Positive Brain Health Now

Five investigative sites have confirmed their participation in the Brain Health Now Project

Upcoming Events

June The Brain Health Now research project has been reviewed and approved by McGill's Ethics Review Board

July The Chronic Viral Illness Clinic at the Montreal Chest Institute, McGill University Health Centre will start enrollment of research participants

Sept The rest of Investigative sites participating in the study will start enrollment of research participants

Our Brain Health Now website will go live. http://www.brainhealthnow.mcgill.ca

The HIV Brain Health monthly videoconferences will resume.

Five Investigative sites will be participating

Clinique Médicale L'Actuel in Montréal, AIDS Research Program (at St Paul's Hospital), Southern Alberta HIV Clinic (University of Calgary), Special Immunology Services Clinic in Hamilton (McMaster University Medical Centre) and the Chronic Viral Illness Service at the Montreal Chest Institute, McGill University Health Centre, will be the investigative sites participating in the Brain Health Now Research Project. These sites, collectively manage over 5000 patients, with diverse demographic and HIV risk profiles, most of whom are routinely followed at three-month intervals. At least 3000 are expected to be eligible for the Positive Brain Health Now project: A total of 900 participants (between 150 and 300 per clinic) will be comprehensively assessed and followed longitudinal at 9 month intervals over a 3 year period (4 assessments), providing insights into the natural history of cognitive symptoms and deficits, allowing us to define the heterogeneity underlying poor brain health, and for those who report good brain health at baseline, shedding light on the incidence of cognitive deficits in this aging population.

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Clinique Médicale l'Actuel

Founded in 1984, L'Actuel Medical Clinic pioneered development in matters of detection and treatment of sexually transmitted infections (STIs) as well as patient management services for individuals living with HIV and AIDS.

L'Actuel today comprises specialized clinics, laboratory and pharmacy services, and a clinical research centre. The team of twenty physicians conducts more than 30 000 medical consultations a year. This clinic has the largest population of French-speaking HIV-positive men and women in North America. The Clinic recently opened a free, drop-in screening clinic in Montreal called L'Actuel sur rue, the first of its kind in Canada where people can come for free screening tests for HIV, hepatitis C and syphilis, and they will have their results within 10 minutes. The clinic's priority clientele is groups at risk such as addicts and women and men in the sex industry.

For more information: www.cliniquelactuel.com

Southern Alberta HIV Clinic

This clinic opened in 1989 and provides medical care to all HIV-positive patients in southern Alberta. The multidisciplinary team includes physicians, nurses, social workers, pharmacists, a dietitian, clerical staff and researchers. In 2011, the total number of registered patients was 1,376, of whom 82% were men and 18% women. Their average age was 47 years old.

For more information: www.albertahealthservices.ca

Special Immunology Services Clinic

This clinic located at McMaster University Medical Centre in Hamilton, serves HIV-positive clients, both pediatric and adult, and clients co-infected with HIV and Hepatitis C. Its clientele comes from the Local Health Integration Network (LHIN) catchment area: Hamilton, Niagara, Brant, Haldimand, and Norfolk, which accounts for the vast majority of the clients. This clinic also provides care for clients from other LHIN's throughout Ontario e.g. Halton, Waterloo/Wellington, South West.

The SIS team is made up of a clinical leader, registered practical nurses (RPN), social workers, dietician, pharmacist, a research team, business clerk and transcriptionist. In 2010 - 2011, the total number of registered clients was 656 (94.5% adult and 5.8 % pediatric). Within the adult population, 70.2% (435) were male and 29.8% (185) were female.

For more information: www.hhsc.ca

Montreal Chest Institute Immunodeficiency

The immunodeficiency service of the Montréal Chest Institute is amongst one of the largest HIV ambulatory care clinics in the province of Québec. An interdisciplinary team approach is provided to patients. The medical staff includes infectious disease specialists, immunologists, and general practitioners with an interest for HIV patient care. The team also includes 4 pharmacists, clinical and research nurses, a dietitian, a social worker, a psychiatrist, a psychologist and a TB expert. There are 1306 patients age > 35 years old in regular follow-up, of whom 167 are over 60 years old. The male to female ratio is 2 :1 across all age strata.

