



The Canadian Longitudinal Study on Aging A platform for interdisciplinary research Christina Wolfson, on behalf of the CLSA team

McGill Social Statistics and Population Dynamics Seminar
February 12th, 2014





Overview

- A little bit of background
- Study Architecture
- What is being collected
- Recruitment
- How data are being collected
- Recruitment and data collection status
- Governance
- Data and Biospecimen access
- Partners/special projects

Background

- Strategic initiative of the CIHR
 - Institute of Aging
- Operations funded
 - 86% through a directed grant from CIHR
 - 14% through PI initiated collaborations
- Infrastructure funded by CFI



Vision

A research platform – infrastructure to enable
state-of-the-art, interdisciplinary population-based
research in aging





Aims

Examining aging as a dynamic process.

Investigating inter-relationships among intrinsic and extrinsic factors from mid-life to end-of-life.

Capturing transitions, trajectories and profiles of aging.

Providing infrastructure and build capacity for sustained high quality research on aging in Canada.

CLSA Working Groups

Developing, reviewing, suggesting content

- Clinical Working Group
 - Dr. Chris Patterson (McMaster)
- Lifestyle Working Group
 - Dr. Hélène Payette (Sherbrooke)
- Psychology Working Group
 - Dr. Holly Tuokko (Victoria)
- Biology Working Group
 - Dr. Cynthia Balion (McMaster)
- Health Services Working Group
 - Dr. Verena Menec (Manitoba)
- Methodology Working Group
 - Dr. Harry Shannon (McMaster)

CLSA Research Team

Debra Sheets, Lynne Young, Holly Tuokko (**Victoria**),
Max Cynader, Michael Hayden, Michael Kobor, Theresa
Liu-Ambrose (**UBC**),
Andrew Wister, Scott Lear (**SFU**),
David Hogan, Marc Poulin (**Calgary**),
Verena Menec, Phil St. John (**Manitoba**),
Cynthia Balion, Christopher Patterson, Parminder Raina,
Lauren Griffith, Mark Oremus, Harry Shannon
(**McMaster**),
Larry Chambers, Vanessa Taler (**Ottawa**),
Christina Wolfson, Ron Postuma (**McGill**),
Hélène Payette (**Sherbrooke**),
Susan Kirkland (**Dalhousie**),
Gerry Mugford, Patrick Parfrey (**Memorial**),
Mary Thompson and Changbao Wu (**Waterloo**)

