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BrainBuzz

camh

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In this month's *BrainBuzz*, we share an in-depth look into the development of CAMH's BrainHealth Databank, an initiative that stems from the research institute's strategic goal of 'open science'. Also included is survey data on the health and substance use patterns of Canadians during the pandemic, as well as exciting news on the establishment of CAMH's Centre for Youth Bipolar Disorder (CYBD). Feel free to reach out to me if you have any questions or feedback.

Aristotle Voineskos
VP Research, CAMH

The CAMH BrainHealth Databank

From the moment Dr. Sean Hill entered discussions with CAMH that would ultimately lead to him being appointed the inaugural director of the Krembil Centre for Neuroinformatics, he had a clear vision for how he wanted to improve the lives of patients and foster research innovation.

Three years later, that vision is being brought to the real-world of patient care at CAMH in the form of the BrainHealth Databank.

“I knew it would be essential from the very first interviews,” says Dr. Hill. “CAMH was already a leader in adopting electronic health records, which was an important prerequisite, but that was not enough. We needed a system in place where clinicians, researchers, patients and families are all engaged in helping us get high-quality data that can improve care.”

The core goal of the BrainHealth Databank team, led by Senior Portfolio Manager Dr. Joanna Yu, is to re-engineer how CAMH collects and uses patient data to deliver improved, personalized mental health care,

while accelerating clinical research, discovery and innovation at CAMH and ultimately around the world.

It is also at the heart of a culture shift embodied in the CAMH's strategic plan, one where all stakeholders—from clinicians to researchers to patients and families—are part of a hospital-wide collaborative effort to enhance patient-centred, measurement-based care.

"What we are hoping to achieve is the building up of a learning-based health system where clinical and research are integrated such that care and research findings are translated back into clinical practice," says Dr. Yu. "For example, later this year, we will be launching a depression biomarker study in which the collection of additional personalized measures are embedded within the Major Depressive Disorder-Integrated Care Pathway (MDD-ICP). In this study, a saliva sample is collected for genetics analysis and a wrist wearable monitoring device passively collects daily activity and sleep data. Our hope is that we will be able to evolve the current version of the MDD-ICP clinical decision support dashboard by returning genetic test results and visually descriptive information about a patient's sleep patterns which can then be used to inform treatment decisions."

Krembil Centre Operations Director David Rotenberg says that CAMH's dual role as a hospital and an academic research centre makes it the ideal setting to apply the principles of big data and machine learning to provide more individualized mental health care.

"What we are trying to do is build a scaffold that allows us to store and manage different kinds of data and link them together in a way that's intuitive and accessible," says Rotenberg. "The core is the care plan each patient has at CAMH using standard measures. With the BrainHealth Databank, we can now layer new things on it like genetic testing and wearables that can measure sleep and waking activity. Our ultimate goal is that all the patient data and research projects will allow it to continue to grow and become richer over time in a way that will enhance research and improve care now and in the future."

Building a scaffold

The long-term goal will be to enter all CAMH patient and research participant into the Databank. The first step, however, was working with clinicians and patients

from the MDD-ICP using an electronic patient health questionnaire designed in consultation with patient and family stakeholders. As part of the transition to more virtual care visits because of COVID-19, patients are emailed the questionnaire via a secure link to complete before their appointments. Assessment scores are then automatically calculated and a summary report is sent to the health care provider. An immediate benefit is that it has substantially increased capacity at the MDD-ICP clinic, allowing the clinic to see four times as many patients as they were before this new system of digital data collection.

Data collected from more than 1,000 patients so far is being used to analyze the overall effectiveness of current treatment in the MDD-ICP pathway. How unwell are patients when they arrive? How many patients are benefitting from treatment and how quickly? Are there any common characteristics that would help inform clinicians why some patients respond better to treatment than others? Remote digital data collection for measurement-based care has since expanded to 15 different care pathways at seven CAMH clinics.

