

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 

Canadian Institutes of Health Research Strategy for Patient-Oriented Research: Summary of revised BC SUPPORT Unit Business Plan

24 July 2015

The revised business plan was submitted for review on July 29, 2015 to the Canadian Institutes of Health Research (CIHR) by the British Columbia SUPPORT Unit Interim Governing Council.

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* See our [Definitions, Acronyms and Abbreviations](#) PDF for explanations related to health research and health care in BC and beyond.

INTRODUCTION

The Canadian Institutes of Health Research (CIHR) [Support for People and Patient-Oriented Research and Trials \(SUPPORT\) Units](#) are intended to be locally accessible, multidisciplinary clusters of specialized research resources, policy knowledge, and patient perspective. SUPPORT Units will provide the necessary expertise to pursue patient-oriented research and help lead reforms in response to locally-driven health care needs.

The business plan for a SUPPORT Unit in British Columbia (BC) addresses the components established by CIHR as core functions of a SUPPORT Unit. The plan represents a commitment to a fundamental change in the way BC sets priorities for, conducts, and applies health research – and how, collectively, the health sector, BC citizens and the research sector will support continuous learning from these efforts.

Data platforms and services; methods support and development; health systems/knowledge translation/implementation; real world clinical trials; career development in methods and health services research; and consultation and research services have key roles in improving the capacity for patient-oriented research in BC. The BC SUPPORT Unit will harness the strength and expertise of BC's health, research and patient organizations that have *participated in its development and committed financial and moral support to its successful implementation*.

The BC SUPPORT Unit (the 'Unit') will advance BC's new health sector strategy ([Setting Priorities for the BC Health System](#)) within the context of the provincial health research strategy ([Directions for Health Research in BC](#)). The Unit builds on BC's research assets, on a well-developed regionalized health system, and on lessons learned through provincial health services research initiatives involving researchers, health authorities and the BC Ministry of Health (MoH) over the past ten years, including initiatives to build research capacity in health authorities.¹ Finally, BC's SUPPORT Unit will leverage BC's extensive provincial patient engagement platform (Patients as Partners), to ensure patients are meaningfully included in all aspects of the research process.

The model for BC's SUPPORT Unit is a distributed organization connecting patients, providers, decision makers and researchers through a provincial hub, regional centres and specialized methods clusters and supported by a provincial data platform that will leverage, augment and link core disparate data initiatives. The SUPPORT Unit's operations will work through two streams: mobilizing collective action to address select provincial patient-oriented priority research projects and serving people and teams involved in patient-oriented research to enhance its quality and application. The SUPPORT Unit will be hosted at the Provincial Health Services Authority (PHSA). Fiduciary oversight for the Unit will be provided by the PHSA Board, an agency under the *Society Act*. Strategic and operational direction for the Unit, in accordance with the CIHR-approved business plan and budget, will be provided by a multi-partite steering committee representing universities, health authorities, patients, government and the Michael Smith Foundation for Health Research (MSFHR). Over time, the Unit's governance will transition to BC's emerging Academic Health Science Network (AHSN).

¹ The Health Services and Policy Research Support Network was a \$16M grant from the BC MoH to the Michael Smith Foundation for Health Research (MSFHR) in 2003 to build research and evaluation capacity in the province. Funding was overseen by a steering committee of researchers, health authority representatives and MoH staff. The BC Nursing Research Initiative was an \$8M grant from the MoH to MSFHR in 2004 to build practice-relevant nursing research capacity.

A SPOR SUPPORT Unit for BC

The business plan for the proposed SUPPORT Unit in BC was developed through an [extensive consultation](#) facilitated by the [Michael Smith Foundation for Health Research](#) (MSFHR) with the oversight of an [Interim Governing Council](#) (IGC) chaired by the BC [MoH](#). The first iteration of the BC SUPPORT Unit business plan underwent review by an international adjudication panel, convened by CIHR, which subsequently made several recommendations to strengthen the plan.

