

Midterm Evaluation of Alberta's SPOR SUPPORT Unit

Executive Summary

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Background

In 2013, the Alberta's plan for the Strategy for Patient-Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit (AbSPORU or 'Unit' as otherwise referred) 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 and four main types of services for researchers (including 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 towards sustainability.

This report presents the key findings of a midterm (i.e. formative) evaluation of the AbSPORU.

Objectives of the Evaluation

The overall purpose of the evaluation was to identify strengths and potential areas of improvement to ensure the AbSPORU's ultimate success. In addition to providing the unit and CIHR with an assessment of the unit's progress to date in implementation, the evaluation will inform program design and enhancement decisions for course correction as required. The timeframe for the evaluation was from April 2013 to December 2015. The evaluation was overseen by an advisory committee made up of AbSPORU Leadership, secretariat and evaluation staff from AIHS, and Goss Gilroy Inc. representatives. Two documents complement the formative evaluation final results report, this executive summary and a management action response. The final results report is organized into sections that address key evaluation questions and issues around implementation (accountability), progress to date (analysis & learning) and unanticipated consequences. The final results report concludes with the evaluator's recommendations, building on the challenges and key accomplishments identified by stakeholders. These recommendations are the basis for informing the management action and decisions.

The evaluation approach was guided by the unit's performance management strategy. A mixed method approach was used for the evaluation and included: a document review, interviews with 21 key informants and stakeholders, a user survey of portal applicants and four case studies focused on platforms that had provided services at the time of the evaluation.

Key Findings

The use of expert researchers from academia as platform leads and multi-year funding agreements for the platforms were key enabling factors for the AbSPORU during the initial

implementation phase. The use of expert researchers allowed AbSPORU to leverage expertise, existing infrastructure/ resources and credibility in a short time. The use of multi-year funding agreements was advantageous as it enabled long-term planning within the platforms: it provided some security and stability (e.g., in negotiating staff contracts) and allows for flexibility in plans and allocation of funds as required in future years (pending system and/ or user needs).

While not a platform *per se*, the AbSPORU Application Portal is a key delivery mechanism to provide information and access to the unit's services. According to survey results, most initial users (n=17, 75%) were satisfied with the AbSPORU services they received; however, a key aspect to improve in the AbSPORU's service/ support delivery is the application process and support for applicants. While not considered user-friendly by some initial applicants, the Application Portal is seen as a key enabler to reach potential users.

Some constraining factors to the unit's implementation were also identified, including governance activities that reflect the complexities of dealing with multiple institutions: for example, negotiating staff contracts, the flow of funds through different financial systems and procurement of office space. Challenges associated with governance had a number of consequences, including delayed decisions and implementation of some of the platforms.

Platform implementation. The AbSPORU platforms were implemented in a phased roll-out. Unintended delays in implementation were attributed to many factors, including time to recruit platform leads and staff, to negotiate agreements between multiple institutions, and to design an innovative unit structure that adds value, instills patient-oriented research (POR) principles, and has the potential to achieve transformative change.

The Data Platform provides access to 16 datasets of varying types and had responded to over 50 requests. Work is ongoing to increase access to other datasets. The platform is responding to what it perceives as a lack of experience among some clinical research applicants and is providing consultation and advice on key steps in the research process to support them, including research question refinement. Access to the platform has reduced the wait time for data for researchers and data made available through the platform has contributed to published research.

The Methods Platform develops new methods and provides methodological advice, information and tools and had responded to more than 40 requests for support. Training sessions were also organized by the Methods Platform in collaboration with other platforms including a session on randomized control trials (RCT) and a 1-day forum on Patient-reported Outcome Measures (PROMS) and Patient-reported Experience Measures (PREMS). The platform was challenged in recruiting and retaining staff with the necessary expertise. Additionally, the platform's experience shows that it is an ongoing challenge for some stakeholders to understand patient-oriented research and find it valuable. For example, research support requests were received by the Platform that were not patient-oriented: however, when the Methods team worked with the researchers, opportunities for patient-oriented research were found.

The Career Development (CD) Platform aims to facilitate the training, growth and support of health researchers to improve the quantity and quality of research that will have a direct impact on health services and patient outcomes. This is achieved by the provision of infrastructure to support: mentoring of new and junior faculty; training/education of students and health care professionals in the health services research field; and mechanisms to translate research knowledge into applications to improve health and health system outcomes. The CD Platform

works in partnership with the University of Alberta's Faculty of Medicine & Dentistry and the University of Calgary's Faculty of Medicine programs to offer graduate student training. The CD Platform has established a graduate studentship program in patient-oriented research for master and PhD students: in 2015, 10 studentships valued at \$30,000 were offered, nine accepted.

