Creating a BC Centre of Excellence in Palliative Care

Invitational Workshop Report

July 2013

Prepared for IHSTS by Patricia Evans & Associates Inc. and May Communications
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Executive Summary

In March 2013, the Ministry of Health committed two million dollars to support the establishment of a provincial Centre of Excellence (COE) in Palliative Care. The ministry asked the Institute for Health System Transformation & Sustainability (IHSTS) to steward the funding and facilitate the creation of the centre.

IHSTS held an Invitational Workshop on June 26, 2013 to obtain advice from palliative care experts from across BC. Participants developed draft Mission and Vision Statements, which will be refined to articulate the mandate of the new COE:

- Our Mission is to advocate for and accelerate innovation and best practice in palliative care for all British Columbians.
- Our Vision is skilled providers with training, tools and knowledge delivering high-quality palliative care services to British Columbians.

Workshop participants proposed six strategic priorities for developing the COE, with recommendations for draft objectives, activities and outcomes to support each priority area:

1) **Finalize the centre’s purpose, vision and value proposition**

   *Recommendation*: Develop an iterative, consultative planning process to define the COE’s mandate.

2) **Establish COE leadership**

   *Recommendation*: Establish visionary and operations co-leadership to deliver the mandate and develop the platform, supported by communications, fundraising and administrative expertise.

3) **Build coalitions**

   *Recommendation*: Conduct an environmental scan of provincial resources, research capacity, funding partners, advocacy groups and health authority plans to provide a baseline for coalition building and activity planning. Developing a provincial leadership group and a linkage to the palliative care research community are also suggested.

4) **Establish infrastructure in the first year**

   *Recommendation*: Establish governance, produce a strategic plan based on engagement, and develop communications messaging, marketing and tools.
5) Increase COE funding

*Recommendation:* Produce a business plan to obtain more funding for growth and sustainability.

6) Pursue opportunities for potential short-term deliverables

*Recommendation:* Create work teams to pursue readily achievable opportunities such as:

- Symptom guidelines
- Performance indicators
- Increased use of Advanced Care Planning/Medical Orders for Scope of Treatment
- iPanel work
- Electronic Medical Records as a best practice for end-of-life care
- Support for provincial hospice bed development
- End-of-life Practice Support Program next steps for family physicians

In addition, workshop participants recommended creation of an advisory body of palliative care experts to inform the IHSTS Board of Directors and COE co-leaders on the COE governance, structure, strategic direction, projects, partnerships, budget and other issues.

Two working groups were established, one to work on the COE purpose and vision, and one to work on leadership and recruitment. These groups will work remotely during July and August, and bring forward recommendations to workshop participants for their review and comment in September 2013.
Introduction

End-of-life care is a major priority for planning and health service delivery across British Columbia. In March 2013, the Ministry of Health released an action plan to improve access to end-of-life care in BC, and committed two million dollars to support the establishment of a provincial Centre of Excellence (COE) in End-of-Life Care.

The Ministry asked the Institute for Health System Transformation & Sustainability (IHSTS)—a BC-based, independent think tank pursuing practical ways to transform and sustain Canada’s health care system—to steward the funding and support development of the COE. IHSTS held an Invitational Workshop on June 26, 2013 to obtain advice from palliative care experts—clinicians, researchers and administrators—from across BC on three key questions:

- How could a new provincial Centre of Excellence leverage BC’s strengths and help address the province’s service delivery challenges?
- What will be the scope of activities for the centre?
- What type of leadership is needed to best support the centre’s success?

This report outlines the advice provided by workshop participants on:

- Draft Mission and Vision Statements for the new centre
- Driving and restraining forces
- Proposed strategic priorities, objectives, activities and outcomes
- Proposed leadership structure and staffing
- Next steps for confirming the centre’s purpose, leadership and structure

Proposed Mission Statement

A Mission Statement should:

- Describe an organization’s purpose and reason for being
- Explain how the organization is unique
- Clarify who the organization serves and where

The following example Mission Statement was presented at the workshop for discussion:

The Mission of the BC Centre of Excellence in End-of-Life Care is to accelerate innovation and best practice in quality care to improve services for people with life limiting illnesses.

Workshop participants agreed to change the terminology from “end-of-life” to palliative care, as the latter term is broader in scope and includes end-of-life care.
There was also discussion of the need to include advocacy in the Mission; whether the COE would be patient-centred or focus on supporting clinicians to enhance capacity; the traditional role of COEs in research; the potential for overlap/linkage with the federal palliative care network; and the difference between specialist teams in urban settings, compared to primary care physician/nurse teams in rural and remote settings.

