The Canadian Longitudinal Study on Aging Protocol Development

Parminder Raina, PhD Associate Professor & Director Evidence-base Practice Centre McMaster University, Hamilton ON



Overall Aims of the CLSA

- To examine aging as a dynamic process.
- To investigate the inter-relationship among intrinsic and extrinsic factors from mid life to older age.
- To capture the transitions, trajectories and profiles of aging: healthy/successful aging.
- To provide infrastructure and build capacity for high quality research on aging in Canada.

Conceptual Framework

- Healthy/successful aging
- Adult development, lifecourse approach
 - Critical and sensitive periods
- Adaptation

 Complexity: bio-psycho-social aspects of aging, intrinsic and extrinsic level factors, interactions

Development of Scientific Content

- Working Groups responsible for development of theme-specific content
- 30 minutes per working group as a guide
- Domains, research questions, predictors, outcomes, measures
- Guiding principles for content development: relevance, longitudinal, niche, aging

Development of Scientific Content

Working Groups

Biology Psychology Social Clinical Health Outcomes Health Services Lifestyles Methodology Leaders

Karl Riabowol Holly Tuokko Margaret Penning David Hogan Chris Patterson Kevin Brazil Hélène Payette Robert Platt

Content – Physical Functioning

- Activities of daily living/disability
- Frailty/co-morbidities
- Injuries
- Chronic diseases
 - Cardiovascular, cerebrovascular, diabetes, hypertension, PD, dementia, osteoporosis, arthritis, cancer
- Health conditions, states
 - Oral health, communication, sensory impairment, continence, endocrine function

Content – Psychological Functioning

- Cognitive functioning
- Values and meaning
- Everyday competence, adaptive functioning, coping
- Personality, emotion, psychopathology
- Psychological distress

Content – Social Functioning

- Social networks and social support
- Work to retirement transitions
- Structural inequalities
- Matters of place and mobility
- Basic social characteristics

Inter theme Content – Biology

 Biochemical, physiological, metabolic markers of aging

- Genetics of aging
 - Disease susceptibility, longevity
 - DNA repair
 - Antioxidant defence
 - Apoptosis, programmed cell death
 - Immunosenescence
 - Telomere loss
- Use of emerging technologies

Inter-theme Content (continued)

- Lifestyle
 - Nutrition
 - Alcohol/Tobacco
 - Physical activity
 - Sleep
- Quality of LifeSpirituality

- Health services
 - Medications
 - Assistive devices
 - Institutional care
 - Homecare

Pain

Study Design

- Longitudinal design
- Women and men aged 40 and over
- 50,000 individuals
- 20 year follow-up
- Repeated measurement
- Embedded studies
- Linkage to existing databases
- Eventual public access data

Reality Check

- 50,000 subjects examined clinically, interviewed, provide blood samples
- Subjects would have to be selected around major academic centres – not representative
- Expense of collection, preparation, shipping, testing and storage of 50,000 samples repeatedly over 20 years
- Need to address competing objectives

An Innovative Solution

Two sub-cohorts

- From the same sampling frame: LFS area frame
- Overlapping content
- Identical follow-up schedule
- Comprehensive CLSA (30,000)
 - Extensive testing sampled from around academic centres
- Tracking CLSA (20,000)
 - Computer assisted telephone interviews only, nationally representative
- Retains a <u>large</u> sample with:
 - Comprehensive data to answer complex analytical questions
 - Policy relevant data collection at level of province

CLSA DESIGN

Canadian Community Health Survey (CCHS): Aging Module Cross-Sectional Survey



Inter-relationship with CCHS

Two questions to be added to CCHS content:

 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?

Comprehensive Cohort Data Collection

- Six study sites within six regions
- Fasting blood samples taken at clinical assessment
- Biological samples (from blood, urine, skin) shipped to central location
- Questionnaire data transmitted to central location
- Data stored centrally
- Standard biochemical analyses processed centrally
- Specialized analyses done in labs of co-investigators

Tracking Cohort

- Computer assisted telephone interviews only
- Conducted from one coordinating centre
- Content overlap with comprehensive CLSA
- Representative at provincial level
- Essential for policy directed/relevant research
- Can be used as pool for add-on or specific embedded studies

Planned Study Structure

3 Coordinating Centres

Dalhousie:

- Tracking CLSA
- CATI Centre

McMaster

Comprehensive CLSA

Bio Processing Centre
McGill

- Comprehensive CLSA
- Statistical Analysis Centre

Linkage between data collection sites, processing centres, and coordinating sites



Data Linkage

- Data linkage at the individual level to existing databases:
 - Administrative databases: physician services, hospitalizations, medications
 - Homecare, community services, mental health
 - Vital statistics: mortality
 - Disease registries: cancer, diabetes surveillance, notifiable diseases, trauma, agricultural injuries
 - Motor vehicle registration and accidents

Data Linkage

- Data linkage at the macro level to existing databases:
- By geographical region (postal code)
 - Pollution: air, water, noise
 - Climate: temperature, precipitation
 - Distribution of industry, toxic chemical compounds
 - Motor vehicle density
 - Neighbourhood characteristics (census): Income, education, proportion lone parents
 - Neighbourhood characteristics (municipality): Crime, proportion involved in voluntary sectors, newspaper readership

Ethical and Legal Issues

Informed consent

- 20 year duration
- For biological samples, clinical assessment, questionnaire based information
- Genetic and biochemical testing
- Products from biological samples: cell lines
- For unspecified research projects in the future
- Harmonization
- Privacy laws

Next Steps

- Response to reviewers, May 31, 2004
- Developmental Phase
- Refine Proposal, March 31, 2005
- Proposed submission to CFI May 2005

Next Steps: Developmental Phase

Protocol for Feasibility/Pilot Studies

- Phase 1 May 31, 2004
 - Conducted between April 2004-December 2005
- Phase 2 Sept. 30, 2004
 - Conducted between January 2005-December 2006
- Phase 3 Dec. 15, 2004
 Conducted in 2007
- Launch Full CLSA in 2008

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Contact Information

- E-mail: CLSA@epid.jgh.mcgill.ca
- Web site: www.fhs.mcmaster.ca/clsa

Design Considerations Comprehensive CLSA Follow-up

Birth Cohort	Frequency of Major Follow-up	Frequency of Minor Follow-up	Sample Size
40 - 59 yrs	3 years	1 year	≈ 15,000
60 - 79 yrs	3 years	1 year	^a 10,000
80+	1 years	6 months	^a 5,000

Major follow-up includes:

- Complete survey/questionnaires
- Complete clinical/physical measures
- Bio-samples on all subjects at baseline

Minor Follow-up includes:

• Questionnaire to collect frequently occurring changes (self-report) and to maintain contact

Design Considerations Tracking CLSA Follow-up

Birth Cohort	Frequency of Major Follow-up	Frequency of Minor Follow-up	Sample Size
40 - 59 yrs	3 years	1 year	≈ 10,000
60 - 79 yrs	3 years	1 year	^a 5,000
80+	1 years	6 months	^a 5,000

Major follow-up includes:

Computer assisted telephone interviews

Minor Follow-up includes:

• Brief telephone contact to collect frequently occurring changes and to maintain contact

Biological Specimen Processing Scheme

