

# TORONTO DEMENTIA RESEARCH ALLIANCE



**IMPACT REPORT  
2023**



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## Executive Summary

This September marked the completion of my first three-year term as TDRA Executive Director, and I am humbled by what we have come together to achieve as a community during the past three years.

We celebrated growth with the addition of **two new partners**: Ontario Shores Centre for Mental Health Sciences and Unity Health Toronto as partners. We organized a series of themed working groups resulting in over **\$10.3 million in external funding**. Our connection to patients and families has grown stronger through our **Lived Experience Advisory Partner council**. This highly engaged, dedicated council comprises 19 persons living with and affected by dementia; they ground our work, and embed meaning, and a perspective that is often overlooked by actively supporting the development of research.

This year we offered a **third round of seed grants**: two funded by previously unspent TDRA funds, and a third from remaining funds in the Temerty gift. We have also been able to award our **first set of Black graduate scholarships in dementia research** to two excellent Black scholars. This award will provide a total of \$30,000 to each student for two years. We continue to build capacity in clinical dementia research by funding **three medical students**, one in the Graduate Diploma in Health Research program, and two through the Comprehensive Research Experience for Medical Students.

TDRA continues to build supportive infrastructure that is making collaboration more efficient. Our legal research group led to an **accelerated completion of a multi-site agreement** in just over 2 months, a significantly expedited timeline. We also continue to increase access to research via our partnership with the Alzheimer Society of Toronto with **exceptional successful enrolment rate of 27% across a cumulatively listed 53 studies at TDRA partner sites**.

More recently, TDRA has begun to coordinate and implement initiatives that have the potential to make a profound impact on care. To increase the use of the **TDRA Cognition MRI protocol**, two University of Toronto-accredited courses were developed: the first introduced the protocol to primary care and the second to radiologists. To date **more than 1,780 scans have used the TDRA protocol across four clinical sites**. In the same vein, TDRA standardized **Toronto Cognitive Assessment (TorCA)** saw **294 downloads across 13 countries**. Finally, in November, TDRA gathered world class researchers and clinicians working in the area of **neuromodulation for cognitive disorders**, to present at a workshop on this emerging therapeutic area.

Moving forward, we are excited to build on past successes with our partners, and to leverage our network of clinicians, researchers, and persons with lived experience to achieve a future without dementia.

Respectfully,

Tarek K. Rajji

## Standardization of Dementia Care

The TDRA actively seeks opportunities to standardize elements of dementia care by making evidence-informed protocols widely available. Taking this approach improves the quality of care, and creates a set of data that are consistent and comparable. Those standardization initiatives are:

- 1. Standardized Clinical Cognition MRI Protocol:** The common clinical MRI protocol for dementia implemented in 2021 continues to be in use at Sunnybrook Health Sciences Centre (SHSC), University Health Network (UHN), and Unity Health Toronto (UHT). North York General Hospital (NYGH) has also started using this protocol. Since April 2021, more than 1780 clinical scans have utilized this protocol (SHSC: 828; UHT: 287; UHN: 540; NYGH: 128).
- 2. Educating Clinicians on TDRA's Standard MRI Protocol:** The approach to imaging dementia outside of the academic hospitals varies. In a move toward establishing TDRA's Clinical Cognition Protocol as the standard for imaging in dementia, two courses were developed by TDRA members: the first provided an overview of the various dementias, introduced the standardized protocol, and walked clinicians through some of the scales used by radiologists, linking scores to different pathologies and symptoms. This University of Toronto-accredited course was held on May 12th, 2023 and had 70 attendees from 7 different provinces and as far away as California, and generated \$5,775 in revenue from registrations. The presenters were **David Tang-Wai** (UHN), **Carmela Tartaglia** (UHN), and **Luca Pisterzi** (TDRA), and the recordings and content will be housed on TDRA's portal for future viewers. See [appendix 14](#) for metrics and feedback from Accredited Courses.

*Scientific Planning Committee:* **Sid Feldman** (Baycrest), **Alexander Forcina** (Primary Care Physician), **David Tang-Wai** (UHN), **Carmela Tartaglia** (UHN)

On June 23<sup>rd</sup>, TDRA hosted a second accredited course for radiologists led by **Paula Alcaide-Leon** (UHN) and **Carmela Tartaglia** (UHN). Once again, a background on the various types of dementia was provided, but with a focus on how the various pathologies manifest in MR images. A number of validated tools that help measure key changes to the brain in dementia were also reviewed. To reinforce the concepts, a simulator that was developed by **Eric Bartlett** (UHN/JDMI) which guided learners through nine validated cases that provided the opportunity for learners to test the concepts taught in the course. The simulation component of the course provided registrants with Section 3 credits from the Royal College of Physicians and Surgeons of Canada. This course had 44 participants, with attendees from five different provinces and as far away as Australia. Registrations generated \$5,500; this course is featured on the RADUCATE platform for future viewers at the following link: <https://www.raducate.ca/course/dementia-mri-report-simulator>. See [appendix 14](#) for metrics and feedback from Accredited Courses.

*Scientific Planning Committee:* **Eric Bartlett** (UHN/JDMI) **Sandra Black** (SHSC), **Amer Burhan** (Ontario Shores) **Corinne Fischer** (UHT), **Martin Ingelsson** (UHN), **Anish Kapadia** (SHSC), **Sanjeev**

**Kumar (CAMH), Paula Alcaide Leon (UHN), Walter Montanera (UHT), Alan Moody (SHSC), Andrea Para (UHN), Chris Scott (SHSC), David Tang-Wai (UHN), Carmela Tartaglia (UHN).**

- 3. Memory Clinic Standardization:** This working group continues to focus on standardizing assessments for people living with dementia, and improving accessibility for the Toronto Cognitive Assessment (TorCA), which has been downloaded **294 times across 13 countries**. A French Canadian version of the TorCA was completed recently and is now available on the TDRA website, and has been downloaded 10 times.

This group below has remained cohesive since collaborating to develop the TorCA, and continues to be a source of studies that test innovative modes of improving care in dementia.

*Investigators:* **Sandra Black (SHSC), Bradley Buchsbaum (Baycrest), Howard Chertkow (Baycrest), Daniel Felsky (CAMH), Corinne Fischer (Unity Health), Morris Freedman (Baycrest), Sean Hill (CAMH), Sanjeev Kumar (CAMH), Ekaterina Rogaeva (UofT), Stephen Strother (Baycrest), David Tang-Wai (UHN), Carmela Tartaglia (UHN).**

Active studies by the group:

- a. *Artificial Intelligence (AI) in the Memory Clinic:* Funded in 2021 for \$1.68 million, this project is developing artificial intelligence-based approaches to support the diagnosis of dementia. It is building on the data gathered by the Memory Clinic Standardization working group, which will serve to train the AI system. An initial model has been developed for the patient triage system, which has shown high specificity, giving great confidence in the model's predictive capabilities. To strengthen the model's predictive power, analysis of clock drawings has been added; 40,000 clock drawings from the National Health and Aging Trends Study (NHATS) dataset have been accessed. A partnership with the Ministry of Transportation has emerged, which will provide valuable data and potential access to funding.
- b. *Hybrid-Virtual Cognitive Program:* This project was funded in 2022 for \$450,000 and aims to develop a novel model of care for the efficient diagnosis of cognitive impairment. It would be applicable to tertiary memory clinic either virtually or in-person. The study protocol is nearing completion. A neuropsychologist for the project has been hired, and the process of recruiting a Research Coordinator has been initiated.
- c. *Virtual Assessment of Praxis as a predictor of basic activities of daily living:* Funded for \$99,932, this study explores whether virtual assessments of praxis are more informative than traditional questionnaires to assess impairments in activities of daily living. To date, 60 participants have been enrolled.

- 4. Long-Term Care (LTC) Standardization:** This group has designed a standardized intake assessment for Neuropsychiatric symptoms in LTC residents with dementia. This form has been developed in REDCap, and will generate an automated consultation note. There are ongoing plans among stakeholders that included psychiatrists, nurses, and occupational therapists at Ontario Shores, UHT, UHN, and CAMH to gather feedback on the form’s content and structure, and to assess the feasibility and logistics of implementing the form; as well as PointClickCare to discuss an approach to incorporating the assessment into the electronic medical records at the LTCHs. A pilot that will test the use of this standardized form in the clinical setting will take place in late summer at CAMH. Upon completion of the pilot, a plan to begin capturing data for research purposes will begin (Funding: \$200,000)

*Investigators:* **Amer Burhan** (Ontario Shores), **Peter Derkach** (West Park Healthcare), **Anuroop Duggal** (LEAP), **Corinne Fischer** (UHT), **Morris Freedman** (Baycrest), **Sean Hill** (CAMH), **Andrea Iaboni** (UHN), **Sanjeev Kumar** (CAMH), **Krista Lanctôt** (SHSC), **Clement Ma** (CAMH), **Frank Palmer** (LEAP), **Gillian Strudwick** (CAMH).

