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)

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CLSA Research Team

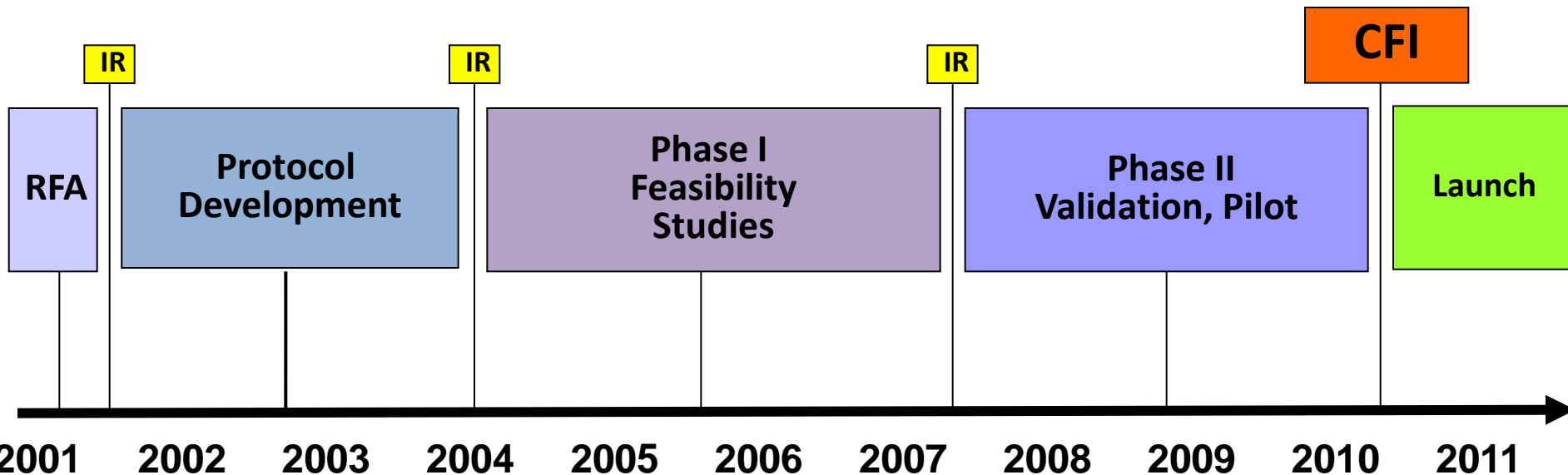|	
	Debra Sheets, Lynne Young, Holly Tuokko (**Victoria**), Max Cynader, Michael Hayden, Michael Kobor, Theresa Liu-Ambrose (**UBC**), Andrew Wister, Scott Lear (**SFU**), David Hogan, Marc Poulin (**Calgary**), Verena Menec, Phil St. John (**Manitoba**), Cynthia Balion, Christopher Patterson, Parminder 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

CFI

IR		IR		IR	

RFA	Protocol Development	Phase I Feasibility Studies	Phase II Validation, Pilot	Launch

2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011

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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

