CCNA LORIS - Data Dissemination

Oct. 21st Workshop

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Jessica Callegaro (CCNA LORIS Developer)
National Neuroinformatics Framework for Canadian Consortium on Neurodegeneration in Aging (CCNA)

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**Goal:**
- strengthen research groups to better manage the causes, detection, and treatment of AD.
- Help Advance findings and understanding of AD

**Longitudinal**
**Online**
**Research & Imaging System**

“...is a modular and extensible web-based data management system that integrates all aspects of a multi-center study:

From heterogeneous data acquisition (imaging, clinical, behavior, genetics) to storage, processing and ultimately dissemination.”
LORIS: Heterogeneous Data Management

Data Acquisition → Data Quality Control → Data Dissemination

data management system that integrates all aspects of a multi-center study
INTRO - Data Acquisition

LORIS: Heterogeneous Data Management

Data Acquisition ➔ LORIS ➔ Data Dissemination ➔ Data Quality Control
INTRO – Data Acquisition

Uploading/collecting heterogeneous data-sets (imaging, clinical, behavior, genetics)
POSSIBLE CONTENTS

INTRO - Data Acquisition - BVL

**Behavioural/Neuropsych**

<table>
<thead>
<tr>
<th>Patient Profile</th>
<th>Percentile Range</th>
<th>Standard Score Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain Scores</td>
<td>Subject Score</td>
<td>Standard Score</td>
</tr>
<tr>
<td>Neurocognition Index (NCI)</td>
<td>NA</td>
<td>85</td>
</tr>
<tr>
<td>Composite Memory</td>
<td>102</td>
<td>103</td>
</tr>
<tr>
<td>Verbal Memory</td>
<td>51</td>
<td>95</td>
</tr>
<tr>
<td>Visual Memory</td>
<td>52</td>
<td>110</td>
</tr>
<tr>
<td>Processing Speed</td>
<td>48</td>
<td>79</td>
</tr>
<tr>
<td>Executive Function</td>
<td>54</td>
<td>75</td>
</tr>
<tr>
<td>Psychomotor Speed</td>
<td>174</td>
<td>96</td>
</tr>
</tbody>
</table>

**Biosample**

**Imaging**

**Genetics**
- Registration of a candidate
- Creation of a visit
- Uploading the Scanned copy of the assessment/Instrument
INTRO – Data Acquisition – Stats

LORIS Data Entry Flow

<table>
<thead>
<tr>
<th>Candidates (total)</th>
<th>Candidates (CND only)</th>
<th>Sites</th>
<th>Configured Timepoints</th>
<th>Cohorts (and sub-studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1423</td>
<td>1115</td>
<td>61 (22 of which are imaging sites)</td>
<td>39</td>
<td>22</td>
</tr>
</tbody>
</table>
- Repeated for all the instruments at the given visit
- Requirement for setting the entire visit to approval and uploading to DQT
<table>
<thead>
<tr>
<th>Instruments /Forms Coded</th>
<th>Fields</th>
<th>Candidates with Baseline Visits Started</th>
<th>Candidates with Baseline Visit Completed</th>
<th>Candidates with Follow Up Visit Started</th>
<th>Candidates with Follow Up Visit Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>247 (165 translated)</td>
<td>12 506</td>
<td>1339 (out of 1423)</td>
<td>413(out of 1423)</td>
<td>865</td>
<td>382</td>
</tr>
</tbody>
</table>
INTRO - Data Acquisition - Biosample

SAMPLE COLLECTION AND DISTRIBUTION

Sample Collection

DNA and RNA sequencing
Director: Kathy Siminovitch
Clinical Genomics Centre
Mount Sinai Hospital
Toronto, ON

Long term storage of samples
Director: Dr Bruce Ritchie
Canadian Biosample Repository
University of Alberta
Edmonton, AB

Aliquots sent to labs for analyses

CSF samples for Clinical Biomarkers
Dr Mari DeMarco
St. Paul’s Hospital
Vancouver, BC

CSF Samples for Experimental Biomarkers
Dr Judes Poirier
Douglas University Hospital
Vancouver, BC

Blood Plasma & Serum Samples
Dr Shun Erintochi
Jawa General Hospital
Montreal, QC

Saliva Samples
Dr Roger Dixon
University of Alberta
Edmonton, AB

Buccal & Fecal Swabs for Microbiome Analysis
Director: Dr Brett Finlay
Microbiome Insights
Vancouver BC