- 5. Dementia Caregivers Skills-Training through Virtual Reality Simulation (VR-SIM CARERS):** Funded for \$546,218 in 2022 as part of the NRC-CIHR Aging in Place Challenge, this project seeks to build in immersive virtual reality training environment for caregivers/care partners. Several team members have been recruited, including a simulation researcher and two PhD students. A recently held focus group – attended by 25 stakeholders, such as knowledge users, researchers, and clinician-scientists – provided feedback that helped shape a caregiver survey. Initial results were presented at this July at the International Psychogeriatrics Association Congress in Lisbon, Portugal, and in the fall, the study team visited community sites and agencies in Ontario and Quebec to introduce and coach dementia caregivers in the use of VR. In August, **Mary Chiu** was invited to discuss her work on the FLOW podcast.

*Investigators:* **Amer Burhan** (Ontario Shores), **Ron Beleno** (AGE-WELL), **Mary Chiu** (Ontario Shores), **Kristina Kokorelias** (UHN), **Irene Rubenstein** (Knowledge User), **Joel Sadavoy** (Mount Sinai), **Adriana Schnall** (Baycrest), **Michael Smith** (NRC), **Jeanie Zabukovec** (Ontario Shores), **Lynn Zhu** (Ontario Shores).

- 6. TDRA Dementia Clinical Research Database:** Funded for \$2,774,955 from Brain Canada, this project established a clinical research platform that provided a consistent and efficient approach to managing research and clinical care in patients with neurodegenerative conditions. The platform provided epidemiological data, tracked disease burden, filled gaps in medical evidence such as therapeutic effectiveness, and enabled evaluation of “real world” effectiveness of medical therapies in practice outside the highly controlled conditions of clinical trials. Click link [here](#) to read a paper by Matan Soffer *et al*, published in December 2023 and accessing the clinical research database.

*Principal Investigator:* **Morris Freedman** (Baycrest)

## Dementia Prevention

Several modifiable factors have been identified that contribute to the risk of dementia. TDRA's efforts to advance work in this area focus largely on building capacity in translational research, and on supporting the development of promising ideas through small, targeted grants.

- 1. Temerty-Tanz-TDRA Initiative:** In partnership with the Temerty Faculty of Medicine and the Tanz Centre for Research in Neurodegenerative Diseases, TDRA launched a 3-year and \$1.05 million initiative focused on exploring the link between dementia and depression. Depression has been identified as a key modifiable risk factor for dementia, and modifiable risk factors account for 40% of dementia cases. There are three elements to this initiative:

### Temerty-Tanz-TDRA Research Fellowships:

- i) Temerty-Tanz-TDRA Brain Medicine Research Fellowship #1:** Eleven applications were received, and reviewed by a Selection Committee with representatives from Baycrest, CAMH, SHSC, UHN, and U of T. The Committee selected **Iryna Palamarchuk**, who began her work in March 2022 on a collaborative project between **CAMH** and **SHSC**. Iryna's work focuses on the use of transcranial alternating current stimulation and focused ultrasound to enhance prefrontal cortical function in older people living with depression or mild cognitive impairment (more information [here](#)).
- ii) Temerty-Tanz-TDRA Brain Medicine Research Fellowship #2:** Seven applications were received, and the Committee selected **Adrian Espiritu** in 2022. Adrian is conducting a collaborative project between **Ontario Shores** and **UHN**. The project uses repetitive transcranial magnetic stimulation (rTMS) as a novel intervention for people living with treatment-resistant late-life depression (TR-LLD) and motor-cognitive risk syndrome. The study is currently active and open for participant enrollment.
- iii) Temerty-Tanz-TDRA Post-Doc Research Fellowship:** Thirty-four applications were received and reviewed by a Selection Committee with representation from all TDRA sites. The Committee selected **Samar Elsheikh** in 2022, who will lead a collaborative project between **CAMH** and **UHT** that examines genetic factors that may reveal correlations between response to anti-depressants and cognition in late life.

Temerty-Tanz-TDRA Seed Funding: Awards valued at \$70,000 to seed innovative research at the intersection of depression and dementia were launched in June of 2021. Submissions were to be multi-site, or collaborative among basic and clinical sciences. In the first year's competition, nine applications were reviewed by a panel of five external reviewers and a member of TDRA's Lived Experience Advisory Partners (LEAP) Council. Those funded projects and their updates are:

- i) **Impact of lipopolysaccharide on immune response and cerebral amyloid deposition in older adults with a history of major depressive disorder:** This study has been completed and the manuscript has been published in the American Journal of Geriatric Psychiatry.

*Investigators: Damien Gallagher (SHSC), Ariel Graff-Guerrero (CAMH)*

- ii) **The contribution of cerebrovascular disease to depression in patients with and without Alzheimer's disease:** This project has concluded, and the results suggest that a past history of depression did not predict Alzheimer's disease (AD) biomarker status or cerebrovascular injury. These results will be replicated in a larger cohort of the [Alzheimer's Disease Neuroimaging Initiative \(ADNI\)](#). This study has been completed and the manuscript has been published in the Journal of Alzheimer's Disease (doi: 10.3233/JAD-221097).

*Investigators: Angela Golas (CAMH), Carmela Tartaglia (UHN)*

- iii) **Assessment of heart rate variability in older adults with lifetime history of depression or mild cognitive impairment:** A research student has joined the team to lead the project which started in fall 2022, the study is currently recruiting participants.

*Investigators: Jean Chen (U of T), Linda Mah (Baycrest)*

The **second round of the Temerty-Tanz-TDRA Seed Fund competition** closed for submissions on June 30<sup>th</sup>, 2022. Seven LOIs were invited to submit full applications. After careful review and scoring by a panel of five external reviewers and two members of LEAP, two projects were selected for seed funding. These projects, launched in 2023, are:

- i) **Cognitive and neuroimaging patterns in individuals with Alzheimer's disease and depression: A machine learning study:** The project has received data from four cohorts (Alzheimer's Disease Neuroimaging Initiative; Harvard Aging Brain Study; Wisconsin Registry for Alzheimer's Prevention; Prevent-AD, and is in the process of securing two additional datasets (PACt-MD, OASIS).

*Investigators: Jennifer Rabin (SHSC), Mary-Pat McAndrews (UHN)*

- ii) **Targeting  $\alpha$ -synuclein with a novel peptide inhibitor to treat cognitive impairment and depression in Parkinson's disease:** The novel peptide constructs to be used in this study have been designed and received by the lab, and their expression is being tested in rat neurons. Appropriate time points to measure depressive-like features in a rat model have also been determined. Next, the time points to test cognitive dysfunction in the rat model will be assessed, as will the expression of the AAV-



peptide constructs in rat and ultimately the effects of treatment with AAV-peptide on depressive-like features and cognitive dysfunction in a rat model.

*Investigators:* **Lorraine Kalia** (Tanz, UofT), **Philip Kim** (Donnelly Centre, UofT), **Suneil Kalia** (UHN), **Clement Hamani** (SHSC)

The **third round of the Seed Fund competition** closed for submissions on June 1, 2023, with twenty-three submissions received. Three seed funds were available, each up to \$70,000. One seed fund was reserved for projects that examine the link between depression and dementia, funded by Temerty-Tanz-TDRA Initiative. Two seed funds were reserved for projects focusing more generally on dementia, funded by TDRA. Twenty full applications were received, and evaluated by a committee consisting of nine external reviewers and two LEAP members. The three projects selected for seed funding, beginning in January 2024 are:

- i) Harnessing vagal nerve function to curb depression and dementia (*Depression & Dementia*)**  
This study will test the hypothesis that vagal nerve function regulates the emergence of depression and cognitive decline. Researchers anticipate that subjects with enhanced vagal function will be protected against increased neuroinflammation, depression and cognitive deficits. Better understanding of the molecular mechanisms that regulate vagal function will have implications for application of vagal nerve stimulation, which is already approved for refractory (or hard to treat) depression.  
*Investigators:* **Minna Woo** (UHN), **Thomas Prevot** (CAMH)
- ii) Using functional imaging to evaluate the effect of photobiomodulation in patients with Mild Cognitive Impairment**  
This study focuses on investigating the efficacy and underlying mechanisms of photobiomodulation (PBM), a novel non-invasive candidate treatment that delivers infrared light to the brain and that has shown promise in preclinical studies and case series. This experimental protocol presents a unique opportunity to gain a deeper understanding of the PBM's mechanisms of action on brain health and function, and to assess the potential of the collected data to provide biomarkers of PBM utility.  
*Investigators:* **Corinne Fischer** (UHT), **Simon Graham** (Sunnybrook), **Tom Schweizer** (UHT)
- iii) On the Road to Acceptance: Optimizing Naturalistic Driving Monitoring Systems for Individuals with Dementia**  
A major challenge in dementia care is determining the point at which driving safety becomes significantly compromised for drivers with dementia. While a diagnosis of dementia directly impacts driving abilities, it is insufficient for revoking one's driving privileges. This study aims to investigate the acceptability and usability of naturalistic driving monitoring systems to enhance driving-related decision-making in individuals with dementia. When fully developed, driving monitoring technologies could serve as early

indicators of declining driving performance. This would enable a more evidence-based approach to decision-making regarding driving in dementia. The present study will allow us to anticipate how this technology can be implemented in practice.