**Scientific Working
Groups and Co-
Investigators**

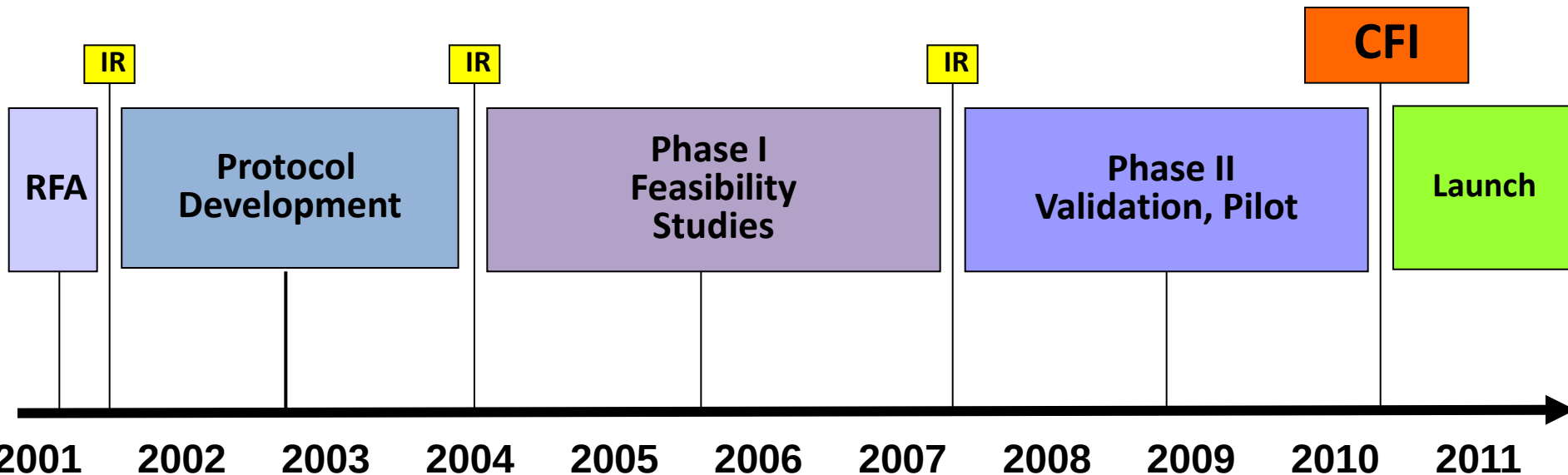
See our website: www.clsa-elcv.ca

CLSA Timeline and Milestones

Team
Design
Objectives
Content

Acceptability
Specimen Collection
Recruitment
Data Linkage

Pilot recruitment
Validate measures
SOPs,
Pilot protocol



Selected Research Domains

- Trajectories of **health** from middle age to older old age
- Determinants of **well-being and quality of life**
- **Social participation, social relationships and caregiving**
- Socioeconomic and health **inequalities**
- **Retirement and post-retirement** labour market activity
- **Cognitive functioning, mental health and neurological conditions**
- Health of aging **veterans**
- **Disability** and the compression of morbidity



Photo: Horia Varlan

Architecture

50,000 women and men aged 45 - 85 at baseline

n=20,000
Randomly selected within 10 provinces

Questionnaire
• **By telephone (CATI)**

n=30,000
Randomly selected within 25-50 km of 11 sites

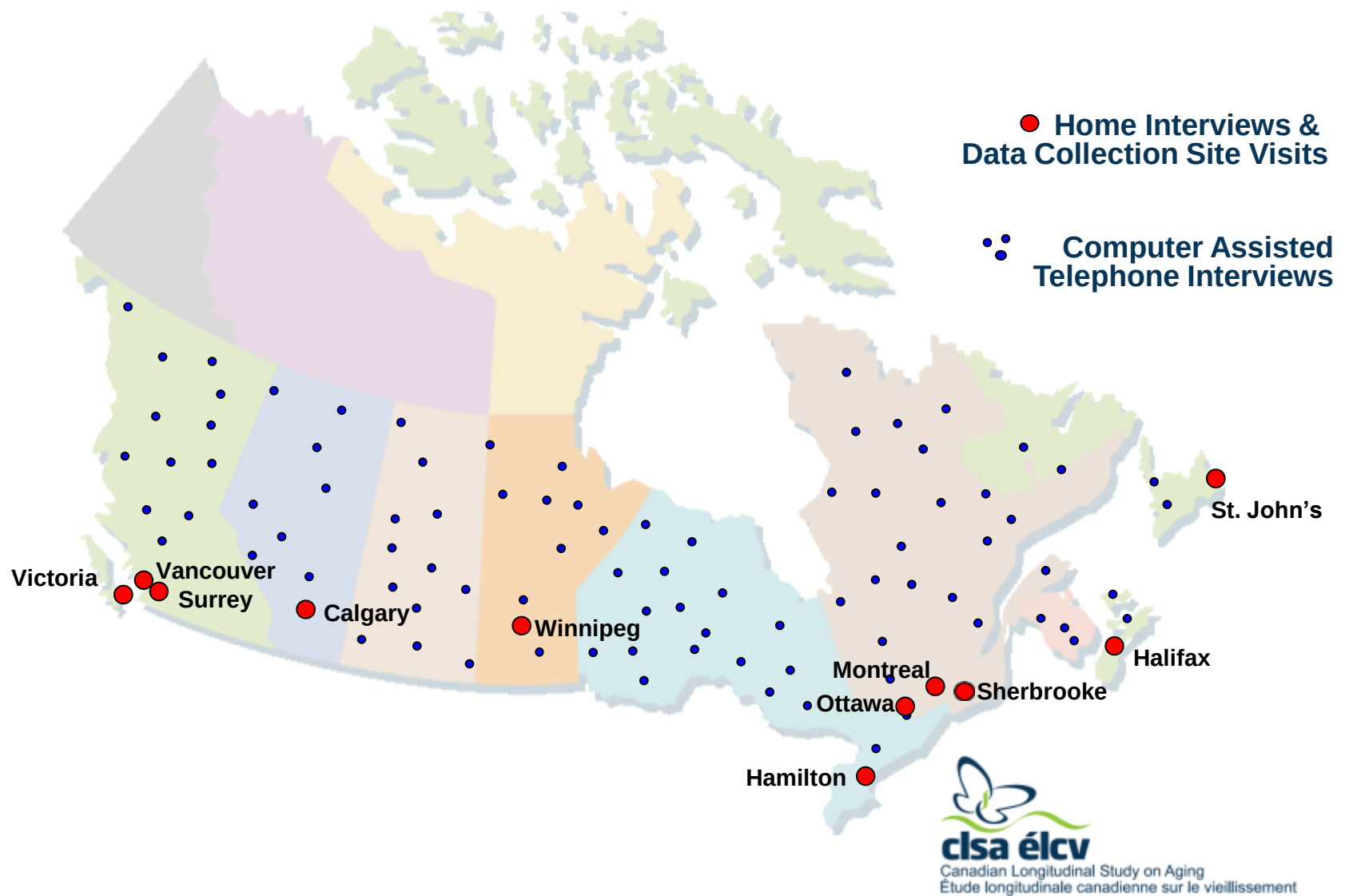
Questionnaire
• **In person, in home (CAPI)**

