BRAIN & MENTAL HEALTH RESEARCH CLINICS

About Us

The BMRC is a collaboration between the University of Calgary, Hotchkiss Brain Institute (HBI), Departments of Clinical Neurosciences and Psychiatry, and the Clinical Research Unit (CRU). The Brain and Mental Health Research Clinics (BMRC) is a research service with the goal of implementing registries across specialty clinics and facilitating research in neuro and mental health conditions in neurosurgery, psychiatry, and physiatry. Expected benefits of the initiative include:

- Increased competitiveness for external funding/grants
- Cost savings due to centralization of services
- Optimized recruitment strategies
- Knowledge translation
- Participatory action research
- Facilitated and optimized patient care
- Online resource for trainees, researchers, health professionals, and patients (coming soon!)
- Support to increase sustainability of registries
- Increased patient engagement
- Increased patient and physician health literacy
- Increased patient participation in research
- Increased opportunities to be involved in research activities and/or training for learners and clinicians
- And many others!

The development of patient registries also presents an exciting opportunity to improve information available on neurological and psychiatric conditions and enhance community awareness of local research through a strong focus on community engagement and knowledge translation.
Demonstration Clinic Updates

The Calgary Comprehensive Epilepsy Program Registry currently has over 5000 patients enrolled, and recently conducted an analysis registry data to improve data quality and inform revisions to the case report forms and database.

The PROMPT Registry now has over 1000 patients enrolled. The registry has recently been used to recruit patients for NMRCI focus groups and identify patients that have consented to be approached for research for the Neurological Disease and Depression Study.

The Neuromuscular Program Registry has recently received ethics approval for the registry and has begun recruiting patients. The registry will collect information on the epidemiology of neuromuscular conditions as well as an expanded dataset for myasthenia gravis.

Registries in Action

A Longitudinal Cohort Study on the Impact of the Clobazam Shortage on Patients with Epilepsy

In May 2016, a shortage of the Level I critical antiepileptic drug clobazam became serious. In order to study the impact of this shortage on patients, we needed to recruit patients and collect the survey data before the shortage was over to minimize recall bias. It was also important to ensure the results could be reported in a timely manner so that the effect of this study on policy change could be maximized. By using the Calgary Epilepsy Program REDCap registry, we were able to identify patients on clobazam (who had previously agreed to be contacted for future research), recruit these patients, and collect data from these patients within a 3-month period. As a result, we were able to uncover the multifaceted ways in which patients with epilepsy were affected by the clobazam shortage and use these findings to make recommendations for how to mitigate the impact of drug shortages on patients in the future. The study is currently under review with a high impact peer review journal.

NMRCI Activity Updates
The NMRCI is conducting focus groups with patients in a variety of NMRCI clinics with the following aims to:

1. Understand, from the perspective of patients and caregivers, perceived barriers and facilitators to registry participation, and use this information to inform the development of communication and recruitment materials.
2. Explore knowledge gaps and educational needs from the perspectives of patients to inform future research projects and NMRCI website content development, and ensure that research being conducted is of relevance to patients.
3. Identify effective methods of knowledge translation and community engagement regarding awareness of diseases/conditions and local research.

To date, our team has conducted two focus groups with patients in the Cognitive Clinic to discuss barriers and facilitators to registry participation. The results will be used to inform future focus groups and ensure registry development in other clinics meet patient needs.

**Neuro and Mental Health Hub**

The NMRCI is working to develop a comprehensive online knowledge hub that aims to increase knowledge of research in neurological and psychiatric conditions and facilitate engagement of the local community. The website will contain information and resources targeted at patients, researchers, health care providers, and learners.

A Website Working Group has been created to ensure the online hub contains the input from various stakeholders. The Working Group has representation from DCNS Communications, HBI, the Department of Psychiatry, and the Divisions of Neurology, Neurosurgery, and Physiatry. Progress includes identification of the target audiences and overall vision of the website. Currently, the Epilepsy Program page is being populated with content as a template for other clinics.

Additionally, two resources for patients are being developed for inclusion on the Hub: an iSupport Tool that contains a collection of modules for caregivers of persons with dementia, and an online resource to address the unique needs of patients with epilepsy and depression.

As work on the online hub progresses, our team hopes to begin the development of content for each of the specialty clinics working with the initiative.

If you have resources, events, or information you would like to include for your clinic, please contact the NMRCI Program Manager!
Publications & Grants

Recent Publications from the Demonstration Clinics


Successful Grants

2017-2018 ($32,000) - University of Calgary Cumming School of Medicine (Calgary Center for Clinical Research) - A longitudinal study of determinants of severity and burden of disease in persons with migraine.
Pl: T. Sajobi, F. Amoozegar
Co-I: N. Jetté, S.B. Patten

2016-2018 ($248,250) - University of Calgary Brain and Mental Health Strategic Research Fund Team Grant Competition - Creating a new and world-leading center for epilepsy focused on the postictal period.
Pl: N. Jetté
Co-Pl: C. Teskey
Co-I: Dr. Samuel Wiebe; Dr. Colin Josephson; Jeff Dunn, PhD; Ismael Gaxiola Valdez; Dr. Walter Hader; Grant Gordon, PhD; Colin Dalton; Dr. Morris Scantlebury; Matthew Hill, PhD; Roger Thompson, PhD

Executive Committee Members

Dr. Eric Smith (Lead)
Do you have an idea for an upcoming newsletter? Please contact us!

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