



Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Decedent Questionnaire

(Tracking and Comprehensive)

Follow-up 1 Version

v1.2, 2018 June 13

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Participant Information (previously collected) (PIC)

A_1 (PIC_SEX_DCQ)	Sex:	1 Male	2 Female
A_2 (PIC_DOB_DCQ)	Date of Birth:	____/____/____ DD/MM/YYYY	
A_3 (PIC_LDATE_DCQ)	Date of last interview:	____/____/____ DD/MM/YYYY	

[PRESCREEN]

Fill in the information specific to the participant and respondent below:

Please write your answers here:

Name of responder: _____

Participant UID: _____

First name of CLSA Participant: _____

Last name of CLSA Participant: _____

Date of last interview with Participant: _____

Address of participant: _____

I would like to make sure that this experience is as comfortable as possible for you. For that reason, I would like to know how you would like me to refer to Mr./Ms./Miss/Mrs. **[decedent's name]**? **[If responder is unsure: Would you like us to refer to him/her as Mr./Ms./Miss/Mrs. [decedent's last name], as [decedent's first name], or as [decedent's full name] or by another name?]**

Enter name to be used: _____

I appreciate your consideration and time in completing this interview. I recognize that some of the content of the questionnaire may cause some distress, so please let me know if you want to take a break, or not answer certain questions. You may also decide that you would like to end the interview at any time.

As a participant in the CLSA, **[decedent's name]**'s contribution was very valuable. It would, however, be very helpful to have further information about how they managed day-to-day during the last part of their life. I will first ask a few questions about your relationship with **[decedent's name]**, and then some questions about the details surrounding their death. Be assured that this information collected will remain confidential.

Q1	PIC_RELN_DCQ	
[ALWAYS ASK THIS QUESTION]		
[If responder has already indicated their relationship with the decedent, just confirm that relationship]. What was your relationship to [decedent's name] ? You were their ?		
WE ARE INTERESTED IN THE RELATIONSHIP OF THE RESPONDER TO THE DECEDENT, NOT THE OTHER WAY AROUND. SO, IF THE RESPONDER IS THE SON OF THE DECEDENT, THEN THE CORRECT ANSWER IS 'SON/DAUGHTER.'		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
SPOUSE	01	Husband/wife
COMMON_LAW	02	Common-law partner
PARENT	03	Father/mother
CHILD	04	Son/daughter
SIBLING	05	Brother/sister
GRAND_PARENT	06	Grandfather/grandmother
GRAND_CHILD	07	Grandson/granddaughter
PARENT_IN_LAW	08	Father-in-law/mother-in-law
CHILD_IN_LAW	09	Son-in-law/daughter-in-law
SIBLING_IN_LAW	10	Brother-in-law/sister-in-law
OTHER_RELATIVE (PIC_RELN_ORSP_DCQ)	11	Other relative (specify:_____)
FRIEND	12	Friend
NEIGHBOUR	13	Neighbour
OTHER PIC_RELN_OTSP_DCQ	97	Other (please specify: _____)
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q1a	PIC_CLOSE_DCQ	
[ALWAYS ASK]		
How close were you to [decedent's name] ?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
VERY	01	Very
SOMEWHAT	02	Somewhat
NOT_ALL	03	Not at all
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q1b	PIC_KNOWN_DCQ	
[ALWAYS ASK THIS QUESTION]		
How long had you known [decedent's name]? In years and months.		
ROUND UP TO THE NEAREST MONTH		
LESS_MONTH	996	LESS THAN ONE MONTH
PIC_KNOWN_YR_DCQ	_____	YEARS (MIN=0; MAX=999)
PIC_KNOWN_MT_DCQ	_____	MONTHS (MIN=0; MAX=11)
DK_NA	998	[DO NOT READ] Don't know/No answer
REFUSED	999	[DO NOT READ] Refused

Q2	PIC_COHAB_DCQ	
[ASK IF PIC_RELN_DCQ≠NEIGHBOUR]		
Were you living with [decedent's name] at the time of [his/her] death?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q3	PIC_VISIT_DCQ	
[ASK IF PIC_COHAB_DCQ≠YES]		
In the three months before [decedent's name] passed away, how often did you visit with [him/her]? Was it ...		
READ LIST, CODE ONLY ONE RESPONSE		
MORE_DAY	01	At least once a day
MORE_WEEK	02	At least once a week
MORE_WEEK_LESS_DAY	03	More than once a week but less than once a day
MORE_MONTH	04	At least once a month
LESS_MONTH	05	Less than once a month
NOT_ALL	06	Not at all
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused



