



## Ethical, Legal and Social Implications

### Past achievements:

During Phase I of CCNA, under the leadership of Dr. Serge Gauthier (Chair, Dr. Julie Robillard: Co-chair), the ELSI team conducted high-impact, high-visibility research in the following areas:

#### Patient engagement in research & research ethics

Sample publications:

- Robillard, J.M., Feng, T.L. (2017) When patient engagement and research ethics collide: lessons from a dementia forum. *Journal of Alzheimer's Disease*, 59(1):1-10.
- Tam, M.T., Gauthier, S., Ng, K.P., Everett, F., Robillard, J.M. (2019) Facilitating recruitment for dementia research: insights from an international panel. Under Review, *Dementia*.
- Kabacinska, K., Sharma, N., Kaye, J., Mattek, N., Kuzeljevic, B., Robillard, J.M. (2019) Investigating the concept of participant burden in aging technology research. Under Review, *BMC Geriatrics*.
- Gauthier, S., Robillard, J.M., de Champlain, J. (2017) Progress in transnational scientific and ethics review: Commentary on the proposal for a single North American review board for research on dementia. *Alzheimer's & Dementia*, 1-2.

#### Informed consent and data sharing

Sample publications:

- Adrian Thorogood, Anna Mäki-Petäjä-Leinonen, Henry Brodaty, Gratien Dalpé, Chris Gastmans, Serge Gauthier, Dianne Gove, Rosie Harding, Bartha Maria Knoppers, Martin Rossor, Martin Bobrow, Consent recommendations for research and international data sharing involving persons with dementia, *Alzheimer's & Dementia*, Volume 14, Issue 10, 2018, Pages 1334-1343.

#### Ethical issues in assistive technology for dementia research and care

Sample publications:

- Robillard, J.M., Wu, J.M., Feng, T.L., Tam, M. (2019) An ethical analysis of dementia technology policies. In Press, *Journal of Alzheimer's Disease*.
- Robillard, J.M., Cleland, I., Hoey, J., Nugent, C. (2018) Ethical adoption: a new imperative in the development of technology for dementia. *Alzheimer's & Dementia* 14(9):1104-13.
- Robillard, J.M., Hoey, J. (2018) Emotion and motivation in cognitive assistive technologies for dementia. *IEEE Computer*, 51(3):24-34.

- Gold, M., Amatniek, J., Carrillo, M.C., Cedarbaum, J.M., Hendrix, J.A., Miller, B.B., Robillard, J.M., Rice, J.J., Soares, H., Tome, M.B., Tarnanas, I., Vargas, G., Bain, L.J., Czaja, S.J. (2018) Digital technologies as biomarkers, clinical outcomes assessment and recruitment tools in Alzheimer's Disease Clinical Trials. *Alzheimer's & Dementia: Translational Research and Clinical Implications* 4:234-42.
- Teipel, S., Konig, A., Hoey, J., Kaye, J., Kruger, F., Robillard, J.M., Kirste, T., Babiloni, C. (2018) Home-based pervasive information and communication technology provides real world evidence for future clinical trials in dementia. *Alzheimer's & Dementia* 14(9):1216-31.
- Konig, A., Francis, L.E., Joshi, J., Robillard, J.M., Hoey, J. (2017) Qualitative study of affective identities in dementia patients for the design of cognitive assistive technologies. *Journal of Rehabilitation and Assistive Technologies Engineering*, 4:1-15.

### **Ethical issues in eHealth for dementia**

Sample publications:

- Robillard, J.M., Feng, T.L. (2016) Digital health advice: quality of online articles about the prevention of Alzheimer disease. *Journal of Alzheimer's Disease*, 55:219-29.
- Robillard, J.M., Ta, M., Tam, M.T., Hayden, S., Lyle, A., Kuzeljevic, B. (2019) Online health information-seeking in older adults at risk for dementia: an exploratory survey. Under Review, *Journal of the American Geriatrics Society*.
- Robillard, J.M., Sporn, A.B. (2018). Static vs interactive online resources about dementia: a comparison of readability scores. *Gerontechnology*, 17(1):29-37.

### **Ethical issues in computerized assessments for dementia**

Sample publications:

- Robillard, J.M., Illes, J., Arcand, M., Beattie, B.L., Hayden, S., Lawrence, P., McGrenere, J., Reiner, P.B., Wittenberg, D., Jacova, C. (2015) Scientific validity and ethics of online tests for Alzheimer disease. *Alzheimer's Disease and Dementia: Diagnosis, Assessment and Disease Monitoring* 1(3):281-8.
- Robillard, J.M., Lai, J.A., Wu, J.M., Feng, T.L., Hayden, S. (2018) Patient perspectives on the experience of computerized cognitive screening in a clinical setting. *Alzheimer's & Dementia: Translational Research and Clinical Implications* 4:297-303.

### **Suicide and assisted dying in dementia**

Sample publications:

- Diehl-Schmid, J., Jox, R., Gauthier, S., Belleville, S., Racine, E., Schüle, C. Richard-Devantoy, S. (2017). Suicide and assisted dying in dementia: What we know and what we need to know. A narrative literature review. *International Psychogeriatrics*, 29(8), 1247-1259.

In addition to scholarly work, ELSI Committee members engaged with the national dementia community through public presentations, panels and events. Examples include a panel on patient engagement in dementia research at the Alzheimer Disease International meeting in Chicago in 2018, a public event on medical aid in dying by CCNA ELSI member Jennifer Chandler as part of Brain Awareness Week (2018), and a number of outreach events in communities across the country.