Physical Assessments
Blood, urine
• **At Data Collection Site**

Maintaining contact, follow up every 3 years by phone

Linkage with Administrative Databases

National



PHYSICAL & COGNITIVE MEASUREMENTS

- Height & weight
- Waist and hip measurements
- Body composition
- Arterial pressure
- Heart rate
- ECG
- Grip strength
- Timed up-and-go
- Chair rise, 4-m walk
- Standing balance
- Vision
- Hearing
- Spirometry
- Bone density
- Aortic calcification
- Carotid intima-media thickness
- Cognitive assessment



PSYCHOSOCIAL MEASURES

- Social participation
- Social networks and support
- Caregiving and care receiving
- Mood, psychological distress
- Satisfaction with life
- Wealth
- Personality traits
- Work-to-retirement transitions
- Retirement planning
- Social inequalities
- Mobility-lifespace
- Built environments
- “Successful aging”



HEALTH INFORMATION

- Chronic disease and symptoms
 - Screening for PD/Epilepsy
- Post traumatic stress disorder
- Medication and supplement use
- Women's health
- Health services utilization
- Oral health
- General health
- Injuries
- Pain/discomfort
- Functional status
- Activities of daily living (ADL)
- Administrative data linkage health services and drugs
- Other administrative databases



LIFESTYLE & SOCIODEMOGRAPHIC



Smoking

- Alcohol consumption
- Physical activity
- Nutrition
- Place of birth
- Ethnicity/race/gender
- Marital status
- Education
- Income
- Transportation
- Home ownership

Recruitment & Data Collection

Telephone Interviews

- Recruitment* of 20,000 participants for telephone interviews:
 - ✓ Statistics Canada Canadian Community Health Survey HS on Healthy Aging (2008-2009)
 - ✓ CLSA added a younger age category, developed the content for CCHS
 - ✓ Provincial Health Registration Databases (MOH)
 - ✓ Random Digit Dialing
- Baseline data collection 2010 to 2014
- Maintaining contact interviews initiated 2013
- First follow-up 2015

*sampling weights for multiple frame sampling are being created

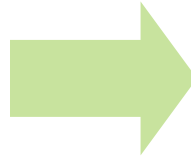


CLSA Data Collection

Telephone Interviews



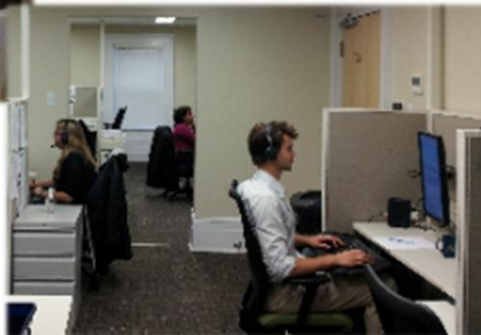
**4 CATI Sites conduct
telephone interviews**



**Participants provide
questionnaire data in a 60
minute interview (n=20,000)**

CLSA Infrastructure

4 Telephone Interview Centres



UNIVERSITY
OF MANITOBA



DALHOUSIE
UNIVERSITY
Inspiring Minds



UNIVERSITÉ DE
SHERBROOKE



University
of Victoria

Recruitment & Data Collection

Home Interviews and Data Collection Site Visits

- *Recruitment of 30,000 for Home Interviews and Data Collection Site Visits:
 - ✓ Provincial Health Registration Databases
 - ✓ Random Digit Dialing
- Baseline data collection 2012-15
- Maintaining Contact Interviews initiated 2014
- First follow-up begins 2015