Blood, Saliva, Urine, Cerebrospinal Fluid, Fecal Swab, Buccal Swab, etc.
INTRO – Data Acquisition – Biosample

- Biobanking tool/module to import and track the collection process
- Tracking tool to streamline interaction with Canadian Biosample Repository (CBSR) Database
- Allow import of analyzed and processed data
INTRO - Data Acquisition - Biosample

### Sample Collection and Distribution

#### Sample Collections
- Blood
- CSF
- Saliva
- Buccal
- Urine
- Fecal

#### DNA and RNA sequencing
- Director: Valeria Seminara
- Clinical Genomics Centre
- Mount Sinai Hospital
- Toronto, ON

#### Long term storage of samples
- Director: Dr. Bruce Rochon
- Canadian Biosample Repository
- University of Alberta
- Edmonton, AB

#### Samples for Clinical Biomarkers
- Dr. Max Delhaize
- St. Paul's Hospital
- Vancouver, BC

#### Samples for Experimental Biomarkers
- Dr. Juno Park
- Vancouver General Hospital
- Vancouver, BC

#### Blood, Plasma & Serum Samples
- Dr. Robert Deans
- University of Alberta
- Edmonton, AB

#### Saliva Samples
- Dr. Roger Dean
- University of Alberta
- Edmonton, AB

#### Buccal & Fecal Swabs
- Dr. Mark Heiken
- Montebello Heights
- Vancouver, BC

#### Raw Data

<table>
<thead>
<tr>
<th>Sample Type</th>
<th>Blood</th>
<th>CSF</th>
<th>Saliva</th>
<th>Buccal</th>
<th>Urine</th>
<th>Fecal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raw</td>
<td>1014</td>
<td>125</td>
<td>1072</td>
<td>767</td>
<td>1037</td>
<td>633</td>
</tr>
</tbody>
</table>
INTRO – Data Acquisition – Biosample

**SAMPLE COLLECTION AND DISTRIBUTION**

**Sample Collection**
- Blood, Saliva, Urine, Cerebrospinal Fluid, Fecal Swabs, Buccal Swabs, etc.

**DNA and RNA sequencing**
- Director: Kathy reminski
  - Clinical Genomics Centre
  - Mount Sinai Hospital
  - Toronto, ON

**Long term storage of samples**
- Director: Dr. Bruce Ritchie
  - Canadian Biosample Repository
  - University of Alberta
  - Edmonton, AB

**Acquire sent to labs for analyses**

<table>
<thead>
<tr>
<th></th>
<th>Blood</th>
<th>CSF</th>
<th>Saliva</th>
<th>Buccal</th>
<th>Urine</th>
<th>Fecal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Raw</strong></td>
<td>1014</td>
<td>125</td>
<td>1072</td>
<td>767</td>
<td>1037</td>
<td>633</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>313</td>
<td>72</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
INTRO - Data Acquisition - Imaging

1 hour acquisition to acquire scans for different modalities
### INTRO – Data Acquisition – Imaging

<table>
<thead>
<tr>
<th>Scout</th>
<th>3D T1</th>
<th>PD/T2</th>
<th>FLAIR</th>
<th>T2*</th>
<th>DTI</th>
<th>BOLD</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 mins</td>
<td>5 mins</td>
<td>7 mins</td>
<td>5 mins</td>
<td>6 mins</td>
<td>11 mins</td>
<td></td>
</tr>
</tbody>
</table>

- MRI scans are anonymized using the DICOM Anonymizer tool
- Anonymized scans are uploaded to LORIS using the MRI Upload tool
- Scans are viewable online through Brainbrowser
INTRO - Data Acquisition - Imaging

MRI scans are anonymized using the DICOM Anonymizer tool.

Anonymized scans are uploaded to LORIS using the MRI Upload tool.

Scans are viewable online through Brainbrowser.

<table>
<thead>
<tr>
<th>Subject Scans Uploaded</th>
<th>Phantom Scans Uploaded</th>
<th>Modalities</th>
<th>Scans Undergone QC (phantoms + subjects)</th>
<th>Scans Passed QC (phantoms + subjects)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1103</td>
<td>228</td>
<td>11</td>
<td>1140</td>
<td>1053</td>
</tr>
</tbody>
</table>
INTRO – Data Acquisition – Genetics

Biosample

Behavioural/Neuropsych

Genetics

Imaging

Work in Progress
• Samples Genotyped at the University of Toronto

• Sequencing on an Illumina MiSeq platform with a NeuroX or Affymetrix UK Biobank chip

