

# Diagnostic Assessment Of Dementia for LASI

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## WAVE 2. INFORMANT REPORT

This project is funded by the National Institute on Aging [R01 AG051125].

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Jinkook Lee, Alexandra Crosswell, Marco Angrisani, Sarah Petrosyan, Pranali Khobragade, Joyita Banerjee, A.B. Dey (2022). Harmonized Diagnostic Assessment of Dementia for the Longitudinal Aging Study in India (LASI-DAD) Wave 2 Informant Report, DOI: 10.25549/w6ft-m365. Produced and distributed by the University of Southern California with funding from the National Institute on Aging (R01AG051125, U01AG065958).

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[Changes or additions for Wave 2 indicated in blue font]

## SECTION INTRO – Introducing the Informant Interview

VOL\_STMT

Before we begin, I want you to know that this interview is completely voluntary. If we should come to any question that you don't want to answer, just let me know and I will go on to the next question. Your identity as a participant and any personally identifying information you provide will be kept confidential.

We may report to state or local officials' evidence of harm or abuse to any vulnerable person, but we will not ask you any questions about such topics.

An Indian Council of Medical Research Approval covers this research in order to help ensure your privacy. This helps protect the investigators from being forced to release any research information that identifies you.

RecordedIw\_Consent

This Interview with you may be recorded for quality control purposes. Do you agree for this interview to be recorded?

IWER: Has the Respondent consented to the digital recording of this interview?

Answering "Yes" to this question will allow DRI to start.

1= Consent to record

5=No consent to record

INTRO 102

INTRO SCRIPT

Thank you for agreeing to participate in this study. In this interview I will be asking you some questions about you and some about [CAPI: R NAME], how [CAPI: he/she] performs on daily tasks, and what social and cognitive activities [CAPI: he/she] is involved in.

1 = Continue

## SECTION DM – DEMOGRAPHICS

DM\_Age. What is your age?

RANGE 18-110

DM\_Gender

IWER: INDICATE INFORMANT GENDER

1=MALE

2= FEMALE

DM\_EDUC1

Have you ever attended school?

1. Yes
2. No

DM\_EDUC2 [CAPI: ask if DM\_EDUC1 = 1]

What is the highest grade of school or year of college you completed?

1. Less than Primary (Standard 1-4)
2. Primary Completed (Standard 5-7)
3. Middle Completed (Standard 8- 9)
4. Secondary Completed (Standard 10 -11)
5. Higher Secondary completed (Standard 12)
6. Diploma and certificate holder
7. Graduate degree (B.A., B.Sc., B. Com.) completed
8. Post-graduate degree or (M.A., M.Sc., M. Com.) above (M.Phil, Ph.D.,Post-Doc) completed
9. Professional course/degree (B.Ed, BE, B.Tech, MBBS, BHMS, BAMS, B. Pharm, BCS, BCA, BBA, LLB, BVSc., B. Arch, M.Ed, ME, M.Tech, MD, M.Pharm, MCS, MCA, MBA, LLM, MVSc., M. Arch, MS, CA, CS, CWA)

97= Other

DM\_RTR

What is your relationship with [CAPI: RESPONDENT NAME]?

1. Spouse/partner [GO TO DM\_YEARS]
2. Son [GO TO DM\_Freq]
3. Daughter [GO TO DM\_Freq]
4. Son-in-law [GO TO DM\_YEARS]
5. Daughter-in-law [GO TO DM\_YEARS]
6. Grandchild [GO TO DM\_YEARS]
7. Parent [GO TO DM\_Freq]
8. Parent-in-law [GO TO DM\_YEARS]
9. Brother [GO TO DM\_Freq]
10. Sister [GO TO DM\_Freq]
11. Grandparent [GO TO DM\_Freq]

12. Other relative [GO TO DM\_YEARS]
13. Servant [GO TO DM\_YEARS]
14. Friend [GO TO DM\_YEARS]
15. Other, non-relative; please specify \_\_\_\_\_ [GO TO DM\_YEARS]

## DM\_Years

How many years have you known [CAPI: RESPONDENT NAME]?

ASSIGN DM\_Years = 10 IF RTR = 2, 3 (CHILD), 9, 10 (SIBLING), 7 (PARENT)

RANGE 1-100

## DM\_Freq

On average in the past year how often did you see [CAPI: RESPONDENT NAME]?

1=LIVES WITH RESPONDENT

2=DAILY

3= SEVERAL TIMES/WEEK

4=ONCE A WEEK

5=ONE-THREE TIME A MONTH

6=LESS THAN ONCE A MONTH

7=NEVER

8=OTHER (SPECIFY)

## DM\_Care

Are you a caregiver for [CAPI: RESPONDENT NAME]?

1=Yes

5=No

## DM\_Mem

Has [CAPI: RESPONDENT NAME] been diagnosed with memory problems?

1= yes

5=No

DM\_Stroke

Has [CAPI: RESPONDENT NAME] been diagnosed with stroke?

1= Yes

5=No

DM\_Park

Has [CAPI: RESPONDENT NAME] been diagnosed) with Parkinson's disease?

1= Yes

5=No

DM\_AD

Has [CAPI: RESPONDENT NAME] been diagnosed) with Alzheimer's disease?