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Architecture

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

**n=20,000
Randomly selected within 10 provinces**

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

**Questionnaire
• By telephone (CATI)**

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

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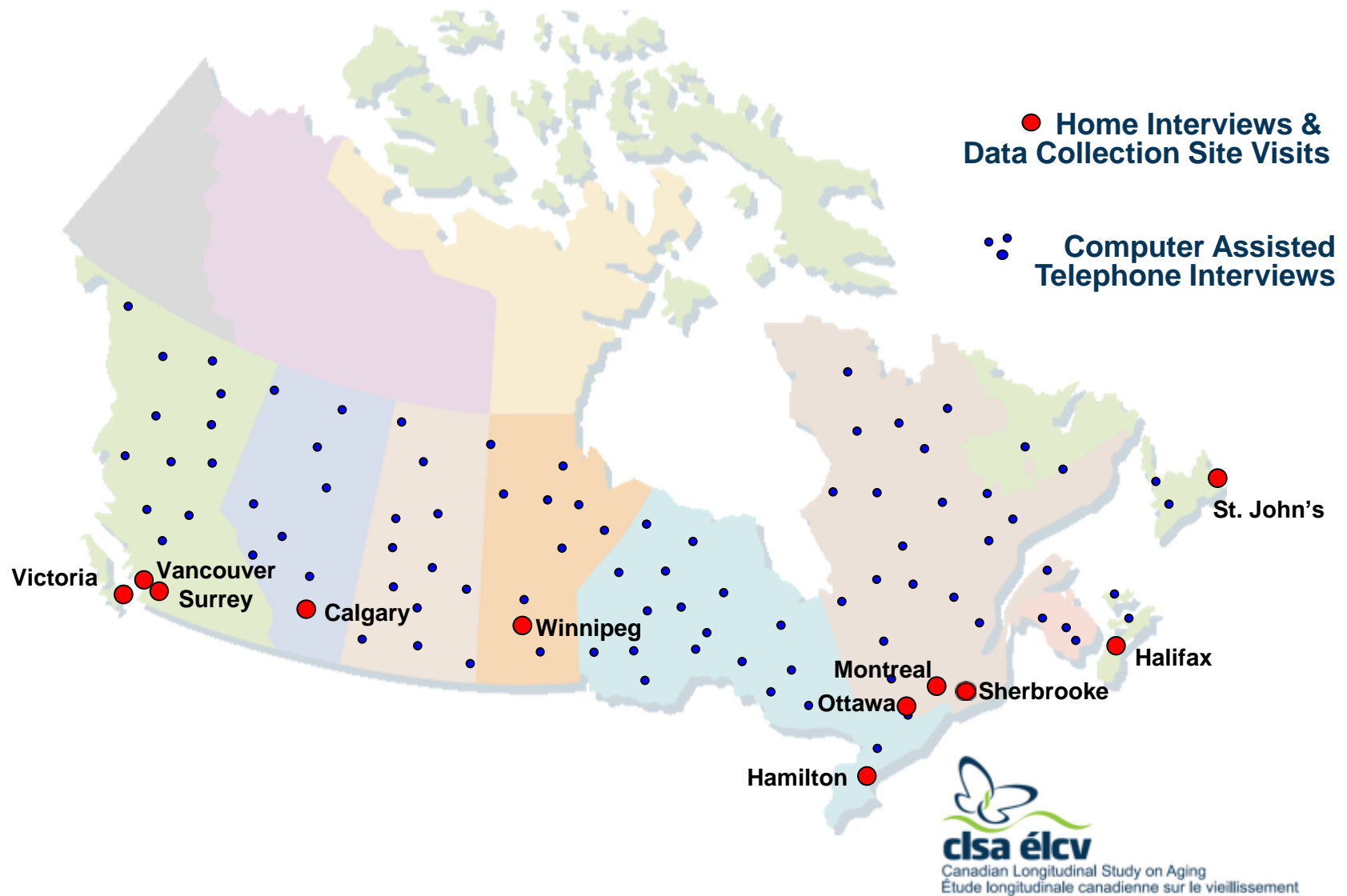Blood, urine
•   At Data Collection Site**

Maintaining contact, follow up every 3 years by phone

Linkage with Administrative Databases

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National

Home Interviews & Data Collection Site Visits

Computer Assisted Telephone Interviews

Victoria • Vancouver • Surrey • Calgary • Winnipeg • Montreal • Sherbrooke • Ottawa • Hamilton • Halifax • St. John's

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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"

Photo: Health Canada

Photo: Health Canada

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

Photo: Health Canada

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LIFESTYLE & SOCIODEMOGRAPHIC

Photo: Health Canada

Photo: Health Canada

Photo: Health Canada

Smoking

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

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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
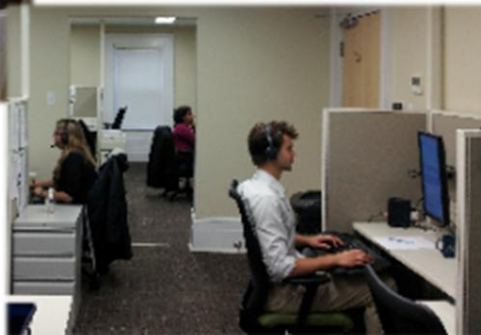## Telephone Interviews