• Aligned, annotated and variant calls at the analysis site
- Genotyped at the University of Toronto
- Sequencing on an Illumina MiSeq platform with a NeuroX or Affymetrix UK Biobank chip
- Aligned, annotated and variant calls at the analysis site
- Storage of raw and processed files/genetic data in LORIS
INTRO – Data Acquisition – Genetics

- Genotyped at the University of Toronto

- Sequencing on an Illumina MiSeq platform with a NeuroX or Affymetrix UK Biobank chip

- Aligned, annotated and variant calls at the analysis site

- Storage of raw and processed files in LORIS

- To view/QC through Genomic and SNP browser
Request an account on https://ccna.loris.ca/login/request-account/

Request data access through data access module → Download Data

Download non-imaging packaged datasets → Data Release Module

Query/download all datasets → DQT

Download imaging datasets → ProFTP
Request Data Access

1. Request an account on https://ccna.loris.ca/login/request-account/
2. Request data access through data access module
3. Download Data
   - Query/download all datasets
   - Download non-imaging Packaged datasets
   - Download imaging datasets

DQT
Data Release Module
ProFTP
Request Data Access

Current process

Step 1: Victor sends out the PDF form to be filled.

Step 2: The researcher fills the form and returns to Victor via email.

Step 3: The form is sent via email to PDAC committee.

Step 4: Upon approval necessary access to data will be granted.
Data Access module was designed to facilitate the process of both requesting and granting access to data.

Proposed process

Step 1

The researcher will request an account on LORIS.
Request Data Access Module

Proposed process

Step 1
The researcher will request an account on LORIS.

Step 2
The researcher will fill out the Data-Access form on LORIS.
### Request Data Access Module

#### Administrative Information

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name*</td>
<td></td>
</tr>
<tr>
<td>Affiliation:*</td>
<td></td>
</tr>
<tr>
<td>Your status:</td>
<td></td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Street:</td>
<td></td>
</tr>
<tr>
<td>City:</td>
<td></td>
</tr>
<tr>
<td>Province:</td>
<td></td>
</tr>
<tr>
<td>Postal Code:</td>
<td></td>
</tr>
<tr>
<td>Email:*</td>
<td></td>
</tr>
<tr>
<td>Phone number:</td>
<td></td>
</tr>
</tbody>
</table>

#### Type of Data Requested

- [ ] Screening/Clinical/Behavioural
  - Individual test/elements (optional):
- [ ] Neuropsychological
  - Individual test/elements (optional):
- [ ] MRI
  - Individual test/elements (optional):
- [ ] Biomarker results
  - Individual test/elements (optional):

[Submit] [Reset]
The researcher will request an account on LORIS.

The researcher will fill out the Data-Access form on LORIS.

Admin will be notified by email to approve the request.
Dear CCNA data access admin,

A data access request was done by

Name: PP PS
Email: pierrepacsooo@gmail.com

To process the application please go to the CCNA data access admin panel. You can find the admin panel at the following link: 'http://localhost:3080/data_access/'.

Thank you,

LORIS Team
## Request Data Access Module

### Selection Filter

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher</td>
<td></td>
</tr>
<tr>
<td>Affiliation</td>
<td></td>
</tr>
<tr>
<td>Category (visit)</td>
<td>Biomarker results, MRI, Neurocognitive Screening/Clinical</td>
</tr>
<tr>
<td>Date</td>
<td></td>
</tr>
<tr>
<td>Status</td>
<td></td>
</tr>
</tbody>
</table>

### Table

<table>
<thead>
<tr>
<th>No.</th>
<th>Researcher</th>
<th>Affiliation</th>
<th>Category (visit)</th>
<th>Date</th>
<th>Application form</th>
<th>Status (select to change)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>researcher 1</td>
<td>affiliation 1</td>
<td>Screening/Clinical, MRI</td>
<td>2020-10-10</td>
<td>View Form</td>
<td>in-progress</td>
</tr>
<tr>
<td>2</td>
<td>researcher 2</td>
<td>affiliation 2</td>
<td>MRI, Biomarker results</td>
<td>2020-10-19</td>
<td>View Form</td>
<td>approved</td>
</tr>
</tbody>
</table>

### Status Options
- requested
- approved
- in-progress
- rejected
- requested
Request Data Access Module

Proposed process

Step 1
The researcher will request an account on LORIS.

Step 2
The researcher will fill out the Data-Access form on LORIS.

Step 3
Admin will be notified by email to approve the request.

