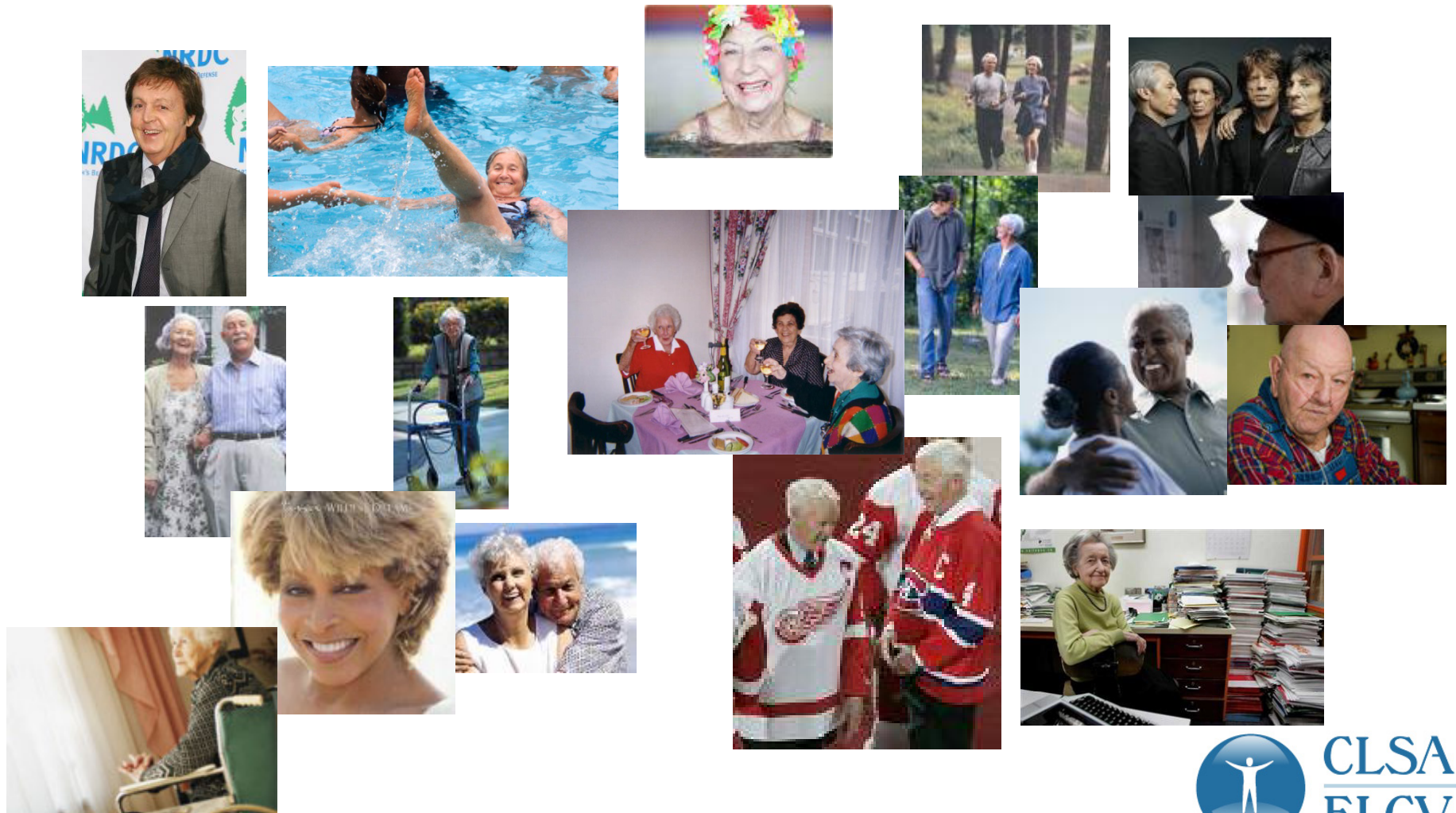


Images of Aging





Overview of the Canadian Longitudinal Study on Aging - Emphasis on Newfoundland and Labrador ¹

Dr. Gerry Mugford

Associate Professor of Medicine & Psychiatry

Jan. 19th, 2010

1. Adapted from Dr. Christina Wolfson CLSA slides and MUN CLSA slides





Boomers International™

World Wide Community for the Baby Boomer Generation

- Born 1946-1964
 - Depression Cohort: 1929-1945
 - Roaring twenties: 1911-1928
 - Turn of the century: 1893-1910
- Trends starting to emerge
 - solo living will take on a greater relevance
 - a larger proportion of tomorrow's seniors will be childless
 - higher levels unemployment
 - higher levels of job stress
 - men entering the labour market later, leaving earlier
 - women more likely to be in workforce, staying longer

How will the boomers age?



Healthy Aging or Anti-Aging?

The three basic rules of anti-aging medicine:

- Don't get sick
- Don't get old
- Don't die



“Bridge the gap to Immortality” – by taking good care of your physical and mental self, you will be around to avail yourself of the latest biotechnological advancements to further optimize your life and achieve that triple-digit lifespan.