An interim operations team, including BC SUPPORT Unit Interim Leader, Dr. Bev Holmes (seconded from her role as MSFHR VP, Research & Impact), and Interim Scientific Lead, Dr. Martin Schechter (seconded from his role as MSFHR Chief Scientific Officer), was convened to address these recommendations and to commence implementation activities under the guidance of the Unit's IGC. The current version of the BC SUPPORT Unit business plan incorporates the adjudication panel's recommendations and provides further details on several sections of the plan that have evolved since the original plan was written.

Throughout the initial development of the business plan and its revision, engagement with stakeholders – including patients – has crystallized the features of BC's proposed SUPPORT Unit and has provided the opportunity to explore more seriously the vision for a responsive, high quality research infrastructure in BC. As part of the development process, a call for [expressions of interest](#) from researchers and research teams interested in providing services through the SUPPORT Unit was launched. The material submitted by the respondents provides a strong basis for understanding the range and details of expertise and services available to achieve the SUPPORT Unit vision and identifies key health and research organizations that will formally partner with the SUPPORT Unit. The business plan draws on the strength of these respondents as well as identifies key health and research organizations that will formally partner with the SUPPORT Unit.

Among the greatest strengths of BC's proposed SUPPORT Unit will be its:

- full engagement of patients and other knowledge users in the design, conduct and translation of health research;
- strong connection to the provincial health sector strategy and alignment with BC's health research strategy;
- strategies that will determine the criteria by which the SUPPORT Unit meets its dual mandate of collective action and supporting teams;
- creation of better systems and mechanisms that make the conduct of high quality and highly relevant patient-oriented research easier;
- emphasis on expanding cultural competency in health research, and expanding inclusiveness of cultural practices of patients, including First Nations patients;
- excellent data, research and patient engagement expertise, services and structures;
- distributed decision making and action that ensure provincial priorities have regional relevance; and
- collaborative structures and mechanisms to harness the strength of BC's scientific expertise.

The SUPPORT Unit will catalyze fundamental change by engaging patients as key members of a new partnership that includes decision makers, practitioners and researchers. Guided by research priorities based on the health sector strategy, and aligned with the health research strategy, this partnership will work together to plan, design, conduct, apply and learn from research that prioritizes patients' values and preferences, and that drives innovation and improvement in BC's health system.

BC'S SUPPORT UNIT: VISION, MISSION AND GOALS

Vision:

A health system that continuously improves through high-quality, relevant, timely, and patient-oriented research.

Mission:

Close the gap between high-quality research and implementation through a new partnership engaging patients, providers, decision makers and researchers in all aspects of the research enterprise.

Goals:

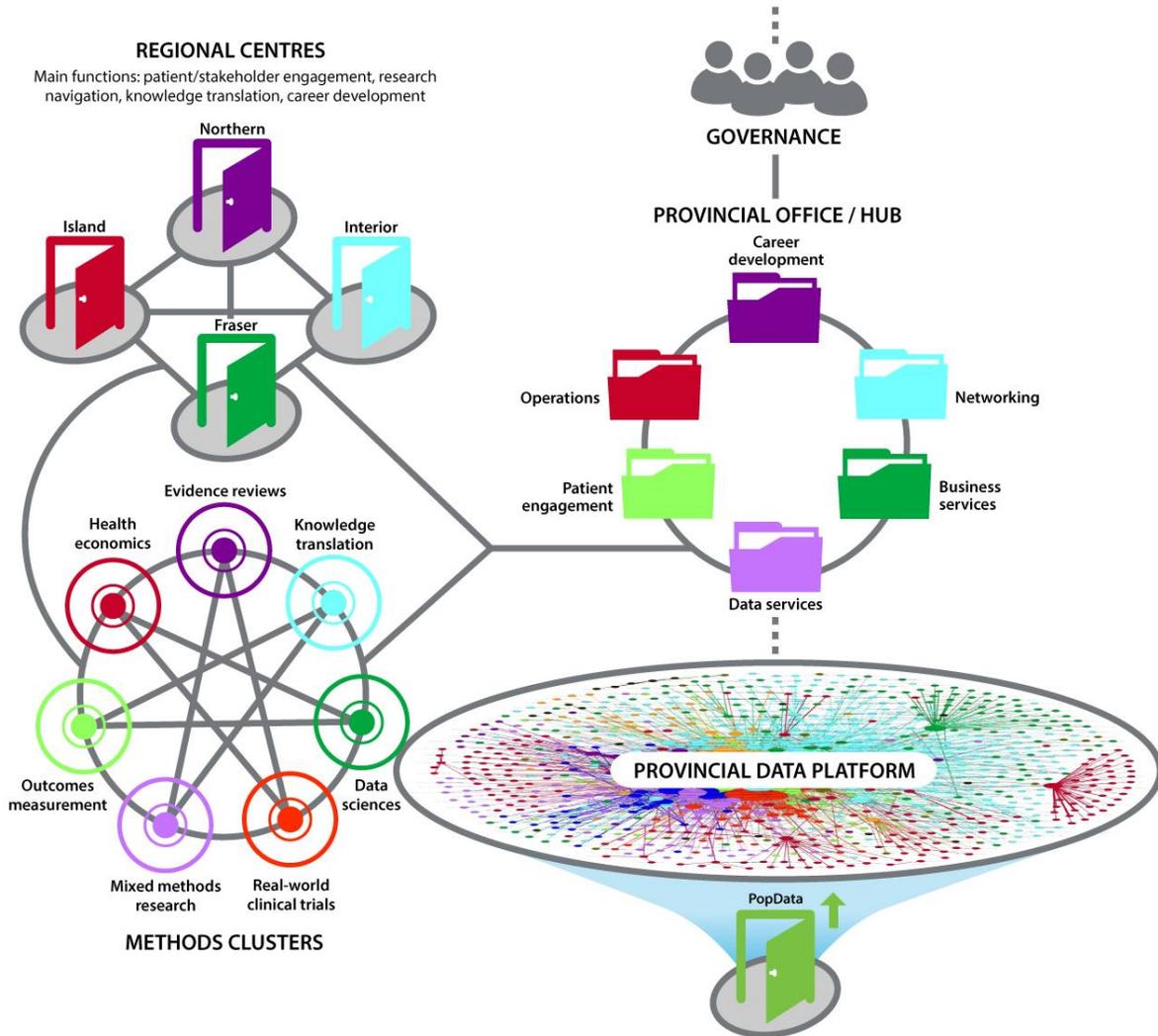
1. Create opportunities for patients from all regions of BC to engage in patient-oriented research
2. Build BC's capacity to conduct, apply and learn from patient-oriented research
3. Create opportunities for collaborative inquiry among health system decision makers, patients, providers and researchers
4. Increase the utility and availability of patient-oriented data and supports for its use
5. Demonstrate the impact of patient-oriented research on health and health care

Objectives will be set for the above goals in the first year of the Unit's operations. With approval of the business plan, an action plan drafted for years 1 to 5 of the Unit's operations will be finalized and implemented. A performance measurement and outcomes evaluation framework already developed will enable assessment of the SUPPORT Unit's impact in the near-, medium-, and long-term.

BC'S SUPPORT UNIT: MODEL AND OPERATIONS

BC SUPPORT Unit: Model*

*Some names that describe functional detail are shown in short form



Model

As noted in the Introduction, the model for BC's SUPPORT Unit is a distributed organization connecting patients, providers, decision makers and researchers through a **provincial office/hub**, **regional centres** and specialized **methods clusters**, and supported by a separate but integral provincial data platform. The [Provincial Health Services Authority](#) (PHSA) will host the SUPPORT Unit and provide administrative services and space. Fiduciary oversight for the Unit will be provided by the PHSA Board, and strategic and operational direction for the Unit will be provided by a multi-partite steering committee. Ultimately, the Unit will be governed by the emerging Academic Health Science Network (AHSN). The SUPPORT Unit will directly support enhancement of research infrastructure.

