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
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.”
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.”
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
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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