4 CATI Sites conduct telephone interviews
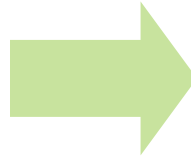
Participants provide questionnaire data in a 60 minute interview (n=20,000)

CLSA Infrastructure
4 Telephone Interview Centres

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 <u>and</u> 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
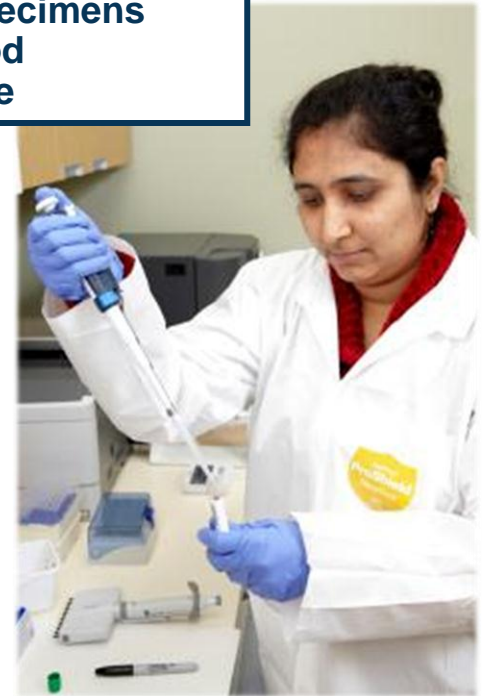## At the Data Collection Site

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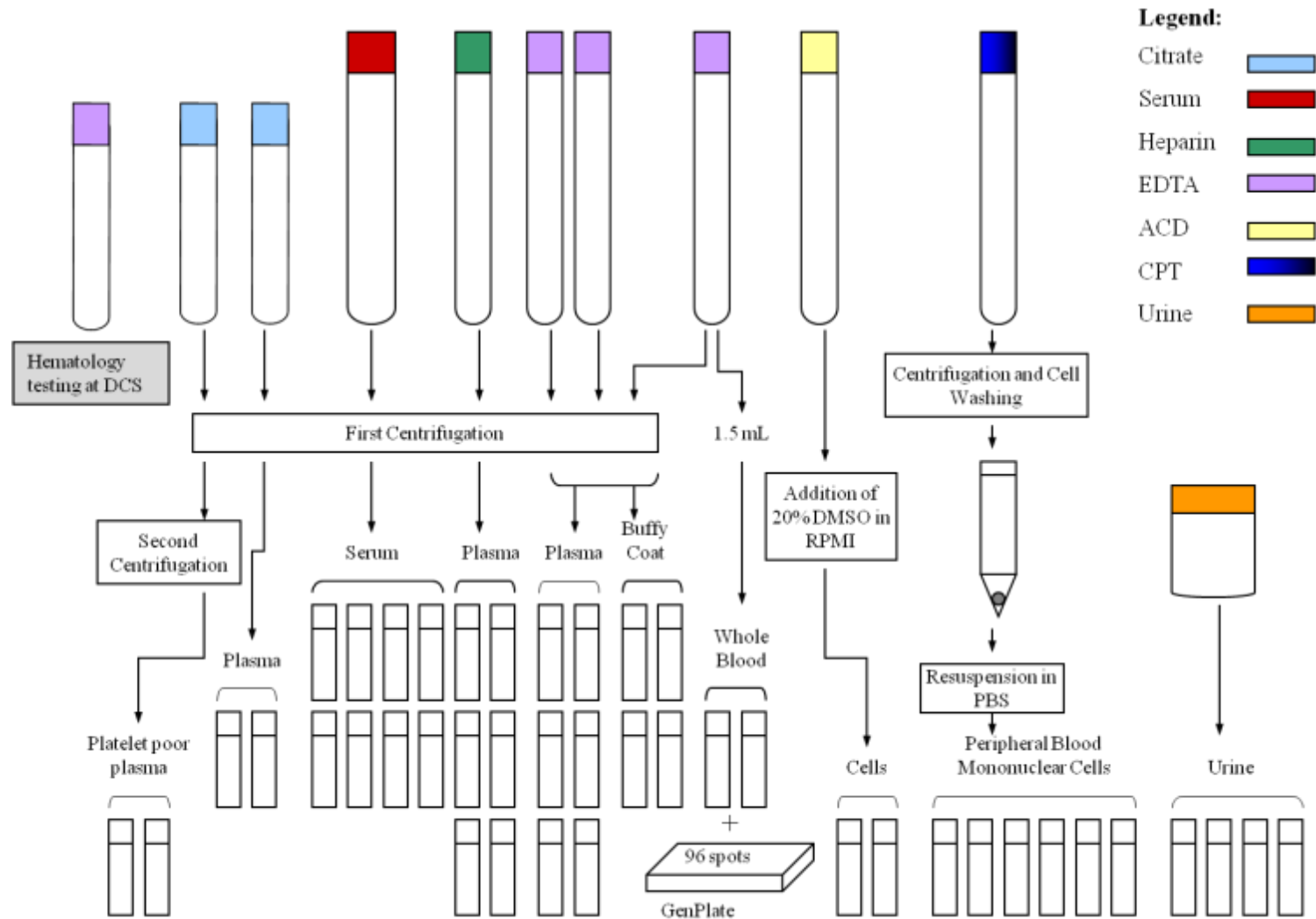- Vision and Hearing