*sampling weights for multiple frame sampling are being created



CLSA Data Collection

Home Interview and Data Collection Site Visit

Electronic Data Entry



**Participants provide
questionnaire data in a 60
minute home interview
(n=30,000)**



**Participants visit one of 11 data collection
sites for a 2-3 hour assessment
(n=30,000)**

CLSA Infrastructure

11 Data Collection Sites



Biospecimen Room

Collection, processing, analysis

- 5 – 6 participants per day
- 50 mL blood
- Urine sample
- 2 hours from blood collection to storage
 - Weekly shipping to BBC



AcT DIFF, Beckman Coulter

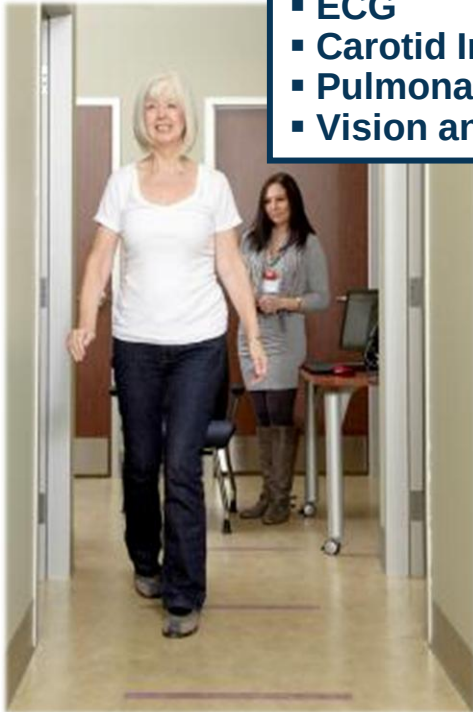


CLSA Data Collection

At the Data Collection Site

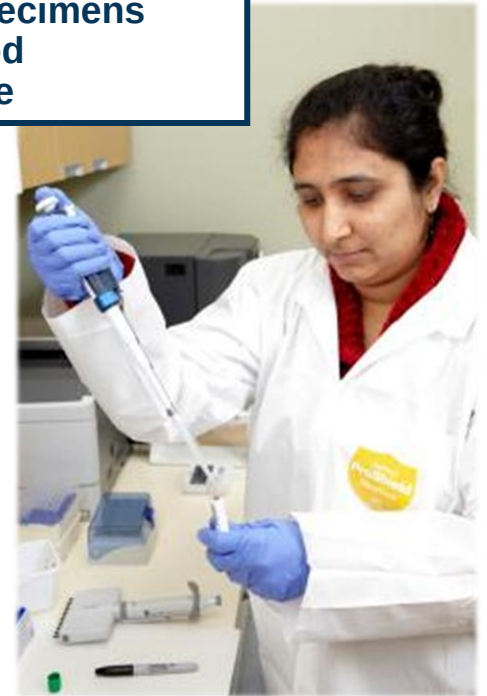
Physical Data Collected

- Bone Density, Body Composition
- Aortic Calcification
- ECG
- Carotid Intimal-Medial Thickness
- Pulmonary Function
- Vision and Hearing



