

Data Support Document

Changes in data collection procedures in the comprehensive cohort during follow-up 2 assessments amidst the COVID-19 Pandemic (Comprehensive Cohort – Follow-up 2)

1.0 PURPOSE AND SCOPE

The purpose of this Data Support Document is to provide a brief, high-level overview of the changes in data collection procedures within the Comprehensive Cohort during follow-up 2 (2018-2021) assessments as a result of the onset of the COVID-19 pandemic. This document describes the modifications made to the data collection methods, modules which were impacted, and the documentation of these changes in the data dictionary.

2.0 BACKGROUND

2.1 Brief overview of the Canadian Longitudinal Study on Aging (CLSA)

The Canadian Longitudinal Study on Aging (CLSA) is a national, longitudinal research platform that collects extensive data across a wide range of health domains along with biological samples.¹⁻² The CLSA recruited 51,338 participants aged 45-85 years at baseline (2011-2015) and consists of two main cohorts:

- i) Tracking Cohort: This cohort includes 21,241 individuals at baseline who were randomly selected from all ten provinces in Canada. Participants in this cohort are interviewed via telephone.
- ii) Comprehensive Cohort: The Comprehensive cohort is comprised of 30,097 individuals at baseline who were randomly selected from within a 25-50 km radius of 11 Data Collection Sites (DCS) across seven provinces in Canada. Participants in this cohort undergo face-to-face interviews in their homes, physical assessments at a DCS, and provide biological samples (blood and urine).

All participants are followed-up every 3 years or until death or loss-to-follow-up.

3.0 IMPLEMENTATION

3.1 Data collection in Comprehensive cohort at Follow-up 2

Follow-up 2 data collection was completed between April 2018 and September 2021. On March 11, 2020, the World Health Organization declared COVID-19 a pandemic. The data collection method for the Tracking cohort remained unchanged, except that staff transitioned to conducting the telephone interviews from their homes. However, data collection for the Comprehensive cohort was interrupted due to public health restrictions at the CLSA sites aimed at reducing the spread of COVID-19. Starting March 16, 2020, visits at all DCS sites and in-person home interview visits for follow-up 2 were suspended. To mitigate the impact of the pandemic on data collection efforts, the CLSA adapted by administering in-person home visit and DCS questionnaires with participants via telephone (Figure 1).