Q3a	PIC_CONT_DCQ	
[ASK IF PIC_COHAB_DCQ≠YES]		
In the three months before [decedent's name] passed away, were you in contact with [him/her] in any of the following ways:		
READ LIST, CODE MULTIPLE RESPONSES		
PIC_CONT_PR_DCQ	01	In person
PIC_CONT_PH_DCQ	02	By phone
PIC_CONT_EM_DCQ	03	By email
PIC_CONT_SM_DCQ	04	By social media (Facebook, twitter, etc.)
PIC_CONT_CG_DCQ	05	Through contact with [his/her] caregiver
PIC_CONT_OT_DCQ (PIC_CONT_OTSP_DCQ)	06	Other (specify: _____)
PIC_CONT_DK_NA_DCQ	08	[DO NOT READ] Don't know/No answer
PIC_CONT_REFUSED_DCQ	09	[DO NOT READ] Refused

PIC_END

Details Surrounding Death (DSD)

The next questions will ask about **[decedent's name]**'s death. I know that these questions will be difficult to think about, but they are very important for our study to learn more about aging and the end of life. Please let me know if you don't want to answer any of the questions.

Q4	DSD_DOD_DCQ	
[ALWAYS ASK]		
When did [decedent's name] pass away?		
IF RESPONDER DOES NOT KNOW EXACT DATE, COLLECT YEAR AND MONTH AND ENTER "00" FOR DAY. ASK FOR CLOSEST ESTIMATE IF MONTH IS UNSURE.		
DSD_DOD_DD_DCQ	_____	DAY (DD)
DSD_DOD_MT_DCQ	_____	MONTH (MM)
DSD_DOD_YR_DCQ	_____	YEAR (YYYY)
DK_NA	9998	[DO NOT READ] Don't know/No answer
REFUSED	9999	[DO NOT READ] Refused

We are trying to understand how **[decedent's name]** died. There are generally four ways to describe how people die. Once you've heard the categories, I will ask you which one best describes how **[decedent's name]** died.

- Sudden death: To die suddenly with little or no warning. Function is normal up to the time of death.
- Terminal illness: A distinct terminal phase of an illness. Function is reasonably good for a long time before the illness becomes overwhelming. Decline is rapid, often within a 1-2 month period.
- Chronic illness: A serious illness or illnesses over a period of years. Gradual decline with times of worsening illness followed by partial or full recovery. Hard to predict length of illness and time of death.
- Slow, gradual decline: A slow, gradual decline usually over years with steadily increasing disability before dying.



