

WORKING TOGETHER TO END DEMENTIA

OCTOBER 13, 2020 (PRE-EVENT)
SESSION DESCRIPTIONS AND SPEAKER BIO

Learning from and working with participants in ELSI: the experience of the European Prevention of Alzheimer's Dementia project

With guest speaker Richard Milne, Julie Robillard and John Fisk, presenters

This presentation describes the work of the ethics workgroup within the European Prevention of Alzheimer's Dementia (EPAD) project, a five-year public-private collaboration to establish a platform for clinical trials in Alzheimer's disease. The EPAD project contacted participants from memory clinics and existing research studies to take part in a deep-phenotyped longitudinal cohort to facilitate rapid recruitment for an adaptive clinical trial platform. From an ELSI perspective, specific challenges were presented by the mode of recruitment, the focus on early and asymptomatic stages of disease and the disclosure of AD risk information, and the intensity of research participation. I present the findings of studies and activities that aimed to work with EPAD participants to address these challenges. Finally, I draw out the lessons from our experience for ELSI activities in large-scale AD research.



Dr Richard Milne is Senior Social Scientist in the Society and Ethics Research Group at the Wellcome Genome Campus and Senior Visiting Research Fellow in the Department of Public Health and Primary Care at the University of Cambridge. His research focusses on social and ethical questions associated with the development of new medical technologies, particularly related to dementia and genomic medicine. He co-leads the ELSI theme within the Cambridge Centre for Public Health, and ELSI work within the IMI EPAD and Early Detection of Neurodegeneration (EDoN) projects. He is currently working on a Wellcome Trust-funded study of how experts and members of the public address ethical questions associated

with the development of data-driven tools for the detection of cognitive decline.

What can ELSI do for me? Exploring the ethical, legal, and social implications of CCNA dementia research

Trainee workshop with Julie Robillard and John Fisk, leaders

This interactive session is divided into three sections: 1) Overview of the key ethical, legal, social implications (ELSI) of dementia research taking place across the CCNA, including basic research using a variety of models, translational research, and technology research; 2) Trainee perspective on the challenges and rewards of ELSI research, including insights on how to engage in a meaningful and ethical manner with persons with lived experience; 3) Practical information about integrating ELSI in your own work: identifying knowledge gaps, handling research ethics, finding funding and collaborators.



Dr. Julie Robillard is an Assistant Professor of Neurology at the University of British Columbia (UBC), Scientist in Patient Experience at BC Children's and Women's Hospital (C&W) and Faculty member of Neuroethics Canada. She leads the Neuroscience, Engagement and Smart Tech (NEST) lab and oversees a range of initiatives related to patient experience research at C&W. Dr. Robillard brings her background in neuroscience and biomedical ethics to the evaluation and development of novel technologies to support brain health across the lifespan. A particular interest of her research is the integration of emotion modeling in a wide range of technologies, from eHealth resources to mobile apps. More recently, she has secured one of the inaugural New Frontiers in Research grants to implement emotional alignment algorithms into social robotics. Together with her team and through international interdisciplinary collaborations, she is exploring co-creation processes, development and applications of social robots in both older adult and youth populations. Dr. Robillard is passionate about patient engagement and in her role as a Scientist in Patient Experience she is working with a number of groups at C&W and UBC to advance the capture, analysis and improvement of patient experience in both research and care. She is interested in using technology to provide novel means of engagement and patient experience evaluation strategies. Dr. Robillard holds provincial, national and international leadership roles: she is Chair of the Ethical, Legal, Social Impacts Committee of the Canadian Consortium on Neurodegeneration in Aging, a member of the Technology and Dementia Executive Committee of the International Society to Advance Alzheimer's Research and Treatments, and a member of the Board of Directors of the Medical Device Development Centre of British Columbia, among others.



John Fisk has been a clinical Neuropsychologist with the Nova Scotia Health Authority since 1985 and holds academic appointments at Dalhousie University in the Departments of Psychiatry, Medicine (Division of Geriatric Medicine) and Psychology and Neuroscience. He has 10 years' experience as a member and Chair of the Camp Hill Medical Centre Research Ethics Board. He contributed to the Alzheimer Society of Canada Ethical Guidelines (1997), the National Placebo Working Committee Report on the appropriate use of placebos in clinical trials in Canada (2004), as well as the Third CCCDTD Conference recommendations for disclosure of the diagnosis of dementia, and for decision making for treatment and research participation (2007). His clinical and research programs are focused on persons with neurodegenerative and immune-mediated inflammatory disorders. He is currently Co-Lead of the CCNA ELSI program.