Biospecimens

- Blood
- Urine

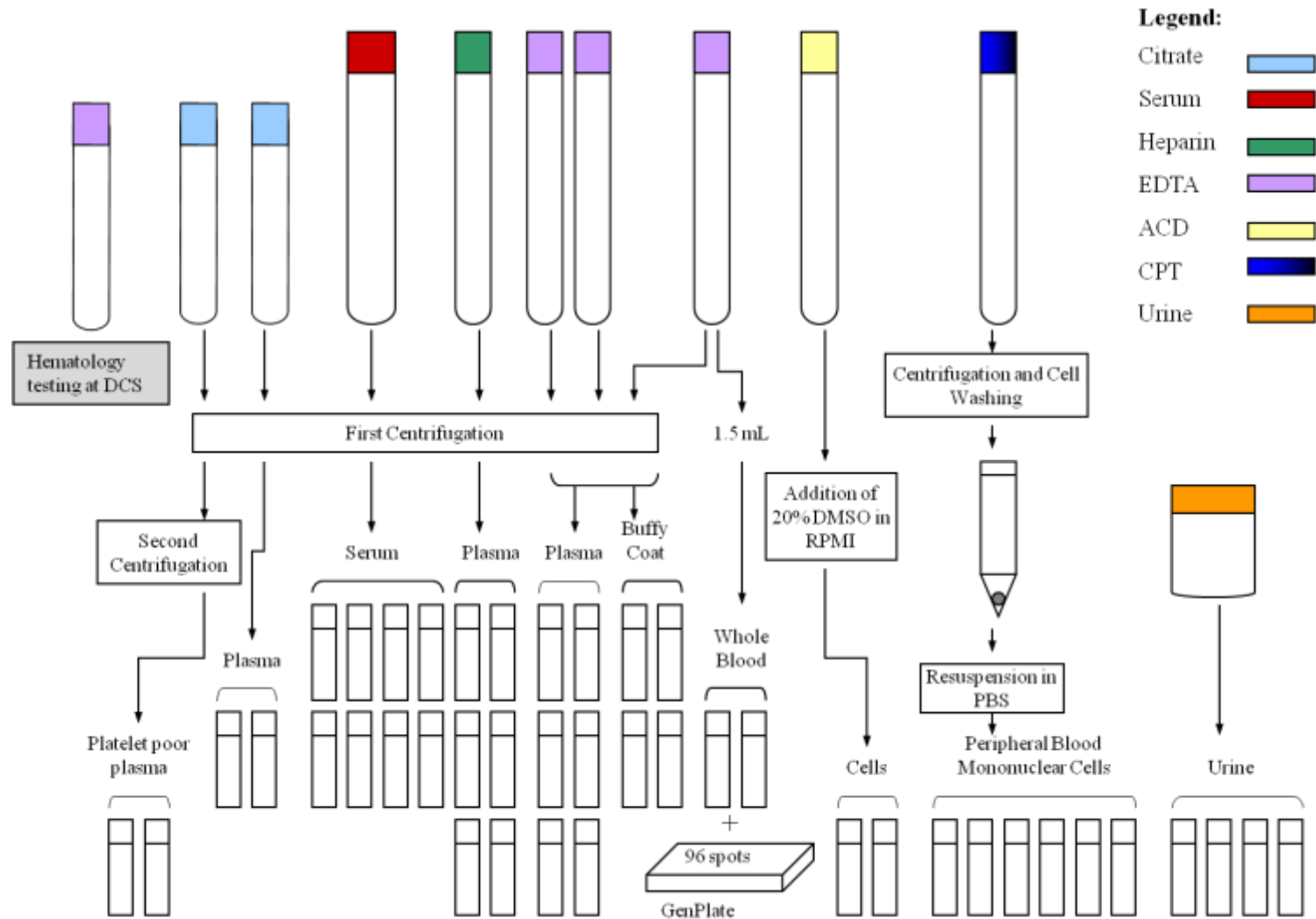


Psychological Data Collected

- Neuropsychological Battery
- Performance Testing
- Anthropometric Measures



42 aliquots per participant



CLSA Data Processing



Telephone interview
(n=20,000)



Home interview and data
collection site visit (n=30,000)



Blood and urine
stored in
Biorepository and
Bioanalysis Centre
(BBC)