Q5	DSD_DECLINE_DCQ	
[ALWAYS ASK]		
Based on these descriptions, which of the following terms would best describe the death of [decedent's name] ?		
IF RESPONDER HAS TROUBLE WITH THE CATEGORIES, OFFER TO READ THE DESCRIPTIONS AGAIN, AND ASK THEM TO CHOOSE THE ONE THAT FITS BEST.		
READ LIST, CODE ONLY ONE RESPONSE		
SUDDEN	01	Sudden death
TERMINAL	02	Terminal illness
CHRONIC	03	Chronic illness
SLOW	04	Slow, gradual decline
OTHER (DSD_DECLINE_OTSP_DCQ)	97	Other (please specify: _____)
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q6	DSD_MCAUS_DCQ	
[ALWAYS ASK]		
What was the primary cause of [decedent name] 's death? This is the main thing that lead to [his/her] death.		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
CANCER	01	Cancer
HEART_DIS	02	Heart disease
STROKE	03	Stroke
HEART_FAIL	04	Heart failure
RESPIRATORY	05	Respiratory disease (emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease)
DEMENTIA	06	Dementia (e.g. Alzheimer's)
ACCIDENT	07	Accident (e.g., fall, motor vehicle accident)
FLU_PNU	08	Influenza or pneumonia
SUICIDE	09	Suicide
KIDNEY	10	Kidney disease (e.g., nephritis, nephrotic syndrome or nephrosis)
OTHER (DSD_MCAUS_OTSP_DCQ)	97	Other (please specify: _____)
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q7	DSD_OCAUS_DCQ	
[ALWAYS ASK]		
Were there other contributing causes of [decedent's name] 's death? If so, what were they?		
DO NOT READ LIST, CODE MULTIPLE RESPONSES		
DSD_OCAUS_CA_DCQ	01	Cancer
DSD_OCAUS_HD_DCQ	02	Heart disease
DSD_OCAUS_SR_DCQ	03	Stroke
DSD_OCAUS_HF_DCQ	04	Heart failure
DSD_OCAUS_RD_DCQ	05	Respiratory disease (emphysema, obstructive lung disease, asthma, congestive obstructive pulmonary disease)
DSD_OCAUS_DE_DCQ	06	Dementia (e.g. Alzheimer's)
DSD_OCAUS_AC_DCQ	07	Accident (e.g., fall, motor vehicle accident)
DSD_OCAUS_FL_DCQ	08	Influenza or pneumonia
DSD_OCAUS_SU_DCQ	09	Suicide
DSD_OCAUS_KD_DCQ	10	Kidney disease (e.g., nephritis, nephrotic syndrome or nephrosis)
DSD_OCAUS_AD_DCQ	11	Addiction, substance abuse
DSD_OCAUS_DP_DCQ	12	Depression
DSD_OCAUS_NONE_DCQ	13	None
DSD_OCAUS_OT_DCQ (DSD_OCAUS_OTSP_DCQ)	97	Other (please specify: _____)
DSD_OCAUS_DK_NA_DCQ	98	[DO NOT READ] Don't know/No answer
DSD_OCAUS_REFUSED_DCQ	99	[DO NOT READ] Refused



Q8	DSD_LOC_DCQ	
[ALWAYS ASK]		
In which location did [decedent's name] pass away?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
OWN_HOME	01	Their own home
PRIV_HOME (DSD_LOC_RLSP_DCQ)	02	Other private home (owned/rented by another person) Relationship to decedent: (please specify: _____)
RESIDENCE	03	Residence for seniors
HOSPITAL	04	Hospital
HOSPICE	05	Hospice
PALLIATIVE	06	Palliative care unit
NURS_HOME	07	Nursing home or other long-term care facility
OTHER (DSD_LOC_OTSP_DCQ)	97	Other (please specify: _____)
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

DSD_END

Living Arrangements Prior to Death (LAP)

Thank you for that information. I am now going to ask you some questions about [decedent's name]'s living situation before [he/she] passed away.

Q9	LAP_ADDRESS_DCQ	
[ALWAYS ASK]		
During the last year of [decedent's name]'s life, did [decedent's name] change where [he/she] was living for longer than 1 week?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q10	LAP_MOVE_DCQ	
[ASK IF LAP_ADDRESS_DCQ=YES]		
How many times?		
IF RESPONDER DOES NOT REMEMBER, ASK FOR BEST ESTIMATE		
LAP_MOVE_NB_DCQ	_____	Number of times MASK: MIN=1, MAX=10
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q11	LAP_MOVELOC_i_DCQ (1 ≤ i ≤ LAP_MOVE_NB_DCQ)	
[ASK IF LAP_MOVE_DCQ > 0]		
[Decedent's name] moved [RECALL RESPONSE FROM LAP_MOVE_DCQ] time(s) in the last year of [his/her] life. Thinking about the [first/second/third/etc.] time, where did [he/she] move?		
<p>NOTE: 'Hospice' refers to a facility or institution expressly intended to provide palliative care (i.e., relief of the symptoms of a disease or disorder) for those dying.</p> <p>'Palliative care unit' refers to a unit where palliative care is provided for a disease or disorder, whether or not it can be cured. These are often found in hospitals.</p> <p>Distinction between Hospice and Palliative Care Unit: Hospice care is always palliative, but not all palliative care is hospice care. The objective of both hospice and palliative care is pain and symptom relief, but the prognosis and goals of care tend to be different. Hospice is comfort care <u>without</u> curative intent; the patient no longer has curative options or has chosen not to pursue treatment because the side effects outweigh the benefits. Palliative care is comfort care <u>with or without</u> curative intent. Palliative care can begin at diagnosis, and at the same time as treatment. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness. In Canada, hospices are often free-standing facilities, separate from hospitals.</p>		



