The Canadian Longitudinal Study on Aging (CLSA): Understanding the complexity of aging and health through interdisciplinary research

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Why Study Aging in Canada?

• Canadians are living longer and older people are making up a larger share of the population.

• Between 1980 and 1999, the average Canadian’s life expectancy increased to 79 years from 75 years.

• By 2025, 1 out of every 5 Canadians (20%) will be 65 or older, compared to 1 in 8 (12%) in 2000.
Why Study Aging in Canada?

• Baby boomers begin turning 65 in 2011

• Different needs, expectations

• Implications for health care system, social programs

• Need for evidence based decision making

• Generation of new knowledge
Why does Aging happen?

• What is “normal” in the aging process - primary aging
• More susceptibility to disease - secondary aging
• More heterogeneity in the elderly population
• Onset indeterminable and progression varied
• Genetic and environmental factors
Why does Aging Happen?

- Genes
- Nutrition
- Lifestyle
- Environment
- Chance
Future of Research on Aging

• Age-related changes—”complexity”
  – INDIVIDUAL LEVEL
  – SOCIETAL AND CONTEXTUAL LEVEL

• Innovative study design that advance science of aging and health as well as inform health and social policy

• Need for interdisciplinary long-term longitudinal studies
What is the Canadian Longitudinal Study on Aging (CLSA)?
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)
CLSA Conceptual Framework

• Characterize aging beyond the absence of disease: Healthy/successful aging
• Aging not aged
• Life course approach
• Determinants of health
• Continuum of micro to macro levels
• Complex interplay of bio-psycho-social
• Gene-environment interactions
• Adaptation
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 sustained high quality research on aging in Canada.
Who will Participate in the CLSA?

• Longitudinal study
• Women and men aged 40 and over
• 50,000 individuals
• 20 year follow-up
• Repeated measurement (every 3 years)
• Linkage to existing databases
• Eventual public access data
What Issues is the CLSA Trying to Address?
PHYSICAL HEALTH

- Activities of daily living/disability
- Co-morbidities
- Chronic diseases
  - Cardiovascular, cerebrovascular,
  - diabetes, hypertension, Parkinson’s disease, cognitive impairment, osteoporosis, injuries, arthritis, cancer
- Health conditions and states
  - Oral health, communication, vision, hearing
PSYCHOLOGICAL HEALTH

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

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

- Biochemical, physiological, metabolic markers of aging
- Genetics of aging
  - disease susceptibility
  - longevity
BEHAVIOURS
- Nutrition/diet
- Obesity
- Physical activity
- Alcohol/Tobacco
- Sleep

HEALTH SERVICES
- Medications
- Assistive devices
- Institutional care
- Homecare
What kind of Information will the CLSA collect?
Active data collection

• Telephone Interviews

• Face-to-face Interviews
  – Psychological, social, economics, nutrition

• Clinical examination
  – Neuropsychological, medical, physical measures

• Blood and urine samples
“Passive” Data Collection

• Data linkage at the individual level (with consent) to existing databases:

  • Administrative databases:
    – physician services, hospitalizations, medications
    – homecare, community services, mental health
  • Death certificates
What are some Ethical, Privacy and Confidentiality Issues in the CLSA?
• Informed consent
  – Capacity to consent
    • Cognitive versus other factors that may impact on the capacity to consent
    • Proxy consent
  – Full consent versus staged consent
    • 20 year duration
    • For biological samples, clinical assessment, questionnaire based information
    • Genetic and biochemical testing
    • For unspecified research projects in the future
      – Blanket consent versus issues related to re-consent
• Informing participants/family physicians
• Risks and benefits
• Linkage with existing healthcare and other data bases
  • Privacy and confidentiality
  • Data ownership issues
• Facilitating the Public access of CLSA data
  • protecting confidentiality and privacy
  • Timely use of the data
  • Promoting innovative research
How will Canadians benefit from the CLSA?
Benefits

– New knowledge on factors that affect health and aging.

– Identification of ways to prevent disease and disability, and promote healthy aging and improved services.

– Rapid adoption of sound research into practice, programs and policies.
Benefits

– Building capacity and providing opportunities for existing and new Canadian and international researchers.
– Platform for future research.
– Recognition of Canada’s position as a leader in cutting edge health and health care research.
– Stimulation of the economy through discovery and innovation.
Who is Working Behind the Scenes on the CLSA?
The CLSA Research Team

• 3 Principal Investigators
  – Christina Wolfson (McGill)
  – Parminer Raina (McMaster)
  – Susan Kirkland (Dalhousie)

• 180 clinicians and researchers from across Canada
  – All 10 provinces
  – 26 Universities
Ethical, Legal, Societal Issues (ELSI)

- Special committee set up by CIHR
  - Lawyers
  - Ethicists
  - Philosophers
  - Geneticists
  - Epidemiologists
  - Social scientists
  - Privacy commissioner
  - Community representative
Canadian Institutes of Health Research

- Institute of Aging (Dr. Anne Martin-Mathews)
- Other Institutes of CIHR
- Dr. Alan Bernstein (President of the CIHR)
- Governing Council (CIHR)
Where is the CLSA Train now and where is it going next?
November 2001
Planning Workshop and RFP launch

January 2002
Investigator Team Responds to RFP

October 2002 – December 2003
Protocol Development

March 2004
International Peer Review Site Visit

June 2004
Review of Development Phase Activities

April 2004 - December 2005
Revision of Protocol and CLSA Feasibility Studies
CLSA Developmental Phase

- **Phase I: April 1, 2004 to December 2005**
  - Refine the study content
  - Conduct methodological feasibility studies
- **Phase II: January 2005 to December 2006**
  - Content related feasibility studies
  - Validity, reliability testing and translation of selected measures
- **Phase III: January 2007 to March 2008**
  - Pilot full protocol
Proposed CLSA Launch 2008!
Contact Us:

www.CLSA-ELCV.ca