1. Update on the Canadian Longitudinal Study on Aging (CLSA)

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McMaster University, Hamilton

Operations Committee Meeting
Hamilton, Ontario
July 4-5, 2019
Participants aged 45 to 85 at baseline (51,338)

Questionnaire data (telephone and in-person interviews) (>50,000)

Physical assessments and biological specimens (>30,000)

Active follow-up (FU) every 3 years
- Questionnaire
- Physical assessments
- Biological specimens
- Health-care utilization
- Disease registries
- Mortality databases

Data and Biological Sample Repositories

To date >300 Researchers & Partners are using the CLSA Research Platform
The CLSA Research Platform in 2019

Follow-up 1 (FUP1) Data and Biospecimen Collection Completion
(includes our last effort to reach those participants who had not been responsive)

• **Telephone Interviews**
  (Baseline Recruitment of 21,241 participants aged 45-85)
  • 16,728 Telephone Interviews completed
  • 140 Web Questionnaires completed
  • 892 (4.2%) withdrawn
    669 (3.1%) withdrawn after Baseline

**Home Interviews and Data Collection Site Visits**
(Baseline recruitment of 30,097 participants aged 45-85)

• 27,765 In-Home Interviews completed (419 IH by Phone)
• 27,209 DCS Visits completed (824 DCS by phone & 308 DCS at home)
• 925 (3.1%) withdrawals
  355 (1.2%) withdrawals after Baseline
The CLSA Research Platform in 2019

Data and Biospecimen Collection
Follow-up 2 (FUP2)

**Telephone Interviews**
- 4,701 Telephone Interviews completed
- 152 withdrawn in FUP2 to date

**Home Interviews and Data Collection Site Visits**
- 10,536 In Home Interviews completed (111 IH by Phone)
- 9,064 Data Collection Site Visits completed (50 DCS by phone)
- 170 withdrawn in FUP2 to date
Noteworthy:
Data Access & Platform use successes

- Launched Magnolia for online data access in February 2019
- Now have >230 approved applications for data access
- > 75 other users (methodology, enriching data collection, infrastructure use)
# Approved Applications Summary

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<th>Researcher</th>
<th>Trainee</th>
<th>Total</th>
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<td>2019</td>
<td>40 + (13)</td>
<td>17 + (15)</td>
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<tr>
<td>Total</td>
<td>152</td>
<td>82</td>
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Approved Applications

234 applications approved since 2014

Year

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*28 applications currently under review
Where do applications come from?

Up to end of 2018

Upcoming Baseline Releases

- Epigenetics ($n = 1,488$) – Summer 2019
- Genomics ($n_{\text{curr}} = 9,896$; $n_{\text{add}} = \sim 17,000$) – Fall 2019
- Medications – May 2020
- Metabolomics ($n = 10k$) – Summer 2020
Upcoming Follow-up 1 Releases

• **First release** – July 2019
  • Questionnaires, Vital status, Physical assessments (performance measures)

• **Second release** – Fall 2019
  • Cognition, Physical assessments (images, complex data), Hematology Report

• Not included: Chemistry report, Linked data, Open text
Approved user outputs

- 41 peer-reviewed publications*
- 33 submitted to journal
- 1 “in press”
- 6 submitted for CLSA pre-publication review
Communications
June 2018 to May 2019

Twitter
New Followers: 252
Total Followers: 2,296
Retweets: 804

Facebook (Eng)
New Likes: 93
Total Likes: 1,283
Facebook (Fr)
New Likes: 17
Total Likes: 188

Media Tracking
July 2018 – June 2019
Print: 11
Online: 56
Broadcast: 2
Requests: 7

CLSA Website
Visits: 68,844
Unique Visitors: 40,023
Pageviews: 196,439
Unique Pageviews: 147,890

Top Eng Pages:
• Participant Newsletters
• Data Access
• Researchers

Top Fr Pages:
• Bulletin destiné aux participants
• Modifier vos coordonnées
• Accès aux données
Noteworthy

- CFN/METABOLON PARTNERSHIP for Metabolomics analyses on 10,000 biospecimens -> Developed process for private industry to access CLSA data
- Use of Dalhousie CATI site and CLSA software for 5,000 participant back pain study
- Starting another CLSA website overhaul
- In discussion to house CLSA data at Statistics Canada RTRA (Real time rapid access) portal, ideal for governments
- CLSA Quality Management System
  - BBC is applying for the College of American Pathologists CAP accreditation
  - Overall CLSA is preparing for the IQMH (Institute for Quality Management in Healthcare) certification.
Current Focus for the CLSA

- CLSA Platform Use
  - Data Access process
  - Biospecimen Access
  - Partnerships models using the CLSA Platform
- Sustainability Action Plan for the CLSA Research Platform
- Linkage administrative data (CIHI collaboration)
- Biomarker analyses -> Omics platform
- Funding applications:
  - CFI 2020 (NOI due Sept 16, full proposal due Jan 20, 2020)
  - CIHR 2020 (expected deadline of Spring 2020)
- Development of a CLSA Training Program
- Quality Management Systems
- Implementation of the Proxy Questionnaires following REB approval