



CLSA Canadian
Longitudinal
Study on Aging

ELCV Étude Longitudinale
Canadienne sur le
Vieillessement

**The Canadian Longitudinal Study on Aging
(CLSA): Approach to Sampling and
Recruitment**

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Montreal, March 2006

The Canadian Longitudinal Study on Aging (CLSA)

- One component of the Canadian Lifelong Health Initiative, a strategic initiative of CIHR
 - The Canadian National Birth Cohort
 - The Canadian Longitudinal Study on Aging (CLSA)



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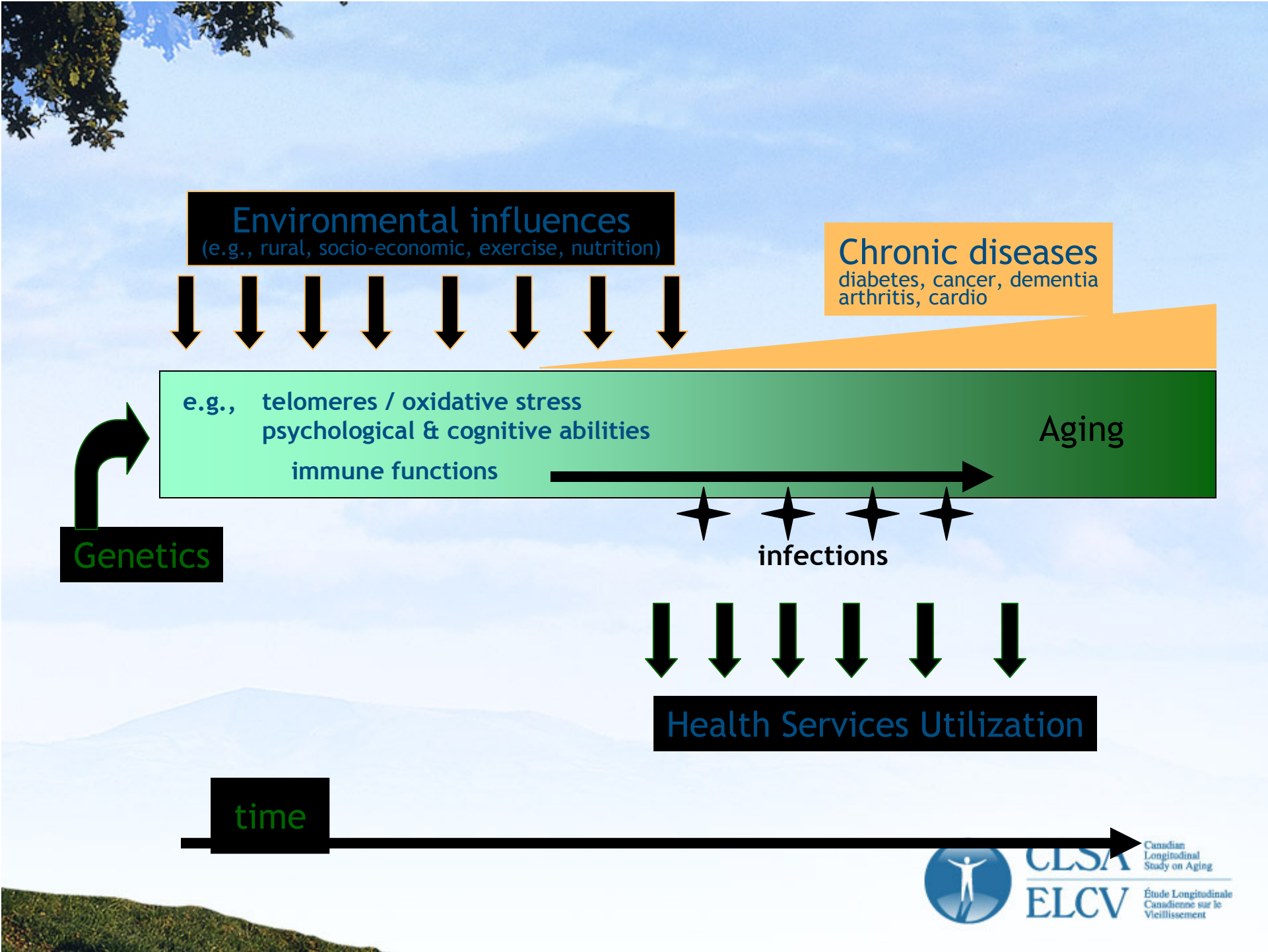
Life Course as a Framework

- Multiple contexts
- Health development as an adaptive process
- Track patterns over time
- Examine relationships between earlier factors and later outcomes
- Examine pathways, trajectories
- Quantitative traits
- Identify critical, sensitive periods in adult development
- Determine the relative contributions of multiple factors to the pathways, patterns and outcomes



