's patient and family member engagement activities aimed to address these gaps.

### *Patient engagement*

Patient engagement is a movement that has been building momentum at a rapid pace over the past few decades. World-wide, health care providers and organizations strive to improve the quality of health care by integrating new drugs and technologies, modifying physical spaces, increasing education for patients and professionals, and appropriately allocating resources. However, until more recently, it was rare to engage patients as full partners with health professionals to design and implement change.

Although the language used to define patient engagement differs globally, including terms such as “patient and public involvement” and “public participation,” the fundamental principles of each are aligned.<sup>16</sup> At its core, patient engagement is based on the belief that patients should be recognized as experts in their own health experiences and in turn, have the right to be involved in all levels of decisions that affect them. Existing literature and leading patient engagement organizations recognize that the term “patient” extends beyond the individual receiving care and refers to any individual or group with lived experience of a health or health systems issue, including family members, caregivers, and advocacy organizations.<sup>17</sup>

In Canada, organizations advocating for the integration of patients as advisors in health system quality improvement have become mainstream.<sup>18</sup> Patient engagement is playing a role in supporting health system improvement by contributing to achieving the

“quadruple aim” of improving an individual’s care experience, improving the health of populations, reducing the per capita cost of health care, and improving a health care provider’s experience.<sup>19,20</sup> With the support of health system leaders and stakeholders, “Patient Partners” are shifting the culture of health care system thinking and design; crafting a system that is more responsive to patient experience, patient priorities, and patient outcomes - in other words, a system that is truly “patient-centred.”<sup>21</sup> Once hailed the “Patient Revolution”<sup>22</sup> and the “blockbuster drug of the century,”<sup>23</sup> the inclusion of patient and family caregiver voice has become the norm in current health care philosophy.

Building on patient engagement in health care system improvement is patient engagement in health research. Historically, the role of the patient in research has been passive; a study subject or data point. However, in the last 10 years, the move to actively and meaningfully engage patients in decision-making across the health research lifecycle has become increasingly normalized<sup>24</sup>; with significant efforts to incorporate the patient perspective in clinical and health services research. Advocates for engaging patients in health research argue that it increases the quality, appropriateness, acceptability, transparency, and relevance of research - ensuring health research addresses issues of importance to people, families, and communities living with health conditions.<sup>25</sup>

Informed by the patient engagement momentum in the United States<sup>26</sup> and the United Kingdom,<sup>27</sup> Canada developed a strategy to improve health outcomes and enhance patient care through the levers of research: the Strategy for Patient-Oriented Research (SPOR). The Canadian Institutes of Health Research (CIHR) defines Patient-Oriented Research (POR) as a continuum of research that engages patients as partners, focuses on patient-identified priorities, and improves patient outcomes.<sup>28</sup> A key principle of SPOR is that research is conducted by multidisciplinary teams and key stakeholders including patients and their families, researchers, health care providers, and decision makers. Together, teams collaborate to build a sustainable, accessible, and equitable health care system to bring about positive changes in the health of people living in Canada.<sup>28</sup> The patient engagement efforts outlined in this manuscript are guided by the SPOR initiative as this work underpins all research activities by the AT-HOME team.

## **AT-HOME Patient & Public Engagement Initiative**

### *Engagement process*

Guided by best practices in public participation and POR,<sup>29-33</sup> the AT-HOME team partnered with PFCs at two distinct engagement levels: 1) as active members of the team (Patient Partners) and 2) as participants in the broader public engagement initiative. They began their engagement efforts by including two Patient Partners as equal members of their team. The engagement opportunity was at the level of “Collaborate” on the International Association of Public Participation (IAP2)’s Spectrum of Public Participation.<sup>34</sup> In March 2020, the two Patient Partners were recruited and on-boarded with the support and guidance of the BC SUPPORT for People and Patient Oriented Research and Trials Unit (BC SUPPORT Unit) Vancouver Island Centre. To ensure meaningful and active collaboration, the AT-HOME team upheld guiding principles of patient engagement, including:

- Inclusiveness: support for patient partners to be able to fully contribute (e.g., creating safe environments, appropriate training, education, and compensation);
- Mutual respect: where the value of experiential knowledge is recognized by all research team members;
- Co-building: where patients, researchers, and practitioners work together from the beginning to identify problems and gaps, set priorities, and collaboratively produce and implement solutions;
- Co-learning: where patient and public partners learn more about the research process and researchers learn more about patient-centred engagement;
- Reciprocal relationships: where team members share power and decision-making.<sup>29, 35</sup>

Early insights and contributions from AT-HOME team members highlighted the need to engage stakeholders who will be impacted by HaH in the decision-making process. In April 2020, the AT-HOME team hired a third-party public engagement consulting firm to lead a large-scale public engagement initiative. The focus of this initiative was to engage people with expertise in health, including lived/living experience, to inform the development, implementation, and evaluation of a customized, made-in-British Columbia HaH program. The Patient Partners played an integral role in all public engagement decision making, including question development, promotion, interpreting feedback, and knowledge translation activities. The engagement initiative was funded by a grant from the BC SUPPORT Unit Vancouver Island Centre Planning and Development Awards.

### *Engagement objectives*

With the opportunity to be one of the first teams in Canada to develop a HaH program and evaluation framework that is grounded in the expressed priorities and expertise of patients, caregivers, clinicians, health care staff, and health care leaders, the large-scale public engagement initiative had two main objectives:

1. To listen and learn from all stakeholder groups to determine what HaH program success looks like and how the team might measure it.
2. To ensure the HaH program embeds stakeholder priorities into the overall design and rollout of the program.

The evaluation component focused on identifying key measures for evaluating the following features: patient experience, caregiver experience, staff experience, patient health outcomes, and general success measures. The HaH program design component of the engagement focused on better understanding what factors could be either facilitators (supports) for HaH or barriers, as well as understanding policy considerations for successful implementation of HaH. Collectively these components are informing the research activities of the AT-HOME team.

### **Engagement techniques**

The engagement was developed based on IAP2 planning methodology and best practices. The engagement activities consisted of key interviews and an online survey, with a total of 807 responses across both platforms. The online survey was promoted internally to health care staff as well as publicly through traditional media and social media outlets. An online survey instrument was developed by the engagement consultant firm and the AT-HOME team members. It was launched on Island Health's instance of REDCap (Research Electronic Data Capture) site on September 21, 2020 and was open for submissions until January 4, 2021.

A total of 784 responses were collected via the online survey. Respondents selected whether they were patients ("In the past 10 years, I have stayed overnight in the hospital as a patient"), caregivers ("In the past 10 years, I have been a caregiver for a family member or friend"), clinicians ("I am a clinician [doctor, nurse, pharmacist, or other health care professional] working in the health care system"), clinical support team members ("I am a clinical support team member [not a clinician] working in the health care system") or belonged to another group. Participants had the option to select any and all groups they belonged to, resulting in overlap.

Although the public engagement initiative sought insights from a wide range of health system stakeholders, the remainder of this case study will specifically focus on what was heard from those who identified themselves as patients and family/friend caregivers (PFCs), n=543 and how those insights informed the HaH evaluation framework and overall program design.

### **What we heard**

This section presents the feedback we heard through the online survey. It is important to note this survey was conducted via an open link that was accessible to anyone with internet access. As the survey respondents were self-selected and not a random sample, and the findings were not weighted to be reflective of a larger group (i.e., the public), the findings may not be representative of the population. Respondent demographics can be found in Table 1.

The online survey sought feedback from PFCs on: HaH program awareness; importance of patient and caregiver experience; patient health outcome priorities; general success measures; barriers and enablers to success; and general advice for the program. The survey included questions with traditional Likert scales and open text questions where PFCs had the opportunity to share more in-depth answers if they so wished. The summary of these findings is presented below.

Findings showed that 60% of all those who participated in the survey were "not at all" or "not very familiar" with the HaH program. In particular 44% and 43% of patients and caregivers respectively had never heard of the program and 17% and 15% respectively had only heard the name.