The other platforms – Knowledge Translation (KT), Consultation and Research Services (CRS), Pragmatic Clinical Trials (PCT), and Patient Engagement (PE) – were in early and varied stages of implementation. Some of the unanticipated delays to their implementation were due to challenges with staff recruitment and the complexities of negotiations between multiple institutions. Never-the-less, all platforms were actively involved in the unit's development and contributed to its implementation with representatives participating in advisory groups and committees.

Innovative aspects of AbSPORU. The main innovative aspect of the AbSPORU is its pan-provincial structure based on a network of academic organizations. Working with recognized experts ensured relatively quick access to available high quality supports for those seeking services. Among SPOR units, Alberta's PE Platform is unique and a first in Canada although literature shows that patient (and citizen) engagement is more common in health and drug research institutions abroad (US, UK and Europe). Due to the developmental nature of patient-oriented research regionally and nationally, staffing the platform was a challenge. Additionally, other platform leads and staff are supportive of the PE Platform, but some expressed concern that the creation of a separate platform may eventually “compartmentalize” patient engagement.

Efficiency. Apart from the application process and the longer than expected implementation time frame, for those offering comment, there was agreement that the delivery of the AbSPORU services was efficient. For other evaluation participants, it was too early to tell; as such, process efficiencies would need to be monitored over time. From a governance perspective, there is an opportunity to review the platforms' activities to ensure that they are better integrated. From a user (i.e., customer service) perspective, the AbSPORU services have created efficiencies in the research process for researchers through more timely access to data and advisory services, i.e., assistance offered to enhance grant applications, ethics review submissions, etc.

The Consultation and Research Services (CRS) Platform is being implemented with a partial cost-recovery formula. This Platform's service model can inform the unit's options for sustainability beyond 2018. The evaluation assessed the potential for user fees for all platforms. Opinions were split about this opportunity. For some, it was too early to consider fees. On the plus side, fees could contribute to the long-term viability of the AbSPORU, although cost-recovery might only be feasible for some platforms (i.e., data, methods, and PCT). Concern was also expressed that user-fees may create barriers for users where the net impact of the AbSPORU support may be the greatest, that is, services for users with fewer resources.

Recommendations

Based on the results of the evaluation, the following recommendations were put forward:

1. The AbSPORU needs to ensure that the monitoring system in place to monitor key performance indicators, including applications, user information, and services provided is enhanced to address information gaps. The Portal would be a key tracking mechanism but other mechanisms could be necessary to track the informal advice provided by platform leads

and staff.

2. It is recommended that future business plans include sections about PE and how it is addressed by the platforms (e.g., coordination of activity identified/ cross-referenced in platforms' business plans, co-design and delivery of common outputs – training events, information products, etc.).
3. By the end of 2016, the platforms should report on progress (including the connections between platforms) and review their plans. These platform progress reports will be an opportunity for the Steering Committee to re-assess the overall approach for the unit, including the platform structure.
4. The findings suggest that awareness of patient-oriented research (including understanding of what its definition encompasses) affects various aspects of the AbSPORU. It is recommended the definition of patient-oriented research be further operationalized and disseminated to ensure the AbSPORU achieves its objectives, including increased stakeholder awareness and understanding of patient-oriented research, and can contribute to transformative change in the broad uptake of patient-oriented research, regionally and nationally.
5. While the Application Portal has been significantly improved since its inception, it may have been a source of frustration for initial applicants. The Portal is a critical success factor for the AbSPORU in ensuring fair and equitable (i.e., transparent) access to supports and services and deserves attention. An initial step would be to create a service standard with respect to applications, such as response times to applications (e.g., acknowledgement of receipt, initial assessment of eligibility and updates on application status). Implementing a service standard will likely involve a systematic direction of all applicants through the Portal for monitoring purposes.
6. If AbSPORU is still considering user fees as an option for the unit/platform sustainability, 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 and CRS platforms. The business case should be based on a scan to identify potential users and demand for specific services. The business case should also assess risks and impacts on all potential users, including those in the various categories of researcher (junior researchers, “new” patient-oriented researchers, senior researchers, private sector researchers, etc.). Financial options should be developed, including full and partial cost-recovery models based on estimates of hourly rates. These options should also include an assessment of the administrative costs to implement and maintain over time.

Concluding Remarks

Despite its early stage of development at the time of the evaluation, the AbSPORU is progressing towards its goals. Although it experienced initial challenges in implementation given its ambitious and novel unit structure, it had notable achievements in providing timely access to data, methods and capacity building supports in patient-oriented research. Implementation barriers and facilitators have been identified for action and learning, and results of the evaluation can be a valuable resource for other unit's nationally: to learn and build upon the insights generated as a result of the AbSPORU's early uptake of the national Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit initiative. The AbSPORU is contributing to the knowledge base of best practices on ways to support new innovative initiatives in patient-oriented research to optimize investments and returns for improved patient outcomes and health system delivery.