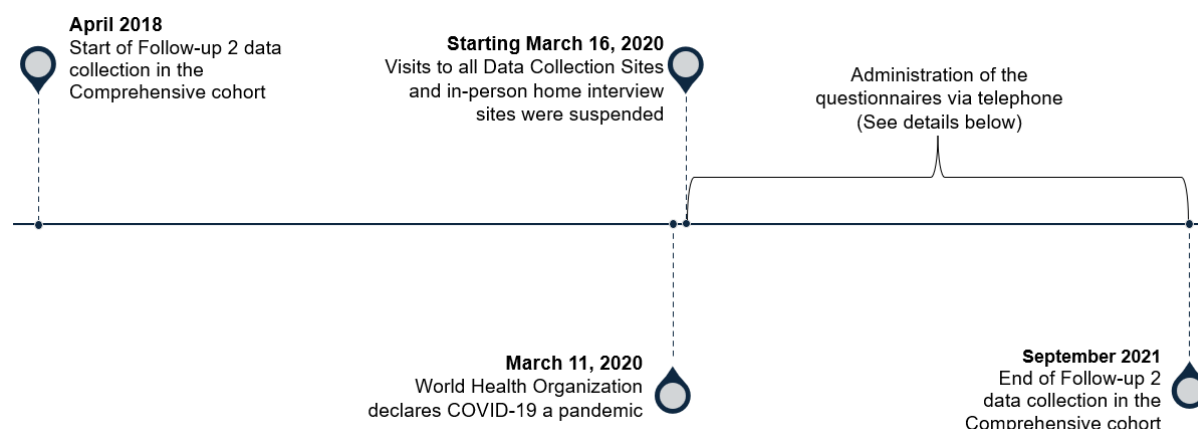


Figure 1: Timing of data collection in Comprehensive cohort at Follow-up 2

Of the 30,097 participants recruited to the Comprehensive cohort at baseline, 25,563 participants (85%) completed follow-up 2. **Table 1** describes the distribution of follow-up 2 data collection methods before and during the pandemic. Of the 25,563 participants, 15,769 (61.7%) completed assessments before the pandemic and 9,794 (38.3%) completed assessments during the pandemic. Before the pandemic, a majority of the participants (n=13,937, 88.4%) completed the regular in-person home visit and attended a DCS for physical assessments and to provide biological samples. Due to health- or mobility-related reasons, a small proportion of participants were accommodated by completing in-person home visits and/or DCS visits by telephone. Due to pandemic-related public health restrictions, a substantial proportion of participants completed both in-person home visit and the DCS visit by telephone (9,511, 97%) during the pandemic.

Table 1: Mode of data collection at follow-up 2 in the Comprehensive cohort before and during the COVID-19 pandemic (n=25,563)*

Follow-up 2 data collection method	Before pandemic n (%)	During pandemic n (%)
Regular in-person home visit & Regular DCS	13,937 (88.4)	-
Regular in-person home visit & DCS by phone	1,161 (7.4)	-
Regular in-person home visit & DCS at home	83 (0.5)	-
Regular in-person home visit & No DCS	268 (1.7)	-
In-person home visit by phone & Regular DCS	142 (0.9)	-
In-person home visit by phone & No DCS	11 (0.07)	213 (2.2)
In-person home visit by phone & DCS by phone	167 (1.1)	9,511 (97.1)
Assessment by web [£]	-	70 (0.7)
Total	15,769	9,794

*Date of participation is the earlier of the date of in-home visit and the date of DCS visit

[£]See details in section 3.2

4.0 Pre-pandemic assessment at follow-up 2

4.1.1 In-home interview

At follow-up 2, the following modules were administered at in-home interview visits: sociodemographic characteristics, health behaviours (smoking, alcohol use, physical activity,

nutrition), general health, women's health, subjective cognitive decline, functional status, basic and instrumental activities of daily living, life space index, transportation and mobility, satisfaction with life, loneliness, posttraumatic stress disorder, psychological distress, positive mental health, cognition (Rey Auditory Verbal Learning Test, Verbal Fluency - Animal Naming Test, and Mental Alternation Test), meta memory, caregiving and receiving, injuries and falls, retirement and labour force participation, online social networking, health care utilization, unmet healthcare needs, medications, and weight perception.

4.1.2 Data collection site (DCS) assessment

Physical assessment: At the DCS, participants underwent a detailed physical assessment with the following tests being performed: dual-energy X-ray absorptiometry (DEXA), carotid intima-media thickness (cIMT), electrocardiogram (ECG), spirometry, retinal scan, visual acuity, tonometry, audiometry, 4-metre walk test, timed get up and go test, standing balance, chair rise test, hand grip strength, body measures (height, weight, hip and waist circumferences), and pulse rate and blood pressure measurements.

Questionnaires: At follow-up 2, participants completed questionnaires on bone mineral density, social networks, social support availability, social participation, social cohesion, generalized anxiety disorder, nutritional risk, oral health, sleep, pain and discomfort, vision and hearing, chronic conditions and symptoms, contraindications, resiliency, and intimate partner violence.

Neuropsychological battery: In addition to the neuropsychological tests that were performed during the in-home interview, further assessments were administered during the DCS visit. These included the Prospective Memory Test, Controlled Oral Word Association, Stroop Neurological Screening Test, and Choice Reaction Time.

Biological specimens: Participants provided blood and urine samples.

4.1.3 Assessment by web

Accommodation strategies involve modifications to the standard protocol to allow flexible participation as individuals age and encounter circumstances that may impact their continued involvement in the study. Accommodations were developed for participants who could not complete the assessments as per the standard protocol. Depending on the participant's accommodations, the following modules may have been completed online: sociodemographic characteristics, height and weight, health behaviours (smoking, alcohol use, physical activity, nutritional risk), general health, oral health, women's health, subjective cognitive decline, pain and discomfort, vision and hearing, Hearing Handicap Inventory for the Elderly, chronic conditions, parkinsonism, epilepsy, injuries, falls, functional status, basic and instrumental activities of daily living, depression, generalized anxiety disorder, satisfaction with life, loneliness, positive mental health, social networks, social support availability, social participation, social cohesion, online social networking, care receiving and care giving, retirement status and planning, labour force, health care utilization, unmet care needs, medication use, dietary supplement use, built environments, transportation and mobility, and wealth.