Those who identified themselves as patients were then asked to rate the importance of a number of patient experience measures that could be included in the program evaluation and measures of success.

### **Patient-identified priorities (high level themes with quotes)**

- Robust safety measures - *"The proper equipment to deliver the health care required that provides safety for the patient AND the nurse, caregiver, family member, care aids [sic]."*
- Effective and reliable communication channels - *"The most important factor in this program to my mind would be access to hospital personnel in case of emergency. For example, if I needed more pain medication, at hospital you push a button and the nurse comes in"*
- Receiving respectful treatment - *"Feeling culturally safe, that personal values are respected"*
- Provision of supports to reduce caregiver burden and recognition of the importance of caregiver roles

- *“The mental health of patient and caregivers, immediate and ongoing”. “Ability of my caregiver to access and understand the system”*

When asked to rate the level of importance of these measures, patients’ top priorities were seeking assurances around safety and effective communication. Among survey participants identifying as a patient, 84% rated receiving care that was as safe as that in the hospital and ensuring there were no potential causes of additional harm as “very important.” Similarly, 84% of patient participants indicated that receiving clear information from health care providers (HCPs), and the responsiveness of HCPs to patient questions or concerns (80%), were top priorities. Of the responses, 80% rated receiving respectful treatment and 75% rated feeling connected with the HCPs as top priorities. Near 70% of the responses rated general measures of care such as pain management, continuity of care in transitioning between hospital and home, and having the right medical supplies at home as top priorities. Comfort was also rated as “very important” in 64% of the responses.

When patients were asked about the priority measures of health that should be included in program evaluation, 81% of the responses rated safety, 70% rated successful recovery, and 61% rated readmission to the hospital shortly after discharge as “very important” measures of patient health outcomes. Other prominent themes that emerged from the open text fields focused on supports for caregivers and the impact of the role on the caregivers; it was seen as important to ensure that they have the ability to provide care and the resources to do so.

After indicating their awareness of the program, those who identified themselves as family caregivers were asked to rate the importance of a number of supports the program should put into place to make participation feasible to them.

***Family caregiver-identified priorities (high level themes with quotes):***

- Creation of supports (mental, technical, clinical) to enable effective patient care in the home - *“Being coached to be a full partner in care, being consulted as part of the planning - not a passive recipient, excellent communication links with the clinical Care Team, adequate Home Support services including respite, referral to caregiver support services and resources e.g., Family Caregivers of BC and disease-based caregiver supports”*
- Responsive, hospital level quality service - *“Ability to be responsive for medication changes or needs and having quick access to them to meet a change in medical condition.”*

- Clear understanding of roles and expectations - *“Clear expectations of caregivers of the program. It cuts both ways.”*

Family caregivers’ top priorities were “sufficient supports from clinicians and support workers,” with 86% of the respondents rating this as “very important”; “responsiveness of clinicians to caregivers’ questions and concerns” (83%); and having a “clear understanding of expectations and the caregivers’ roles” (82%). When participants were asked what other supports caregivers might require (open text field), the top themes identified were similarly around responsive care (in cases of emergencies, questions and concerns) and supports for caregivers, including emotional (respite and mental health needs met) as well as practical (having access to equipment and education to assist with care).

When family caregivers were asked to rate which factors they perceived as barriers in participating in the HaH program, the “emotional toll of caregiving” was rated as a “big barrier” or a “very big barrier” in 57% of responses. Similarly, when this question was asked of participants in the open text field, the top themes identified were “burden of care”, including “complexity” of care to be provided, and “mental and physical health of caregivers.” These themes included concerns about having the expertise to provide care, being able to reach a provider in case of emergencies and exhaustion, energy, social isolation, lack of physical fitness to support a patient, or caregivers’ own health issues.