Biospecimens
- Blood
- Urine

Psychological Data Collected
- Neuropsychological Battery
- Performance Testing
- Anthropometric Measures

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Biospecimen processing
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)
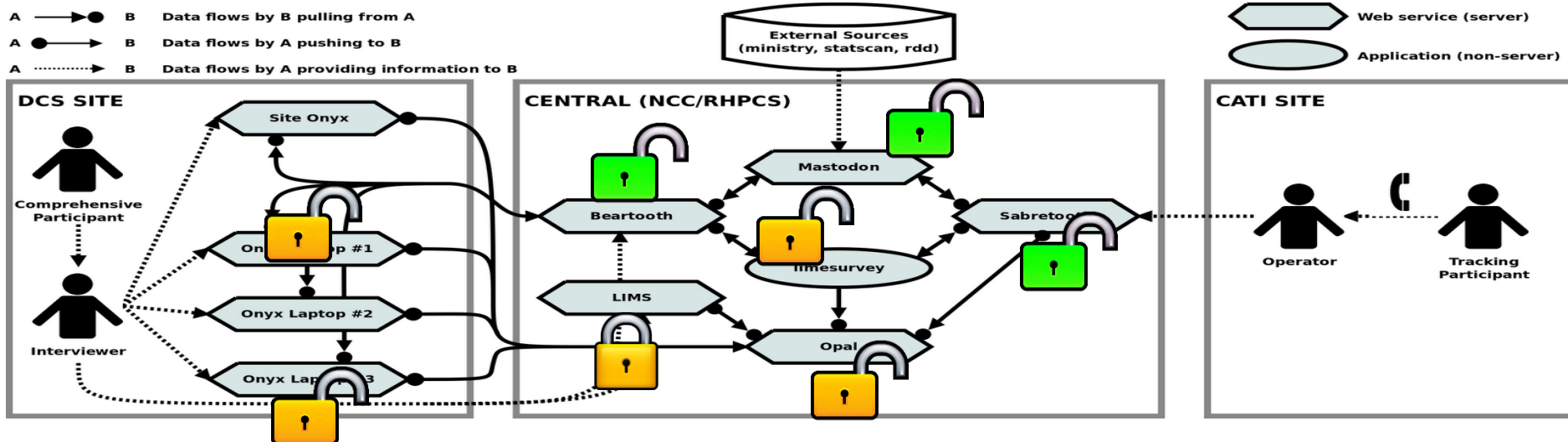
Alphanumeric data and images