But more efficient patient data collection is just the beginning. In partnership with MDD-ICP psychiatrists, the BrainHealth Databank co-developed a patient-level clinical decision support dashboard targeted to launch this summer. In parallel, the BrainHealth Databank has co-designed a patient-facing version of this—called a clinical journey dashboard—with the CAMH Patient Advisory Committee. These interactive data visualization dashboards will enable clinicians and patients to monitor at-a-glance how each individual patient's mental health is changing over the course of their treatment.

Finally, there is the intersection of care and research at the heart of the BrainHealth Databank's mission. With an IT infrastructure now in place to allow CAMH to collect, store and analyze unprecedented amounts of electronic health information, another next step with patients who consent is to layer that with a variety of other biomarker data, including DNA and physiological data like daily activity and sleep patterns gathered through wearable devices. Later this year, MDD-ICP patients interested in donating DNA to the Databank could provide electronic consent remotely and have a saliva swab kit and a wearable device mailed to them.

Over time, the hope is that the collection of millions of data points from thousands of patients will allow CAMH researchers to make data-driven discoveries and innovations that until now have been hampered by the lack of biomarkers needed to provide evidence-based care along the lines of what currently exists for cancer and other illnesses.

Privacy

The privacy of patient personal health information is a priority for the BrainHealth Databank team. It is the job of David Rotenberg to ensure that, from an IT perspective, the confidentiality of each patient's health information is strictly protected. This is managed via an elaborate series of firewalls that ensure that all patient data is 'de-identified' and that CAMH researchers or anyone else outside the clinical care team are not able to access identifiable individual patient records.

"We talk privacy every day," says Rotenberg. "Everything we have built is secure behind CAMH firewalls. Everything is encrypted and gated. Every request for data must be formalized in writing for approval and the status of all data requests are catalogued and tracked. We are fully compliant with all privacy legislation."

While still prioritizing privacy, the BrainHealth Databank is meant to be an open science initiative, accessible to as many researchers as possible inside and outside CAMH, in pursuit of mental health discoveries. The technical term for that according to Dr. Hill is creating "interoperable health records." In lay terms, it's the ability for scientists to compare apples to apples when it comes to health research data from sources outside their own hospitals and research centres.

All of this fits under Rotenberg's guiding principle in regards to data, which applies to all aspects of information technology, not just health records.

"In the industry it's known as FAIR: findable, accessible, interoperable and reusable. It means it's really intuitive to search for what's important to you and you can find what you need. It's accessible to the right people at the right time. Interoperable is really the key to this entire strategy because open science is our ultimate goal. Reusable means the data being entered into the bank is not just for one-time use. These donations, so to speak, continue to grow over time."

The heterogeneity problem

Two core features of mental illnesses that have hampered the search for better treatments for decades are their heterogeneity combined with a frustrating lack of biomarker evidence for those illnesses.

The BrainHealth Databank was designed to address both of those challenges.

"We desperately need this kind of grounding," says Dr. Hill. "Look at a radiology scan and you can see a

tumour. Do an EEG and you can see a seizure. That is different than trying to precisely diagnose a mental health disorder. Every single patient that comes into CAMH has their own individual background and their own journey through care. By collecting all this data, we can analyze across patients and look for similarities. So we can say if this treatment works for a patient with this particular background and with this response to a particular medication, we can better personalize the treatment for each individual."

Dr. Hill says that an indicator as seemingly straightforward as patient self-reports of sleep quality can be highly inaccurate. A patient might say they slept poorly when in fact they slept all night. Conversely, a patient may report having slept well when it was actually disrupted all night long.

That is just one of the gaps he is hoping the BrainHealth Databank can fill by having consenting patients use wearable watches to track their sleep and other biological measures for up to 28 days at a time, 24-hours a day.

"We can track patients over time on multiple dimensions," says Dr. Hill. "We can look at their depression severity and their anxiety, as well as their sleep, their medication, their weight, and use that data over thousands of patients to provide much deeper insight into how to help diagnose and treat each individual."

Researchers and clinicians working as one

Like every other hospital in Canada, CAMH had to rapidly implement system-wide changes at the onset of COVID-19. For Krembil Centre for Neuroinformatics scientist and BrainHealth Databank partner Dr. Shreejoy Tripathy, it led to an epiphany.

