

**Management Action Response to the Midterm Evaluation Recommendations**

In 2013, Alberta’s plan for the Strategy for Patient-Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit (AbSPORU) was created in response to the Canadian Institutes of Health Research’s (CIHR) partnership initiative to create SUPPORT units as part of a national SPOR strategy. The intent of the initiative is to provide access to expertise and infrastructure to support patient-oriented research and help lead reforms in response to locally-driven health care needs for Alberta and the Northwest Territories.

The AbSPORU is delivered through seven platforms that provide services and support for researchers and students. The support provided is intended to ensure that research is relevant and responsive, and contributes to better decisions for improved patient outcomes and experience. Ultimately, the AbSPORU aims to contribute to the national SPOR goal of influencing a change in culture where patients, health care providers and researchers work together to achieve better outcomes and enhance healthcare systems provincially and nationally. Alberta Innovates – Health Solutions (AIHS) was the first provincial agency to create a support unit with a total award value of \$48 million over a five year period (May 1, 2013 to April 30, 2018), with a goal of sustainability.

A midterm evaluation of AbSPORU was conducted by Goss Gilroy Inc. The overall purpose of the evaluation was to identify strengths and potential areas of improvement during the early formative stage of the AbSPORU’s implementation to ensure the unit’s future success. The evaluation was initiated in November 2015 and recommendations presented in June 2016. Table A outlines the evaluation recommendations, and provides a summary of actions prepared by AbSPORU in response: note, the actions identified were informed not only by the formative evaluation results, but also information acquired through ongoing AbSPORU operations and feedback solicited from its stakeholder community.

The purpose of the Management Action Response (MAR) is to provide a method of recording the unit’s action plans in response to the evaluation recommendations. The MAR was compiled by the AbSPORU secretariat based on input from the AbSPORU steering and management committees.

**TABLE A. AbSPORU Management Action Response to the Formative Evaluation Results**

Recommendation	Response	Action Plan	Responsibility	Timeline
<b>1. AbSPORU needs to ensure that there is a monitoring system in place to monitor key performance indicators, including applications, user information, and services provided. The Portal would be a key tracking mechanism but other mechanisms could be necessary to track the informal advice provided</b>	Agree, work to address will be ongoing and iterative	<ul style="list-style-type: none"> <li>The AIHS Performance Management and Evaluation (PME) and AbSPORU secretariat IT support are working to identify information requirements and ensure these are captured within CRM and/ or other systems as required.</li> <li>PME will engage AbSPORU stakeholders</li> </ul>	AbSPORU Secretariat and Platform Associate Directors  PME & IT  PE and CD Platform Staff	Summer/ Fall 2016, ongoing as required  Other actions, ongoing as required

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<p>by the Platform leads and staff.</p>		<p>to refine the PM Strategy, which will include identification of key performance metrics (KPIs) to be built into a dashboard for ongoing monitoring and automated reporting capability</p>		
<p><b>2: There were concerns expressed about the risk of isolating PE issues to the PE platform. To mitigate this risk, it is recommended that future business plans include sections about PE and how it is addressed by the platforms.</b></p>	<ul style="list-style-type: none"> <li>Agree AbSPORU recognizes the importance of not creating a silo around patient engagement; many patient engagement activities will emerge through cross-platform efforts or activities developed by the unit.</li> </ul>	<ul style="list-style-type: none"> <li>Opportunities for cross-platform efforts will continue to be discussed at management committee meetings; (see examples of cross-platform activity in the Appendix).</li> <li>While there is a willingness to lead by example (i.e. engaging patients in governance activities), it is recognized that patient engagement should be meaningful; as such, individual platforms may have limited need for patient engagement in certain activities. Greater impact will be realized by ensuring researchers or research teams requesting AbSPORU services have adequate and appropriate patient engagement. This issue has been addressed as part of the operationalization of POR (see Recommendation 4).</li> </ul>	<p>AbSPORU Management Committee, coordination support from PE Platform and Secretariat</p>	<p>Coordination of activity ongoing as required</p>
<p><b>3: In the end of 2016, the Platforms should report on progress (including the connections between</b></p>	<p>Agree, there is a need to assess progress; review timeline to align with business</p>	<ul style="list-style-type: none"> <li>Platforms will be required to report on progress at regular intervals, and the steering committee will</li> </ul>	<p>AbSPORU Steering and Management Committees, coordination</p>	<p>Spring/ Summer 2017</p>

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<p>platforms) and review their plans. These platform 12 month progress reports will be an opportunity for the Steering Committee to re-assess the overall approach, including the platform structure. This will also be an opportunity to review their implementation strategies, especially those that experienced unexpected delays. The draft plans should be shared with the other platforms to ensure an integrated and coordinated approach.</p>	<p>needs and existing processes</p>	<p>review the platform’s proposed service approach and implementation strategy.</p> <ul style="list-style-type: none"> <li>Platform business plans will be shared and Platform leads will be encouraged to work with each other to develop and coordinate plans.</li> <li>The Management Committee recognizes that if the initiative is going to be sustained, review of the structure of the AbSPORU will help ensure that services and activities are delivered in the most efficient and effective manner.</li> <li>It is recommended that this review takes place prior to the summative evaluation.</li> </ul>	<p>through Secretariat</p>	
<p><b>4: The findings indicate that the definition and awareness of Patient Oriented Research affects various aspects of AbSPORU. It is recommended the definition be further operationalized and disseminated to ensure the AbSPORU reaches its objectives, including transformational change.</b></p>	<p>Agree</p>	<ul style="list-style-type: none"> <li>A Working Group was established to refine and operationalize the definition. Their proposal was presented to the Steering Committee in June, 2016. Further activity will depend on feedback.</li> <li>The Working Group identified a need to also define “patient” as some research that is currently being supported by AbSPORU relates to population health. Defining this term will assist in</li> </ul>	<p>POR Working Group, definition</p> <p>POR Working Group, classification</p>	<p>(definition) Summer 2016</p> <p>(classification) Spring 2017</p>