4.2 During pandemic assessment

4.2.1 In-home interview

With the exception of the weight perception module, all other modules that would typically be administered at in-home interview visits (listed above) were administered by telephone. Weight

perception assessment involves looking at a diagram to indicate which picture best reflects the participant's body build across different ages, and therefore this module could not be administered by telephone.

Note: Normative data are available for the Rey Auditory Verbal Learning Test, Verbal Fluency - Animal Naming Test, and Mental Alternation Test for participants who completed the testing in-person during the in-home interview before the pandemic and by telephone during the pandemic.

4.2.2 Data collection site (DCS) assessment

Physical assessment: All physical assessment testing was suspended during the pandemic.

Questionnaires: All the previously mentioned questionnaire modules that would typically be administered during the DCS assessment were administered by telephone, except for the resiliency scale and the intimate partner violence questionnaire, which were not administered.

Neuropsychological battery: Assessments including the Prospective Memory Test, Controlled Oral Word Association, Stroop Neurological Screening Test, and Choice Reaction Time that are usually administered at the DCS visit were not administered over the telephone.

Note: For these tests, normative data are only available for participants who completed the testing in-person before the pandemic.

Biological specimens: Biological samples were not collected during the pandemic.

4.2.3 Assessment by web

All the previously mentioned questionnaire modules that were typically administered online as part of accommodation strategies continued to be delivered via the web during the pandemic.

4.3 Documentation of the changes in the data dictionary

The variables 'ADM_SPECIAL_INHOME_COF2' and 'ADM_SPECIAL_STATUS_COF2' specify how the data were collected for the in-home interview and DCS assessment, respectively. The categorical values these variables can take, and their descriptions are provided in the tables below.

ADM_SPECIAL_INHOME_COF2:

Value	Description	Notes
0	Regular in-home visit	
1	In-home interviews completed via telephone	
2	In-home interviews completed via telephone due to COVID-19 restrictions	New category to indicate the changes in data collection implemented due to COVID-19 restrictions.

ADM_SPECIAL_STATUS_COF2:

Value	Description	Notes
0	Regular DCS	
1	DCS by phone	
2	DCS at home	
3	Reduced DCS (per standard operating procedures)	
4	Regular DCS (not per standard operating procedures)	
5	Did not complete a DCS visit	
6	Interview conducted under COVID-19 restrictions	New category to indicate the changes in data collection implemented due to COVID-19 restrictions.

Furthermore, a new missing data category of ‘-99993’ has been implemented in FUP2 variables to indicate that the participant did not complete the assessment due to COVID-19 restrictions in how data were collected. Participants who completed their in-home interview and DCS assessment by phone due to the pandemic restrictions will have variables from the resiliency scale module, intimate partner violence module, the neuropsychological battery, the physical assessments and the biological specimens all coded as ‘-99993’.

5.0 REFERENCES

- 1) Raina PS, Wolfson C, Kirkland SA, Griffith LE, Oremus M, Patterson C, Tuokko H, Penning M, Balion CM, Hogan D, Wister A, Payette H, Shannon H, & Brazil K. The Canadian longitudinal study on aging (CLSA). Canadian Journal on Aging/La Revue canadienne du vieillissement. 2009 Sep;28(3):221-9.
- 2) Raina P, Wolfson C, Kirkland S, Griffith LE, Balion C, Cossette B, Dionne I, Hofer S, Hogan D, Van Den Heuvel ER, Liu-Ambrose T, Menec V, Mugford G, Patterson C, Payette H, Richards B, Shannon H, Sheets D, Taler V, Thompson M, Tuokko H, Wister A, Wu C, & Young L. Cohort profile: the Canadian longitudinal study on aging (CLSA). International Journal of Epidemiology. 2019 Dec 1;48(6):1752-3j.