The **provincial hub** will provide a key *coordination* function. Hub resources will support services and programs offered and delivered across BC. The hub will manage service agreements with partners and memoranda of understanding (MoU) with the regional centres; facilitate provincial action; coordinate the provision of business services; facilitate networking and research team development; coordinate patient engagement and career development and training; and provide operational oversight for data services. Rather than developing services and programs from the ground up, the SUPPORT Unit will build on what exists in BC, such as the capacity building and knowledge translation programs established by MSFHR, health authorities and research institutes. An existing provincial resource is the MSFHR-funded [InspireNet](#) (Innovative health Services & Practice Informed by Research & Evaluation Network), a virtual network using Web 2.0, web conferencing and social media which will be leveraged as the provincial hub platform. Largely through this platform, the hub will coordinate SUPPORT Unit operations such as communications and evaluation; it will also coordinate demonstration projects and develop and oversee implementation of a patient engagement strategy and a career development and training strategy. The hub will also be the nexus for formal interactions with SPOR networks, other provincial SPOR SUPPORT Units and with CIHR on other SPOR initiatives.

Regional centres, corresponding with regional health authorities and their affiliated universities, will provide a key *integration* function, ensuring that patient-oriented research is conducted and research evidence is used to improve patient experience and outcomes - and that patients are engaged in these efforts. The BC SUPPORT Unit will have a regional centre in each of the four health authorities outside of the Vancouver Coastal region: [Northern](#), [Fraser](#), [Island](#) and [Interior](#). For stakeholders within the Vancouver Coastal region, the provincial hub and existing local service providers resourced by the SUPPORT Unit will provide services.

The regional centres will serve as the initial point of contact for clients of the SUPPORT Unit located outside of the Vancouver Coastal region. They will build on existing scientific capacity, expertise, infrastructure and connections among health authorities, universities and other organizations in each region.

Regional centres will have four main functions related to patient-oriented research: patient and stakeholder engagement, research navigation, knowledge translation, and capacity building through career development and training.

Methods clusters will be focused on *methodology support and development*. They will be directed by leading scientific experts who will connect people from across the province to create virtual clusters or communities of practice. Leveraging the platform developed by InspireNet, a virtual network of over 4,000 researchers, health care decision makers and students working together to improve health services in BC, seven clusters will enhance the application of specific methods in patient-oriented research by providing support and advice, fostering methodological innovation and advancement, and enabling collaboration with national and international colleagues. By adopting a virtual platform, communications across the clusters will be cost-minimal and optimally efficient with no travel time/cost incurred and asynchronous discussion enabled via online discussion forums. Day-to-day operations of the clusters will be administered centrally for the purpose of facilitating increased engagement with and between members, reduced duplication of common elements and services, increased efficiencies and economies of scale, and increased cross-cluster collaborations and communications.

These three functional areas – the provincial hub, the regional centres and the methods clusters – will harness existing resources and expertise, and will in turn access the **provincial data platform through [PopData](#)**.

The provincial data platform is a common and secure shared environment for use by researchers, the MoH and health sector partners. The platform will provide a privacy-compliant technical environment to which participating data holders/providers can connect, ensuring trusted flows and storage of sensitive information. It will enable authorized researchers access to the same data sets and products available to MoH and health authority staff, resulting in access to a broader array of data sets that are more contemporaneous in their coverage and increased ability to share and leverage work across the participating groups. The development of the provincial data platform will happen alongside significant provincial investments (outside the SUPPORT Unit) of over one billion dollars over five years to a) electronically capture clinical data in the health authorities and administrative data in the Ministry; and b) develop secondary use environments. The funding described in the business plan relates to the small proportion of costs associated with providing researchers timely and secure access to this unprecedented resource.