*Investigators:* **Mark Rapoport** (Sunnybrook), **Gary Naglie** (Baycrest), **Sayeh Bayat** (University of Calgary)

- 2. Improving Prognostic Confidence in Neurodegenerative Diseases Causing Dementia using Peripheral Biomarkers and Integrative Modeling:** This collaborative project funded in 2021 for \$600,000, brings together a team of scientists from across CAMH Krembil Centre for Neuroinformatics (KCNI), the Tanz Centre for Research in Neurodegenerative Diseases, and the TDRA to develop non-invasive diagnostic and prognostic algorithms – based on biomarkers and supported by AI – in older individuals presenting with cognitive complaints. The aim of this project is to better diagnose neurodegenerative diseases and ultimately enable targeted treatment in people with specific underlying disease pathologies. This project has enrolled 13 participants at UHN, with Baycrest, CAMH and SHSC to soon initiate enrollment.

*Investigators:* **Daniel Felsky** (CAMH/KCNI), **Morris Freedman** (Baycrest/TDRA), **Ekaterina Rogueva** (UHN/Tanz), **David Tang-Wai** (UHN/TDRA), **Carmela Tartaglia** (UHN/Tanz)

- 3. Optimization of Prefrontal Theta-Burst Stimulation to Treat Depression: A Bench to First-in-Human Study:** This project, funded by Brain Canada-Bell Let's Talk (\$950,000), is truly translational in nature, as it seeks to optimize the parameters of theta-beta stimulation (TBS) – a novel treatment for depression – to induce neuroplasticity in animal models of depression, and then apply those optimized protocols in persons living with depression. Enhancing neuroplasticity in depression, a high-risk condition for dementia, could not only improve depression outcomes but also reduce dementia risk. With agreements in place, experiments are underway to establish long-term potentiation in the prefrontal cortex. An integrated Knowledge Translation (iKT) lived experience advisory committee is in place and has already had its first meeting. Preparation has begun on two manuscripts, the first will discuss translational neuroscience approach as a model to advance brain stimulation, and the second is a review paper on the TMS and electrophysiology concepts.

*Investigators:* **Tarek Rajji** (CAMH), **Graham Collingridge** (Tanz), **Evelyn Lambe** (U of T), **Sanjeev Sockalingam** (CAMH)

- 4. Focused Ultrasound (FUS) – transcranial Alternating Current Stimulation (tACS) Project:** This externally funded (\$500,000) collaborative project between SHSC and CAMH will test the effects of two non-invasive stimulation methods – focused ultrasound (FUS) and transcranial alternating current stimulation – on enhancing working memory in older adults. It will assess whether the combined stimulation will result in synergistic effects. The Investigational Testing Authorization for the tACS machine has recently been approved. The study has received REB approval at CAMH and

Health Canada approval, but is currently awaiting REB approval for an amendment to separate the project into tACS and FUS components.

*Investigators:* **Kullervo Hynynen** (SHSC), **Tarek Rajji** (CAMH), **Abhishek Datta** (Soterix Medical), **Iryna Palamarchuk** (CAMH)

- 5. Levetiracetam to modulate hippocampal hyperactivity in a population at risk (ALEVIATE):** This study, funded for \$1.4 million by the Weston Brain Institute in 2021, aims to explore what could be a promising biomarker present in the prodromal stages of dementia, and test a possible treatment. Excess activation of the hippocampus in persons with normal cognition carrying an ApoE4 gene – compared to the level of activation in non-ApoE4 carriers – is thought to contribute to progression of disease. ALEVIATE aims to characterize and describe this excess activation, and test levetiracetam’s ability to quell elevated activation, and potentially preserve the hippocampus. In the first phase of this study, the baseline level of activation in non-ApoE4 carriers will be measured, and in the second phase levetiracetam will be tested in ApoE4 carriers for its ability to quell excess activation. With 22 participants enrolled in phase 1 to date, this study is on track to recruit all 30 participants by next June. In anticipation of successful completion of phase 1, we are beginning protocol development and start-up activities for phase 2, which will be launched next summer.

*Investigators:* **Sandra Black** (lead applicant, SHSC), **Arnold Bakker** (Johns Hopkins University), **Howard Chertkow** (Baycrest), **Morris Freedman** (Baycrest), **Maged Goubran** (SHSC), **Nathan Herrmann** (SHSC), **Alex Kiss** (SHSC), **Sanjeev Kumar** (CAMH), **Ben Lam** (SHSC), **Krista Lanctôt** (SHSC), **Mario Masellis** (SHSC), **Mary Pat McAndrews** (UHN), **Sara Mitchell** (SHSC), **Luca Pisterzi** (CAMH), **Jennifer Rabin** (SHSC), **Tarek Rajji** (CAMH), **Joel Ramirez** (SHSC), **Pedro Rosa Neto** (Douglas Hospital Research Centre), **Antonia Strafella** (UHN), **David Tang-Wai** (UHN), **Carmela Tartaglia** (UHN), **Kamil Uludag** (UHN), **Neil Vasdev** (CAMH), **Don Weaver** (UHN), **Richard Wennberg** (UHN), **Katherine Zukotynski** (McMaster University).

- 6. Identifying Pre-agitation Biometric Signature in Dementia Patients: Preliminary Feasibility Study:** This study aims to integrate the use of wearable multisensory devices in dementia care. These devices collect physiological parameters that will be used to create a biometric signature that can predict episodes of emotional distress, allowing early introduction of interventions and treatments preventing critical incidents in this population. The funding (\$40,000) was from Team 11 of the Canadian Consortium on Neurodegeneration in Aging (CCNA). This study has recruited 7 participants

*Investigators:* **Amer Burhan** (Ontario Shores), **Sarah Elmi** (Ontario Shores), **Krista Lanctôt** (SHSC), **Tarek Rajji** (CAMH), **Arany Shanmugalingam** (Ontario Shores), **Robin Waxman** (Ontario Shores)

- 7. Leveraging Artificial Intelligence to Detect Behavioral and Psychological Symptoms of Dementia on a Clinical Demonstration Unit – A Validation Study:** Here, researchers seek to integrate wearable multisensory devices in dementia care. The device collects physiological parameters that will be used to create a biometric signature that can predict episodes of emotional distress, allowing for early introduction of interventions and treatments to prevent critical incidents in this population. The study also uses cameras that are being trained with AI to be able to identify episodes of agitation. The project is funded by the Ontario Shores Foundation (\$14,000). This study has recruited 4 participants.

*Investigators:* **Amer Burhan** (Ontario Shores), **Khalid Elgazzar** (Ontario Tech University)

## Investing in Learners

TDRA aims to build capacity in dementia research and care by facilitating training opportunities for the next generation of leaders through our network of world-leading clinicians and researchers. The programs and learners funded this year include:

- 1. CREMS Summer Students:** This program provides medical students the opportunity to lead a Summer research project. In 2023, TDRA co-funded **Pooja Sankar**, who is working with **Amer Burhan** at Ontario Shores on a study that examines the effects on cognition and gait of repetitive transcranial magnetic stimulation in older persons with depression. Data collection for a systematic review is complete and a manuscript is being drafted. A randomized clinical trial for this research question is pending Health Canada approval.

In 2022, TDRA co-funded **Elizabeth Boyd**, who worked with **Krista Lanctôt** at SHSC. Elizabeth examined MRI data from the COMPASS-ND study to determine the association between grey matter atrophy and neuropsychiatric symptoms underlying neurodegenerative processes. This study has concluded, and it was found that neuropsychiatric symptoms may develop early in the presence of vascular brain periventricular regions. Decreased drive and motivation may be an early indicator of vascular mild cognitive impairment (vMCI). The project was presented at Hurvitz Brain Science Summer Student Research Conference 2022, Sunnybrook Research Institute Summer Poster Competition 2022, Canadian Consortium on Neurodegeneration and Aging (2022), and University of Toronto Medical Student Research Day 2023. A manuscript is in preparation.

- 2. GDipHR Program:** Over 20 months, medical students in this program take graduate-level courses and lead a research project. In 2023, TDRA is co-funding **Julie Midroni** who is working with **Andrew Lim** at SHSC. The project will use machine learning approaches to link wearable sensor data acquired from older adults participating in various studies to clinical, imaging and histopathological dementia-related outcomes.

In 2022, TDRA co-funded **Shreya Jha**, who worked with **Sanjeev Kumar** at CAMH on metabolites in dementia and their association with clinical symptoms using Magnetic Resonance spectroscopy. The study found that those with AD have lower metabolites in the dorsolateral prefrontal cortex compared to healthy controls. The project was presented at 2022 Department of Psychiatry Research Day and 2023 Medical Student Research Day, and is now in preparation of a manuscript for journal submission.