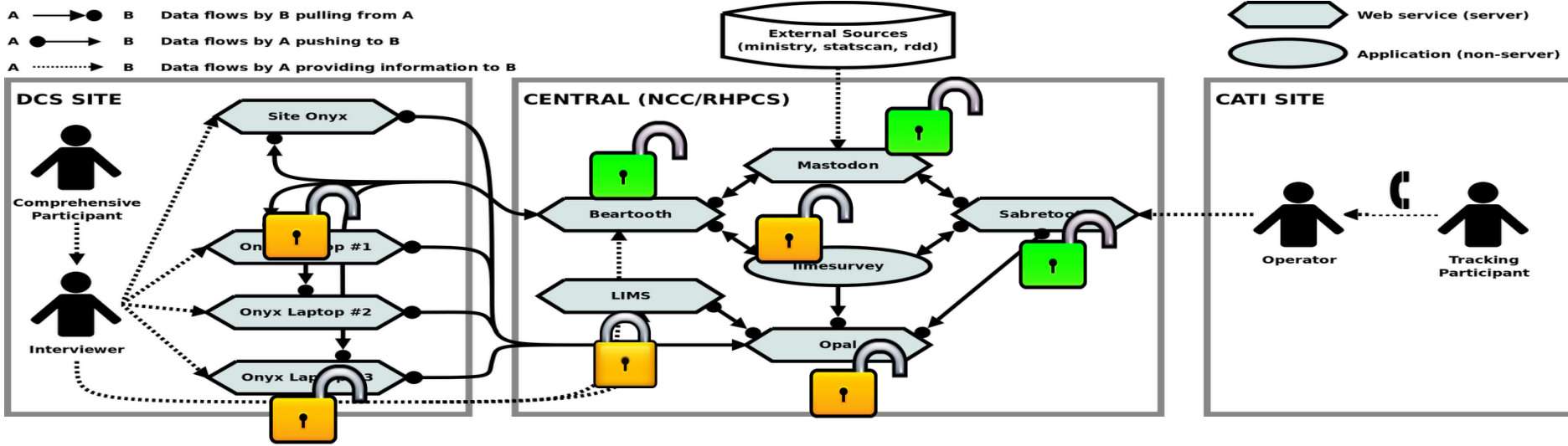
Alphanumeric data and images



Linkage with
administrative data

Data stored in National Coordinating Centre
and at the Statistical Analysis Centre

CLSA Software Architecture, IT Integration Systems for Paperless Data Collection



Mastodon - manages interactions with participants and securely stores identifying information

Sabretooth & Limesurvey – CATI software manages participant data collection, Interview scheduling and tracks the status of the interviews through to completion

Beartooth & Onyx – CAPI software used by the Data Collection Sites to coordinate the collection of questionnaire responses, physical measurements and biospecimens from participants

Opal – Central Data Repository – or databank – stores and manages all non-identifying data collected using Sabretooth, Beartooth and Onyx

CLSA Infrastructure

4 Enabling Units



**National Coordinating
Centre (NCC)**
Director: Parminder Raina



**Biorepository and
Bioanalysis Centre (BBC)**
Director: Cynthia Balion



Genetics and Epigenetics Centre (GEC)
Directors: Michael Kobor and Michael Hayden



