

Leading the way to connect Alberta's communities with health researchers

Patient engagement work often means stepping outside of university campuses and hospitals and into local libraries, schools, and coffee shops. AbSPORU's Patient Engagement (PE) Platform team members meet and connect with people within their community to create spaces where patients and health researchers can work together. Recently Robyn Laczy, Program Coordinator with the PE Platform, attended a Caregivers Alberta meeting. Founded in 2001, [Caregivers Alberta](#) is focused on the needs and supports of caregivers. Robyn has been a member of the Support Team Group within Caregivers Alberta for the last year as a liaison for the Alberta SPORSUPPORT Unit, the PE Platform, and the services it offers patients and researchers. "Being a part of this group helps me to learn about their unique perspectives as caregivers and patients", says Laczy. "It's not enough to just drop by now and again, this is about building relationships over time, understanding patient perspectives and engaging with people whose voices have been missing in past research. One of the PE Platform initiatives that engages patients in health research is the [Patient/Family Registry](#). This is an online registry tool that is patient-driven, open to all Albertans, and allows the PE Platform to manage registered patients/members of the public who are interested in engaging in health research. "To be able to be part of research confirms that the caregiver's voice has value in a setting that will go forward and carry some weight," said Debra Paches of Caregivers Alberta. "Robyn's role provides clients, patients and their caregivers a way of getting their concerns out there - where somebody is going to hear it." The PE Platform team encourages the active and meaningful inclusion of patient partners in patient-oriented research. Learn more about the [AbSPORU Patient Engagement Platform](#).



Debra Paches (left) of Caregivers Alberta with Robyn Laczy (right) of AbSPORU PE Platform

AbSPORU: Building capacity for patient-oriented research within elder care research group

One of the strengths of the Alberta SPOR SUPPORT Unit is the collaboration among our platforms in delivering services and solutions for researchers. Recently the Patient Engagement (PE) and Career Development (CD) Platforms came together to assist Andrea Gruneir, PhD, University of Alberta to build capacity for patient-oriented research within the Translating Research in Elder Care (TREC) research group which is led by Scientific Director, Dr. Carole Estabrooks. AbSPORU assisted with a Letter of Support for a \$40,000 CIHR POR Research Collaboration Grant which Gruneir's application was ranked first. The grant is helping to move their patient-engagement strategy forward. It will support a one-day workshop that will bring together over 70+ TREC investigators, decision-makers, trainees, staff, and citizens group to learn and implement best practices in patient engagement from AbSPORU PE and CD Platforms. The grant will also assist TREC with a priority setting process in directing research questions. "We hope that through this grant we'll be able to implement patient engagement and have the tools to do it" says Gruneir. "One of the benefits of connecting with AbSPORU is we knew we could access training, get it locally and the staff were responsive to our team customizing training to our group and linking us to our experts such as evaluation tools and resources that were able to help us." [Read about TREC](#) and how they are focused on developing solutions for improving the quality of care provided to nursing home residents, enriching the work life of their caregivers, and enhancing system efficiency. If you would like to access AbSPORU services, visit absporu.ca.

Consultation and Research Services Platform: making an impact

The AbSPORU Consultation and Research Services Platform helps researchers every step of the way by providing specialized high quality services in research design and methodology, data management, biostatistics and more. Over 95% of clients they served were extremely satisfied or satisfied with the services they received and 98% would recommend the platform to their colleagues. Take look their impact infographic or visit [their web page](#) to learn more.

Consultation and Research Services: Impact on Patient-Oriented Research

The infographic is divided into four main sections, each featuring a gear icon and a quote from a user:

- I Building Capacity**: A purple gear icon. Includes a list of 7 actions and a quote from Dr. Penny Deyth, Neurologist.
- II Highly Qualified Personnel**: A grey gear icon. Includes a list of 3 actions and a quote from Dr. Shwan Mohideen, Internal Medicine Resident.
- III Collaboration**: An orange gear icon. Includes a list of 5 actions and a quote from Camer Webb, Research Coordinator.
- IV Increasing quality of POR**: A green gear icon. Includes a list of 5 actions and a quote from Dr. Alessandro Merello, Infectious Disease Resident.

Goal: Increasing Quality and Quantity of Patient-Oriented Research

Building Capacity:

- a) Total of 105 ABSPORU portal applications
- b) Facilitating the conduct of POR for early career researchers and clinicians (42)
- c) Starting residents, graduate students and trainees on the right foot (14)
- d) Recommending and encouraging researchers to include POR in their projects (14)
- e) Helping researchers obtain grants (**100% Success rate!**)
- f) Reaching out to researchers in the community (e.g. PCNs, Edmonton Seniors Centre, Rocky View Hospital, etc.) (10 and 3 pre-portal consults)

"CRS has provided the support and structure to design, then carry out a clinical trial."

Dr. Penny Deyth, Neurologist

Highly Qualified Personnel:

- a) Training the new generation of researchers by involving the ABSPORU scholarship awardees in consultations. (3 out of 8 scholarship recipients have participated in at least one research consultation)
- b) Training residents, graduate students and trainees to conduct POR. (14 and 3 pre-portal consults)

"It was great working with Imran (statistician). His help was much appreciated and I owe him big time."

Dr. Shwan Mohideen, Internal Medicine Resident

Collaboration:

- a) Working with other platform(s) (50), referring applicants to other platforms (15), bringing other platform(s) to the conversation (12)
- b) Connecting applicants with patients and/or other health care professionals to create multidisciplinary teams
- c) Decision makers (16 applications from AHS or SCNs)
- d) Institutions across the province (e.g. University of Lethbridge, Covenant Health, PCNs, etc.)
- e) Researchers from a variety of health disciplines (e.g. physicians, pharmacists, nurses, etc.)

"Lily (programmer), was fantastic help when I was first learning REDCap."

Camer Webb, Research Coordinator

Increasing quality of POR:

- a) Providing high-quality POR advice and service (105)
- b) Referring ABSPORU portal applications to the Patient Engagement Platform and including them in conversations (43)
- c) Highly successful grant applications
- d) Providing a multitude of services including:
 - 62 design & methods consultations,
 - 50 database creation & data management,
 - 47 statistical analyses, 45 analytical plans,
 - 30 sample size calculations, 29 Case report forms,
 - 29 quality assurance, 19 randomization,
 - 5 clinical event adjudications & 2 qualitative services.

"Professional and prompt and very helpful collaborating to help me figure out what I needed."

Dr. Alessandro Merello, Infectious Disease Resident

Alberta SPOR SUPPORT Unit | **Consultation & Research Services Platform**