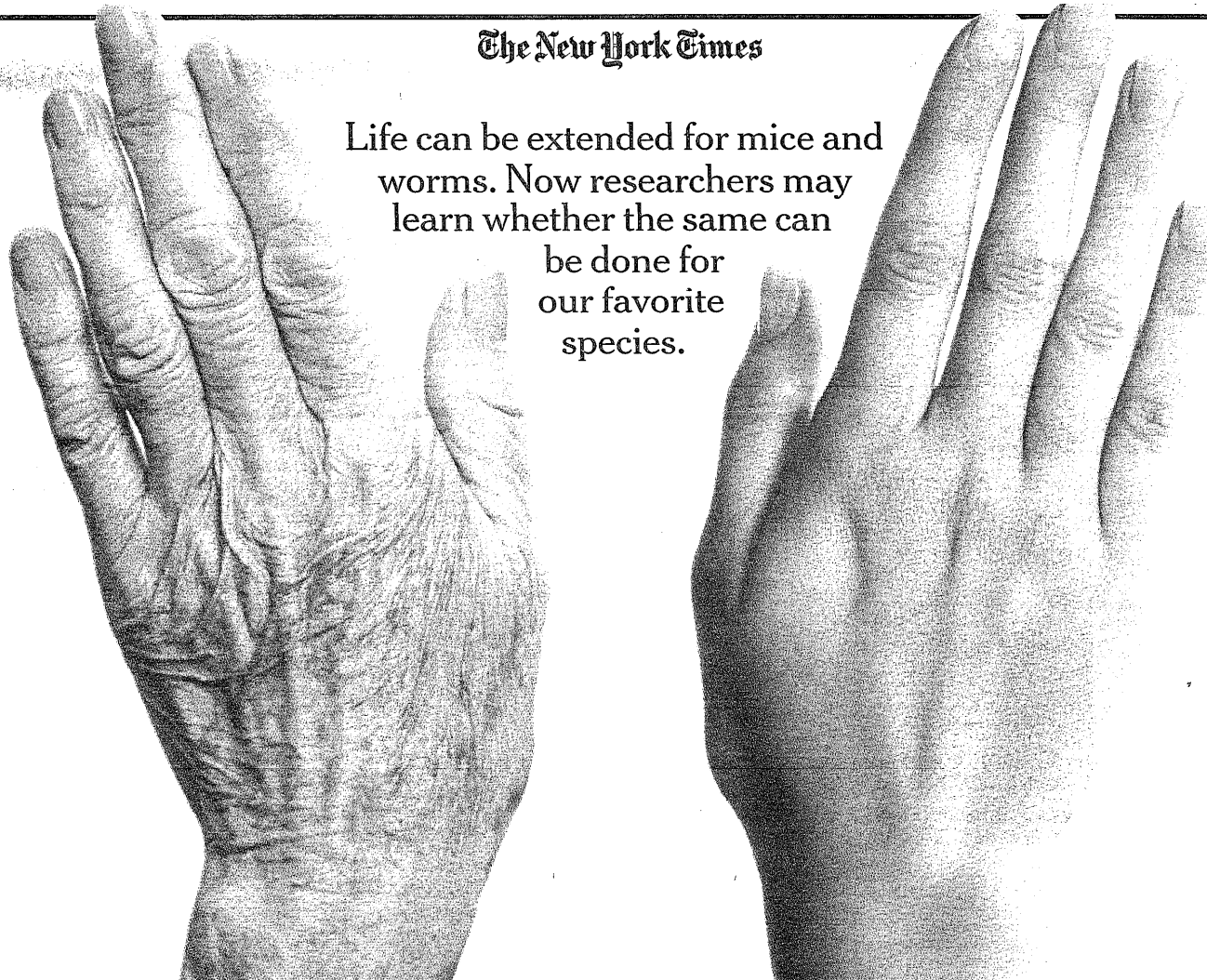
The Aging Revolution

- The rapid and continuing increase in human survival.
- New scientific understanding of the ageing process.
- The changing nature of old age and its determinants.
- Expectations, adjustments and policy.

Is this the right goal?

The New York Times

Life can be extended for mice and worms. Now researchers may learn whether the same can be done for our favorite species.





Canada's Response

- To propose a cohort study of aging
- CIHR (Institute of Aging) RFP launched in November 2001
 - Deadline January 2002
- RFP Objective – to fund a research team to write the protocol for the study