**Impact**

This section discusses the impacts and resulting actions based on what we heard and learned through the engagement activities. The findings from the survey illuminated the lack of familiarity with the HaH concept among participants. While these findings cannot be interpreted as representative of the broader public perception, it is important to note the value of engagement and building public awareness when introducing a new program. It is well established that public awareness, participation, and communication are pillars in effecting social change and altering behavior. This is unequivocally true when implementing a health care program. Communication and public engagement are essential, not only to convey crucial information to the public, but to ensure adequate program uptake and sustainability by rallying the right supports.<sup>36</sup> By including PFC voices, we can better capture, understand, and implement patient- and caregiver-identified priorities in order to improve health outcomes and experiences.

**Table 1. Respondent Characteristics**

	<b>Patients (n=238)</b>	<b>Family Caregivers (n=305)</b>
<b>Sex</b>		
Female	195 (82%)	275 (90%)
Male	36 (15%)	21 (7%)
Prefer not to answer	7 (3%)	9 (3%)
<b>Age (yrs)</b>		
≤ 20	0 (0%)	0 (0%)
21-30	7 (3%)	9 (3%)
31-40	26 (11%)	43 (14%)
41-50	24 (10%)	27 (9%)
51-60	38 (16%)	70 (23%)
61-70	57 (24%)	92 (30%)
71-80	67 (28%)	46 (15%)
≥ 81	12 (5%)	6 (2%)
Prefer not to answer	7 (3%)	12 (4%)
<b>Do you consider yourself ... (Yes)</b>		
A person with disability?	33 (14%)	27 (9%)
A member of a visible minority group?	7 (3%)	9 (3%)
An Indigenous person (First Nations, Inuit, Métis)?	5 (2%)	3 (1%)
A member of the LGBTQ2+ community?	7 (3%)	9 (3%)
<b>Primary language</b>		
English	219 (92%)	275 (90%)
French	7 (3%)	6 (2%)
Another language	10 (4%)	18 (6%)
Prefer not to answer	2 (1%)	7 (3%)
<b>Comfort level with new technology</b>		
Not very savvy	21 (9%)	15 (5%)
Somewhat savvy	143 (60%)	177 (58%)
Very savvy	71 (30%)	110 (36%)
Prefer not to answer	2 (1%)	0 (0%)

Having an understanding of the HaH model of care - prior to being offered the program at the hospital - would enable the patient and their caregiver to make more informed decisions and ask more effective questions about the program and their care. This in turn can improve PFC and clinician experiences with the program. Having some prior knowledge would also alleviate some of the pressure on PFCs, who may be in a state of stress at the hospital and unable to completely absorb new information about a program and its logistics as well as understanding the complexities of their primary health needs. Having accurate information that educates the public about the program can increase access and give the clinicians the confidence to focus on the patient's specific needs. Knowing the public's priorities and measures of success can inform the development of the program and the understanding of what information needs to be disseminated to the stakeholders.

To directly address the priority needs identified by the PFCs, the following actions took place:

- The development and implementation of a “virtual call bell”
- Integration of a comprehensive communication platform (voice and text messaging)
- A HaH evaluation framework grounded in PFC priorities
- Developments of AT-HOME research activities grounded in PFC priorities
- Perceived shifts in the organizational culture at the health authority (more inclusive and respectful of PFC voices)
- A less hierarchical decision-making process

We heard from both patients and family caregivers that effective and responsive communication with the health care team was a high priority, and that measuring this was “very important” when evaluating the success

of the program. As a result, the HaH program implemented a call bell device to simplify the mode of connection between patient and HCP. A single button that can be used remotely to reach HCPs easily, similar to traditional hospital call bells, became a key feature of the technology used in the program. The aim of this implementation was to respond to the need recognized by both patients and caregivers for a rapid mode of communication. The efficacy of the call bell and potential use cases are an avenue for further research and evaluation within the program. Furthermore, a single phone number for the program was implemented to connect patients and caregivers directly to the HaH program team members at any time. A comprehensive communication platform was also implemented to support these channels of communication.