In parallel to these technical investments, there are processes in place aimed at addressing structural, administrative and procedural barriers to the effective and appropriate use of data. For example, end to end process reviews of both university-based researcher access and health authority based data access are underway with an eye toward improving the speed and transparency of those processes. The ultimate objective is to make the data access process for all potential users clearer, easier and faster, while maintaining the highest standards for data protection.

Operations

As noted in the Introduction, the SUPPORT Unit's operations will work through two streams: mobilizing collective action to address select provincial patient-oriented priority research projects and serving people and teams involved in patient-oriented research to enhance its quality and application.

Several provincial patient-oriented research priority projects per year will be addressed by **mobilizing collective action** on research of importance to BC, thereby contributing to the advancement of knowledge, including how best to undertake and apply patient-oriented research and measure its impact. The SUPPORT Unit Steering Committee will approve these priority projects, which need to meet criteria similar to those presented below for the SUPPORT Unit demonstration projects. Criteria include:

- potential to lead reforms in response to local needs, the provincial health sector and health research strategies;
- encompass one or more core areas, including KT/implementation science, data services, and real-world clinical trials; and
- approved or anticipated funding.

The provincial hub and regional centres **will serve people and teams**, drawing on the methods clusters for specific expertise in order to enhance the quality and application of patient-oriented research across BC. The hub and each regional centre will have common eligibility criteria for clients – individuals and teams – who wish to access services from the SUPPORT Unit. These criteria will be monitored on an ongoing basis to ensure the Unit is providing the right type of service to the right client at the right time.

As described in the sustainability plan, the BC SUPPORT Unit will provide service to clients from the public and private sectors. It is anticipated that different criteria will apply, according to the source of funding for a particular research project.

Mobilizing collective action on provincial patient-oriented research priorities

The SUPPORT Unit will be responsible for advancing new knowledge in priority areas based on the BC health sector and health research strategies described in the introduction to the business plan. The process, informed by previous health research priority setting efforts in BC, will be facilitated by the SUPPORT Unit scientific and operational leadership and will engage patients and caregivers as well as stakeholders from regional centres and methods clusters. Oversight will be provided by the SUPPORT Unit Steering Committee. As guiding principles, the priority research projects supported by the SUPPORT Unit will:

- align with priorities articulated in BC's health sector and health research strategies;
- address a problem for which BC-applicable evidence does not exist;
- be led by a team representing patients, providers, decision makers and researchers;
- employ appropriate, innovative methods for research, co-developed by researchers and those in the system tasked with implementation;
- be deployed in as many regions of the province as feasible;
- be approved by the Steering Committee in line with that committee's Terms of Reference (ToR); and
- include a dissemination strategy and, if applicable, an implementation strategy, co-designed with key stakeholders.

Serving people and teams involved in patient-oriented research

In addition to mobilizing action on provincial priorities, the SUPPORT Unit will build capacity for patient-oriented research across BC by providing programs and services to people and teams through the regional centres and coordinating hub (see infographic [BC SUPPORT Unit: Model](#)). Services will be grounded in areas of BC's strength and need and refined as the Unit is operationalized. They will begin from those identified by applicants to the fall 2013 call for expressions of interest, which confirmed BC people, teams and organizations in BC who are supporting patient-oriented research.

Data on the type of Unit client, their requests, and the responses provided will be collected and analyzed to develop a robust understanding of needs and abilities to respond so as to continually improve the suite of services offered by the SUPPORT Unit.

Many SUPPORT Unit offerings, such as tools and resources available through the hub's website, will be accessible on an open-access basis to anyone. For services that involve more intensive engagement – for example expert methodological consultation for established research teams, linking of researchers to additional partners and team members, or face-to-face career development and training opportunities – certain criteria will need to be met.