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

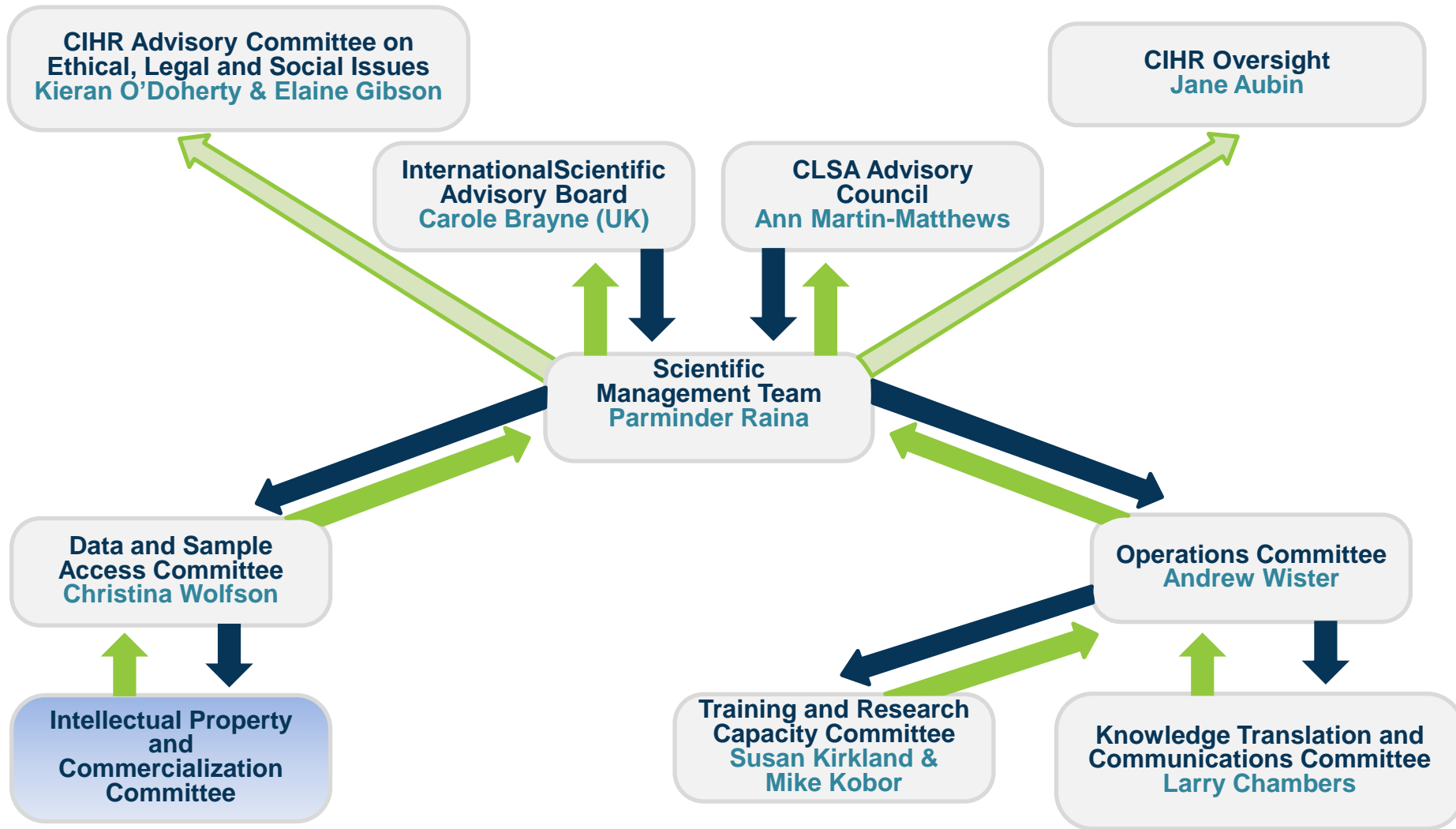**Statistical Analysis Centre (SAC)**
Director: Christina Wolfson

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

CIHR Advisory Committee on Ethical, Legal and Social Issues
Kieran O'Doherty & Elaine Gibson

CIHR Oversight
Jane Aubin

InternationalScientific Advisory Board
Carole Brayne (UK)

CLSA Advisory Council
Ann Martin-Matthews

Scientific Management Team
Parminder Raina

Data and Sample Access Committee
Christina Wolfson

Operations Committee
Andrew Wister

Intellectual Property and Commercialization Committee

Training and Research Capacity Committee
Susan Kirkland & Mike Kobor

Knowledge Translation and Communications Committee
Larry Chambers

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.