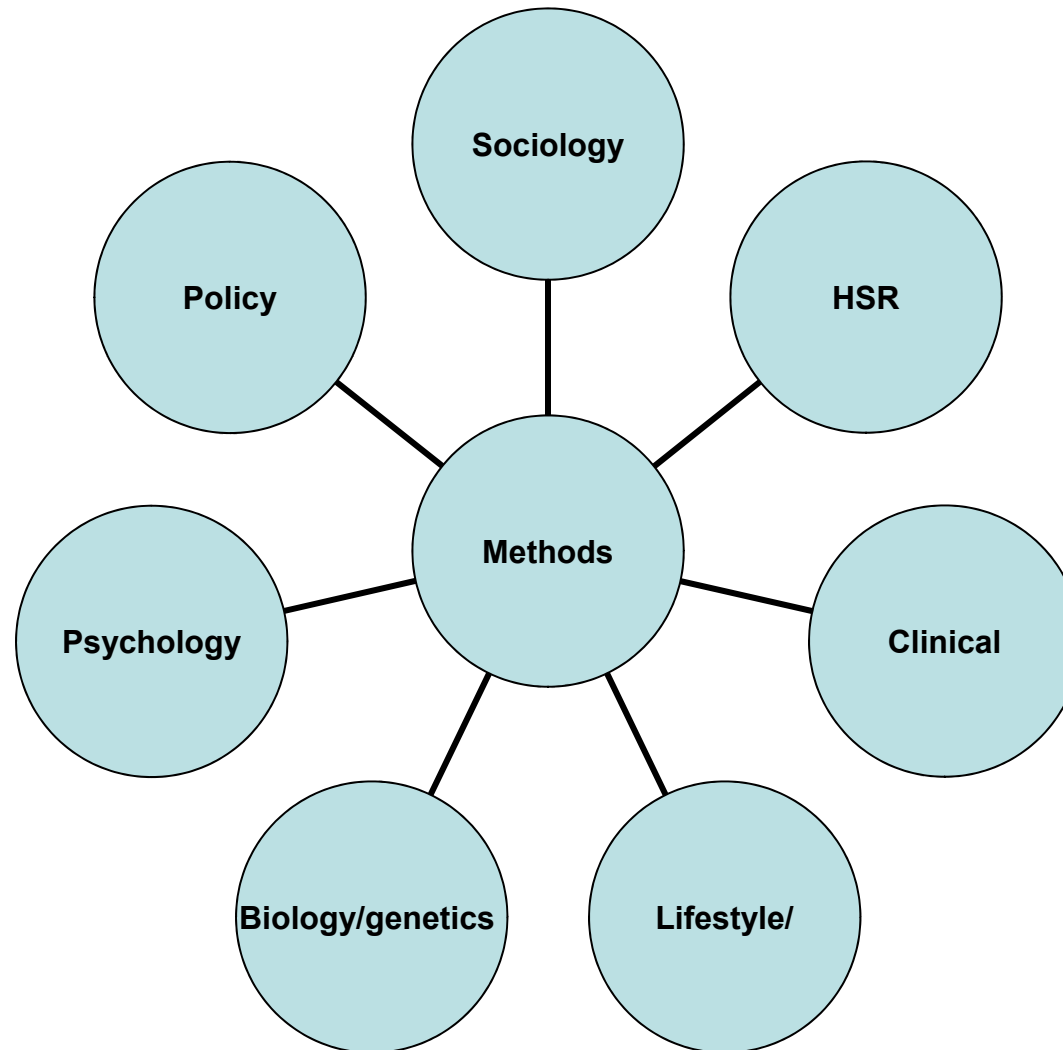
Specific Mandate (RFP)

1. To develop a Canadian Multi-centre Study to determine:
 - genetic, immunologic and molecular determinants of aging
 - effect of physical exercise, nutrition and other habits
 - evolution of physical, psychological, and cognitive abilities
 - role of psychological determinants of health
 - role of social and cultural determinants of health
 - health services utilization of this population
2. To identify preventive strategies and health services that would promote healthy aging
3. To translate the findings into clinical practice, health delivery and policy

CIHR-IA RFP



Content Working Groups



Some Observations

- In working towards developing the protocol we identified more than 70 longitudinal studies of *aging* worldwide
 - The majority were studying people over the age of 65 – these are studies of *the aged*
 - The studies generally fell into one of two main types
 - Those that collected a great deal of information on social factors and/or retirement transitions but lacked detailed information on health, especially clinical and biological measures
 - *OR*
 - Those that collected a great deal of information on disease status (often a specific disease) but lacked detailed information on social factors or retirement

.....more observations

- Very few studies have looked at the aging process from mid-life through to old age in the *same* individual
- Very few were/are population-based studies capturing the changing individual within a changing context and incorporating multiple levels of inquiry, the cell, the individual and society
- Very few examined how individuals *cope* or *adapt* to changing circumstances and how these changing circumstances (good and bad), in turn, have an impact on their well-being
- Based on our observations, we concluded that there was an urgent need to move from describing *old age* to the determination of mechanisms that underlie changes with age

A longitudinal study of aging should look at!

- The progression of **health** from middle-age to early old age to older old age
- The determinants of **well-being and quality of life** at older ages
- **Cognitive functioning** and **mental health** at older ages
- **Disability** and the compression of morbidity
- The examination of socioeconomic and health **inequalities** in an ageing population
- **Social participation** and **social relationships** at older ages
- **Retirement** and **post retirement** labor market activity
- **Genetics, health behaviours, expectations, life history,** and determinants of **SES** ...