Based on the discussion, the following draft Mission Statements were put forward for further consideration and confirmation by the Purpose & Vision Working Group (see page 12):

Our Mission is to advocate for and accelerate innovation and best practice in palliative care for all British Columbians.

OR

Our Mission is to advocate for and accelerate innovation and best practice in palliative care, building and optimizing system quality and capacity for all British Columbians.

Proposed Vision Statement

A Vision Statement should:

- Tell stakeholders about the future the organization exists to help create
- Provide a vivid idealized description of a desired outcome
- Help create a mental picture of a shared target/destination/desired future

The following example Vision Statement was presented at the workshop for discussion:

The Vision of the BC Centre of Excellence in End-of-Life Care is a province where care providers have access to the knowledge they need to improve and deliver high-quality services for British Columbians with life-limiting illnesses and their families.

Workshop participants discussed broadening the Vision Statement to be more inspirational, by including system transformation; access to training and tools to build provider capacity for delivering equitable, default access to palliative care; and developing cutting edge evidence for innovations in palliative care in BC for other jurisdictions to benefit from.

Based on the discussion, the following draft Vision Statements were put forward for further consideration and confirmation by the Purpose & Vision Working Group (see page 12):

Our Vision is skilled providers with training, tools and knowledge delivering high-quality palliative care services to British Columbians.

OR

Our Vision is a provincial palliative care system with the capacity to deliver innovative, high quality services for all British Columbians.
**Driving & Restraining Forces**

Workshop participants identified current and anticipated forces that will affect the COE’s ability to make a difference in palliative care delivery in BC. These forces set the scene for determining priority opportunities and gaps for the COE to focus on:

<table>
<thead>
<tr>
<th>Driving Forces</th>
<th>Restraining Forces</th>
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<tbody>
<tr>
<td>• $2 million in funding</td>
<td>• Not enough funding for sustainability</td>
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<tr>
<td>• Strong government support</td>
<td>• Facing urgent need with an aging population; currently behind in capacity</td>
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<td>• The timing is right with an aging population and increased</td>
<td>• A “culture of cure” needs to contend with care of the dying</td>
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<td>demand for palliative services/integration with other services</td>
<td>• The way funding mechanisms and resources are structured and allocated</td>
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<td>• Strong existing provincial palliative programs and leadership expertise</td>
<td>• Health authorities offer variable levels of care, leadership, structure and</td>
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<tr>
<td>• Provincial End of life Action Plan</td>
<td>resources</td>
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<td>• A collaborative environment with common goals for palliative care (</td>
<td>• Turf protection and system resistance</td>
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<tr>
<td>among health authorities, the Canadian Hospice Palliative Care Association,</td>
<td>• Public and provider misconceptions about what palliative care should be</td>
</tr>
<tr>
<td>University of BC (UBC), Division of Family Practice, BC Medical Association (</td>
<td>• Competing agendas need to be recognized and managed</td>
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<tr>
<td>BCMA), Ministry of Health, patients and families, etc.)</td>
<td>• Lack of coordination in research and interdisciplinary education</td>
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<td>• BC has international leadership in palliative care planning, research</td>
<td>• Lack of consistent messaging and language</td>
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<td>and innovation</td>
<td>• Lack of capacity for knowledge translation, exchange and synthesis (KTES)</td>
</tr>
<tr>
<td>• Revitalized UBC division of palliative care</td>
<td>• Lack of capacity/policy to drive palliative care integration</td>
</tr>
<tr>
<td>• Enhanced program capacity (Practice Support Program/after-hours nursing</td>
<td>• Lack of performance indicators</td>
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<td>line)</td>
<td>• Lack of core palliative care education components in the health system</td>
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<tr>
<td>• Funding for 200 more hospice beds in BC</td>
<td>• No natural industry partners for research funding</td>
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<td>• Opportunities for national collaboration (e.g., with the National</td>
<td>• Leaders have reached capacity and lack succession plans</td>
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<tr>
<td>Centre of Excellence, University of Manitoba)</td>
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<tr>
<td>• Opportunities to obtain additional funding</td>
<td></td>
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<tr>
<td>• Achieving physician credentialing in palliative care, so people from</td>
<td></td>
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<tr>
<td>outside Canada can be recruited to work here</td>
<td></td>
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Proposed Strategic Priorities