For more information: www.muhc.ca/pfv/mci

AIDS Research Program (St-Paul's Hospital)

The John Ruedy Immunodeficiency Clinic (IDC) at St. Paul's Hospital is a collaboration between the BC-CfE and Providence Health Care (PHC). The IDC brings together an interdisciplinary team of family doctors, specialists, nurses, pharmacists, counsellors, social workers, and nutritionists to provide a broad range of primary care and support services for HIV-positive patients. In 2009, the IDC received the Excellence in Quality and Patient Safety Award from the BC Patient and Safety Quality Council in recognition of its innovative model of care and outstanding contributions to improving the health of HIV-positive individuals. There are 1122 patients in regular follow-up, of whom 89% are male. 926 of these patients are over 35 years old and 116 are over 60 years old.

For more information: www.cfenet.ubc.ca/our-work/programs/john-ruedy-immunodeficiency-clinic-idc

The Brain Health Research Project Platform

The core of the Brain Health Now research program is the development and follow-up of a comprehensively characterized cohort of persons with HIV that will provide insights into the natural history of cognitive symptoms and deficits, allowing us to define the heterogeneity underlying poor brain health, and for those who report good brain health at baseline, shedding light on the incidence of cognitive deficits in this aging population.

The platform will also provide a basis for gathering sample-wide data on self-management priorities, acceptability and accessibility of computer-based cognitive training, and on behavioural factors that are the target of interventions: physical activity, exercise barriers and preferences, smoking, drug use, and healthy eating behaviours. This information, along with data collected in tandem from the broader HIV community in Quebec and British Columbia through Internet surveys and focus groups facilitated in tandem with our team's knowledge user members, will be used to define more intensive, targeted interventions to improve cognitive ability beyond what can be accomplished with basic information alone. Intensive self-management, exercise, and cognitive training, optimized for this population and the Canadian context, will be developed and tested.

Data collection

Data collection will be carried out using a common, secure, web-based data capture system. Participants will be given several options to complete questionnaire measures. These include: completing them on paper or directly on a clinic-based computer, guided and overseen by the study research assistant as needed; on a computer (on a secure server), at another location of their choice (such as home); or over the phone with the research assistant. Most of the objective measures will also be administered in this format, implemented in Inquisit web-based stimulus presentation program (www.millisecond.com).

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Nancy Mayo, PhD

Dr. Nancy Mayo is a James McGill Professor in the Department of Medicine and the School of Physical and Occupational Therapy, McGill University (Division of Geriatrics and Division of Clinical Epidemiology). She is also a research scientist at the McGill University Health Centre Research Institute, where she is the head of the Health Outcomes Axis. Within the Division of Clinical Epidemiology, Dr. Mayo leads the Health Outcomes Research Unit and conducts research in geriatrics, neurology, musculoskeletal disorders, oncology, rehabilitation, health informatics, and psychology; her team includes doctoral-trained research associates, research assistants and multiple graduate students.

Trained originally as a physical therapist, Dr. Mayo holds a Ph.D. in Epidemiology and Biostatistics. She has more than 160 publications to her name and has given more than 500 scientific presentations in Canada, North America and Europe.

Dr. Mayo has been in charge of the study design, selection and development of the study questionnaires. She will be the head of the study data management committee which includes the management of the computerized study database .