"In the early days of the pandemic, I really wanted to ensure I remained a part of the care process. For me with this project now, when I'm asked what I do at CAMH, I say I help figure out how to make the care of CAMH patients better. I feel more comfortable saying that in a direct way now."

In alignment with CAMH's strategic plan, a key plank in the BrainHealth Databank scaffolding is the necessity of close working relationships between all the neuroinformatics researchers and the frontline clinicians from whom they are gathering patient data. The better understanding they have of how mental health care is delivered at CAMH and what the patient experience is, the better they will be able to know what kind of data points to pursue and the best ways to obtain them.

"The main advantage for me in being given the opportunity to work on this is to get a really close-up view of the state of care in psychiatry," says Dr. Tripathy, who specializes in a field called Computational Genomics. "As a researcher, it is so important to know what's there clinically in my own backyard at CAMH."

Whole Person Modelling

To explain whole person modelling at its most simplistic level, consider what is displayed on the home office walls of Dr. Daniel Felsky, Head of Whole Person Modelling at the Krembil Centre and partner of the BrainHealth Databank team. On one wall hangs a guitar. On the other, a Lego model race car. If you want to understand what makes Dr. Felsky tick, you have to ask him about *both*.

That's the basic idea behind whole person modelling being applied at the BrainHealth Databank.

"What happens if we look not just at the physiology of the brain, and not just at the genetics of an individual, but we also take into account the holistic aspects of what makes a person who they are?" says Dr. Felsky. "Their social interactions, their home and work environment, their life history. Other aspects of physical health like vascular health, gut health, the immune system. There is also sleep, diet and activity to consider. All of these are factors that do affect our mental health but are not often accounted for in neuroinformatics research. They are all so important when you are meeting an individual seeking care. Everyone is so different. No two patients, even with the same diagnosis, are alike."

As for the guitar, turns out Dr. Felsky is an amateur musician who gets nostalgic reminiscing about a pre-COVID performance he had with his former PhD supervisor, CAMH Pharmacogeneticist Dr. James Kennedy, at the old Hard Rock Café in downtown Toronto.

"He plays guitar and sings, and more than once we performed as supervisor and student playing mental health-themed events. He felt that musical people, and their musical brains, make for great scientists. Guitars, race cars, science, it's all led to the same path."

The patient voice

In the end of course, it all comes down to the patient, and the BrainHealth Databank has put patient-centred care at the heart of everything. Patient and family perspectives have been actively sought not just for feedback on what has been designed, but at all stages of planning and development.

For Manager of Patient and Family Experience Miriam McCann, the watershed moment in CAMH's shift to a truly patient-centred hospital came with the patient and family engagement roadmap implemented in 2018.

"That really gave us a guiding document to ensure that patient and family engagement is a cornerstone of all the work we do," says McCann, citing Physician-in-Chief Dr. Vicky Stergiopoulos as a guiding force at the senior executive level. "There is an expectation from the bottom up to the top down that this is the right way to do things. There is definitely a hospital-wide commitment and a shared sense of ownership for the work being done."

That is evident in design of the patient-facing dashboard currently in development for patients in the MDD-ICP. The project is being co-led by CAMH's Patient Advisory Committee co-chair Rohan Mehta, who jointly designed patient questionnaires and conducted a series of interviews with individuals with lived experience, family members and health care providers to inform the dashboard design.

Diagnosed with major depressive disorder and anxiety, Mehta, who has been an outpatient at CAMH for about three and a half years now, has already been actively involved as a patient consultant on several CAMH research studies.

He says his involvement in the BrainHealth Databank has been a win-win.

"I always wanted to be in this space where my lived experience, passion and background can be leveraged meaningfully for better treatment outcomes. I can see the impact that we can together make and am definitely grateful for being able to partner in this vital project as the experience has been benefitting my own ongoing recovery journey as well. During the interviews with other patients in this project, I could relate to so many aspects of what I have been through. I firmly believe my perspectives and expertise can really help in achieving the patient dashboard objectives."