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 to reveal healthy aging, successful aging, optimal aging
- To provide infrastructure and build capacity for sustained high quality research on aging in Canada

CLSA research team + others

- BC: Neena Chappell; Max Cynader; Michael Hayden; Andrew Wister; Mike Kobor; Margaret Penning; Holly Tuokko
- AB: David Hogan; Russ Hepple
- **NFLD: Gerry Mugford: Patrick Parfrey**
- QC: H el ene Payette; Tamas Fulop; Ron Postuma; Brent Richards; Daniel Tessier;
- Ont: Sonia Anand; Cynthia Balion; Joseph Beyene; Larry Chambers; Richard Cook; Matt McQueen; Mark Oremus; Harry Shannon; Mike Veall
- Manitoba: Verena Menec
- NS: Ken Rockwood

CLSA Timeline

- Protocol development 2002-2004
- International Peer Review 2004
- Phase I feasibility studies 2004-2006
- **International Peer Review 2006**
- Phase II pilot studies 2006-2008
- Canada Foundation for Innovation Application 2008
- National/international Peer Review 2008
- Launch 2009



Phase 1: Feasibility Studies (selected)

- 1. Exploring the acceptability and feasibility of conducting a large longitudinal population-based study in Canada
- 2. Feasibility of accessing health care utilization databases across Canada
- 3. Feasibility of blood and urine specimen collection and OGTT in private and hospital based clinical laboratories
- 4. Return of individualized test results to participants and/or nominated health care providers
- 5. The CCHS as a potential participant recruitment vehicle for the CLSA
- 6. Development & evaluation of disease ascertainment algorithms
- 7. Telephone cognitive tests as tools for the identification of eligible study subjects in population based research

Key messages (selected studies)

■ Views of Canadians

- Healthy aging considered important, timely
- Universities trusted to carry out the study; government to fund
- Private companies should not profit from the study
- Providing blood and urine samples adds credibility
- Trust that confidentiality will be protected
- Concerns around the use of DNA
 - Why needed, how would it be used, who would have access
- Altruism is a key motivator for most participants

■ Linkage to health utilization databases

- Standard approach in all jurisdictions does not exist
- Informed consent: study questions, data accessed, for how long, where stored, how used, who has access, periodic re-consent
- Data access agreement: Provincial/territorial MOH
- Provincial privacy legislation AND health information legislation is constantly evolving
- Lack of standardization of variables, coding, completeness, updating
- Complex process, but possible

■ Biological samples

- Not all provinces have private labs; Considerable variation in capacity among private labs and hospital labs
- Reasons for declining participation: current demands, space and time constraints, complex, demanding protocol
- Average lab charges per participant: \$144 (range \$66 to \$270) in hospital labs v.s. \$254 (range \$96 to \$535) in private lab settings
- Participant satisfaction high





CLSA Study Design

- 50,000 individuals
- Women and men aged 45 – 85 at baseline
- Community dwelling at baseline
- No cognitive impairment at baseline
- Signed informed consent
- 20 year follow-up
- Waves of data collection every 3 years
- Inter-wave contact (by telephone)



CLSA Study Design

- Recruitment via
 - Canadian Community Health Survey on Healthy Aging (2008-2009)
 - Health Registration Databases
 - Dual Sampling Frames
- Linkage to existing databases
- Research platform
- Data access

CLSA Architecture



Inception Cohort of 50,000 (at 10 sites)

Questionnaires, Biological, Physical

Follow-up over 20 years

Every 3 years age 45-85



CLSA
ELCV



CLSA Program of Research

- **Biological Function**
 - genetics/epigenetics
- **Physical Function**
 - Mobility/Chronic diseases/Injury
- **Psychological Function**
 - Cognition/Mental Health/Coping
- **Social Function**
 - work and retirement/Social Participation/Housing

Measurements

Biomedical

- Health status, Quality of life, healthy aging
- Activities of daily living/disability/injuries
- Frailty/co-morbidities
- Function/Performance
- Physical measures
- Chronic diseases and symptoms
- Injuries
- Cognitive function, Mental Health
- Oral health
- Vision, **hearing (proposed)**
- Medications
- Health and Social Services Use
- Institutional care
- Genetics/Biology
 - Disease susceptibility/longevity genes
 - Epigenetics
 - Biomarkers
- Nutrition