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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

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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)

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CLSA Funders and Partners

Acknowledgements CLSA Montreal

- **Data Collection Site**
  – Amelie Pelletier (Coordinator)
  – 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
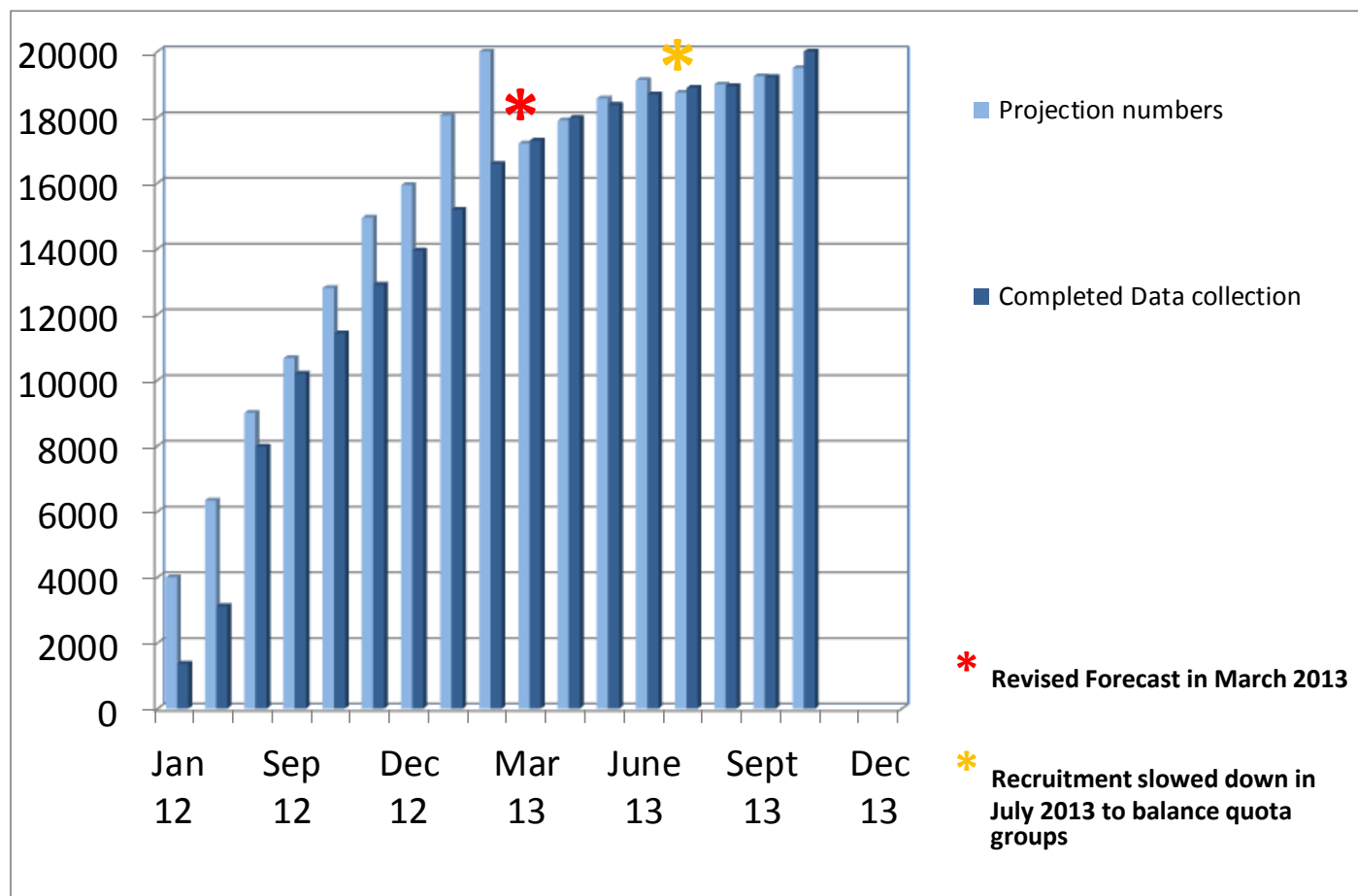
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Projections and Recruitment (Completed Data Collection) CATI

Projections and Recruitment (Completed Data Collection) DCS Visits