

# The Canadian Longitudinal Study on Aging: Recruitment and Retention

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## Recruitment

- Creating awareness through
  - Public Relations Strategies (general public and community groups) including the input of Canadians concerning participation in a longitudinal, population-based study
- Identifying Participants by
  - Possible alternative sample frames
    - Creating partnerships with Statistics Canada
    - Investigating the possibility of releasing participant coordinates in the Canadian Community Health Survey
    - Contracting with firms
    - Random Digit Dialing
  - Accessing provincial health data bases (soliciting input from data stewards and privacy commissioners)
- Targeting the Population
  - Eligibility Criteria
    - Women and men aged 40 to 84 at baseline
    - Community dwelling at baseline
    - Screening for capacity to provide informed consent (Development and evaluation of tools to screen for cognitive impairment)
  - Informed Consent: Complexity of informed consent
    - Identifying the optimal consent process for the CLSA: partial at baseline or global consent
    - Presentation of the form: options
      - One form
      - Divided into several forms (i.e.: 1) Main participation, 2) Clinical Assessment, 3) Linkage)
      - Form does not matter
    - Content of Consent Form
      - Basic points of the study and participant involvement OR
      - Basic points of the study and participant involvement and detailed information about each component
    - Data Linkage and data storage
      - Strategies to enhance data linkage with health care utilization data bases and disease registries
      - Feasibility of proposed blood and urine sample collection/shipping/storage and analysis strategies

I agree to:	YES	NO	Comments
1) Participate in the CLSA study	<input type="checkbox"/>	<input type="checkbox"/>	
2) Complete health related questionnaires	<input type="checkbox"/>	<input type="checkbox"/>	
3) Participate in a face-to-face interview (1 hour)	<input type="checkbox"/>	<input type="checkbox"/>	
4) Complete a routine physical exam where blood and urine will be collected for routine tests	<input type="checkbox"/>	<input type="checkbox"/>	
5) Complete a neuro-psychological assessment to test aspects of your cognitive functioning (e.g. memory)	<input type="checkbox"/>	<input type="checkbox"/>	
6) Donate blood and urine for current biological test (e.g. genetic tests)	<input type="checkbox"/>	<input type="checkbox"/>	
7a) Storing my blood and urine and wish to be recontacted for permission before conducting genetic tests that may be discovered in the future	<input type="checkbox"/>	<input type="checkbox"/>	
OR			
7b) Storing my blood and urine for genetic tests that may be discovered in the future	<input type="checkbox"/>	<input type="checkbox"/>	
8) Link my information to other databases such as medical records	<input type="checkbox"/>	<input type="checkbox"/>	

### Example of Consent List at Baseline

- Renewal of consent
  - Options: 1) Yearly, 2) Every 3 years, 3) Automatic unless participants withdraws
  - Appointed substitute decision-maker provides informed consent if participant develops mental incapacity. Mental incapacity may be determined by CLSA researchers involved or by substitute decision-makers' input.
- Issues to be explored
  - Participant requirements, response burden
  - Unforeseen uses of data
  - Commercialization of results

## Retention

- Adaptive strategies
  - Substitute decision-makers
  - Tracking participants over time
  - Responding to changing participant needs e.g. mobile units for data collection
- Foster Participant Motivation
  - Personalization of Participant Communications
  - Continuity of contacts
  - Ensure convenience
  - Develop public relation strategies
  - Informing community groups about study results
  - Promote altruistic benefits and option to participate in add on studies
  - Return of study results to participants
    - Preliminary findings of a developmental study about the return of clinical information to study participants featuring ethical and legal responsibilities:
      - 75% of respondents recommended return of their individualized test results; 25% recommended no return
      - Reasons given for favoring the return of clinical information included participant retention. Ethical considerations and perceived benefits to participants were highlighted.
      - Reasons given for not favoring the return of clinical information included tests not conducted in a clinical setting, reliability too low and results not readily interpretable.

Acknowledgments: Funding was provided by the Canadian Institutes for Health Research (CIHR), Le Fonds de la recherche en santé Québec (FRSQ) - Réseau québécois de recherche sur le vieillissement, and McGill, Dalhousie and McMaster Universities.