- 3. MITO2i-TDRA Fellowship:** The Mitochondrial Innovation Initiative (MITO2i) and TDRA have partnered to co-fund a fellowship focusing on the role of the mitochondria in dementia. **Neda Rashidi-Ranjbar** – under the supervision of **Tom Schweizer** and **Corinne Fischer** at Unity Health Toronto – is leading a study that investigates the efficacy of photobiomodulation, a form of light therapy, in the treatment of mild cognitive impairment. Health Canada approval has been obtained, and the study has obtained final REB approval and is actively recruiting. Eleven participants have

completed the study, two are currently enrolled, and another four participants are being screened. Initial findings reveal significant improvements in both Montreal Cognitive Assessment (MoCA) scores and the Trail Making Test in the group receiving active photobiomodulation compared to the sham group.

#### 4. **Sandra E. Black Award in Clinical Dementia Research:**

The recipient of the 2023 Sandra E. Black Award is **Madeline Wood Alexander**, who is a PhD candidate under the supervision of Jennifer Rabin at SHSC. Her thesis will be on investigating the combined contributions of vascular risk and menopause history to Alzheimer's disease in Canadian women.

The recipient of the 2022 Sandra E. Black Award is **Durjoy Lahiri**, who is under the supervision of **Howard Chertkow** at Baycrest. Durjoy's research focuses on amyloid negative and positive individuals and their clinical trajectory, neuroimaging features, and novel blood-based biomarkers. He is also working on neuromodulation therapy in people living with degenerative aphasia. The interim results of this study were presented at the Division of Neurology Annual Silversides Day, where it was awarded the James A. Sharpe Award for the best presentation by a Neurology Fellow. The results of the clinical comparative data were recently presented at the annual meeting of the Alzheimer Association International Conference (AAIC) in Amsterdam, 2023.

5. **Supporting Black and Indigenous learners:** This year, TDRA launched two scholarships at the graduate (*i.e.*, MSc or PhD) level to support typically underrepresented groups in research. As a part of this scholarship, TDRA assembled community-specific mentorship networks to engage the successful applicants; they include **Mireille Norris** from SHSC and **Notisha Massaquoi** from the U of T. TDRA received five submissions for this scholarship from Black students; unfortunately no applications were received from Indigenous students. The applications were scored by a review committee, and two exceptional candidates were selected as recipients: **Tristin Best** and **Chinaza Dibia**. Tristin Best, a PhD candidate, is collaborating with **Howard Chertkow** at Baycrest. His research involves exploring olfactory dysfunction as a potential predictor of AD in individuals experiencing subjective cognitive decline. In parallel, Chinaza Dibia, another PhD candidate, is working with **Isabelle Aubert** at SHSC investigating innovative non-invasive gene delivery methods to treat AD-affected brain regions. We will continue to work with our Indigenous colleagues to promote the next round of fellowships, which we plan to offer in 2024.

## Building Research Infrastructure

Administrative and operational hurdles in clinical and multi-site research initiatives can cause significant delays and they are often not unique. TDRA is working across sites to develop harmonized solutions to pressing issues and build infrastructure to fill gaps that impact progress.

**1. Legal Research Working Group:** A legal Research Working Group has been established with representation from Baycrest, CAMH, Ontario Shores, SHSC, UHN, UHT, and the U of T. The group meets monthly to work towards building solutions that add efficiency to the review of legal agreements. One significant achievement of the working group has been expediting the agreement outlining shared ownership for the TorCA, and an inter-institutional agreement (IIA) for a collaborative TDRA study. This agreement was between UHN and three other institutions; typically it would be negotiated separately between UHN and each of the parties. Through this working group the agreement was discussed and reviewed together by all parties. As a result, this agreement was able to be **executed in two months** on account of the diligent work of this group. In December 2023, the group has also finalized a templated licensing agreement that will allow for translations of the TorCA in to different languages – urgently needed to support Toronto’s multicultural population – to be carried out by groups outside TDRA. Through the collective efforts of the Legal Research Working Group, the TDRA has made significant strides in promoting efficient and effective legal frameworks, fostering valuable partnerships, and advancing research initiatives in the field of dementia. See appendix 13 for a comparison between previous model of legal processes and the approach undertaken by the legal research working group.

**2. Supporting Recruitment to Research Studies:** TDRA continues to partner with the Alzheimer Society of Toronto (AST) to help connect the public with research through two initiatives:

- i. *Listing Research on the Toronto Dementia Network:* The **Toronto Dementia Network (TDN)** is a site operated by the AST that lists services such as respite care, nursing, transportation and other forms of support. On July 29, 2021, [a section](#) was added that lists plain-language descriptions of research studies led by members of the TDRA community. Individuals can indicate their interest in a specific study and be connected to the research team. If they cannot find a study, they can choose to be triaged to a study based on information they enter (ex., preferred location, intervention vs observational, age, etc.). A process to equitably triage these potential participants was developed with input from all TDRA sites.

Fifty-three cumulative studies have been listed on the TDN website over time; twenty-two of these studies are now inactive or closed. To date, the mechanism has yielded 212 referrals to studies in the TDRA network, including 57 that are enrolled or have completed a study, i.e. with an **exceptional successful enrolment rate of 27%**. See [appendix 2](#) for details. In one case, the TDN was the source of 50% of a study’s participants, recruited in 1 month.

Efforts to spread awareness of the TDN and increase recruitment continue, including engaging community organizations, being part of newsletters, arranging presentations, and distributing printed brochures. Additionally, the TDN is featured in various outreach initiatives; see [Knowledge Translation section 6](#) for more details.

- ii. *Webinar Series: [Advances in Dementia Research](#)*: Hosted in partnership with AST, this series features bi-monthly, plain-language webinars delivered by TDRA-affiliated researchers. Researchers are encouraged to provide an overview of a research topic in dementia, and to discuss a related study that is actively recruiting and listed on the TDN. The webinars are open to anyone, allowing members of the public to engage directly with researchers. **Thirteen webinars have been hosted, with 608 attendees and 14 referrals to studies to date.** Webinar recordings are posted on both AST and TDRA's YouTube channels.

3. **Working with the Alzheimer Society of Ontario:** TDRA has engaged in a strategic partnership with the Alzheimer Society of Ontario (ASO) to advance opportunities to scale and spread some of our initiatives related to the standardization of dementia care. One key area of collaboration is the recently formed Ontario Dementia Care Alliance (ODCA), which aims to serve as an independent expert advisory body to the Government of Ontario. The ODCA will deliver actionable recommendations that would meaningfully improve dementia care for both care recipients and providers. TDRA members serve a prominent role on the ODCA, with **Sandra Black** (SHSC), **Tarek Rajji** (CAMH), and **Carmela Tartaglia** (UHN) all serving on this important group.

ASO and TDRA will also cross-promote and amplify relevant initiatives and messaging (on social media and otherwise). The research section of the ASO website now features [information on TDRA and links to our website](#), the TDN, and the Advance in Dementia Research webinar series.

4. **Open Science:** To support the accessibility of data and to encourage its use, TDRA created a working group to collate a set of principles to support the practice of open science among its community of researchers. Using approved open science principles from Baycrest and CAMH, along with researcher expertise, TDRA has produced a draft set of open science principles that are under review. Researchers who adopt the common standards will be encouraged to make their data available based on these principles, which will acknowledge the producers of the data.
5. **Equity, Diversity, and Inclusion (EDI) in Research Design:** In 2023, TDRA has formed an Equity Research Group in order to increase the involvement of traditionally underrepresented groups in research. The group is comprised of collaborators within our network with extensive EDI and EDI – based research experience. The first meeting was held in August and it aims at creating a Mentorship Circle for Black and Indigenous trainees as well as to expand standardization of dementia care to Black and Indigenous communities.



## Knowledge Translation

TDRA aims to inform its broad range of stakeholders (*i.e.*, people with lived experience, researchers, learners, decision-makers, and donors) of ongoing progress through several knowledge products, as well as opportunities to share information. They include:

1. **TDRA Website:** [TDRA's website](#) is the main knowledge product, hosting information about research and tools, plain language dementia-related resources, news, and events. TDRA also hosts two blogs: the [Scientist Explains Series](#), which offers plain-language summaries of key topics in dementia, and the [TDRA Spotlight Series](#), which provides plain-language overviews of the work led by a TDRA researcher. Both series are now being produced largely as videos rather than written materials. Together, the six vlogs produced in 2023 have acquired 1,287 views. The new format is also associated with positive trends in TDRA's YouTube channel. See [appendix 8](#) for preliminary YouTube analytics.

The website links to the [TDRA Portal](#), where the standardized tools for clinicians and researchers are hosted. These tools are evidence-based, standardized, and are broadly available to improve diagnosis and care for people living with dementia. The tools include the TorCA, the BNA-SF, the standardized clinical cognition MRI protocol, SOPs for processing bio samples, and others. Since 2021 when our two new websites launched, the main site had 229,811 visits, and the portal had 1,071 visits\*. See [appendices 4 and 5](#) for website analytics.

\*by end of Q1 2023/24.

