DATA SHARING: PERSPECTIVES OF THE CANADIAN CONSORTIUM ON NEURODEGENERATION IN AGING (CCNA)

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Chair, CCNA ELSI Committee
Mise-en-contexte: CCNA

- The CCNA is a CIHR and multi-partners funded five-year study which includes a cohort of 1600 subjects with various levels of cognitive impairment (SCI, MCI, dementia) and etiologies (AD, DLB, FTD, PD)
Access to data

• The CCNA is planning to share data from its cohort study, one year after the primary investigators have had a chance to analyze the data in order to test their initial hypothesis

• A data sharing agreement is being finalized in order to facilitate access to data while preserving anonymity
Access to biosamples

• The CCNA is planning to share aliquots from biosamples (CSF, blood, saliva, stools).

• A biosamples sharing agreement is being finalized in order to facilitate access while preserving anonymity and to insure best use for finite amounts of non-replaceable specimens.
Issues for discussion

• Should participants be told of “clinically meaningful findings” from their samples?
• Can/should we contact them in the future if practice guidelines change?
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• Can/should we contact them in the future if clinical practice guidelines (CPG) change?
  Sub-committee of the ELSI committee will monitor changes in CPG
CURRENT MEMBERSHIP OF CCNA ELSI COMMITTEE

• Lynn Beattie
• Jennifer Chandler
• Johane De Champlain
• John Fisk
• Serge Gauthier

• Theresa Green
• Judy Illes
• Kristen Jacklin
• William Lacy
• Mario Masellis
• Julie Robillard
ETHICAL CONSIDERATIONS TOWARDS DISCLOSURE OF INDIVIDUAL RESULTS IN OBSERVATIONAL STUDIES

• Poster at 2016 INS Annual Meeting, San Diego, mid-November
• S Gauthier, J De Champlain, M Massellis
• Issue of “right to know” vs “do no harm” when individual results have uncertain clinical meaningfulness (CM)
• Proposal for COMPASS consent form to allow for future contacts as CM evolves over time
ETHICAL ISSUES IN BIG DATA DEMENTIA RESEARCH

• Part of a new CIHR *BRAIN* grant
• Review of relevant literature
• Discussion at ADI Annual Congress in Kyoto April 2017 with input from multiple countries
• Symposium at combined ADI-AAIC Chicago July 2018