



CLSA Canadian
Longitudinal
Study on Aging

ELCV Étude Longitudinale
Canadienne sur le
Vieillessement

Exploring the Acceptability and Feasibility of Conducting a Large, Longitudinal, Population-Based Study in Canada

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About the Canadian Longitudinal Study on Aging

- ❖ Proposed 20 year longitudinal study of 50,000 Canadians aged 40 and older
- ❖ Funded by CIHR under the Canadian Lifelong Health Initiative
- ❖ 3 Principal Investigators at 3 institutions: Dalhousie, McGill and McMaster
- ❖ Multidisciplinary approach to studying the process of aging
 - Biological, clinical, psychological, social and economic factors will be examined



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Feasibility Phase Underway

- ❖ One of 11 studies undertaken to demonstrate the feasibility of conducting a study of this magnitude in Canada
- ❖ Other feasibility studies include:
 - The consent process
 - Collection of biological samples
 - Linkage to health databases
 - Return of clinical information to participants/physicians
 - Logistics of data collection, transmission & storage
 - Sampling frames

Goal & Objectives of Study

- ❖ To explore Canadians' beliefs and attitudes toward participating in a multi-faceted, long term study on aging
 - Provision of health, psychosocial, lifestyle and biological data
 - Willingness to participate, response burden
 - Privacy issues associated with data collection and storage, particularly biological samples, including DNA

Rationale

- ❖ Undertaking a study of this magnitude and cost requires a clear understanding of the factors that encourage or inhibit participation
- ❖ Lack of empirical data on factors that influence the decision to participate
- ❖ A better understanding of these factors will enhance recruitment and retention and improve the participant experience
- ❖ Results may be applicable to other longitudinal studies

Methodology

- Six focus groups were conducted in six locations: Halifax, Montreal, Hamilton, Winnipeg, Calgary and Vancouver
- A sample was drawn by generating random telephone numbers and comparing these to published telephone directories
- The sample included telephone numbers within a 100 km radius of each location
- Using this sampling frame the Institute for Social Research at York University conducted the recruiting



Methodology

- Twelve participants were recruited for each focus group
 - ✓ Groups were balanced by gender and age
 - ✓ All groups were conducted in English except Montreal which was conducted in French
- Focus groups ranged in size from 4 to 10 with 44 participants in total
- Participants were given \$40 to offset the cost of attending the focus groups
- All sessions were recorded and transcribed
 - ✓ The Montreal transcript was translated into English



Qualitative Analysis

- ❖ Framework analysis appropriate (Lacey & Luff, 2001)
 - Specific research questions and objectives
 - Emergent themes
- ❖ NVivo qualitative analysis software used to code transcripts
 - Themes developed by research team based on moderator guide and review of transcripts
 - Transcripts and themes entered into NVivo software
 - All transcripts coded by two staff and the results compared
 - Preliminary analysis only



Identified Themes

- ❖ Healthy aging
- ❖ Importance of research
- ❖ Bio-samples
- ❖ DNA
- ❖ Data linkage
- ❖ Unforeseen uses of data
- ❖ Benefits to participants
- ❖ Impact on participant behaviour
- ❖ Intergenerational
- ❖ Return of clinical results
- ❖ Responsibility/commercialization
- ❖ Privacy & confidentiality
- ❖ Participant requirements, response burden,
- ❖ Withdrawing from the study
- ❖ Conduct of the study

Healthy Aging

❖ Physical Factors

- Disease/freedom from disease, lifestyle and nutrition, staying active, physical independence

❖ Emotional Factors

- Attitude, enjoying life, wisdom, “feeling your age”

❖ Social Factors

- Loneliness, friends and family

❖ Other Factors

- Spiritual, Financial, Govt. Policy, Societal perceptions

“...for me what it means is being physically, mentally, emotionally and spiritually balanced”



Bio-samples/Genetics

- ❖ General willingness to provide blood and urine samples
 - Concerns: what are you using it for?
 - Adds credibility to the study
- ❖ Some concern about providing a DNA sample
 - Need to have the purpose properly explained
 - Desire for more information on analysis and storage
 - Willingness to provide sample if it helps others
 - Concerns about DNA use and access
 - ✓ Association of DNA testing with criminal investigations
 - ✓ Association of DNA with cloning
 - ✓ Access by outside parties, e.g. insurance companies

“Hopefully you’re not doing Frankenstein type stuff with my DNA”

Who Should Conduct the Research?

- ❖ Universities should conduct the study
 - Universities in general are trusted, credible
 - Dalhousie, McGill and McMaster respected
- ❖ Government should fund the research
- ❖ Concern about private funding
 - Suspicion about pharmaceutical companies
 - Concern about profit motive in a volunteer study

“I think when you put 3 names like that together across the top of your letterhead, that lends a lot of credibility, you know, McGill, McMaster, Dalhousie.”



Commercialization

- ❖ Participants asked how they would feel if study results were used as the basis for commercial products
 - Distrust of Pharmaceutical companies and profit motive
 - Acknowledgement of the potential benefits of new treatments
 - Desire that the study benefit from any discoveries that are commercialized

“...if they used the findings to develop a drug...if the price is affordable I would agree but if you give them your data and they kill you with the price then it is not right.”



Privacy and Confidentiality

- ❖ Most participants had no concerns
 - Assumption that confidentiality would be protected
 - Several participants indicated that only those with something to hide would be concerned about providing a DNA sample
 - Most concerns centered around the use of DNA
 - ✓ Information not be shared with insurance companies
 - ✓ Why do you need it
 - ✓ How would it be used
 - ✓ Who would have access to it

“...I think if the research is done by a credible group like a university, I think you can rely that they will keep it confidential.”



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Willingness to Participate

- ❖ Most participants would agree to participate
 - Altruism a major motivating factor
 - Some said they would consider participating but would want additional information about the study
 - Participants expect that the study will accommodate their needs in terms of
 - ✓ Scheduling
 - ✓ Location
 - ✓ Reimbursement
 - ✓ Information about the study and themselves

“If it is for the good of society, no problem.”



Limitations

- ❖ Representativeness of sample
 - Numerous calls were necessary to recruit 12 participants per group
 - Those willing to participate in the focus group would probably also be more likely to participate in health research
- ❖ Follow-up with a quantitative survey would give an indication of the proportion of the population willing to participate

Key Findings

- Healthy aging seen as a complex multi-dimensional process
- Participants willing to provide bio-samples but had some concerns about providing DNA
- Universities are trusted to carry out the study; Government to fund
- Participants do not feel that private companies should profit from the study results
- Most participants trust that their privacy will be protected
- Altruism is a key motivator for most participants



Contact Us

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Paper presented at the 34th Annual Scientific and Educational
Meeting of the Canadian Association on Gerontology
Halifax, Nova Scotia
October 21, 2005