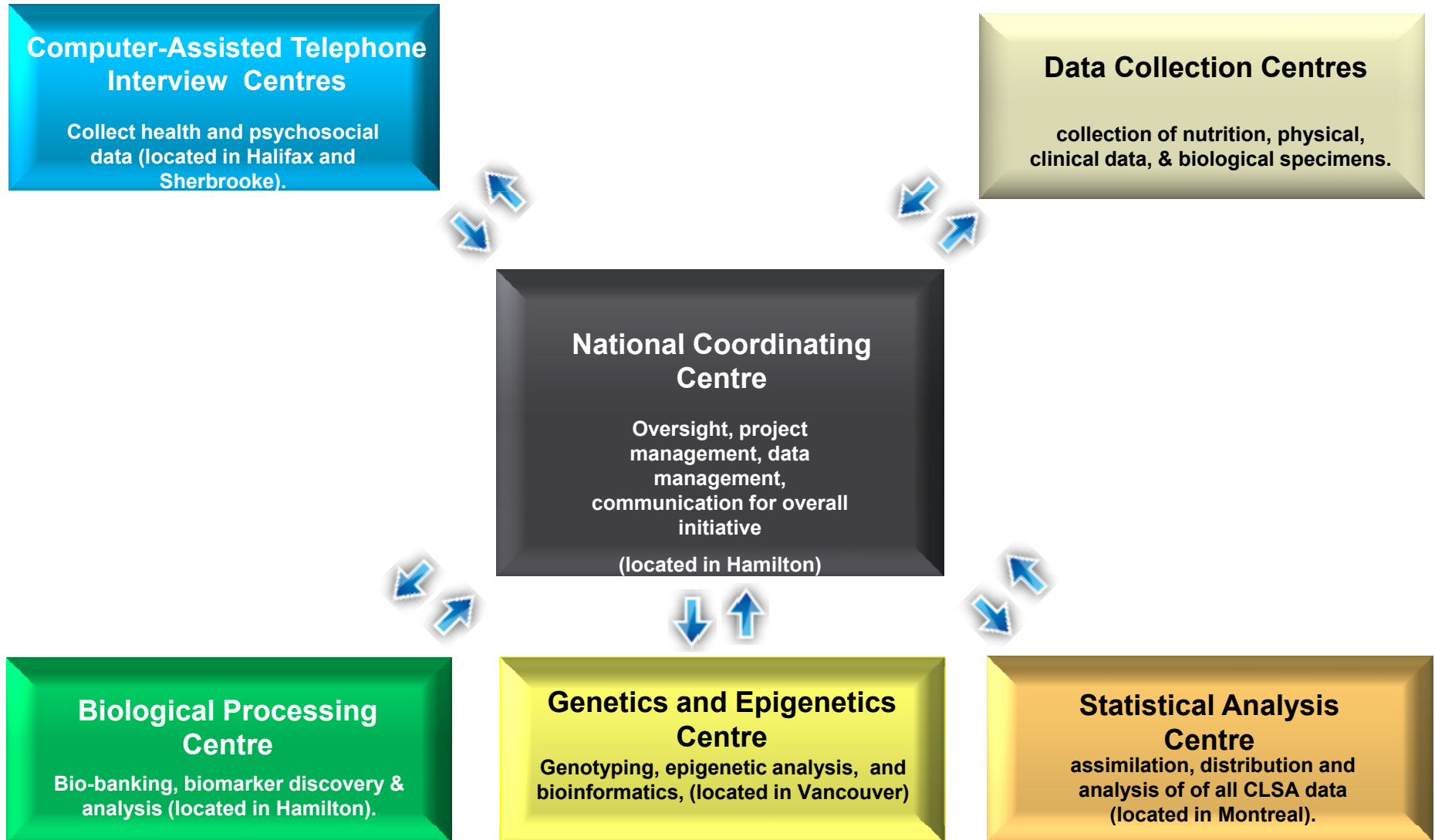
Psychosocial

- Social participation
- Lifestyle/behaviours
- Social networks and social support
- Care giving/Care receiving
- Coping, adaptation
- Mood, psychological distress
- Work to retirement transitions
- Work ability
- Retirement Planning
- Job-Demand/Effort-Reward
- Social inequalities
- Mobility-Lifespace
- Built environments/physical environment/Housing
- Economics/Wealth
- Demographics
- Linkage to data bases
 - Health care use, homecare
 - Disease registries e.g. Cancer
 - *Environmental*
 - *Contextual*
 - Medications

Vocabulary

- CLSA Cohort (all 50,000)
- **Tracking** Cohort (20,000 followed through computer assisted telephone interviews)
 - Nationally representative
- **Comprehensive** Cohort (30,000 interviews plus indepth physical assessment – face to face)
 - Selected from within a 25km radius of 10 CLSA data collection sites

Equipment and Infrastructure Supporting Research on Aging



Collaboration with Statistics Canada

- CCHS 4.2: Healthy Aging and CLSA
 - CLSA expertise for content development
 - Recruitment for CLSA
 - Release of CCHS participant names to CLSA with written consent
 - Sharing of CCHS survey data with written consent
 - MOU between SC and Universities