Step 4
Upon approval necessary access to data will be granted and the user is notified by email.
How to access the data

1. Request an account on https://ccna.loris.ca/login/request-account/
2. Request data access through data access module
3. Download Data
   - Query/download all datasets
   - Download non-imaging Packaged datasets
4. Download imaging datasets
5. Download using DQT
6. Download using Data Release Module
7. Download using ProFTP
Data Query Tool (DQT)

Request an account on https://ccna.loris.ca/login/request-account/

Request data access through data access module

Download Data

Download non-imaging Packaged datasets

Query/download all datasets

Download imaging datasets

Data Release Module

DQT

ProFTP
Data Query Tool (DQT) – What is it?

- Query and retrieve data without technical expertise (or a programmer)
Data Query Tool (DQT) – What is it?

- Query and retrieve data without Technical expertise

- Design, execute, and save queries in a simple and intuitive manner
Data Query Tool (DQT) – What is it?

- Query and retrieve data without Technical expertise

- Design, execute, and save queries in a simple and intuitive manner

- Selection of variables, and quick download in most commonly used formats
Data Query Tool (DQT) - What is it?

- Query and retrieve data without Technical expertise
- Design, execute, and save queries in a simple and intuitive manner
- Selection of variables, and quick download in most commonly used formats
- Save and reload any query
Data Query Tool (DQT) - Define Fields

1. Define Fields
2. Define Filters
3. View Data
4. Download Data

**Fields**

- Add All
- Remove All

**Instrument:**

- Annual Follow up, Phone Call
- Acetylcholine, Tissue Inventory
- Acetylcholine, Neurotransmitter Report
- Benoxe, Complex, EOG, Test
- CERAD, Visual, Test
- Clinical, Biomarker, Blood Analysis, Data
- Clinical, Biomarker, CSF, Analysis, Data
- Clinical, Biomarker, CSR
- Clinical, CBC
- Clinical, Current, Medication
- Clinical, Current, Medication, Flu
- Clinical, Dilution, Assessment
- Clinical, Diagnosis, Confirmation
- Clinical, DII
- Clinical, Family, History

**Add All**

- Select All

**Remove All**

- Clear All

**Fields**

- Select One

**Instrument:**

- Select One

**Fields:**

- Select One

**Administration**

- CERAD, Visual, Test

**Conflicts, Exit**

- Conflict for instrument data entry

**Data, entry**

- Data entry for CERAD, Visual, Test

**DDE, Complete**

- Double Data Entry was completed for instrument

**Validity**

- Validity of data for CERAD, Visual, Test
Data Query Tool (DQT) - Define Filters

Detailed examples During the Live Demo!
### Data Query Tool (DQT) – View Data

#### Query Criteria
- **Run Query**
- **Download Data as ZIP**

#### Data
- **Cross-sectional**

20 rows displayed of 413. (Maximum rows per page: 20)

<table>
<thead>
<tr>
<th>Identifiers</th>
<th>Clinical_Medical_History,000_Administration</th>
<th>Clinical_Medical_History,000_Date_taken</th>
<th>Clinical_Medical_History,000_Viability</th>
<th>Clinical_Medical_History,000_Viability</th>
</tr>
</thead>
<tbody>
<tr>
<td>BCT3499,Clinical_Assessment</td>
<td>All</td>
<td>2018-11-02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BCT3664,Clinical_Assessment</td>
<td>All</td>
<td>2018-08-31</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BCT7918,Clinical_Assessment</td>
<td>All</td>
<td>2018-12-04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BCT9597,Clinical_Assessment</td>
<td>All</td>
<td>2018-09-21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BCT9713,Clinical_Assessment</td>
<td>All</td>
<td>2018-10-19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BCT9968,Clinical_Assessment</td>
<td>All</td>
<td>2018-09-07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BR11080,Clinical_Assessment</td>
<td>All</td>
<td>2018-01-30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BR12365,Clinical_Assessment</td>
<td>All</td>
<td>2017-10-11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Data Query Tool (DQT) - Download Data