Participants then proposed key short-term priorities, objectives and activities for the COE to focus on in the next six to 18 months to leverage opportunities and strengths in palliative care in BC and/or address gaps and constraints:

<table>
<thead>
<tr>
<th>Strategic Priorities</th>
<th>Objectives</th>
<th>Activities &amp; Outcomes</th>
</tr>
</thead>
</table>
| Finalize the centre’s purpose, vision and value           | 1) Define the centre’s mandate  
2) Develop a process to determine the COE’s value proposition                                           | • Plan an iterative process to clarify the purpose, mission, vision, value proposition and priorities for the COE:  
e.g., leadership forum, fluid polls, draft reviews, teleconferences, webinars  
- An inclusive coalition of key partners to communicate with relevant stakeholders  
- Government goes to the COE for input on policy development and planning  
The COE leads research activity coordination and is a resource on research  
Care providers know how and where to access current research initiatives |
| Establish COE leadership                                  | 1) Define leadership principles  
2) Identify inspirational and strategic leadership, supported by communications, fundraising and administrative expertise  
3) Hire an Executive Director who can deliver the mandate and develop the platform | • Hire a respected visionary leader within six months  
• Implement co-leadership (administrative/clinical and research)  
• Create an advisory group with key stakeholders  
• Put well-developed reporting structures in place  
• Hold regular meetings to update senior health authority leaders and key stakeholders on COE priority activities |
## Strategic Priorities

### Build coalitions

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Activities &amp; Outcomes</th>
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</table>
| 1) Develop principles of inclusivity and consensus seeking | - Perform environmental scan within six months:  
- Used to identify gaps and opportunities  
- Used to inform strategic and business plans  
- Published online |
| 2) Conduct an environmental scan of provincial resources, research capacity, funding partners, advocacy groups and health authority plans to identify levers of decision making, policy and capacity for change | - Develop a research network and supports  
- Develop partnerships and alliances within 18 months with:  
- Primary care, specialists, patients, families and caregivers  
- Financial partners (e.g., industry, foundations, research funders)  
- Executive level health authority engagement to ensure palliative care is prioritized  
- Non-cancer disease/chronic condition groups, telehealth |
| 3) Convene a provincial leadership group with health authorities and key stakeholders to reach a common, shared commitment to work together | - COE is structurally linked to major provincial stakeholders  
- Multiple partnerships achieve synergism and integration; increase leverage to push COE agenda; reduce duplication |
| 4) Develop an early, comprehensive linkage to the palliative care research community | - Develop and implement a multi-pronged, robust communication and engagement strategy (e.g., easy to navigate, mobile-friendly website, regular e-newsletter)  
- Knowledge of COE activities across BC and other jurisdictions:  
- Virtual hub for knowledge translation and engagement  
- Hospice and other community/family volunteers feel supported and informed of palliative care  
- Palliative approach to care is seen as valuable for all caregivers  
- Other health care providers define palliative care using COE language  
- The public is aware of the COE |