To increase public awareness of HaH in Victoria, the program is in the process of developing a series of awareness campaigns. These included the development of a short “day-in-the-life” video outlining what a patient and caregiver may expect to experience from admission to discharge in the program. A series of pamphlets, outlining information about the HaH model of care were also developed.

To ensure the continuity of the inclusion of PFC’s voices and perceptions, the AT-HOME team contributed to the development of a robust evaluation framework, grounded in PFC priorities, which includes a comprehensive series of PFC experience survey questions. These questions incorporated the findings of the engagement activities and include questions pertaining to measures that were recognized as “very important.” These included the effectiveness of the communication between health care providers, patients and caregivers; how safe patients and how confident caregivers feel in the program; what challenges caregivers experience monitoring the patient and assisting them with their care, and any identified caregiver burdens; what are the experiences of having nurses and physicians coming into their homes; and how participants find the program overall.

A less tangible, but no less critical, impact has been the perceived incremental shift in organizational culture. By inviting PFCs to the planning table and valuing their input, there has been a shift toward collaboration, inclusivity, and respect at organizational program planning. This has helped to facilitate a greater understanding of the value that PFCs bring as experts on their own experiences and helps shift the culture from individual services delivered by professionals or experts to integrated, collaborative care.

## Limitations

It is important to note that a number of limitations impacted the final results of the AT-HOME engagement initiative, stemming primarily from the snap election that was called by the BC Provincial Government on September 21, 2020. Engagement planning was well underway by the team at this time; indeed, the survey itself was launched on that same day. However, due to the inability to promote the engagement process publicly during an active election, the timelines for this project were significantly delayed, as was the ability to reach the public more broadly.

This inability to promote, coupled with the time constraints to produce a relevant report in a timely manner, impacted the engagement team’s ability to target not only the public as a whole but also the key stakeholders that the HaH program seeks to support. As such, the only medium used to hear from patients, caregivers, and under-represented groups was the online survey (with the exception of one caregiver who volunteered to be interviewed before the announcement of the snap election.)

While the numbers of patients and caregivers that participated in the survey are sizeable (238 and 305, respectively), there was a missed opportunity to speak directly to those who have direct experience with the HaH program and to gather nuanced data to that effect. Interview data that was collected is wholly (with the exception of the one interview of the caregiver) from the perspective of health care staff and administrators.

## Moving Forward

The engagement initiative has informed our future activities. The HaH model offers potential to address the care needs of the Canadian population, and evaluating alternatives to hospital care is an urgent priority given the current COVID-19 pandemic. However, there is little evidence indicating how this model can and should be implemented in a Canadian context.

Expanding the HaH model to other Canadian communities requires formal, robust, systematic evaluation to investigate its impacts and to help develop a model that has the flexibility to address specific population needs. The AT-HOME team have developed a prospective mixed-methods study protocol that will utilize quality improvement and research methodologies to address two key objectives going forward: 1) Identify potential challenges and facilitators in implementing the HaH model in BC and 2) Evaluate meaningful health-related outcomes in measuring the efficacy, safety, and feasibility of this model in BC. This study will be conducted using a Patient-Oriented

Research approach, in alignment with CIHR's SPOR initiative. A robust evaluation of the HaH model will help to ensure patients continue to receive the highest quality of care, and will guarantee the safety of patients, families, and clinicians.

Through the collaboration of the AT-HOME team and the HaH program, this model of care has the potential to be showcased as one of British Columbia's leading learning health systems (LHS). A LHS is an integrated health system in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and health care.<sup>37</sup> The HaH program has the opportunity to use every patient encounter as an opportunity to learn and improve. The AT-HOME team will continue to inform the development of the HaH model in the Canadian and global contexts by generating new evidence to address gaps in the literature.

### Acknowledgements

The authors would like to thank the Island Health Executive, BC Ministry of Health, Island Health Research and Capacity Building, BC SUPPORT Unit Vancouver Island Centre, and Delaney - The Engagement People for their support and commitment to this engagement initiative. A special thanks to our Patient Partners, Beth Bourke and Lisa Thompson, and all the patient and family caregivers who responded to the survey and shared their perspectives.

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