Query Criteria

Data

Identifiers

Download Table as CSV
Live Demo by Jessica Callegaro
# Data Dictionary for DQT

<table>
<thead>
<tr>
<th>No.</th>
<th>Source From</th>
<th>Name</th>
<th>Source Field</th>
<th>Description</th>
<th>Description Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Annual Follow_up Phone_Call</td>
<td>Annual_Follow_up_Phone_Call_Date_taken</td>
<td>Date_taken</td>
<td>Date of Administration</td>
<td>Unchanged</td>
</tr>
<tr>
<td>2</td>
<td>Annual Follow_up Phone_Call</td>
<td>Annual_Follow_up_Phone_Call_Candidate_Age</td>
<td>Candidate_Age</td>
<td>Candidate Age (Months)</td>
<td>Unchanged</td>
</tr>
<tr>
<td>3</td>
<td>Annual Follow_up Phone_Call</td>
<td>Annual_Follow_up_Phone_Call_Window_Difference</td>
<td>Window_Difference</td>
<td>Window Difference (+/- Days)</td>
<td>Unchanged</td>
</tr>
<tr>
<td>4</td>
<td>Annual Follow_up Phone_Call</td>
<td>Annual_Follow_up_Phone_Call_Examiner</td>
<td>Examiner</td>
<td>Examiner</td>
<td>Unchanged</td>
</tr>
<tr>
<td>5</td>
<td>Annual Follow_up Phone_Call</td>
<td>Annual_Follow_up_Phone_Call_years_since_initial_assessment</td>
<td>years_since_initial_assessment</td>
<td>Years since completion of initial</td>
<td>Unchanged</td>
</tr>
</tbody>
</table>
Compare MOCA assessments for hearing-impaired MCI vs hearing-impaired Controls.

Tip: make sure to select ‘Longitudinal’ view when viewing data!
Investigate the link between homocysteine levels and WMH burden in different cohorts (AD, Mixed, MCI, V-MCI).

a) Using blood analysis data and MRI visual measurements related to WMH.

b) Checking specifically for px that meet the vascular dementia / cognitive impairment criteria (ARWMC >= 2)
Request an account on https://ccna.loris.ca/login/request-account/

Request data access through data access module

Download Data

DQT

Query/download all datasets

Data Release Module

Download non-imaging Packaged datasets

ProFTP

Download imaging datasets
Data Release

- The Data Release Module can be used to easily distribute packaged data releases of your study.

- Users can download customized subsets of data from this module.

- Scaling and transferring solutions were implemented for researchers downloading large datasets.
<table>
<thead>
<tr>
<th>File Name</th>
<th>Version</th>
<th>Upload Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Fluid_Bomarker_Data_n_409.csv</td>
<td>03_2020</td>
<td>2020-07-06</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_MRI_Vascular_and_Volumetrics_Data_n_409.csv</td>
<td>03_2020</td>
<td>2020-05-29</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Dx_evolution_n_409_+_discrepancies.csv</td>
<td>03_2020</td>
<td>2020-05-14</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Year_1_Phone_call_Instrument_Data_n_375.csv</td>
<td>03_2020</td>
<td>2020-04-23</td>
</tr>
<tr>
<td>COMPASSND_Apr_20_Data_Dictionary.csv</td>
<td>03_2020</td>
<td>2020-04-21</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Clinical_Instrument_Data_n_409.csv</td>
<td>03_2020</td>
<td>2020-04-13</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Neuropsychology_Visit_Instrument_Data_n_409_with_Hayling_summary_stats.csv</td>
<td>03_2020</td>
<td>2020-03-30</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Screening_Visit_Instrument_Data_n_409.csv</td>
<td>03_2020</td>
<td>2020-03-19</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Neuropsychology_Visit_Instrument_Data_n_409_excluding_RAVLT_data.csv</td>
<td>03_2020</td>
<td>2020-03-19</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Neuropsychology_Visit_Instrument_Data_n_409_excluding_RAVLT_data.csv</td>
<td>03_2020</td>
<td>2020-03-19</td>
</tr>
<tr>
<td>COMPASSND_Feb_2020_datarelease_Neuropsychology_Visit_Instrument_Data_n_410_excluding_RAVLT_data.csv</td>
<td>01-2020</td>
<td>2020-03-17</td>
</tr>
</tbody>
</table>
Data Release

Choose a specific file or an entire release below:

Data Release File

OR

Data Release Version

Add Permission  Cancel
ProFTP/sFTP

1. Request an account on https://ccna.loris.ca/login/request-account/
2. Request data access through data access module
3. Download Data
   - Download imaging datasets
   - Download non-imaging Packaged datasets

DQT
- Query/download all datasets

Data Release Module

ProFTP
Accessing Files Using FileZilla

- An SFTP server is used to securely transfer large data files over a remote system to users based on permission.

- Easy setup and configuration of FileZilla client using LORIS credentials.

- Gain access to and download CCNA data release files.
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Questions

You can email us at ccna@mcin.ca if you have any further questions!