For Susan Conway, co-chair of the Family Advisory Committee at CAMH, her commitment to the Databank is intensely personal. She believes her mother had undiagnosed mental illness, and one of her brothers had severe mental illness, and faced homelessness and incarceration. He recently died of a suspected Fentanyl overdose.

When her son was admitted to the Slaight Family Centre for Youth in Transition four and a half years ago and diagnosed with schizoaffective disorder, she

decided to play an active role in mental health advocacy at CAMH.

"Growing up, like many families at that time, we were always taught 'never talk about any of this. Don't tell anybody any of this. It's something to be ashamed of'," says Conway. "The only thing I'm ashamed of is that it took me this long. Even though I am a nurse, I had never really taken the time to understand mental illness. And then my son got sick and honestly, the mama bear came out in me and I was like 'I'll be damned if I will be ashamed of my son!' I saw what a difference it made for him to have family that took the time to educate themselves and understand what he was going through."

Working with Mehta and other patient advocates, Conway says she is convinced that voices like theirs are truly integral parts of the BrainHealth Databank.

"I'll be honest, I was cynical," says Conway about how she felt when first approached to play a formal role in patient and family advocacy at CAMH. "I thought if this is tokenism I'm not sticking around. Four years later I'm still here and I am convinced there is a great deal of sincerity about this at CAMH and a willingness to learn how to do this better. I feel very valued."

Learn more about the BrainHealth Databank here. The BrainHealth Databank is supported by the CAMH Discovery Fund.

BrainHealth Databank by the numbers:

- Number of participating CAMH clinics: 7
- Number of participating pathways: 15
- Number of patient records: 7,500 +
- Number of patient visits: 49,000 +
- Number of data points: 3,764,000 +

One year into Pandemic, about one in five Canadians reporting high levels of mental distress

As the COVID-19 pandemic enters its second year, the ongoing survey of Canadians' health and substance use in collaboration with research technology and

consumer data collection company Delvinia, indicates that levels of anxiety, depressive symptoms, loneliness and binge drinking remain nearly as high as they were in late May 2020.

The seventh in the series of surveys was conducted with 1,000 adults between March 19 and 23, 2021. Overall, 20.9 per cent of respondents indicated moderate to severe anxiety levels, 20.1 per cent reported feeling depressed, and 21.3 percent reported feelings of loneliness.

"The mental health system in Canada was already under extreme duress before the pandemic began," said CAMH Psychiatrist Dr. David Gratzer, adding that visits to the CAMH Emergency Department had doubled in just the past seven years before the pandemic began. "If this is the new normal in terms of the mental health of Canadians, providing adequate support is unsustainable without a significant increase in resources."

An area that showed a decrease was in regard to worry about getting COVID-19, which went from 29 per cent to 24.6 per cent since the last survey in late November 2020.

"It is possible that the beginning of the vaccines' rollout combined with feelings of 'COVID fatigue' may have led some Canadians to let their guard down a bit about the perceived risk of contracting COVID-19," said Dr. Tara Elton-Marshall, Independent Scientist at the Institute for Mental Health Research at CAMH. "But with cases and hospitalizations on the rise and several provinces implementing more lockdown restrictions again, these data indicate the need for continued public policy messaging about maintaining vigilance and adhering to safety precautions like hand-washing, mask-wearing and social distancing to reduce the spread of the disease."

Key Survey Findings

- Overall, 20.9 per cent of survey respondents indicated moderate to severe anxiety levels in the past week. There was a significant gender gap, with 24.4 per cent of women versus 17.3 per cent of men reporting anxiety.
- 21.3 per cent of respondents reported that they felt lonely occasionally or most of the time in the past week. Again there was a significant gender gap, with 24.2 per cent of women feeling lonely compared to 18.3 per cent of men.
- 20.1 per cent of participants reported feeling depressed occasionally or most of the time in the past weak. Those with children under 18 were significantly more likely to report feeling depressed (25.6 per cent), compared to those without children

(18.3 per cent). Consistent with previous surveys during the COVID-19 pandemic, participants aged 60 and over were significantly less likely to report feeling depressed than the general population.
- 25.7 per cent of participants reported binge drinking in the previous week, a number that has remained relatively consistent throughout the pandemic. Men were significantly more likely to report binge drinking (31.3 per cent) compared to women (19.6 per cent).
- The most common coping strategies used by Canadians during the pandemic remain: following a routine, connecting socially with family or friends online or over the phone, and dedicating time to themselves. Just under one in five Canadians (19.5 per cent) sought help for mental health concerns from a counsellor or health care provider online or in person.