2. **Social Media:** TDRA operates X (formerly *Twitter*) and LinkedIn accounts that aim to extend the reach of knowledge products to broader audiences, provide platforms to promote upcoming opportunities/events, and drive traffic to our websites. Over time, TDRA's social media presence has been steadily growing. See [appendices 6 and 7](#) for social media analytics.
3. **E-Newsletter:** TDRA launched a [monthly e-newsletter](#) for our community in February 2022. The newsletter features a researcher spotlight, announcements, information about upcoming events and current training opportunities, and a plain language summary of a recently published study that features TDRA authors. We have 744 current subscribers and have published 23 editions to-date. Our subscriber list has consistently grown since the newsletter's launch, and we gain many new subscribers via our Advances in Dementia Research webinar series, where we ask about subscription to our newsletter during registration. See [appendix 9](#) for newsletter analytics.
4. **Lived Experience Advisory Partners (LEAP) Council:** TDRA is pleased and fortunate to have a very engaged LEAP council, which maintains the lived experience perspective across all initiatives. There are currently 16 LEAP members and three Council Chairs. To ensure they have the opportunity to contribute, efforts are being made to have a LEAP member join each of the Research Working Groups (RWGs), as well as the Scientific Advisory Committee and the Research Operations

Committee; in total, 10 TDRA committees/groups have LEAP representation. See [appendix 10](#) for notable LEAP contributions throughout 2023.

#### 5. **TDRA Workshop: Neuromodulation for Neurocognitive Disorders**

TDRA's Neuromodulation for Neurocognitive Disorders Workshop took place on November 1, 2023 at the Sheraton Toronto Hotel, from 8:00 AM-5:30 PM.

This event featured 10 expert scientific presentations, on topics ranging from focused ultrasound, to photobiomodulation, to synaptic plasticity mechanisms induced by different patterns of theta burst stimulation. Toronto houses a vibrant research and clinical community with expertise in this specialized field, which allowed the TDRA to draw from its network of hospitals, to put on this unique event.

With a lively question and answer period following each session, the Workshop was attended by over 90 researchers, clinicians, trainees, postdocs and other learners, and was CME accredited. See [appendix 11](#) for the workshop agenda and survey highlights. This workshop received funding from the Ontario Brain Institute. View more on the workshop [here](#).

6. **Eureka Workshop (September 2023):** TDRA presented a workshop on September 13, 2023, targeted to researchers and faculty. The topic: From Research to Headlines: A Step-by-Step Guide to Creating Press Releases. The presenter was **Esme Fuller-Thomson**, Professor and Director of the Institute for Life Course & Aging at the University of Toronto. The on-line workshop was attended by 26 people.

#### 7. **Community Outreach**

- i. **CABHI Summit/Rotman Research Institute Conference (March 2023):** TDRA sponsored the Centre for Aging and Brain Health Innovation (CABHI) 2023 Summit, as well as the 2023 Rotman Research Institute Conference. As part of this, TDRA had a booth in a virtual exhibition space, where we shared posters, videos, and other communications materials.
- ii. **The Silver Wave: Impacts of an Aging Population on Mental Health & More (April 2023):** **Tarek Rajji** participated in a panel discussion on mental health and aging at CAMH. The panel was moderated by **André Picard** of the Globe and Mail, and included representatives from the Ontario Long Term Care Association, the Shkaabe Makwa Centre at CAMH, and the Senior Director of Complex Care and Senior Services at CAMH.
- iii. **Innovations in Research Engagement: Family Partner and Researcher Experience in Collaborating on Geriatric Research (April 2023):** TDRA hosted a virtual panel event with CAMH in celebration of Patient & Family Experience Week. It focused on innovations in engaging people with lived experience in research, drawing on examples from TDRA and the

geriatric division at CAMH. The panel featured **Tarek Rajji** (CAMH), LEAP Council Scientific Co-Chair **Sanjeev Kumar** (CAMH), and a LEAP member. There were 71 attendees in total.

- iv. **AAIC (July 2023):** TDRA was pleased to exhibit at this year's Alzheimer's Association International Conference (AAIC) in Amsterdam, as part of the Canadian Pavilion. We shared many beneficial interactions with attendees and supported a networking event for Canadian researchers and international partners.
- v. **The Last Piece Musical (July 2023):** Composed and written by TDRA trainee **Shreya Jha**, The Last Piece, a new Canadian musical, follows an elderly woman coping with her ex-husband's recent Alzheimer's diagnosis. TDRA had brochures and other resources available for attendees of the play, and helped to coordinate a panel discussion after the show featuring **Sanjeev Kumar** (CAMH) who was available to answer audience questions on Alzheimer's disease. A recording can be found at: [https://www.youtube.com/watch?v=W63UffEn\\_tE](https://www.youtube.com/watch?v=W63UffEn_tE)
- vi. **CAMH Community Outreach Group (ongoing):** The TDRA joined the Geriatric Mental Health Services (GMHS) research team to speak about 'Late-Life Depression' at The Annex, Rivera on August 15<sup>th</sup>, 2023. The TDRA shared information about opportunities to participate in research through the TDN, opportunities to be involved with our LEAP group, and the informational resources available on our website. There were 18 in-person and 6 virtual attendees. The Annex Rivera invited GMHS and TDRA back again for future presentations. TDRA plans to continue working with the GMHS outreach team to speak to community groups.
- vii. **PIPER Research Day 2023 (October 2023):** TDRA participated in two sessions for the PIPER (Pride in Patient Engagement in Research) Research Day on October 5<sup>th</sup>, 2023, at Hart House, in Toronto. One session was an interactive panel, titled 'Innovations in Lived Experience Engagement in Dementia Research'. Panel members consisted of **Tarek Rajji** (CAMH), **Branka Agic** (CAMH), and LEAP members **Cara Sullivan** and **Chaitali Desai**. The second was a lived experience story sharing session lead by LEAP member **Cara Sullivan**, titled 'An INSPIRE-D LEAP: Experiences of a Caregiver Partner in Dementia Research'.
- viii. **Aging in Place: Seniors and Caregivers Resource Fair (October 2023):** TDRA exhibited at Barbara Frum Library on October 27, 2023. The event included speakers and exhibitors and was designed for older adults. TDRA provided information and resources on participating in dementia research. The event was attended by ~30 members of the community.
- ix. **Canadian Conference for Dementia (November 2023):** TDRA exhibited at the CCD in Toronto on November 2-4, 2023, where the focus was highlighting the TorCA tool and the TDN research studies website.

- x. **The Royal Agricultural Winter Fair (November 2023):** The TDRA exhibited at The Royal Agricultural Winter Fair during November 3-12, 2023, at Exhibition Place. TDRA provided informational resources and highlighted research participation opportunities available through the TDN. Demonstrations to engage visitors and educate members of the public regarding tasks involved in dementia research took place, with many TDN study researchers guest hosting the booth. TDRA engaged with over 500 members of the public at this event.
  
- xi. **Ontario Caregiver Coalition General Members Meeting (December 2023):** The TDRA presented to members of the Ontario Caregiver Coalition on December 14, 2023. The presentation featured TDRA initiatives that caregivers can get involved in, such as participating in studies on the TDN website, attending the Advances in Dementia Research webinar series, and getting involved in other TDRA events and knowledge translation activities.

**Appendix 1: TDRA Governance Structure**



\*These individuals collectively share one vote

**Appendix 2: TDN Referral and Enrollment Information since May 22, 2021**

Participating Site	# of Studies	# of studies: Lead Site	# of Referrals	# of Enrollments & Completions	% of Referrals Enrolled or Completed
BYC	17	13	33	5	15%
CAMH	10	7	25	7	28%
OSH	2	0	0	0	-
SHSC	23	19	103	37	36%
UHT (SMH)	4	1	2	0	0%
UHN	16	11	46	6	13%
UofT	2	2	3	2	67%
	<b>Total</b>	53	212	57	27%

### Appendix 3: Metrics for Advances in Dementia Research Webinars

Date	Topic	Speaker(s)	Attendees	Referrals
14-Sep-21	Driving & Dementia	Mark Rapoport/ Gary Naglie	45	0
17-Nov-21	Agitation in Dementia	Sanjeev Kumar	70	1
11-Jan-22	Diagnosis & Self-Care	Richard Swartz	50	3
24-Mar-22	Diversity in Risk & Protective Factors	Ho Yu	55	0
24-May-22	Non-Invasive Brain Stimulation	Tarek Rajji	43	0
12-Jul-22	Sleep, Cognitive Impairment & Stroke	Mark Boulos	36	N/A
27-Sept-22	Novel Drug Treatments for Agitation in Dementia	Krista Lanctôt	68	0
17-Nov-22	Complexity of Aging & Dementia	Sandra Black	67	3
23-Feb-23	Light Therapy & MCI	Neda Rashidi-Ranjbar	50	2
19-Apr-23	Frontotemporal Syndromes	Carmela Tartaglia	38	2
15-June-23	Risk & Protective Factors	Jennifer Rabin	25	1
22-Aug-23	A New Trial for Frontotemporal Dementia	Andres Lozano	29	1
27-Oct-23	Innovative Research on Driving & Dementia	M Rapoport, G. Naglie & S. Bayat	32	0

## Appendix 4: New and Returning Users to the TDRA Website ([www.tdra.utoronto.ca](http://www.tdra.utoronto.ca))

From Q4 FY 2021/22 to Q1 FY 2023/24



### Comparison Website Metrics for Q1 FY 2022/23 and Q1 FY 2023-2024

General Analytics	Q1 2022-23 Sept 1- Nov 30	Q1 2023-24 Sept 1- Nov 31	Percent Change %
Users who have initiated at least one session	3,071	4,100	34%
Returning users	422	647	53%
New users	2,952	3,900	32%
Total sessions	4,407	6,119	39%
Average number of sessions per user	1.44	0.88	-39%
Pageviews	8,550	10,216	19%

All analytics include CAMH's IP address (our internal traffic/use of the website)

#### Metric Glossary:

1. Returning users: Users who have visited the website before.
2. New users: Users visiting the website for the first time on a specific device (e.g., if you visit from your desktop and then again from mobile, you are recorded as two users).
3. Pageviews: A page view occurs when a page on the website is loaded or reloaded, whether the user was already on your page or came from an external page.



