

# Toronto dementia research alliance (TDRA) dementia clinical-research platform: An example of research embedded into clinical care

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## Abstract

**Background:** Dementia is arguably the greatest looming global public health challenge facing today's society and represents an international crisis as the number of affected persons will triple by 2050. Contributing to morbidity of dementia is the presence of combined pathologies, such as Alzheimer's disease (AD), cerebrovascular disease (CVD) and Parkinson's disease (PD). To address this challenge, the TDRA - a collaboration of the University of Toronto's Faculty of Medicine with four University-affiliated tertiary memory clinics - created an electronic platform for research studies embedded in clinical care through development of a unified approach for diagnosis and charting of the natural history of pure and mixed dementias, along with the impact of co-occurring disorders.

**Method:** A detailed clinical intake form and cognitive testing (for mild-to-severe impairment) were created through a collaboration among behavioural neurologists, geriatricians and geriatric psychiatrists. These measures are captured electronically at point-of-care and, simultaneously, the deidentified information uploaded to a central research server (see Figure 1).

**Result:** After approximately 1 year since collecting information, 1182 new patients (622 women; 560 men) have been evaluated - 119 AD; 76 concussion; 20 CBS; 8 delirium; 2 MBI, 278 MCI, 42 mixed AD and CVD; 16 PSP; 1 MSA-P, 16 PD, 17 PD-MCI, 21 PDD; 32 DLB; 24 bvFTD; 7 lvPPA, 13 nfPPA; 12 svPPA, 136 with primary and/or comorbid psychiatric disease; 165 subjective cognitive impairment; 93 VCI; 18 normal cognition; and 18 dementia NYD. Each of these patients have some demographic and clinical details, such as comorbid psychiatric and/or medical disorders, and cognitive testing obtained for research.

**Conclusion:** The TDRA Dementia Clinical-Research Platform is a practising example of research embedded into clinical care with over 1000 new patients with diverse diagnoses evaluated in 1 year and may represent the types of dementia seen in Toronto and surrounding areas. A letter, based on the clinical intake form, is being programmed

to send back to the referring physician and will enhance clinical care, along with scores and graphic display of the cognitive testing results.

Figure 1: Flow diagram of TDRA platform and integration in clinical care.

**Colour Key:**

- BLACK** – patient flow
- BLUE** – advantages of the platform
- GREEN** – capabilities of the database

Elimination of manual entry of data into a database which prevents errors, duplicative work, saves time, and is more efficient

Electronic capture of the data at each clinic/site entails a:

- Unique randomly-generated identification number (GUID) is created for de-identified data sent to a research server
- Identified data remains at the clinic/site's secure research server, Ontario Brain Institute's BrainCode.

The *current* digital "dashboard" (graphic below) provides up-to-date information of patients seen at any of the TDRA memory clinic including:

- Number of patients
- Gender
- Area code
- Diagnoses including confounding medical and/or psychiatric disorders
- Primary language
- Years of education
- Results of cognitive testing



To be completed by the end of 2020: The rest of the clinical intake form including symptoms, chronology, examination results and other investigation results be programmed.

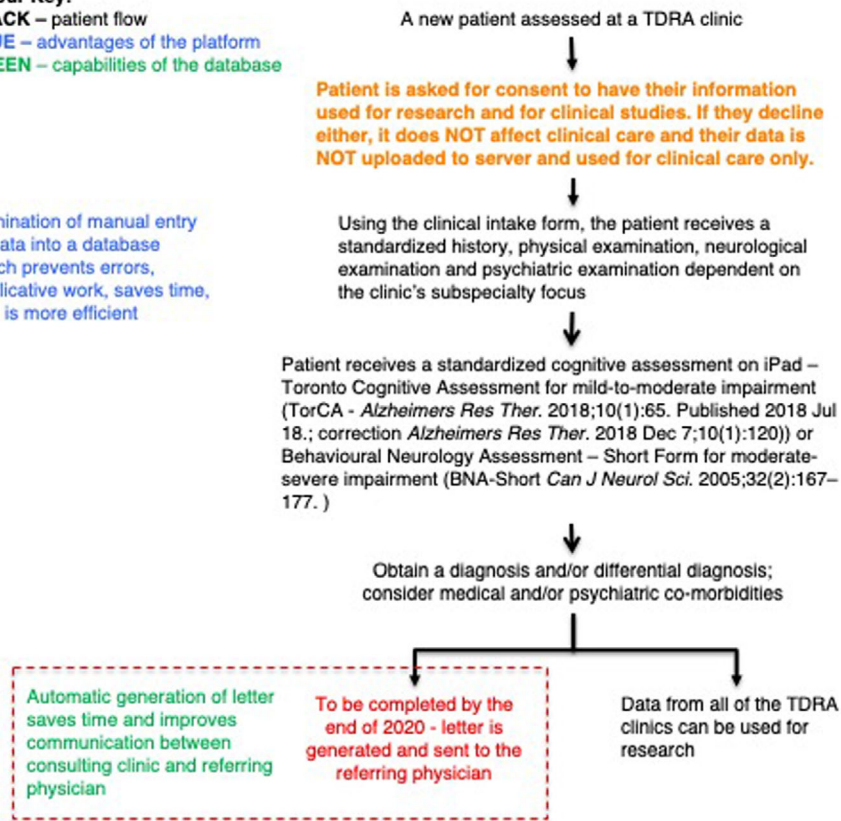


FIGURE 1