Users of SUPPORT Unit services – its clients – can be individuals or groups of patients, providers, decision makers, researchers, and members of research teams. Criteria for access to non-web-based SUPPORT Unit services will be refined as part of the Unit's start-up operations, along with confirmation

of the services themselves. Some services will be provided through regional centres; others will be provided by the coordinating hub either directly or brokered through existing organizations that have made commitments described in organizational letters of support. Services will be offered, variously, on a fully funded, cost-recovery and cost-recovery-plus basis depending on the established criteria.

Patient Engagement

- Patient engagement at BC's SUPPORT Unit, based on a patient engagement strategy, is in line with CIHR's vision where "patients are active partners in health research that will lead to improved health outcomes and an enhanced health care system" ([SPOR Patient Engagement Framework](#)).

The guiding principles are also consistent with those that were co-developed through CIHR:

- **Inclusiveness:** Patient engagement in research integrates a diversity of patient perspectives, cultures, and experiences, and research is reflective of their contribution.
- **Support:** Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement.
- **Mutual Respect:** Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.
- **Co-Build:** Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

Patient engagement is a means to actualize the goals of BC's SUPPORT Unit which speak to: creating opportunities for patients from all regions of BC to engage in patient-oriented research; building BC's capacity to conduct, apply and learn from patient-oriented research; creating opportunities for collaborative inquiry among health system decision makers, patients, providers and researchers; and demonstrating the impact of patient-oriented research on health and health care. Patients will be afforded opportunities to engage in all aspects of the research enterprise, including: governance; committee work (consultative, working, and strategic); peer review; priority-setting activities; and all stages in the conduct of research, including: design, implementation, analysis and knowledge translation.

Mechanisms are being developed to recruit, train and support patients and all other stakeholders and to bring these together in a new partnership. We will build on BC's distributed model with a hub and four regional centres, as well as strengths that are inherent in BC such as ImpactBC's [Patient Voices Network](#), existing health authority patient advisory councils, and individuals who are currently doing patient-oriented research. We will adopt and, where necessary, adapt materials that have already been developed in other jurisdictions throughout Canada and internationally such as [INVOLVE](#) in the UK and the [Patient Centered Outcomes Research Institute](#) in the US and link with CIHR's pan-Canadian patient engagement strategy. Where necessary, we will develop BC-specific materials.

GOVERNANCE

Members of the [IGC](#) established in September 2013 will preside over the SUPPORT Unit until the business plan is approved by CIHR. At that time, the permanent Steering Committee will be established and its members will be nominated by the organizations listed below. The Steering Committee will provide strategic direction, in accordance with the CIHR-approved business plan and budget, over all the core components of the SUPPORT Unit – the hub, the methods clusters, and the four regional centres – and ensure accountability for service delivery.

The SUPPORT Unit Steering Committee membership will represent:

- BC's four research-intensive universities (University of British Columbia, Simon Fraser University, University of Victoria, University of Northern British Columbia);
- BC's five regional health authorities (Vancouver Coastal Health, Fraser Health, Interior Health, Northern Health, Island Health);
- Provincial Health Services Authority;
- Providence Health Care;
- First Nations Health Authority;
- BC Ministry of Health;
- BC Ministry of Advanced Education;
- BC Ministry of Technology Innovation and Citizens' Services;
- Public and patient representatives; and
- Michael Smith Foundation for Health Research.

The BC MoH representative will chair the Steering Committee and the SUPPORT Unit Executive Director will sit on the Steering Committee on an ex officio basis.

To ensure timely decision-making, sub-committees of the Steering Committee will be formed to address subject specific topics such as the hiring process for the permanent leadership of the Unit. The Steering Committee will also, at its discretion, recommend additional partner representation on the council as deemed necessary. The intent is to embrace an integrated approach to leadership, dialogue and decision-making in which representatives of all members of the research partnership engage as equals, rather than to create discrete advisory committees for different partners or constituent groups.