4. Average session duration: Amount of time measured from the moment a user lands on the website until the session ends (i.e., user exits the website or is inactive for a predetermined amount of time). A session includes all the interactions a user has with the website (e.g., visiting pages, downloading pdfs, completing a form).

**Appendix 5: Key Metrics for TDRA Portal Website ([www.portal.tdra.utoronto.ca](http://www.portal.tdra.utoronto.ca))**

**TDRA Portal User Registrations 2023**

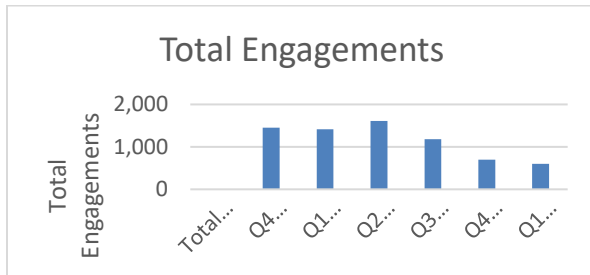
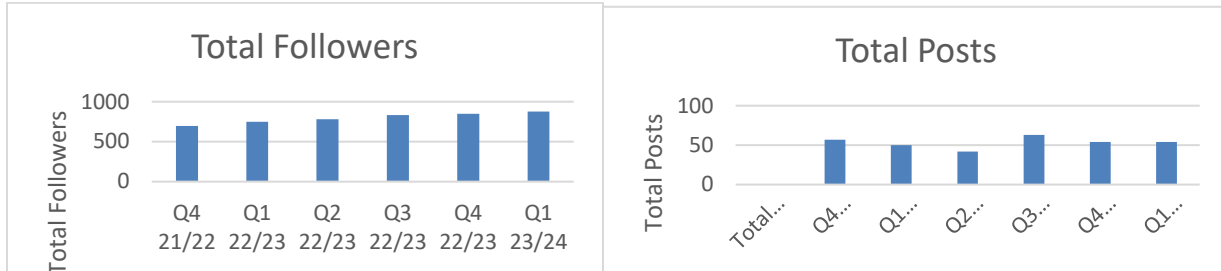
Month	Registrations	Approvals
Jan-23	16	15
Feb-23	6	5
Mar-23	10	10
Apr-23	6	6
May-23	15	15
Jun-23	17	17
Jul-23	8	8
Aug-23	4	4
Sept-23	12	12
Oct-23	17	17
Nov-23	59	30
Dec-23	15	42

**Top Portal Downloads (Q4 FY 2021/-22 to Q1/ 2023-2024)**

	TorCA Manual	TorCA Testing Material	BNA-SF	MRI Protocol Summary
<b>Q4 21/22</b>	13	10	6	0
<b>Q1 22/23</b>	13	22	7	2
<b>Q2 22/23</b>	10	14	2	1
<b>Q3 22/23</b>	14	16	7	1
<b>Q4 22/23</b>	28	37	12	0
<b>Q1 23/24</b>	19	25	15	0
<b>Total</b>	97	124	49	4
<b>Countries Where Downloaded</b>	Canada (84) Australia (3) India (3) Italy (2) Mexico (2) Poland (1) Romania (1) Sweden(1)	Canada (111) Australia (3) India (3) Italy (2) Mexico (2) Poland (1) Romania (1) Sweden (1)	Canada (42) Australia (1) Mexico (3) Poland (1) Romania (1) Sweden (1)	Canada (3) India (1)

## Appendix 6: Key Metrics for X (formerly Twitter)

### Total X Followers, Posts, and Engagements from Q4 FY 2021/22 to Q1 FY 2023/24



### Comparison of X Metrics for Q1 FY 2022/23 and Q1 FY 2023-24

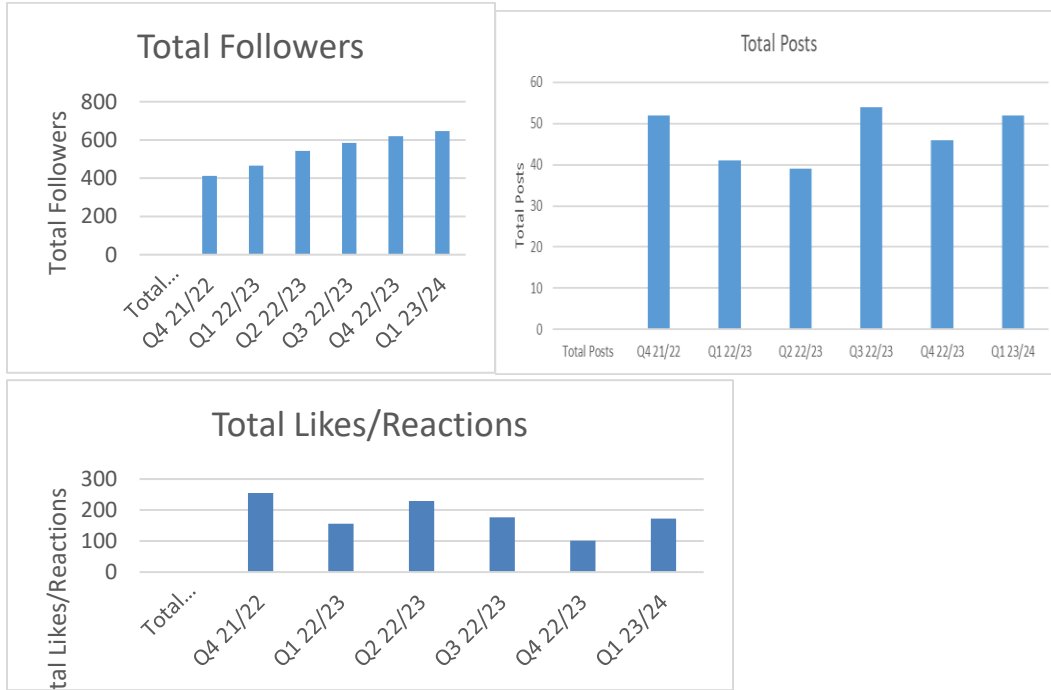
Metric	Q1 2022-23 Sept 1- Nov 30	Q1 2023-24 Sept 1- Nov 30	Percent Change %
Total followers	747	834	12%
Total posts (excluding reposts quote re-posts)	50	63	26%
Total engagements	1,413	1,178	-17%

### Metric Glossary

1. Total followers: Total number of X user accounts that follow the TDRA account.
2. Total Posts: Number of times the TDRA has posted an original post on the TDRA X account (*i.e.*, excluding re-posts).
3. Total engagements: Total number of times that X user accounts interacted with TDRA posts. This includes clicks anywhere on the post (e.g., Reposts, replies, follows, likes, links, cards, hashtags, embedded media, username, profile photo, post expansion).

## Appendix 7: Key Metrics for TDRA's LinkedIn Profile

### Total LinkedIn Followers, Posts, and Likes/Reactions from Q4 FY 2021/22 to Q1 FY 2023/24



### Comparison of LinkedIn Metrics for Q1 FY2022/23 and Q1 FY 2023/24

Metric	Q1 2022-23 Sept 1- Nov 30	Q1 2023-24 Sept 1- Nov 30	Percent Change %
Total followers	466	646	39%
Total posts	41	52	27%
Total post likes/reactions	156	173	11%

#### Metric Glossary:

1. Total followers: Total number of LinkedIn user accounts that follow the TDRA account.
2. Total posts: Number of times the TDRA made an original post on the TDRA LinkedIn page (i.e., excluding shares).
3. Total post likes/reactions: Total number of times LinkedIn user accounts liked or used an available LinkedIn reaction on TRDA posts.