As part of this survey, Canadians were asked for the first time about their intentions with regards to getting a COVID-19 vaccine. Of those who had not been vaccinated, 66.4 per cent indicated they definitely planned to get a vaccine and another 21.8 per cent said they probably would. Just over one in ten, (11.8 per cent) indicated they definitely or probably would not get a vaccine.

"While these numbers are encouraging, vaccine hesitancy remains a concern and robust public policy efforts to encourage Canadians to get the vaccine should be a priority," said Dr. Hayley Hamilton, Senior Scientist at the Institute for Mental Health Policy Research at CAMH.

Survey Methodology

The series is made possible by a collaboration with Methodify by Delvinia, an automated research platform that connects organizations to real people to gain actionable data and insights. Results are based on responses from 1,000 English-speaking Canadians ages 18 and older via an online survey of the Asking Canadians web panel, reflecting a distribution of age, gender, and region. Data was collected between March 19 to 23, 2021.

An interactive dashboard highlighting findings from each of the seven ongoing surveys can be viewed on CAMH's website at camh.ca/covid19dashboard. That page also provides a link to access and download for free the full survey data courtesy of the Methodify by Delvinia platform. Visit camh.ca/covid19 for a variety of other resources, including tips, coping strategies and resources regarding mental health and substance use during the pandemic.

Introducing the CAMH Centre for Youth Bipolar Disorder

CAMH is pleased to introduce the **Centre for Youth Bipolar Disorder (CYBD)** at CAMH. Previously located at Sunnybrook Health Sciences Centre, CYBD is Canada's leading clinical and research team in youth bipolar disorder, and a world leader in the field. The Centre provides clinical services and research make and care. Its goal: to improve outcomes for teenagers with bipolar disorder through cutting-edge treatment, research, education, and advocacy.

Bipolar disorder is a recurrent and severe mood disorder in which individuals experience shifts in "high" moods, also known as manic or hypomanic episodes, and "low" moods, also known as depressive episodes. It affects between 2-5 per cent of adolescents, with the average onset happening between 18-24 years of age. People who live with bipolar disorder can recover through a combination of medication and therapy, further bolstered by peer support, self-help and self-care interventions.

"Part of what first appealed to me about bipolar disorder is that while it is clearly one of the most severe, complex conditions in all of medicine, it is also very treatable, and those affected can experience prolonged recoveries and lead fulsome lives," said **Dr. Benjamin Goldstein**, Clinician-Scientist and Director of the new Centre.

"Bipolar disorder is also a family illness—it is highly heritable and impacts the whole family. In 2004, while attending the annual meeting of the American Psychiatric Association for the first time, I picked up a book about child and adolescent bipolar disorder that caught my eye. That was the beginning of what would become a career dedicated to youth bipolar disorder.

"Inspired by research showing that medical problems were associated with more severe bipolar disorder in adults, I began studying similar links in youth. I learned that there are increased rates and early onset of heart disease in bipolar disorder. At some point it occurred

to me that there was a silver lining in plain sight: what if the heart-bipolar link could guide us toward new ways of understanding and treating bipolar disorder? What if the link could help reduce stigma toward bipolar disorder? Turning those hypothetical questions into real progress for bipolar disorder, and those affected, has been my guiding purpose for over a decade."

With world leading research, evidence-based treatment and expert collaboration, Dr. Goldstein's team—and its focus on the heart-bipolar link—is changing the trajectory for youth with bipolar disorder.

Get In Touch!

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