

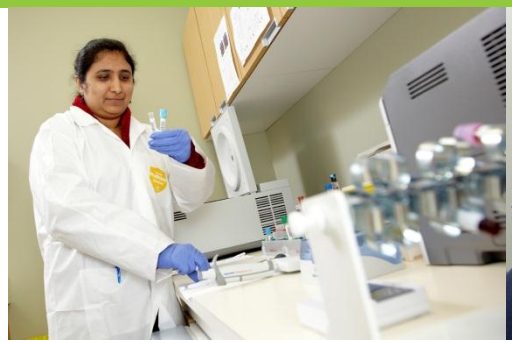
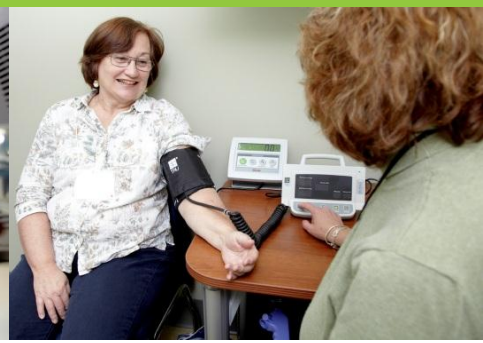

Participation in longitudinal studies in the face of cognitive decline: Identifying and addressing cognitive decline in the Canadian Longitudinal Study on Aging

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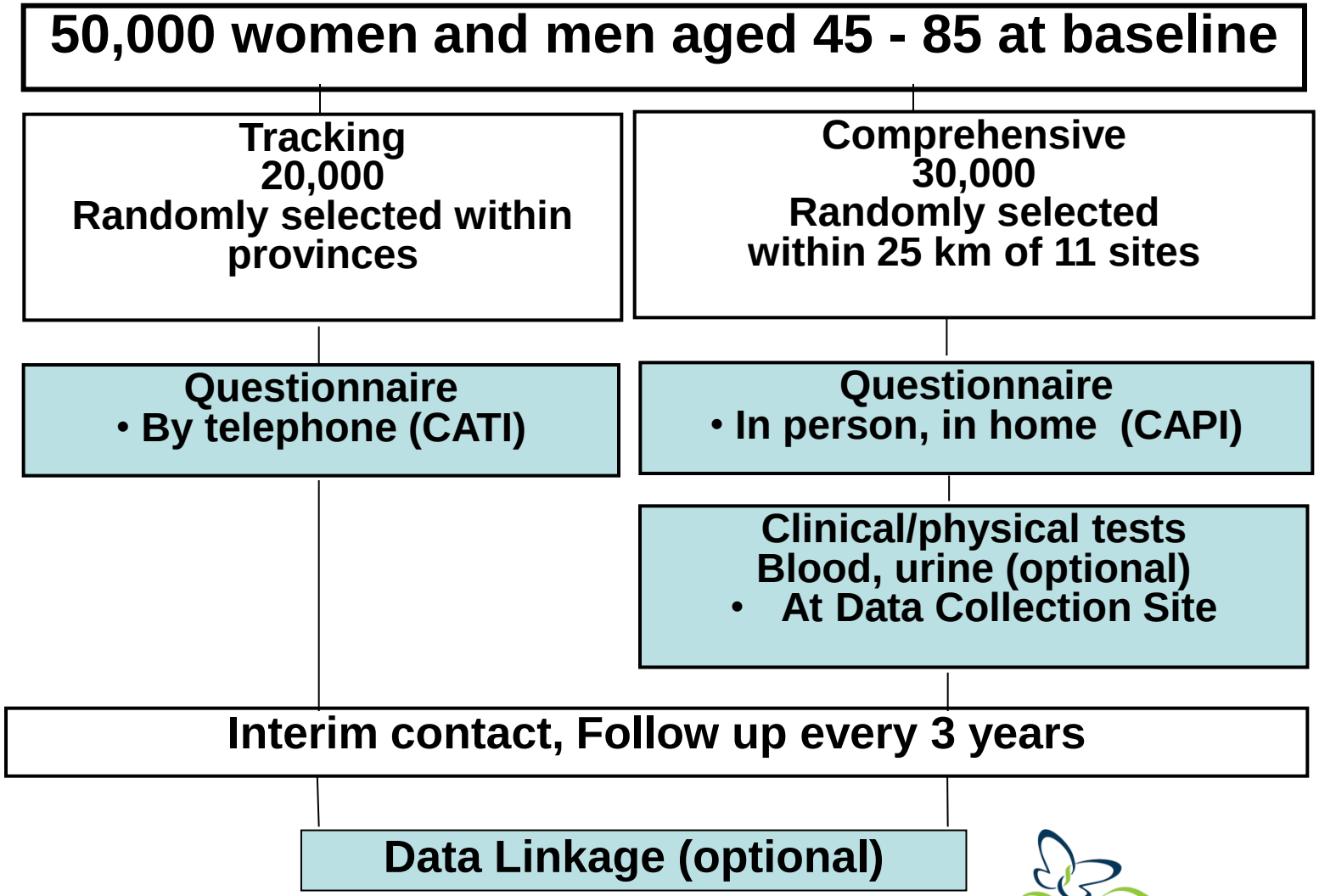
The Challenge