## Appendix 8: Preliminary YouTube Analytics

Metric	Q4 2022/23 June-Aug, 2023	Q1 2023/24 Sept-Nov, 2023	Change
Views	5,400	13,000	141%
Watch time (mins)	168	491	192%
New subscribers	27	46	70%
Total subscribers (end of period)	54	100	85%

## Appendix 9: TDRA Newsletter Analytics 2023

Metrics	Jan 23	Feb 23	Mar 23	Apr2 3	May 23	Jun 23	July2 3	Aug 23	Sept 23	Oct 23	Nov 23	Dec 23	Industry Compar- ison
Open Rate (%)	54.2	44.5	47.6	54.9	55.0	46.2	46.3	45.0	38.0	47.8	46.0	40.7	38.0
Click Rate (%)	6.7	5.5	8.8	18.2	21.0	6.4	6.9	4.1	4.6	6.5	6.3	5.9	5.8
Unsubscribe rate (%)	0	0	0.8	0.2	0.4	0.2	0	0	0	0	0.28	0.41	0.4
New subscribers	4	43	4	19	8	18	2	3	28	2	159	11	N/A
Total opens	242	218	233	281	285	249	250	245	220	274	336	302	N/A

### Metric Glossary:

1. Open Rate: The number of emails opened by your audience divided by the total number of emails sent out, given they were successfully delivered.
2. Click Rate: Percentage that tells you how many successfully delivered campaigns registered at least one click (on any link).
3. Unsubscribe Rate: The number of people who opted out of your emails divided by the number of people who got the email.
4. New subscribers: New individuals who sign up to receive the newsletter.
5. Industry comparisons are based on Medical, Dental & Health Care category using MailChimp.

## Appendix 10: Notable Activity for TDRA's LEAP Council

- Added two new community members and the CEO of the Alzheimer Society of Toronto to the LEAP council in 2023
- Selected three new council chairs (one Lived Experience, two Scientific Co-Chairs) who will begin their terms of service in January 2024
- LEAP members reviewed and scored applications for the 2023 Temerty-Tanz-TDRA Seed Fund Competition in September 2023
- LEAP members participated in three sessions at UHN's PiPER Research Day in October 2023
- Two LEAP members reviewed and provided feedback on a TDRA plain language video describing the differences between investigator-initiated and industry-sponsored studies
- LEAP members provided feedback on TDRA's new strategic goals and directions
- One LEAP member and one Scientific Co-Chair participated in a Panel Event at the Centre for Addiction and Mental Health organized by TDRA. The panel focused on innovations in lived experience engagement in research.
- LEAP Partners on TDRA-Affiliated Studies:
  - **INSPIRE-D Study:** A LEAP member is actively engaged as a lived experience partner on the integrated knowledge translation (iKT) piece of the INSPIRE-D study. They co-chair meetings, participate in an advisory capacity, and will help with reporting in the KT stage.
  - **VR SIM CARERS:** LEAP members participated in a caregiver/care partner consultation session for a project that aims to adopt the CARERS program into virtual reality (VR).
  - **Mechanisms of Cognitive Reserve in Late-Life Depression:** A LEAP member acted as a Lived Experience Advisor for a Canadian Institutes of Health Research (CIHR) grant application examining the links between depression and cognitive impairment. They will have the opportunity to continue in their advisor role should the grant be awarded.

**Appendix 11: TDRA Workshop: Neuromodulation for Neurocognitive Disorders Agenda and Summary Participant Survey Results**

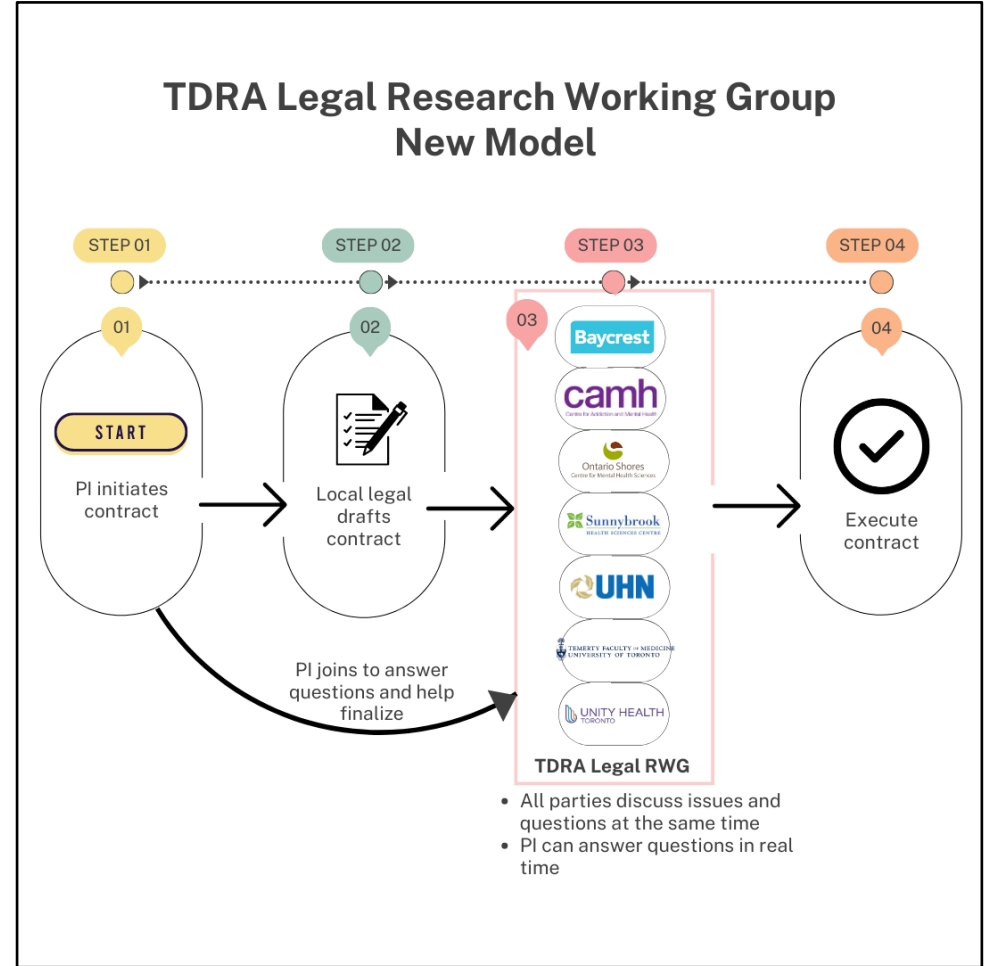
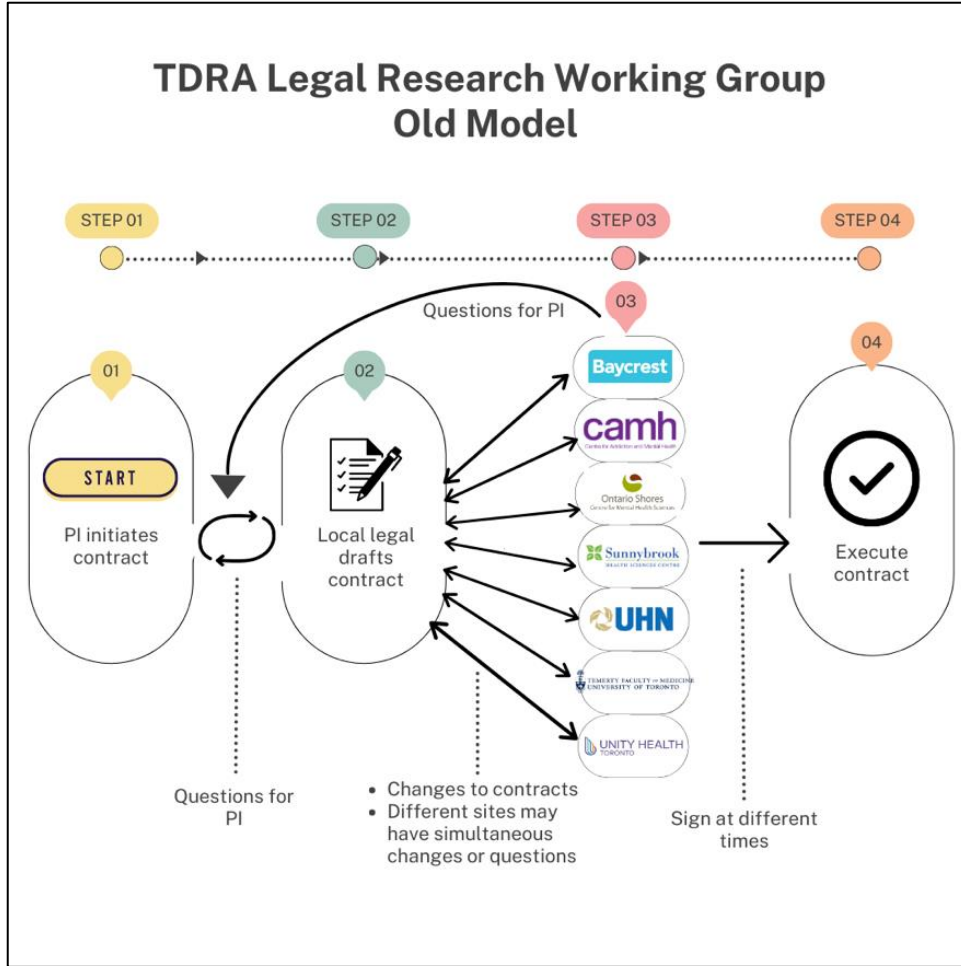
<b>TDRA WORKSHOP: NEUROMODULATION FOR NEUROCOGNITIVE DISORDERS (NOV 1, 2023)</b>		
<b>TIME (ET)</b>	<b>SESSION</b>	<b>CHAIR/PRESENTER</b>
8:00 am	Registration, Breakfast, and Networking	-
8:30 am	Introduction/Welcome Notes	Dr. Trevor Young Dr. Tarek Rajji
<b>SESSION 1: CLINICAL SCIENCE</b>		
8:45 am	Session Introduction	Dr. Tarek Rajji
8:50 am	Why is brain stimulation beneficial? The excitatory-inhibitory balance hypothesis	Dr. Jed Meltzer
9:30 am	Focused ultrasound as a neuromodulation tool	Dr. Kullervo Hynynen
10:10 am	Could repetitive transcranial magnetic stimulation (rTMS) modulate the motoric-cognitive risk syndrome (MCR)?	Dr. Amer Burhan
10:50 am	Morning Break	
11:00 am	Photobiomodulation and neurodegeneration: Shedding a light	Dr. Corinne Fischer
11:40 am	The PACT-MD randomized clinical trial: Prevention of Alzheimer’s dementia with cognitive remediation plus transcranial direct current stimulation in mild cognitive impairment and depression	Dr. Tarek Rajji
12:20 pm	Technologies for studying and effecting deep brain stimulation	Dr. Taufik Valiante
1:00 pm	Lunch Break and Poster Session	
<b>SESSION 2: METHODOLOGY &amp; BASIC SCIENCE</b>		
2:30 pm	Session Introduction	Dr. Tarek Rajji
2:35 pm	Design and conduct of complex innovative trials for neurocognitive disorders	Dr. Clement Ma
3:15 pm	Optimizing stimulation to enhance activation of prefrontal cortex	Dr. Evelyn Lambe
3:55 pm	Afternoon Break	
4:05 pm	Distinct synaptic plasticity mechanisms induced by different patterns of theta burst stimulation in the rodent hippocampus	Dr. Graham Collingridge
4:45 pm	Neuronal and glial stimulation induced by blood-brain barrier modulation with focused ultrasound	Dr. Isabelle Aubert
5:25 pm	Closing Remarks	Dr. Tarek Rajji
<b>SUMMARY PARTICIPANT SURVEY RESULTS:</b>		
<b>Key Feedback/Metrics</b>		
<b>based on rating scale from 1 (strongly disagree or poor) to 5 (strongly agree or excellent)</b>		
<b>Overall rating of workshop content and learning impact: 4.3</b>		
<b>Overall rating of workshop speakers: 4.5</b>		
<b>Overall rating of workshop logistics: 4.9</b>		