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		<p>further determining eligibility for services.</p> <ul style="list-style-type: none"> <li>The AIHS PME unit is leading a project to classify keywords associated with Patient Oriented Research in published literature in order to assess the baseline level of such research in the province. Results from this work are anticipated by spring 2017. This work may inform further development to the operationalization of the definition of Patient Oriented Research used by AbSPORU.</li> </ul>		
<p><b>5: While the Portal has been significantly improved since its inception, findings suggest that the application portal may be a source of continued frustration for applicants. This is a key success factor for AbSPORU and deserves attention. An initial step would be to create a service standard with respect to application, such as response times to applications (e.g., acknowledgement of receipt, initial assessment of eligibility and updates on status of application). Implementing a service standard will likely involve a systematic direction of all applicants through the</b></p>	<p>Agree</p>	<ul style="list-style-type: none"> <li>Portal development will be ongoing and iterative as the services offered by AbSPORU develop; needs of the research community will continue to be monitored to inform developments.</li> <li>The ABSPORU Secretariat intends to establish a service standard for the Portal once it is fully implemented, however it is important to note that the process to review and approve requests for services is still evolving; therefore, caution is advised in setting a service standard prematurely.</li> </ul>	<p>(portal development ) AbSPORU Secretariat and Platform Associate Directors</p> <p>(service standards) AbSPORU Secretariat and Platform Associate Directors</p>	<p>(portal development) Summer/ Fall 2016, ongoing as required</p> <p>(service standards) Fall 2016, revisited as required</p>

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Portal for monitoring purposes				
<p><b>6: If AbSPORU is still considering user fees, the next step would be to develop a business case. This case could consider the findings of this evaluation, as well as the experience of the Data platform and the Consultation and Research Services platform. The business case should be based on a scan to identify potential users and potential demand for specific services. The business case should also assess risks and impacts on all potential users, including those on the various categories of researchers (junior researchers, “new” POR researchers, senior researchers, private sector researchers). Financial options should be developed, including full and partial cost-recovery options based on estimates of hourly rates. These options should also include an assessment of the administrative costs of implementing these options.</b></p>	Agree	<ul style="list-style-type: none"> <li>• SPOR Sustainability Task Force to develop the business case and recommendations for consideration by the Steering and Management Committee.</li> <li>• A discussion needs to occur around gain sharing and the mechanism for managing financial transactions for AbSPORU as university based platforms have encountered challenges receiving revenues into their accounts.</li> </ul>	AbSPORU Sustainability Task Force	December 2016

**Appendix: Examples of Patient Engagement Activities by the AbSPORU other than the Patient Engagement Platform**

Platform	Activities
Career Development	<ul style="list-style-type: none"> <li>• Aim to seek input from patients/communities in developing training programs to ensure researchers and health professionals are trained in how to incorporate patients into the research process, and recognize the value of collaborating with patients.</li> <li>• Within the platform, patients will play a significant role in the development of career development and training in the following ways:               <ul style="list-style-type: none"> <li>○ Take on a membership role as a patient member on the Platform Advisory Committee</li> <li>○ Participate in curriculum planning and engaged as course material presenters</li> <li>○ Assist in the review of appropriateness of Graduate Studentship applications</li> <li>○ Engage in training opportunities, as participants and as presenters</li> </ul> </li> <li>• Infuse activities and outputs with the message that patients have the capacity to be engaged in all stages of research to help researchers and health professionals recognize the value of collaborating with them</li> <li>• Engage patients in the development, delivery and evaluation of the platform work</li> </ul>
Data	<ul style="list-style-type: none"> <li>• Part of the role of the Senior Administrator is to promote knowledge exchange and collaboration between Alberta-based investigators, policy stakeholders from AH and AHS and patients (from the PE Platform).</li> </ul>
Knowledge Translation	<ul style="list-style-type: none"> <li>• Engaged in cross-platform discussions about how to operationalize the definition of POR and how knowledge translation and patient engagement will be included in as many Alberta SPOR SUPPORT Unit projects as possible (and as appropriate)</li> </ul>
Methods Support & Development	<ul style="list-style-type: none"> <li>• Utilize the services provided by the Patient Engagement Platform to involve patients in their new methodological development to make sure that the new research methodology truly incorporates the patient.</li> <li>• Appoint Patient Partner to provide consultation, provide support with the development of the new methodology (e.g. development of patient-centred quality indicators), and providing support running focus groups</li> </ul>
Pragmatic Clinical Trials	<ul style="list-style-type: none"> <li>• Partnering and co-sponsoring with the ACRC on Permission to Contact (PTC) to increase patient engagement and enrollment in research by asking patients for their <i>permission to be contacted</i> about future research opportunities. PTC enables researchers to access and consent broader populations through the creation of a database of potential participants that can be screened for study eligibility.</li> <li>• Workshop Planning Committee, including patient, academic, AHS representatives, is developing a strategy using best practices to fully engage patients and policy makers.</li> <li>• Provide funding support to the CRU for the Trial Tracker tool to improve patient recruitment into trials for any given trial group</li> </ul>
Secretariat	<ul style="list-style-type: none"> <li>• Recruitment, ongoing support and engagement of Patient Members on AbSPORU Advisory committees, e.g., Steering Committee</li> </ul>