- Longitudinal studies, particularly those that target an aging population, must consider participation in the face of cognitive decline
- The CLSA will follow 50,000 Canadians for 20 years
- Involves initial and ongoing participation
- An ethical issue: informed consent requires competence
- A practical issue: meaningful data collection requires cognitive ability

CLSA Study Overview



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Representative Sample Frame for Recruitment

- Statistics Canada: CCHS 4.2 Healthy Aging Survey
- Health Ministries: Health Insurance Card registration databases
- Random Digit Dialing

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Development Phase: Literature Review (CJA 2009)

- Review of telephone-administered cognitive screening tools
- Medline to 2007, English and French
- 12 telephone screening tools identified
- Conclusion: no cognitive screening tool appropriate for a population based study of community dwelling older adults of such a wide age range (45-85)
- General review of literature provided no guidance on standardized protocols for determining cognitive impairment over time

CLSA:
Informed Consent at Study Entry

- Eligibility Criteria: all participants community dwelling, cognitively intact at baseline
- Followed Statistics Canada protocol used in CCHS
- Interviewers trained regarding informed consent
- Requires level of cognitive competence to complete and return Consent to Contact form, arrange home visit over the phone
- Participants required to understand the study, their commitment
- Interviewer review of information package
- Signed, informed consent

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Consider the Future: Proxy Consent

- Participants age 70 or older at baseline, or when they turn age 70, complete a proxy consent
- Indicate future wishes re participation in the CLSA should they be unable to participate on their own
- Provide name, contact information of proxy decision maker, proxy information provider

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From the CLSA Information Package…

What happens if I am no longer able to make decisions or answer questions for myself as I get older?

- The CLSA would like to know about all aspects of the aging process.
- If you are aged 70 or older now (or when you reach age 70) we will ask you to provide the name of another person(s), such as a spouse, adult child or legal guardian. This person(s) will be able to answer questions on your behalf or make decisions for you, such as withdraw you from the study.
- There will be a separate consent package for the process for identifying this person(s).
- Information already collected from you will stay as a part of the CLSA records and be kept for research purposes.

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Participant Proxy Consent

Should I become unable in the future to take part in the CLSA on my own:

- I would like my proxy information provider to continue to answer the research questions asked by an interviewer on my behalf. *Yes / No*
- I would like to continue to do the physical tests as long as it is feasible. *Yes / No*
- If I have agreed to give blood and urine:
  I would like to continue to give blood and urine. *Yes / No*
- If I have agreed to give my health card number:
  I would like to continue to have my information collected by the CLSA linked with information about me in health care records. *Yes / No*

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Beyond baseline: Identifying cognitive decline / flagging cognitive impairment

- Potential data for flagging / decision making at Wave 2:
  - Interviewer and/or participant and/or proxy judgement
  - Self-reported memory problems, AD diagnosis at baseline
  - Scores from validated tests of memory and executive function at baseline

Validation of cognitive functioning categories in the CCHS (HR 2010)

- Four measures of cognitive functioning – immediate and delayed recall (memory), animal-naming and the Mental Alternation Test (executive functioning) -- were coded into five categories
- Validated associations with health outcomes: self-reported general and mental health status, memory and problem-solving ability, activities of daily living, life satisfaction, loneliness, and chronic conditions
- Supports the use of five levels of cognitive functioning for the outcomes examined overall and by age group (45 to 64, 65 or older) and language group (English, French)

Initiating the process from participant to proxy

- Proxy not contacted until required
- Participant informs CLSA / CLSA raises with participant
- Proxy receives participant wishes, study information package, proxy consent
- Proxy provides ongoing consent, information, as appropriate

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Potential Challenges

- Scoring cognitive tests between waves
- Flag based on changing levels of cognitive function or lowest level of cognitive function
- Flag based on 1, 2, 3, or 4 tests
- Use of additional cognitive tests in Comprehensive
- Flag based on 1, 2, or 3 criteria
- Can have evidence of cognitive decline and impairment and still be cognitively competent

Strengths

- Standardized protocol
- Advanced expression of participant wishes
- Increased follow up of participants
- Minimizes loss of valuable information, including outcome information
- Can serve as a guide to other longitudinal studies

Acknowledgements

- Psychology Working Group
- CIHR ELSI Advisory Committee to the CLSA

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