REPEAT LAP_MOVELOC_i_DCQ AS MANY TIMES AS THE NUMBER SPECIFIED IN RESPONSE TO LAP_MOVE_DCQ		
RESIDENCE	01	Residence for seniors
HOSPITAL	02	Hospital
OWN_HOME	03	Their own home
PRIV_HOME (LAP_MOVELOC_i_RLSP_DCQ)	04	Other private home (owned/rented by another person) Relationship to decedent: (please specify: _____)
HOSPICE	05	Hospice
PALLIATIVE	06	Palliative care unit
NURS_HOME	07	Nursing home or other long-term care facility
OTHER (LAP_MOVELOC_i_OTSP_DCQ)	97	Other (please specify: _____)
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q11a	LAP_MOVEDUR_i_DCQ (1 ≤ i ≤ LAP_MOVE_NB_DCQ)	
[ASK IF LAP_MOVELOC_i_DCQ≠98 or 99]		
How long was [decedent's name] at [RECALL RESPONSE FROM LAP_MOVELOC_i_DCQ]?		
REPEAT LAP_MOVEDUR_i_DCQ AS MANY TIMES AS THE NUMBER SPECIFIED IN RESPONSE TO LAP_MOVE_DCQ		
NOTE: If participant moved to this location multiple times, ask for the duration for the specific time (first, second, etc.) we are addressing here. The questions are repeated for each <u>move</u>.		
LAP_MOVEDUR_i_MT_DCQ	_____	Months (MIN=0; MAX=12)
LAP_MOVEDUR_i_WK_DCQ	_____	Weeks (MIN=0; MAX=3)
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q12	LAP_ADM_DCQ
[ALWAYS ASK]	
During the last year of [decedent's name] 's life, how many times was [he/she] taken to hospital, and admitted?	
NOTE: 'Admitted' refers to the formal acceptance by a hospital of a patient who is to be provided with room, board, and continuous nursing service in an area of the facility for 24-hours or more.	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
ONCE	01 Once
TWICE	02 Twice
THREE_TIMES	03 Three times
FOUR_TIMES	04 Four times
FIVE_MORE	05 Five or more times
NONE	06 None
DK_NA	08 [DO NOT READ] Don't know/No answer
REFUSED	09 [DO NOT READ] Refused

Q13	LAP_NOADM_DCQ
[ALWAYS ASK]	
During the last year of [decedent's name] 's life, how many times was [he/she] taken to hospital, but not admitted?	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
ONCE	01 Once
TWICE	02 Twice
THREE_TIMES	03 Three times
FOUR_TIMES	04 Four times
FIVE_MORE	05 Five or more times
NONE	06 None
DK_NA	08 [DO NOT READ] Don't know/No answer
REFUSED	09 [DO NOT READ] Refused



Q14	LAP_PHYS_DCQ	
[ALWAYS ASK]		
When did [decedent's name] last see a physician before [he/she] passed away?		
ASK ABOUT HOW LONG (DAYS, WEEKS, MONTHS) BEFORE DEATH. IF THEY SAW A PHYSICIAN ON THE DAY THEY DIED, ENTER '1' DAY.		
LAP_PHYS_DAY_DCQ	01	_____ (MIN=0; MAX=6)
LAP_PHYS_WK_DCQ	02	_____ (MIN=0; MAX=3)
LAP_PHYS_MT_DCQ	03	_____ (MIN=0; MAX=100)
DK_NA	998	[DO NOT READ] Don't know/No answer
REFUSED	999	[DO NOT READ] Refused

LAP_END

Function at 1 Month Before Death (FBD)

The following questions relate to **[decedent's name]**'s functioning one month before **[he/she]** passed away. I am asking these questions in this way to see how **[his/her]** functioning may have changed. These problems do not always appear in late life and may not be relevant to **[him/her]**, but I have to ask these of everybody in order to be consistent.

These questions are part of a validated questionnaire and follow a specific pattern. Some of the questions may seem redundant, but I want to administer the questionnaire the same way for everyone. Each question asks for a yes or no answer.