Implementation of the CLSA Tracking Cohort



Launch of the CLSA

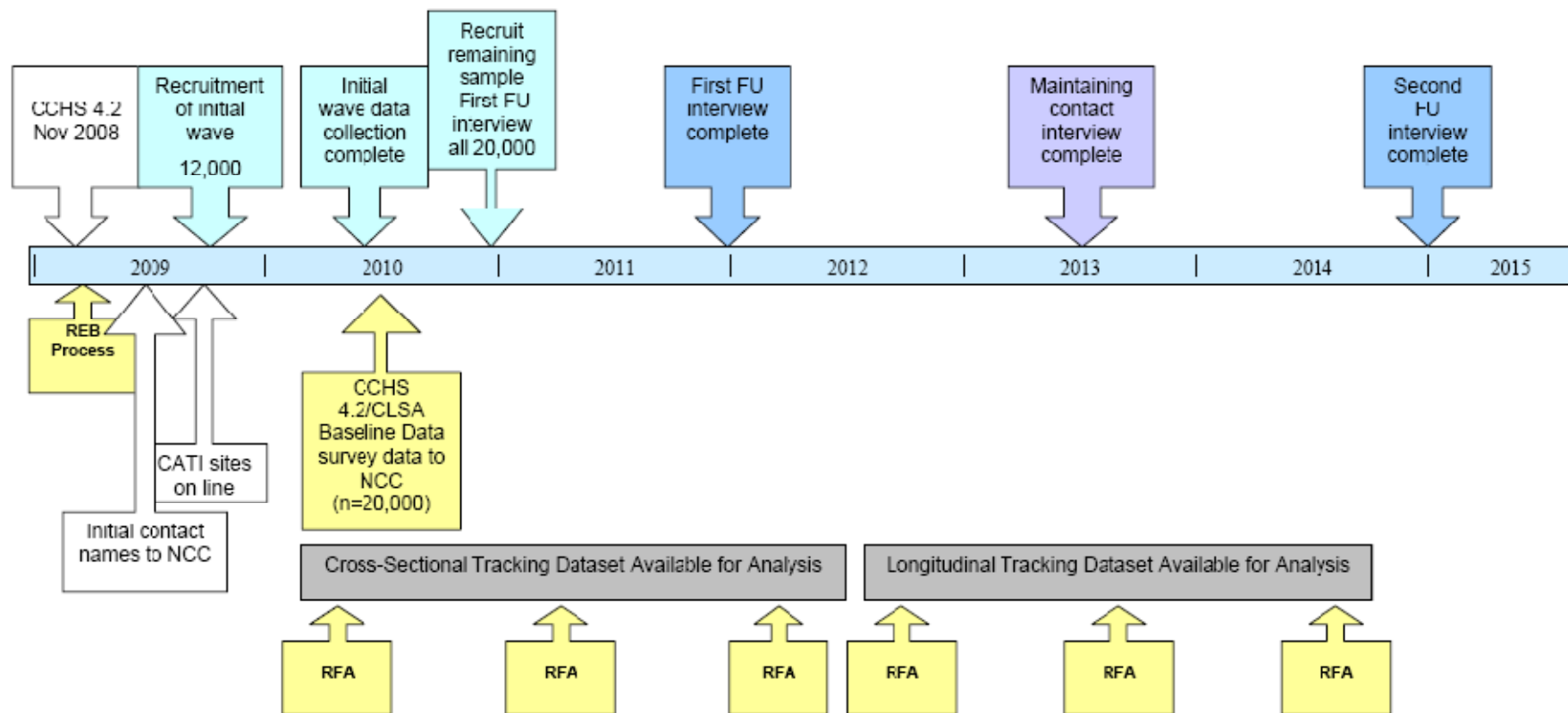
- Identification of first 20,000 started in late 2008 in collaboration with Statistics Canada CCHS Healthy Aging module (Tracking Cohort)
 - Approximately 8000 have agreed to release their names to CLSA so far...CCHS recruitment ongoing



Recruitment

- Release of CCHS participant names by SC to CLSA (first batch released)
- Contact by CLSA
- Computer Assisted telephone interview (return of signed consent)

Tracking Cohort Timeline (2009-2015)





Implementation of the CLSA Comprehensive Cohort

Implementation Plan for the Comprehensive Cohort (n=30,000)

- ❖ Cohort of 30,000 persons to be recruited within 25km radius of 10 data collection sites (DCS)
 - Victoria, Vancouver, Calgary
 - Winnipeg, Hamilton, Ottawa
 - Montreal, Sherbrooke
 - Halifax, **St. John's**

Comprehensive Cohort Rolling Recruitment

- ❖ First batch of 1000 people to be recruited/site (mid-2011 to mid-2012)
 - ❖ Maintaining contact by phone (end of 2012- end 2013)

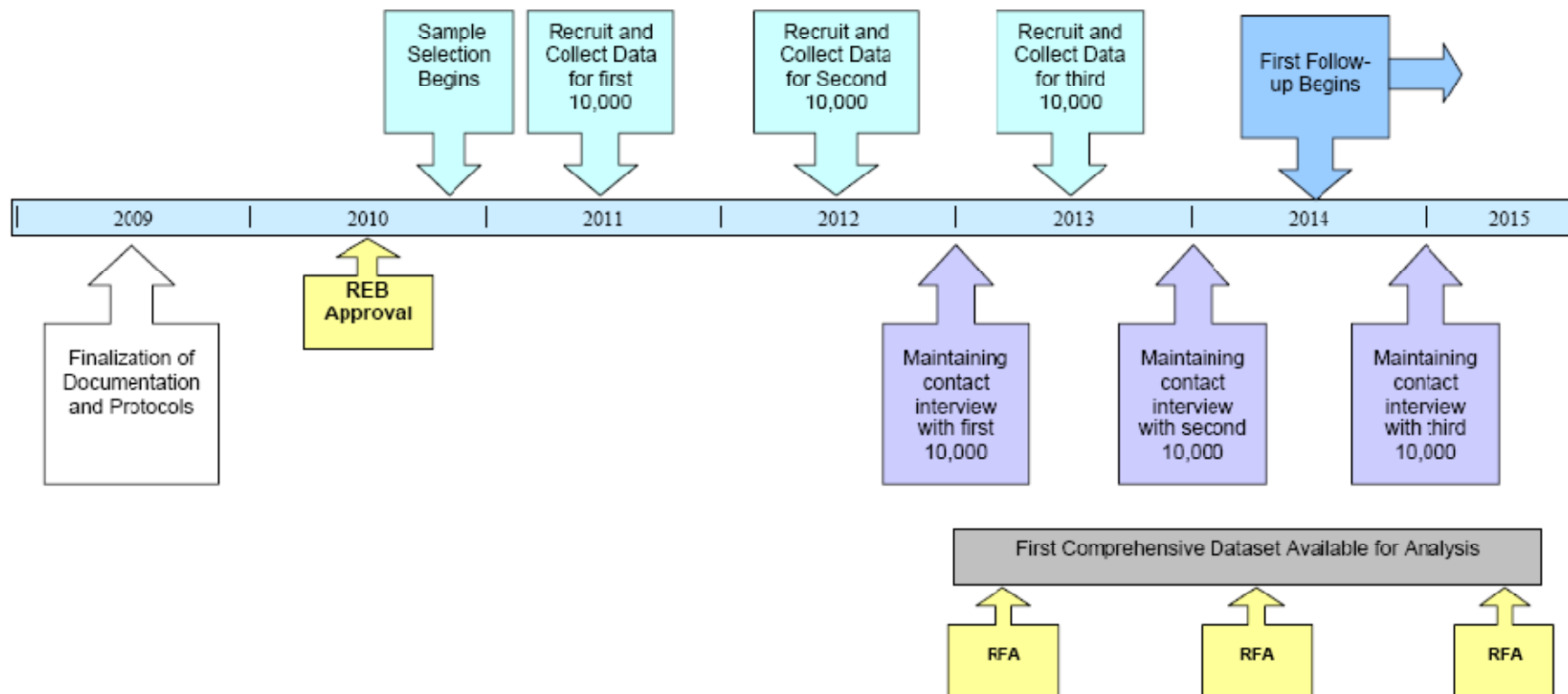
- ❖ Second batch of 1000 people to be recruited/site (mid-2012 to mid-2013)
 - ❖ Maintaining contact: (end of 2013-end of 2014)