## Appendix 12: Research Working Group Members

<b>Basic Science</b> Graham Collingridge Chaitali Desai John Georgiou Evelyn Lambe Tarek Rajji	<b>Memory Clinics Standardization</b> Sandra Black Bradley Buchsbaum Howard Chertkow Morris Freedman Sean Hill Sanjeev Kumar Tarek Rajji Stephen Strother David Tang-Wai
<b>Caregiving</b> Mary Chiu Kristina Kokorelias Kari Quinn-Humphrey Joel Sadavoy Adriana Shnall Sophie Soklaridis Lynn Zhu	<b>Neuroimaging</b> Sandra Black David Bogart Corinne Fischer Sanjeev Kumar Alan Moody Christopher Scott Carmela Tartaglia
<b>EEG</b> Sanjeev Kumar Paul Lea Andrew Lim Mary McAndrews Tarek Rajji Eugenie Roudaia Allison Sekuler Richard Wennberg	<b>Neuropathology</b> Andrew Gao Julia Keith Gabor Kovacs David Munoz
<b>Equity, Diversity and Inclusion</b> Craig Bryan Orrisha Denbow-Burke Corinne Fischer Cathy Fournier Linda Mah Notisha Massaquoi Mireille Norris Tameika Shaw	<b>Neuropsychology</b> Jennifer Rabin Mary-Pat McAndrews Melanie Cohn Keera Fishman Susan Vandermorris.
<b>Fluid Biomarkers</b> Ana Andrezza Fang Liu Joanne McLaurin Walter Swardfager Carmela Tartaglia Erica Vieira	<b>Neurostimulation</b> Howard Chertkow Kullervo Hynynen Suneil Kalia Sanjeev Kumar Nir Lipsman Jed Meltzer Tarek Rajji
<b>Genetics</b> James Kennedy Mario Masellis Ekaterina Rogaeva	<b>Neurotechnology</b> Amer Burhan Chaitali Desai Andrea Iaboni Andrew Lim Abhishek Pratap Allison Sekuler
<b>Long-Term Care</b> Peter Derkach Anuroop Duggal Corinne Fischer Morris Freedman Sanjeev Kumar Frank Palmer Gillian Strudwick Clement Ma Krista Lanctot	<b>Open Science</b> Bradley Buchsbaum Sean Hill Paul Lea Donna Rose-Addis



**Appendix 13:** Comparison of the legal processes in research—Old Model vs. New Model with efficiency gains from the TDRA Legal Research Working Group



## Appendix 14: Metrics and Feedback from Accredited Courses on TDRA's Standardized Imaging Protocol

<b>Update on the diagnosis and treatment of dementia: The role of imaging, new treatments, current research studies and potential future diagnostic markers</b>			
<b>May 12, 2023</b>			
<b>Target Audience: Primary Care Physicians</b>			
<b>Duration</b>	<b>Session Title</b>		<b>Speaker</b>
30 min	<b>Session 1:</b> Overview of Neurodegenerative Diseases		<b>David Tang-Wai (UHN)</b>
30 min	<b>Session 2:</b> Radiological assessment of dementia: A standardized approach		<b>Carmela Tartaglia (UHN)</b>
30 min	<b>Session 3:</b> Update on dementia treatments: Current options and progress		<b>Carmela Tartaglia (UHN)</b>
15 min	<b>Session 4:</b> Emerging diagnostics to support dementia diagnoses		<b>Carmela Tartaglia (UHN)</b>
10 min	<b>Session 5:</b> Supporting a patient's search for clinical trials		<b>Luca Pisterzi (TDRA)</b>
<b>Registrants</b>	<b>Attendees</b>	<b>Accreditation Letters Issued</b>	<b>Revenue Generated</b>
81	76	73	\$5775.00
<b>Key Feedback/Metrics:</b>			
<ul style="list-style-type: none"> <li>- Post-event polling revealed that over 91% of respondents intended to make changes to their practice, including consistently ordering MRI for patients, looking at radiology reports more closely through a newly informed lens, and implementing additional cognitive screening measures.</li> <li>- Attendees from 7 different provinces and as far away as California.</li> </ul>			

<b>Radiological assessment of dementia: a standardized MRI protocol and report</b>			
<b>June 23, 2023</b>			
<b>Target Audience: Radiologists</b>			
<b>Duration</b>	<b>Session Title</b>		<b>Speaker</b>
25 min	<b>Session 1:</b> Overview of Neurodegenerative Diseases		<b>Carmela Tartaglia (UHN)</b>
25 min	<b>Session 2:</b> MR protocol and standardized report in patients with cognitive complaints		<b>Paula Alcaide-Leon (UHN)</b>
25 min	<b>Session 3:</b> The neurologist and the radiologist discuss dementia reporting		<b>Paula Alcaide-Leon and Carmela Tartaglia (UHN)</b>
5 min	<b>Session 4:</b> Dementia Report Simulator Overview		<b>Paula Alcaide-Leon (UHN)</b>
75 min	<b>Session 4 (Continued):</b> Interactive Learning: Simulated review with feedback of 10 sample cases with various confirmed structural pathologies and diagnoses.		<b>Registered Learners</b>
50 min	Interactive Learning: Ensemble review of simulated cases and results, and reflection led by Drs. Alcaide-Leon and Tartaglia.		<b>Paula Alcaide-Leon and Carmela Tartaglia (UHN)</b>
<b>Registrants</b>	<b>Attendees</b>	<b>Accreditation Letters Issued</b>	<b>Revenue Generated</b>
39	52	31	\$5500.00
<b>Key Feedback/Metrics:</b>			
<ul style="list-style-type: none"> <li>- &gt; 90% of post-event survey respondents were encouraged to consider changes in their practice as a result of this program, such as: using the standard MRI and structured reporting template, using the scales discussed in the course, making an effort to report dementia more accurately and paying closer attention to dementia-specific changes (<i>i.e.</i>, atrophy).</li> <li>- Attendees from 5 different provinces and as far away as New South Wales, Australia</li> </ul>			