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Priority Areas for CLSA

- Cardiovascular
- Brain
- Musculoskeletal
- Immune
- Metabolic
- Psychosocial and behavioral environment
- Health and social care environment
- Economic environment



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Study Design

- 50,000 individuals
- 20 year follow-up
- Women and men aged 40 and over at baseline
- Community dwelling at baseline
- Repeated assessment every 3 years (40-74)
- Repeated assessment every year (75+)
- Linkage to existing databases



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Study Design

- Questionnaires administered over the phone or in person to all 50,000
- Subgroup of 30,000 individuals selected to undergo in-depth “comprehensive” assessment over the course of the study
 - within a reachable distance of study sites that can support the data collection
 - able to “reassemble” the 50,000 to provide valid and reliable information on the full sample



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Sampling

- Nationally Representative versus Geographically focused
- Random versus cluster sampling
- Rural vs Urban



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Sampling Frame

- Sampling frame
 - Statistics Canada- CCHS (1)
 - Health Care Registration Data (2)
 - RDD (3)
 - Other sources (4)



Participant Recruitment

- Require sampling strategy for the recruitment of a representative sample of the Canadian population
- Statistics Canada's Canadian Community Health Survey (CCHS) identified as a survey vehicle that could provide a sample frame for the CLSA

Participant Recruitment

Two questions added to Statistics Canada's CCHS:

- Do you agree to share the information you have provided in the CCHS interview with the CLSA for research purposes?

And

- Do you agree to have your name, telephone number and address released to these researchers so that you may be contacted at a later date?



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Consent to Release Coordinates:

Objectives

- Determine the willingness of CCHS participants to share **personal coordinates** (contact information) with CLSA
- Determine the willingness of CCHS participants to share **survey responses** with CLSA
- Explore respondents' concerns in regards to their willingness to sharing either personal coordinates and/or survey responses

Consent to Release Coordinates

Methods

- Additional content related to CLSA was added to the activities of the CCHS 3.1 Pilot Test
- Qualitative testing of the questionnaire and respondent material in one-on-one interviews (25 E 10 F)
- CCHS 3.1 Pilot (summer 2004) Computer Assisted Personal Interview (n=318)
- Content focused on health issues, replicating the context in which CLSA plans to operate.



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Consent to Release Coordinates:

Results

Qualitative

- Majority of respondents did not express concern over giving their consent **HOWEVER** many did not have a clear understanding of what they were actually agreeing to do
- Unsure of who/what CLHI is

Quantitative

- Interviews conducted in Vancouver, Montreal, Halifax

Consent to Release Coordinates: Results by sex

	Males	Females	Total
Share contact info	64.7%	62.8%	63.8%
Share survey data	75.3%	76.4%	75.8%

Consent to Release Coordinates: Results by age

	40-54	55-64	65-74	75+	Total
Share contact info	63.9%	76.8%	46.7%	55.3%	63.8%
Share CCHS data	73.7%	86.6%	64.4%	73.7%	75.8%



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Consent to Release Coordinates: Results by Location

	Vancouver	Montreal	Halifax	Total
Share contact info	44.2%	78.1%	69.7%	63.8%
Share CCHS info	62.5%	90.5%	74.2%	75.8%

Consent to Release Coordinates

Caveat....

n=429	100% of eligible sample
n=319	74.1% of those eligible agreed to participate in CCHS
n= 298	94.9% of those who agreed to participate in CCHS agreed to share their data with the MOH
n=190	63.8% of those who agreed to share with MOH agreed to share contact info with CLSA

Therefore... 44.3% of those originally eligible agreed to share contact info



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Consent to Release Coordinates

Key Findings

- Little variation between sexes
- Considerable variation between age groups, geographic region
- Based on original eligible sample, response low
- 42% of all respondents reported no concerns or did not ask any questions in regards to the CLSA initiative
- Three most often reported concerns were confidentiality, privacy issues (16.4%), lack of interest (7.1%), and commitment issues (6.7%).



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Sampling Frame?

- In process of conducting another study with Statistics Canada this summer
- We have conducted another study to see the feasibility of using Provincial Health Care Registration databases
 - Privacy and Confidentiality concerns
 - BUT
 - Looks very promising and we will be doing a pilot study to test its feasibility



Recruitment

- Mail CLSA and recruitment package
- Telephone contact and screen for cognition
- All eligible individuals go through consent
 - Issues of consent in relation to recruitment
 - Archived data and its future use
 - Return of Information
 - Long-term commitment~at least 20 years
 - Data linkage to Secondary data bases



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Views of Canadians

Objective: To explore Canadians' beliefs and attitudes toward a multi-faceted, long term study on aging

Methods: Focus groups conducted in six Canadian cities: Vancouver, Calgary, Winnipeg, Hamilton, Montreal, Halifax

Preliminary Findings

- Healthy aging seen as a complex multi-dimensional process
- Participants willing to provide bio-samples but have 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
- General sense of enthusiasm and support



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