Do your best to think about **[decedent's name]** at one month before **[he/she]** passed away.

Q15	FBD_CONSC_DCQ	
[ALWAYS ASK]		
At one month before [he/she] passed away, was [decedent's name] conscious?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q16	FBD_ABLDR_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [he/she] passed away, could [decedent's name] dress and undress [him/her] self without help (including picking out clothes and putting on socks and shoes)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q16a	FBD_HPDR_DCQ	
[ASK IF FBD_ABLDR_DCQ=NO]		
At one month before [he/she] passed away, could [decedent's name] dress and undress [him/her] self with some help?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q16b	FBD_UNDR_DCQ	
[ASK IF FBD_HPDR_DCQ=NO]		
At one month before [he/she] passed away, was [decedent's name] completely unable to dress and undress [him/her] self?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q17	FBD_ABLFD_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [he/she] passed away, could [decedent's name] eat without help (i.e., [he/she] is able to feed [him/her] self completely)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused



Q17a	FBD_HPFD_DCQ	
[ASK IF FBD_ABLFD_DCQ=NO]		
At one month before [he/she] passed away, could [decedent's name] eat with some help (i.e., [he/she] needed help cutting [his/her] food, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q17b	FBD_UNFD_DCQ	
[ASK IF FBD_HPFD_DCQ=NO]		
At one month before [he/she] passed away, was [decedent's name] completely unable to feed [him/her] self?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q18	FBD_ABLAP_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [he/she] passed away, could [decedent's name] take care of [his/her] own appearance without help, for example, combing [his/her] hair, shaving (if male)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q18a	FBD_HPAP_DCQ	
[ASK IF FBD_ABLAP_DCQ=NO]		
At one month before [he/she] passed away, could [decedent's name] take care of [his/her] own appearance with some help?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q18b	FBD_UNAP_DCQ	
[ASK IF FBD_HPAP_DCQ=NO]		
At one month before [he/she] passed away, was [decedent's name] completely unable to take care of [his/her] own appearance?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q19	FBD_ABLWK_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [he/she] passed away, could [decedent's name] walk without help?		
IF THEY WALKED WITH A CANE, CODE AS "YES"		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q19a	FBD_HPWK_DCQ	
[ASK IF FBD_ABLWK_DCQ=NO]		
At one month before [he/she] passed away, could [decedent's name] walk with some help from a person, or with the use of a walker or crutches, etc.?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q19b	FBD_UNWK_DCQ	
[ASK IF FBD_HPWK_DCQ=NO]		
At one month before [he/she] passed away, was [decedent's name] completely unable to walk?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q20	FBD_ABLBD_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [he/she] passed away, could [decedent's name] get in and out of bed without any help or aids?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q20a	FBD_HPBD_DCQ	
[ASK IF FBD_ABLBD_DCQ=NO]		
At one month before [he/she] passed away, could [decedent's name] get in and out of bed with some help (either from a person or with the aid of some device)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q20b	FBD_UNBD_DCQ	
[ASK IF FBD_HPBD_DCQ=NO]		
At one month before [he/she] passed away, was [decedent's name] totally dependent on someone else to lift [him/her] in and out of bed?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q21	FBD_ABLBT_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] take a bath or shower without help?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused



Q21a	FBD_HPBT_DCQ	
[ASK IF FBD_ABLBT_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] take a bath or shower with some help (i.e., [he/she] needed help from someone getting in and out of the tub or [he/she] needed special attachments on the tub)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q21b	FBD_UNBT_DCQ	
[ASK IF FBD_HPBT_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] completely unable to take a bath or shower by [him/her] self?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q22	FBD_BATH_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, did [decedent's name] have trouble getting to the bathroom in time?		
IF DECEDENT WAS USING A DIAPER, PLEASE ANSWER 'YES'		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q23	FBD_INCNT_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, how often would [decedent's name] wet or soil [him/her] self (either day or night)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
0_1_TIME_WEEK	01	Never or less than once a week
1_2_TIME_WEEK	02	Once or twice a week
3_MORE_TIMES_WEEK	03	Three times a week or more
CONTINUOUS	04	Continuous
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q24	FBD_ABLTEL_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] use the telephone without help, including looking up numbers and dialling?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q24a	FBD_HPTTEL_DCQ	
[ASK IF FBD_ABLTEL_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] use the telephone with some help (i.e., [he/she] could answer the phone or dial the operator in an emergency, but needed a special phone or help in getting the number or dialling)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q24b	FBD_UNTEL_DCQ	
[ASK IF FBD_HPTTEL_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] completely unable to use the telephone?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q25	FBD_ABLTRV_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] get to places out of walking distance without help (i.e., [he/she] drove [his/her] own car, or travelled alone on buses, or taxis)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q25a	FBD_HPTRV_DCQ	
[ASK IF FBD_ABLTRV_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] get to places out of walking distance with some help (i.e., [he/she] needed someone to help [him/her] or go with [him/her] when traveling)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q25b	FBD_UNTRV_DCQ	
[ASK IF FBD_HPTRV_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] unable to travel unless emergency arrangements were made for a specialized vehicle, like an ambulance?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q26	FBD_ABLGRO_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] go shopping for groceries or clothes without help (taking care of all shopping needs [him/her] self)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q26a	FBD_HPGRO_DCQ	
[ASK IF FBD_ABLGRO_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] go shopping for groceries or clothes with some help (i.e., [he/she] needed someone to go with [him/her] on all shopping trips)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q26b	FBD_UNGRO_DCQ	
[ASK IF FBD_HPGRO_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] completely unable to do any shopping?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q27	FBD_ABLML_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] prepare [his/her] own meals without help (i.e., [he/she] planned and cooked full meals [him/her] self)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q27a	FBD_HPML_DCQ	
[ASK IF FBD_ABLML_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] prepare [his/her] own meals with some help (i.e., [he/she] could prepare some things but was unable to cook full meals [him/her] self)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q27b	FBD_UNML_DCQ	
[ASK IF FBD_HPML_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] completely unable to prepare any meals?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q28	FBD_ABLWRK_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] do [his/her] housework without help (i.e., [he/she] could clean floors, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSE	09	[DO NOT READ] Refused

Q28a	FBD_HPWRK_DCQ	
[ASK IF FBD_ABLWRK_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] do [his/her] housework with some help (i.e., [he/she] could do light housework but needed help with heavy work)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused



Q28b	FBD_UNWRK_DCQ
[ASK IF FBD_HPWRK_DCQ=NO]	
At one month before [she/he] passed away, was [decedent's name] completely unable to do any housework?	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
YES	01 Yes
NO	02 No
DK_NA	08 [DO NOT READ] Don't know/No answer
REFUSED	09 [DO NOT READ] Refused

Q29	FBD_ABLMED_DCQ
[ASK IF FBD_CONSC_DCQ=YES]	
At one month before [she/he] passed away, could [decedent's name] take [his/her] own medicine without help (in the right doses at the right time)?	
IF THE DECEDENT OCCASIONALLY FORGOT, CODE AS "YES, WITHOUT HELP"	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
YES	01 Yes
NO	02 No
DK_NA	08 [DO NOT READ] Don't know/No answer
REFUSED	09 [DO NOT READ] Refused

Q29a	FBD_HPMED_DCQ
[ASK IF FBD_ABLMED_DCQ=NO]	
At one month before [she/he] passed away, could [decedent's name] take [his/her] own medicine with some help (i.e., [he/she] was able to take medicine if someone prepared it for [him/her] or reminded [him/her] to take it)?	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
YES	01 Yes
NO	02 No
DK_NA	08 [DO NOT READ] Don't know/No answer
REFUSED	09 [DO NOT READ] Refused

Q29b	FBD_UNMED_DCQ	
[ASK IF FBD_HPMED_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] completely unable to take [his/her] own medicine?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q30	FBD_ABLMO_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before [she/he] passed away, could [decedent's name] handle [his/her] own money without help (i.e., [he/she] wrote cheques, paid bills, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q30a	FBD_HPMO_DCQ	
[ASK IF FBD_ABLMO_DCQ=NO]		
At one month before [she/he] passed away, could [decedent's name] handle [his/her] own money with some help (i.e., [he/she] managed day-to-day buying but needed help with managing [his/her] chequebook or paying [his/her] bills)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused



Q30b	FBD_UNMO_DCQ	
[ASK IF FBD_HPMO_DCQ=NO]		
At one month before [she/he] passed away, was [decedent's name] completely unable to handle [his/her] own money?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

FBD_END

About the Main Caregiver (MCG)

Q31	MCG_RESPOND_DCQ
[ALWAYS ASK]	
Apart from health care personnel, are you the person who provided the most care in the final 1 month before [decedent's name] passed away?	
NOTE: If decedent had a personal support worker or other paid help, please count that as 'health care personnel'	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
YES	01 Yes
NO	02 No
NOT_APPLICABLE	96 Not applicable
DK_NA	98 [DO NOT READ] Don't know/No answer
REFUSED	99 [DO NOT READ] Refused

Q31a	MCG_MOST_DCQ
[ASK IF MCG_RESPOND_DCQ≠YES]	
Apart from health care personnel, who was the person who provided the most care for [decedent's name] in the final 1 month before [he/she] passed away?	
DO NOT READ LIST, CODE ONLY ONE RESPONSE	
SPOUSE	01 Husband/wife
COMMON_LAW	02 Common-law partner
PARENT	03 Father/mother
CHILD	04 Son/daughter
SIBLING	05 Brother/sister
GRAND_PARENT	06 Grandfather/grandmother
GRAND_CHILD	07 Grandson/granddaughter
PARENT_IN_LAW	08 Father-in-law/mother-in-law
CHILD_IN_LAW	09 Son-in-law/daughter-in-law
SIBLING_IN_LAW	10 Brother-in-law/sister-in-law
OTHER_RELATIVE (MCG_MOST_ORSP_DCQ)	11 Other relative (specify: _____)
FRIEND	12 Friend
NEIGHBOUR	13 Neighbour
OTHER (MCG_MOST_OTSP_DCQ)	97 Other (please specify: _____)
DK_NA	98 [DO NOT READ] Don't know/No answer
REFUSED	99 [DO NOT READ] Refused

MCG_END

Participant’s Health Care Preferences and Decisions (PPD)

Now I would like to ask you a few questions concerning **[decedent’s name]**'s health care preferences. This information is useful to understand the types of decisions people make about their end of life.

Q32	PPD_ARRANGE_DCQ	
[ALWAYS ASK]		
Had [decedent’s name] made arrangements to have someone make health care decisions in case [he/she] was unable to do this for [him/her] self?		
‘HEALTH CARE DECISIONS’ REFERS TO DECISIONS THAT ARE MADE ABOUT WHAT TREATMENT TO UNDERGO, WHAT TYPE OF MEDICATIONS TO TAKE, WHETHER TO BE VACCINATED, ETC.		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don’t know/No answer
REFUSED	09	[DO NOT READ] Refused

Q33	PPD_SDM_DCQ	
[ALWAYS ASK]		
Who would have made health care decisions for [decedent’s name] if [he/she] was unable to do this for [him/her] self?		
DO NOT READ LIST, CODE MUTLIPL E RESPONSES		
PPD_SDM_SP_DCQ	01	Spouse
PPD_SDM_SI_DCQ	02	Sibling
PPD_SDM_CH_DCQ	03	Children
PPD_SDM_FM_DCQ (PPD_SDM_FMSP_DCQ)	04	Other family (specify: _____)
PPD_SDM_NA_DCQ	96	Not applicable
PPD_SDM_OT_DCQ (PPD_SDM_OTSP_DCQ)	97	Other (please specify: _____)
PPD_SDM_DK_NA_DCQ	98	[DO NOT READ] Don’t know/No answer
PPD_SDM_REFUSED_DCQ	99	[DO NOT READ] Refused