### Establish infrastructure in the first year

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Activities &amp; Outcomes</th>
</tr>
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</table>
| 1) Establish governance and stakeholder linkages | - Develop and implement a multi-pronged, robust communication and engagement strategy (e.g., easy to navigate, mobile-friendly website, regular e-newsletter)  
- Knowledge of COE activities across BC and other jurisdictions:  
- Virtual hub for knowledge translation and engagement  
- Hospice and other community/family volunteers feel supported and informed of palliative care  
- Palliative approach to care is seen as valuable for all caregivers  
- Other health care providers define palliative care using COE language  
- The public is aware of the COE |
| 2) Produce a strategic plan based on engagement | - Develop and implement a multi-pronged, robust communication and engagement strategy (e.g., easy to navigate, mobile-friendly website, regular e-newsletter)  
- Knowledge of COE activities across BC and other jurisdictions:  
- Virtual hub for knowledge translation and engagement  
- Hospice and other community/family volunteers feel supported and informed of palliative care  
- Palliative approach to care is seen as valuable for all caregivers  
- Other health care providers define palliative care using COE language  
- The public is aware of the COE |
| 3) Develop communications messaging and marketing | - Develop and implement a multi-pronged, robust communication and engagement strategy (e.g., easy to navigate, mobile-friendly website, regular e-newsletter)  
- Knowledge of COE activities across BC and other jurisdictions:  
- Virtual hub for knowledge translation and engagement  
- Hospice and other community/family volunteers feel supported and informed of palliative care  
- Palliative approach to care is seen as valuable for all caregivers  
- Other health care providers define palliative care using COE language  
- The public is aware of the COE |
| 4) Establish communication tools among groups/practitioners | - Develop and implement a multi-pronged, robust communication and engagement strategy (e.g., easy to navigate, mobile-friendly website, regular e-newsletter)  
- Knowledge of COE activities across BC and other jurisdictions:  
- Virtual hub for knowledge translation and engagement  
- Hospice and other community/family volunteers feel supported and informed of palliative care  
- Palliative approach to care is seen as valuable for all caregivers  
- Other health care providers define palliative care using COE language  
- The public is aware of the COE |
Strategic Priorities | Objectives | Activities & Outcomes
---|---|---
Increase COE funding | 1) Develop a business plan to obtain more funding for growth and sustainability 2) Identify new funding to support sustainable capacity and influence in BC, nationally and internationally | • Develop and implement a feasible business plan to move forward on implementing the mandate • Develop a COE brand to focus fundraising • Double funding in two years • Two successful grant applications for priority research within 18 months
Pursue opportunities for potential short-term deliverables | 1) Establish work teams to pursue readily achievable opportunities: a) Symptom guidelines b) Performance indicators c) Increased use of Advanced Care Planning (ACP)/Medical Orders for Scope of Treatment (MOST) d) iPanel work e) EMR as a best practice for EOL care 2) Support provincial hospice bed development 3) Identify end-of-life Practice Support Program next steps for family physicians | • Establish working groups for quick win provincial projects • Select and disseminate a provincial symptom management guideline • Health care providers look to the centre for best practices in palliative care in BC • Evidence informed practice changes are in place with a plan to develop more: - An inventory of best practices in BC is available online - Stakeholders access palliative care knowledge, pathways, research • Integrate palliative care in Electronic Medical Record (EMR) platforms

Longer Term Priorities

In addition, workshop participants suggested five longer term priority areas for the COE to consider:

1) Support ongoing knowledge generation, knowledge translation and innovation.

2) Promote investment in developing system capacity to deliver high quality palliative care.

3) Develop technologies to support access to and integration of palliative care/ACP resources.

4) Build on national and international leadership strengths to integrate primary, palliative care, ACP and pediatric palliative care.

5) Integrate research, practice, education and policy in the care of patients with serious illnesses.
Advice on Advisory Body Structure

IHSTS representatives confirmed the Institute has been asked to facilitate the creation of a BC Centre of Excellence in Palliative Care, but is not a content expert in this area. The aim of IHSTS is to create an environment for success for the COE in whatever form evolves. Consequently, IHSTS asked workshop participants to offer advice on the structure of an Advisory Body of palliative care experts, which will, in turn, provide subject matter expertise to guide the COE’s development. Participants suggested the following approach:

**Advising Whom?**

- IHSTS Board of Directors
- COE Visionary Leader and Executive Director

**Proposed Structure**

- An Advisory Body of passionate subject matter experts with a blend of skills, knowledge, and representation
- Representation could include inter-professional clinicians, geographical areas, different organizations, large and small communities, BC Hospice Palliative Care Association, BCMA/physicians (would require fee for service), the Tripartite End-of-Life Working Group (ministry, health authorities and clinicians), new UBC palliative care division, research, professional practice, patient voice network (Impact BC), policy expert
- Bring in external champions to draw on existing expertise and avoid reinventing the wheel (e.g., Dr. Diane Meier, Director of the Center to Advance Palliative Care in the United States)
- Consider whether the Executive Director or a member of the IHSTS Board should be part of the advisory group
- 10-12 people in size

**Proposed Advisory Body Roles**

Participants proposed the Advisory Body provide recommendations to IHSTS on:

- Defining the strategic direction and leadership of the COE
- Coordinating COE projects, working groups, partnerships and communications strategy
- Advising the IHSTS Board on COE budget issues and spending decisions
- Acting as champions to the palliative care community
• Broadening stakeholder support at the Ministry of Health beyond home and community care to include acute care, where much of end-of-life care occurs

**Interface with Provincial EOL Action Plan**

There was some discussion of the intended interface between the BC Centre of Excellence in Palliative Care and the Provincial End-of-Life Care Action Plan. It was suggested the COE could:

• Advise the Ministry of Health on best practices and research evidence for policy decisions on palliative care to assist with meeting government commitments in the action plan
• Help achieve EOL priorities like the commitment to double hospice beds, by advising on the definition of hospice bed
• Assist with building capacity for transformational change
• Work in partnership to help address issues that emerge over time and align with/complement each other’s goals

**Advice on Staffing**

Participants suggested a co-leadership model for the COE with a:

• **Visionary Leader** whose characteristics include:
  o Being a visionary, strategic thinker
  o Being well-respected
  o Providing a passionate, effective voice for the centre and fundraising
  o Having knowledge of clinical care, education, research and policy
  o Bringing credibility to the centre
  o Engendering collaboration
  
  This position would likely be part-time, possibly a secondment with a matching part-time faculty position, to complement the operations leader.