- ❖ Third batch of 1000 people to be recruited/site (mid-2013 to mid 2014)
 - ❖ Maintaining contact: (end of 2014-end of 2015)

Components of Data Collection

- Information package and consent forms mailed
- Telephone contact to recruit and set up a home visit
- Home Visit
 - Consent Process
 - Data collection using Computer Assisted Personal Interview
- Set up appointments for a visit to Data Collection Site

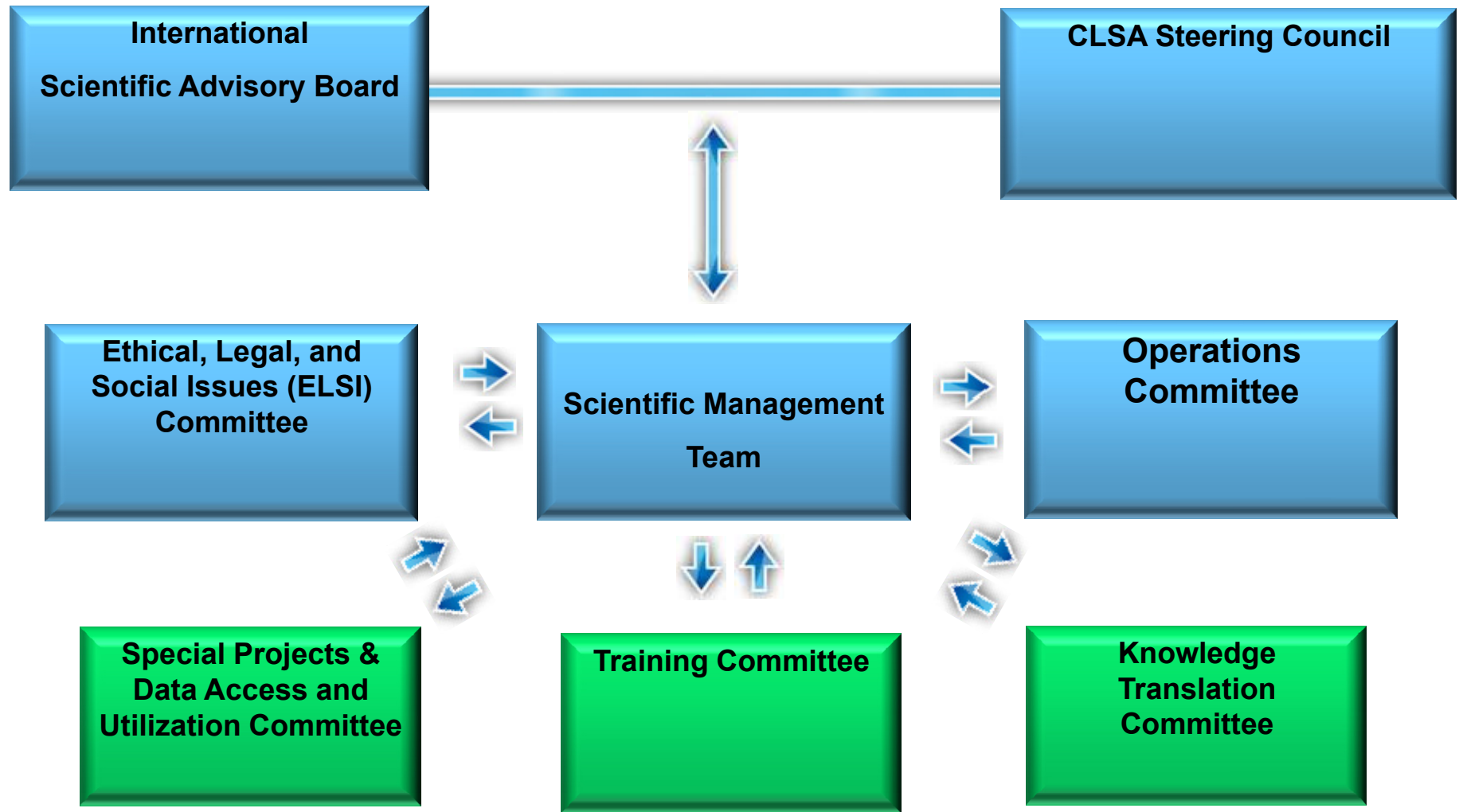
Comprehensive Cohort Timeline (2009-2015)