Statistical Analysis Centre (SAC)
Director: Christina Wolfson

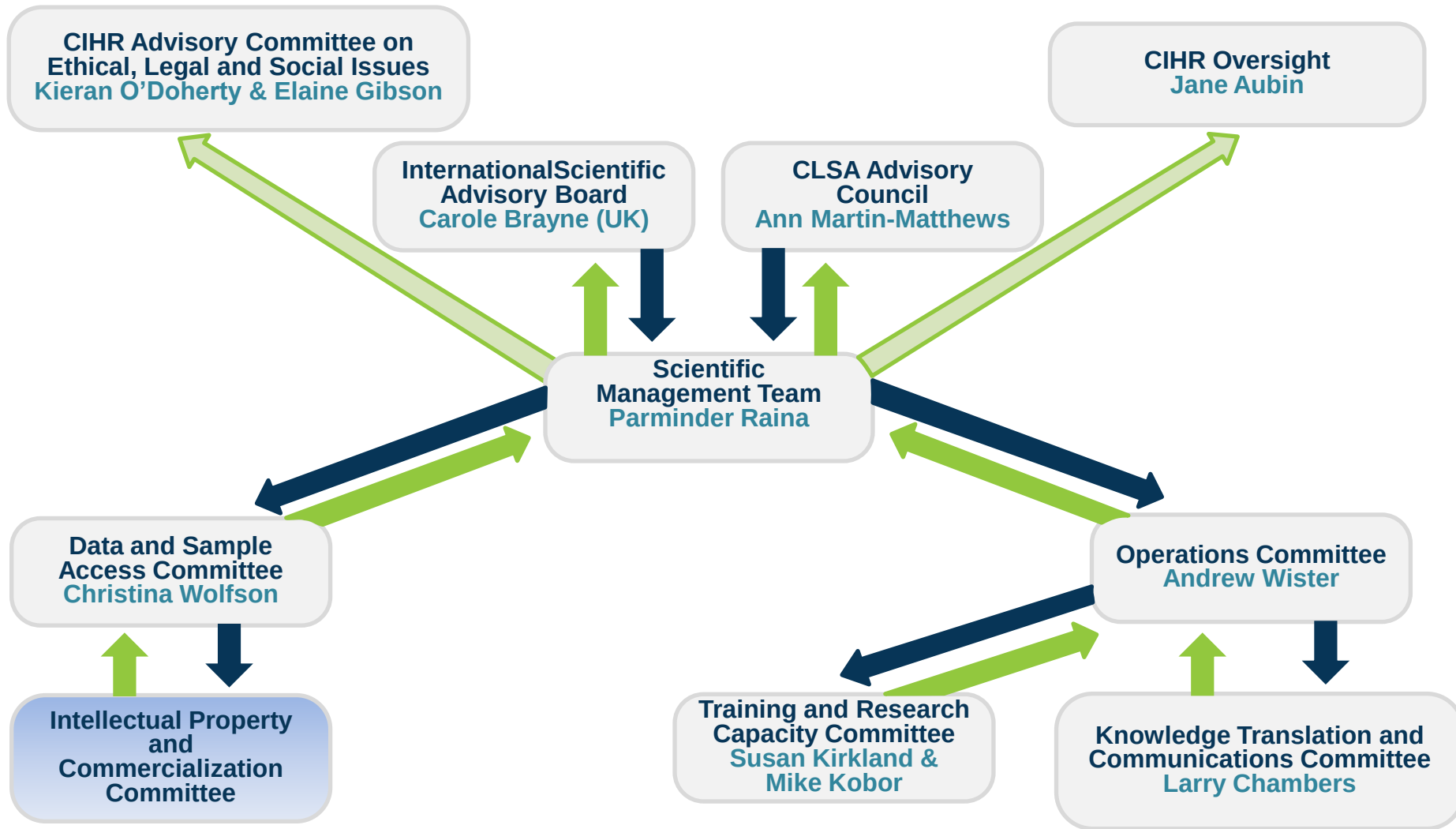
Status

February 12th, 2014

- **Completes for 60-minute CATI: 20,000**
 - Completes MCQ: 2,389
- Completes InHome interviews: 17,367
- Completes DCS Visits: 14,945



CLSA Governance Structure



Ethics Review

- For feasibility and pilot studies we submitted separate applications to each site that was involved
- For the full study (and amendments) we are using a collaborative process
 - Canadian Network for Public Health Intelligence (CNPHI) portal
 - Ethics review boards agree(..) to participate
 - McMaster University REB is the board of record

n.b. 11 data collection sites + 4 CATI sites

Data and Biospecimen Access

- Data and biospecimens available to the research community
- Fundamental tenets:
 - The rights, privacy and consent of *participants* must be protected and respected at all times
 - The confidentiality and security of *data and biospecimens* must be safeguarded at all times
 - CLSA data and biospecimens are resources that will be used optimally to support research to benefit all Canadians.

What is the data access process?

.....a priority activity.....

- 20,000 telephone interviews: first release scheduled for mid-2014
- Application process via CLSA website
- Review, Data and Sample Access Committee recommendation
- Approval, data sharing agreements
 - Proof of ethics approval
- Raw data to approved applicant
 - Cost recovery
- Return of derived variables to CLSA
- Monitoring process

CLSA Partners

- Public Health Agency of Canada
 - Injuries
 - Neurological Conditions Initiative
- Veterans Affairs
 - Veterans Health Initiative
- Statistics Canada
 - CCHS and methodological input
- Ontario Ministry of Health and Long-Term Care
- Provinces
- Universities
- Large number of in-kind contributions from vendors and suppliers (CFI)

CLSA Funders and Partners



Veterans Affairs
Canada



Anciens Combattants
Canada

Health PEI





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- **Data Collection Site**

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- Marie-Eve Martin
- Anil Soobinah
- Roselene Baltus
- Katya Lopez
- Claudia Greco
- Sanjivlall Balgobin
- Sharon Herrera

- **Inhome Interviews**

- Amy Striemer
- Christina DelGaudio
- Rahim Karmali

- **Statistical Analysis Centre**

- Isabel Fortier (Assoc Director)
- Jennifer Uniat (Manager)
- The Minh Luong (Statistician)
- Bin Zhu (Statistician)
- Sarah Youssef (Data Curator)

- **Translation**

- Marie-Eve Veilleux (Coordinator)
- Laurie Torres

- **Administration**

- Karen Zabowski



*Transforming Everyday Life
into Extraordinary Ideas*



Connect
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