• **Operations Leader** (Executive or Managing Director)

  This position would require strong business skills and likely be an interim, full-time posting to lead the operational side of the COE, with administrative support, while the COE leverages additional funding to ensure sustainability.
Proposed Values and Guiding Principles

Based on discussions at the workshop, the following preliminary values and guiding principles are suggested for the BC Centre of Excellence in Palliative Care:

Values: How we will act

- Collaborative
- Inclusive
- Consensus seeking
- Patient and provider-centred

Guiding Principles: How we will work

- Building partnerships
- Integrating research, clinical care, policy, urban/remote, and system sustainability
- Leveraging opportunities and funding
- Mobilizing knowledge

Next Steps

Two working groups were established, one to work on the COE purpose and vision, and one to work on leadership, job descriptions, selection process and recruitment package. These groups will work remotely via video/teleconferencing during July and August, and bring forward recommendations to workshop participants for review and comment in September 2013.

The following workshop participants expressed interest in joining the working groups (see the appendix for a complete list of workshop participants):

Purpose & Vision Working Group

Elisabeth Antifeau, Dr. Doris Barwich, Jacqueline Cardwell, Dr. Pippa Hawley, Dr. Romayne Gallagher, Dr. Douglas McGregor

Leadership & Recruitment Working Group

Dr. Peter Edmonds, Dr. Gillian Fyles, Jill Gerke, Dr. Michael McKenzie, Dr. Kelli Stajduhar
## Appendix: Workshop Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elisabeth Antifeau</td>
<td>Interior Health</td>
</tr>
<tr>
<td>Dr. Doris Barwich</td>
<td>Fraser Health</td>
</tr>
<tr>
<td>Biz Bastien</td>
<td>Northern Health</td>
</tr>
<tr>
<td>Jacqueline Cardwell</td>
<td>Vancouver Coastal Health</td>
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<tr>
<td>Dr. Peter Edmonds</td>
<td>Vancouver Coastal Health</td>
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<tr>
<td>Dr. Gillian Fyles</td>
<td>BC Cancer Agency</td>
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<tr>
<td>Anna Gardner</td>
<td>Ministry of Health</td>
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<tr>
<td>Dr. Romayne Gallagher</td>
<td>Providence Health Care</td>
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<tr>
<td>Jill Gerke</td>
<td>Vancouver Island Health Authority</td>
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<tr>
<td>Dr. Pippa Hawley</td>
<td>PHSA/BC Cancer Agency</td>
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<tr>
<td>Dr. Marnie Jacobsen</td>
<td>Interior Health</td>
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<tr>
<td>Dr. Robin Love</td>
<td>Vancouver Island Health Authority</td>
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<tr>
<td>Dr. Douglas McGregor</td>
<td>VIHA/Victoria Hospice</td>
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<tr>
<td>Dr. Michael McKenzie</td>
<td>PHSA/BC Cancer Agency</td>
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<tr>
<td>Diane Miller</td>
<td>Impact BC</td>
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<tr>
<td>Dr. Linda Peritz</td>
<td>IHSTS</td>
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<tr>
<td>Leigh Ann Seller</td>
<td>Ministry of Health</td>
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<tr>
<td>Dr. Hal Siden</td>
<td>Canuck Place Children’s Hospice</td>
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<tr>
<td>Dr. Kelli Stajduhar</td>
<td>University of Victoria</td>
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<tr>
<td>Megan Stowe</td>
<td>PHSA/BC Cancer Agency</td>
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<tr>
<td>Dr. Simon Sutcliffe</td>
<td>IHSTS</td>
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<tr>
<td>Carolyn Taylér</td>
<td>Fraser Health</td>
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<tr>
<td>Fiona Walks</td>
<td>Provincial Health Services Authority</td>
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<td>Janet Zaharia</td>
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