Data and Sample Flow

- Questionnaire and Clinical Data
 - Tracking and Comprehensive CLSA
 - No paper and pencil data
 - Data are captured directly into computers
 - All data will flow to NCC in real time for data cleaning and quality
 - Data will be sent to SAC
 - For creating derived variables
 - Application of disease ascertainment algorithms
- Biological Samples
 - Prepared at each DCS
 - Shipped to Biobank
 - Core biomarker analyses at centralized high throughput lab
 - Numeric data sent to NCC and then on to SAC
- Access to Data and Samples
 - Data and sample access and utilization committee
 - CLSA core investigators will be given “priority” in a time limited fashion
 - Transparent procedure for access/use by research community-at-large

CLSA Management Structure



Ongoing Activities

- Content Harmonization with HRS, SHARE, ELSA
- Ethical Legal and Social Issues Committee (CIHR)
- Canadian Partnership for Tomorrow Project
- P3G (Public Population Project in Genomics)
- Veteran's Affairs Canada
- Neurological Health Charities Canada
- Federal agencies
- Provincial agencies
- Other charities



Training

- CIHR – CLSA fellowships for research/training related to longitudinal studies on aging – currently available
- CLSA Interdisciplinary Scholar Program in Aging (ISPA) – in development

Sourced Funding

Operating Budget (CIHR) : \$650 per patient estimating 8% recruitment by CCHS

Amount (Millions)	Operation	Source	Funding (In Kind) Secured ?
\$5	Development and Pilot of the CLSA	CIHR	Yes
\$3.85	Operational Support	CIHR	Yes
\$19.65	Operational Support	CIHR	Yes
\$8.0	Recruitment	Statistics Canada (In Kind)	Yes
\$26.06	Infrastructure	CFI	June 2009 - Decision

<http://www.clsa-elcv.ca/en/welcome>



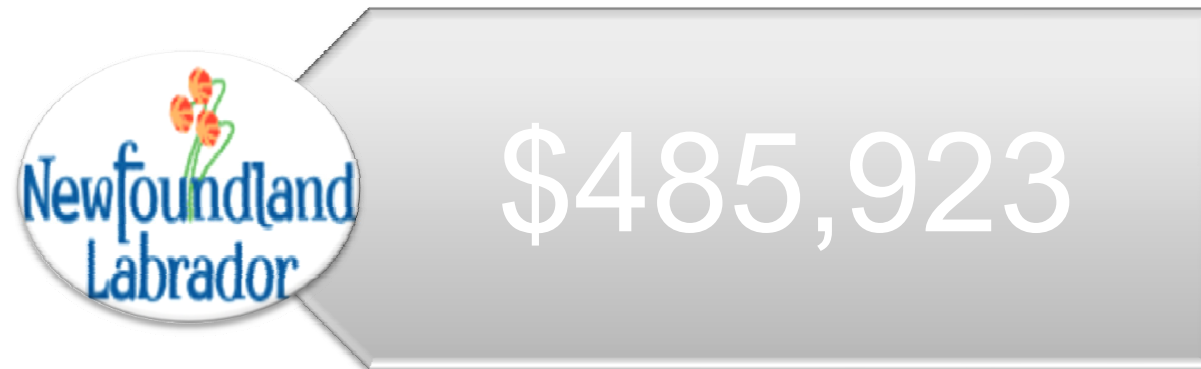
The NL core Team

- Dr. Gerry Mugford
 - Dr. Pat Parfrey
 - Dr. Don MacDonald
 - Dr. Marshall Godwin
 - Dr. Proton Rahman
 - Dr. Elizabeth Dicks
 - **Elizabeth Hatfield**
 - Dr. Anne Sclater
- Gerry
 - Pat
 - Don
 - Marshall
 - Proton
 - Betty
 - Elizabeth
 - Anne

Principal Investigators

Principal Investigators		
Parminder Raina	Susan Kirkland	Christina Wolfson

Contribution Distribution from Newfoundland to NIF



Data Collection at MUN Site

Comprehensive Cohort- N= 30,000

Comprehensive Cohort N=3000 in NL

- N=3,000 participants- 200 per month
- Follow-up visits once every 3 years for 20 years
- Require 1,000 sq ft of dedicated space
- HR- Site Project Manager, Interviewers, 2Nurse, Medical Technologists, 3Research Assistants, database administrator.
- CLSA on site Co-investigator will serve as the site Director