As noted earlier, [Provincial Health Services Authority](#) (PHSA) will host the SUPPORT Unit and provide administrative services and space. Fiduciary accountability to the funders and ultimate governance oversight for the Unit will be provided by the PHSA Board, while the SUPPORT Unit Steering Committee will provide strategic direction on operationalization of the CIHR-approved business plan through the executive director. The SUPPORT Unit will transfer to the AHSN as soon as it has been finalized.

DEMONSTRATION PROJECTS

As soon as the Unit is established, two projects will be initiated to advance research in priority areas and to evaluate the operation of the SUPPORT Unit in the conduct and application of patient-oriented research:

Project #1: Permission to Contact

Principal Investigator: Dr. Robert McMaster, Vice-President, Research of the Vancouver Coastal Health Research Institute and Board Chair of BCCRIN

Project #2: BC Emergency Medicine Network - Research Component

Principal Investigator: Dr. Jim Christenson, Professor and Head of the Academic Department of Emergency Medicine at UBC

Descriptions of these demonstration projects were included in the revised business plan and will be posted on the BC SUPPORT Unit website when the business plan is approved. These projects were selected because they satisfy the following criteria:

- patient-oriented;
- aligned with BC's health sector and health research strategies;
- utilize functions and services from the hub, regional centres and methods clusters;
- encompass one or more of the following: KT/implementation science, data services, and real world clinical trials;
- build on existing work that will be substantively enhanced or improved as a result of the SUPPORT Unit;
- can be feasibly implemented and assessed within two years; and
- have well considered mitigation strategies to address potential risks to the projects' implementation.

SUSTAINABILITY PLAN

A challenge faced by the SUPPORT Unit will be to balance the desire for demonstrable and early impact and the need for measured, evidence-informed development and growth. Early investments will be focused on developing lasting infrastructure and resources that, with basic maintenance and updating, will continue to produce benefits and impacts over many years. Services that are not offered on an open access basis, such as consultation services and career development and training opportunities, will need to be carefully costed to ensure that they do not exceed available portfolio funding.

Costs will be assessed and charged to classes of clients (for example: full time students; researchers with government/non-governmental organization project/program funding support; researchers with funding from for-profit, private sector organizations; and clients from out of province) based on criteria to be set by the SUPPORT Unit leadership team and approved by the Steering Committee. It is anticipated that many, if not most, data and research consultation service costs will be recoverable through clients' existing or anticipated research funding bases. As previously described, the data

platforms and services are not being developed as a stand-alone data research infrastructure - they are integrated as a core element of a larger vision.

In addition to cost-recovery programs for clients who approach the SUPPORT Unit, the Unit will actively market growth opportunities to private and public partners. These partnerships, to be developed once the SUPPORT Unit is in place and over time, will need to be undertaken according to strict criteria, established and approved by the Steering Committee, to ensure that the conditions therein do not divert the SUPPORT Unit from its primary aims.

BC's SUPPORT Unit is viewed not as an independent entity but as an integrated and critical part of BC's transformation to a learning health care system. The SUPPORT Unit is closely linked to an emerging AHSN. The SUPPORT Unit is aligned with MoH health sector priorities and with the province's health research strategy. The Unit will transform the way research is undertaken in BC, bringing the patient voice into a central position in defining research priorities and undertaking research, and in closing the gap between high quality research and the delivery of health care services. The SUPPORT Unit represents a new way of doing business for the health care system in BC, and a combination of providing fee-based services and developing new funding partnerships with private and public partners will sustain the Unit over the long term.

NEXT STEPS

The revised BC SUPPORT Unit Business Plan is currently under review by a CIHR international adjudication panel. In September 2015, a BC SUPPORT Unit delegation is making a presentation about the revisions to the panel. Once the outcome of the business plan review has been determined, it will be communicated to stakeholders.

For more information, please visit the [BC SUPPORT Unit](#) website.