Q34	PPD_LEGAL_DCQ	
[ASK IF PPD_ARRANGE_DCQ=YES]		
Had [decedent's name] formalized [his/her] health care decisions in a legal document (i.e., power of attorney for personal care, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q35	PPD_ELD_DCQ	
[ALWAYS ASK]		
Did [decedent's name] make arrangements for someone to make end-of-life decisions for [him/her] ?		
'END-OF-LIFE' DECISIONS ARE CHOICES SUCH AS WHETHER TO BE RESUSCITATED, WHETHER TO STAY ON LIFE SUPPORT, ETC.		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q35a	PPD_ELDSUB_DCQ	
[ALWAYS ASK]		
Who would have made end-of-life decisions for [decedent's name] if [he/she] was unable to do this for [him/her] self?		
DO NOT READ LIST, CODE MULTIPLE RESPONSES		
PPD_ELDSUB_SP_DCQ	01	Spouse
PPD_ELDSUB_SI_DCQ	02	Siblings
PPD_ELDSUB_CH_DCQ	03	Children
PPD_ELDSUB_FM_DCQ (PPD_ELDSUB_FMSP_DCQ)	04	Other family (specify: _____)
PPD_ELDSUB_NA_DCQ	96	Not applicable
PPD_ELDSUB_OT_DCQ (PPD_ELDSUB_OTSP_DCQ)	97	Other (please specify: _____)
PPD_ELDSUB_DK_NA_DCQ	98	[DO NOT READ] Don't know/No answer
PPD_ELDSUB_REFUSED_DCQ	99	[DO NOT READ] Refused



Q36	PPD_ELDLEGAL_DCQ	
[ASK IF PPD_ELD_DCQ=YES]		
Had [decedent's name] formalized who would make [his/her] end-of-life decisions in a legal document (i.e., living will.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

PPD_END

Quality of Death and Dying (QDD)

I would like to ask you a few questions about **[decedent's name]**'s death and the week leading up to his/her death. Some people find these questions distressing. I ask them because they are issues that are important to people near or at the time of death. I am asking for your opinion of **[decedent's name]**'s situation. These questions may not be relevant to **[him/her]**, but I have to ask these of everybody in order to be consistent.

Q37	QDD_PEACE_DCQ	
[ALWAYS ASK]		
In the last week of [his/her] life, do you feel that [decedent's name] was at peace with dying?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
SOMEWHAT	02	Somewhat
NO	03	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q38	QDD_DIGNITY_DCQ	
[ALWAYS ASK]		
In the last week of [his/her] life, do you feel that [decedent's name] maintained [his/her] dignity and self-respect?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
SOMEWHAT	02	Somewhat
NO	03	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused



Q39	QDD_PAIN_DCQ	
[ALWAYS ASK]		
In the last week of [his/her] life, do you feel that [decedent's name] had [his/her] pain under control?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
SOMEWHAT	02	Somewhat
NO	03	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q40	QDD_LOC_DCQ	
[ALWAYS ASK]		
In the last week of [his/her] life, do you feel that [decedent's name] died where [he/she] wanted to?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q41	DDQ_PAD_DCQ	
[ASK IF DSD_DECLINE_DCQ#SUDDEN]		
Did [decedent's name] consider physician-assisted death?		
NOTE: Physician-assisted death refers to the administration of drugs by a doctor to cause death in a person. This does not include removal of life support, or providing support for someone to stop eating or taking medication.		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	[DO NOT READ] Don't know/No answer
REFUSED	99	[DO NOT READ] Refused

Q42	DDQ_PADHPN_DCQ	
[ASK IF DSD_DECLINE_DCQ≠SUDDEN]		
Did a physician-assisted death take place?		
NOTE: Physician-assisted death refers to the administration of drugs by a doctor to cause death in a person. This does not include removal of life support, or providing support for someone to stop eating or taking medication.		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

Q43	DDQ_ADDINFO_DCQ	
[ALWAYS ASK]		
Is there anything else you would like me to know about [decedent's name] 's end of life and passing?		
RECORD RESPONSE VERBATIM		
DK_NA	08	[DO NOT READ] Don't know/No answer
REFUSED	09	[DO NOT READ] Refused

[Mr./Ms./Miss/Mrs.] [Responder's Name], thank you very much for sharing this information with me. Knowing about the situation surrounding **[Participant's Name]**'s death will be very helpful to researchers who are using CLSA data to investigate aging in Canada. I really appreciate you taking the time to give us this information.

If you have any need to contact the CLSA again, please feel free to call the toll-free number 1-866-999-8303, or email at info@clsa-elcv.ca. We also have a website www.clsa-elcv.ca where we provide updates about the study and the research being done with the data we are collecting.

Thank you again.

END