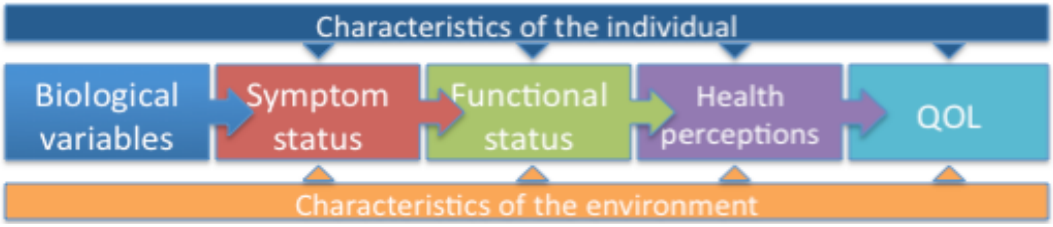
Measurement Framework and Instruments

We will apply a theory-based measurement framework, permitting a comprehensive approach to understanding brain health in HIV. The Wilson-Cleary (WC) outcome model will be used to structure this portion of the study (see figure below). This model is widely used to assess the life impact of medical conditions. It comprehensively considers the relationship between characteristics of the individual, and of their environment, as they relate to a continuum from biological variables, to symptoms, to functional status and quality of life. While the proposed work has a strong a priori focus on brain health, the use of a theoretical model for the measurement framework ensures that important components of the health impact of HIV will be captured: this will also allow an understanding of the relative importance of brain health issues within the whole spectrum of HIV-associated health impact.

The questionnaires we have chosen are all brief, well known in the health literature, and widely tested in various populations, permitting comparisons across health conditions. To assure wide application to the broader clinical context, we selected measures that are in the public domain and available in English and French.

Wilson-Cleary outcome model.

Characteristics of the individual include motivation; characteristics of the environment include psychological and social supports.



Platform cognitive measures

Measurement of cognitive ability is central in this project. This poses a problem that echoes the problems HIV clinicians are facing every day with their patients: How to measure cognitive ability with sufficient accuracy for research (or clinical) purposes, while minimizing the time burden to participants and the cost to research funders and the health care system? The ideal would not rely solely on patient report or on lengthy neuropsychological testing, and would provide information that can be used to accurately monitor change over time. In our opinion, no definitive solution to this problem exists. The core platform and intervention studies will rely on the brief cognitive ability measure (B-CAM), developed and validated by our team over the past three years, which combines self-report and objective items within a single, ruler-like measure of cognitive ability. It will yield a research quality measure of cognition that can be readily applied in the clinic, a tool we believe is absolutely vital to the evidence-based management of cognitive issues in HIV. Finally, B-CAM does not allow the diagnosis of HAND (learning, memory, processing speed, and working memory), which could limit how the knowledge gained through the proposed work can be related to the existing literature. We will therefore administer neuropsychological testing to a validation subset of 260 individuals (Vancouver and Montréal sites only) of the full cohort, allowing the diagnostic sensitivity and specificity of B-CAM to be estimated against the reference standard.

Community Partners

Marc Leclerc
Bénévole, Portail VIH/sida
www.pvsq.org

Marc Leclerc is a volunteer at the Québec HIV / AIDS Portal. Since its foundation in 2008, this province community organization, has established different information services on HIV / AIDS and STBBI (sexually transmissible and blood-borne infections), including community partnernships with research projects related to HIV / AIDS and updating information about this condition on a daily basis on its website.

During the last years, Marc Leclerc has been involved with community volunteer organizations in the fight against AIDS such as: Maison Plein Coeur, CCS-Camp Positive, CPAVIH, the Canadian AIDS Society, COCQ-AIDS. As a person living with HIV / AIDS, he is committed to the psycho-social and legal aspects of HIV and some topical issues like aging and HIV and STBBI prevention.

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Diana Salazar MSc, MBA

Diana Salazar is the study coordinator of the Positive Brain Health Now research project. She is in charge of coordinating/managing all the study operations at all participating sites in Canada. Diana completed a Bachelor's degree in Biology (Genetics) at the University of Antioquia (Medellin, Colombia), a Master of Science (Molecular Biology) at the University of Québec in Montréal and an MBA from Laval University. She has previously worked as a Research Officer at the Institute for Research in Immunology and Cancer (IRIC) and before joining the project; she was Associate in Ethics and Regulatory Affairs at the Independent Ethics Review Board, Veritas IRB.