1= yes

5=No

## SECTION JORM – JORM - IQCODE Test

We want you to remember what [CAPI: RESPONDENT NAME] was like [CAPI: DM\_Years, or 10 if DM\_Years >10] years ago and to compare it with what [CAPI: he/she] is like now. [CAPI: DM\_Years, or 10 if DM\_Years >10] years ago was in [CAPI: current year – DM\_Years/10 if DM\_Years >10]. I will read situations where [CAPI: RESPONDENT NAME] has to use [CAPI: his/her] memory or intelligence and I want you to indicate whether this has improved, stayed the same or got worse in that situation over the past [CAPI: DM\_Years, or 10 if DM\_Years >10] years.

Note the importance of comparing [CAPI: his/her] present performance with [CAPI: DM\_Years, or 10 if DM\_Years >10] years ago. So if [CAPI: DM\_Years, or 10 if DM\_Years >10] years ago [CAPI: RESPONDENT NAME] always forgot where [CAPI: he/she] had left things, and [CAPI: he/she] still does, then this would be considered 'Not much changed'.

(For DM\_Years = DK or RF, display 10 years)

- J1. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at remembering things about family and friends, such as occupations, birthdays, and addresses? Has this improved, not much changed, or gotten worse?
- J2. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at Remembering things that have happened recently? Has this improved, not much changed, or gotten worse?
- J3. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at recalling conversations a few days later? Has this improved, not much changed, or gotten worse?
- J4. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at remembering [his/her] address and telephone number? Has this improved, not much changed, or gotten worse?
- J5. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at remembering what day and month it is? Has this improved, not much changed, or gotten worse?
- J6. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at remembering where things are usually kept? Has this improved, not much changed, or gotten worse?
- J7. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at remembering where to find things which have been put in a different place from usual? Has this improved, not much changed, or gotten worse?
- J8. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at knowing how to work familiar machines around the house? Has this improved, not much changed, or gotten worse?
- J9. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at learning to use a new gadget or machine around house? (Has this improved, not much changed, or gotten worse?)
- J10. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at learning new things in general? Has this improved, not much changed, or gotten worse?
- J11. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at following a story in a book or on TV? Has this improved, not much changed, or gotten worse?
- J12. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at making decisions on everyday matters? Has this improved, not much changed, or gotten worse?
- J13. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at handling money for shopping? Has this improved, not much changed, or gotten worse?
- J14. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at handling financial matters; for example, the pension, or dealing with the bank? Has this improved, not much changed, or gotten worse?
- J15. Compared with [CAPI: DM Years, or 10 if DM Years >10] years ago, how is [CAPI: RESPONDENT NAME] at handling other everyday arithmetic problems; for example, knowing how much food to buy, knowing how long between visits from family or friends? Has this improved, not much changed, or gotten worse?

J16. Compared with [\[CAPI: DM\\_Years, or 10 if DM\\_Years >10\]](#) years ago, how is [\[CAPI: RESPONDENT NAME\]](#) at using his/her intelligence to understand what's going on and to reason things through? Has this improved, not much changed, or gotten worse?

**Response Options:**

- 1 = MUCH IMPROVED
- 2 = A BIT IMPROVED
- 3 = NOT MUCH CHANGED
- 4 = A BIT WORSE
- 5 = MUCH WORSE
- 6 = DOES NOT APPLY; R DOESN'T DO ACTIVITY

JORMSCORE

[\[CAPI Calculated\]](#) JORM Scale Score

THIS SCORE IS THE MEAN (AVERAGE) OF J1SCORE THROUGH J16SCORE. INCLUDE ONLY ITEMS WHERE VALUE OF JSCORE EQUALS 1-5.

## SECTION BLESSED – Blessed Test—Part 2

BL2\_1

Next, I am going to ask you how well [\[CAPI: RESPONDENT NAME\]](#) does with different activities.

BL2\_2

Regarding eating, would you say [\[CAPI: RESPONDENT NAME\]](#) feeds [\[CAPI: himself/herself\]](#) without assistance, with minor assistance, with much assistance, or has to be fed?

- 1 = FEEDS SELF WITHOUT ASSISTANCE
- 2 = FEEDS SELF WITH MINOR ASSISTANCE
- 3 = FEEDS SELF WITH MUCH ASSISTANCE
- 4 = HAS TO BE FED

BL2\_3



Regarding using the toilet, would you say [CAPI: RESPONDENT NAME] can clean and care for [CAPI: himself/herself] at a toilet, has occasional incontinence or needs to be reminded, has frequent incontinence or needs much assistance, or has little or no control?

1 = CLEAN, CARES FOR SELF AT TOILET

2 = OCCASIONAL INCONTINENCE, OR NEEDS TO BE REMINDED

3 = FREQUENT INCONTINENCE, OR NEEDS MUCH ASSISTANCE

4 = LITTLE OR NO CONTROL

BL2\_4

Regarding dressing, would you say [CAPI: RESPONDENT NAME] is able to get dressed unaided, occasionally misplaces buttons, etc., and requires minor help, gets dressed with the wrong sequences, forgets items and requires much assistance, or is unable to dress?

1 = UNAIDED

2 = OCCASIONALLY MISPLACES BUTTONS, ETC., REQUIRES MINOR HELP

3 = WRONG SEQUENCES, FORGETS ITEMS, REQUIRES MUCH ASSISTANCE

4 = UNABLE TO DRESS

## SECTION ACTIVITIES

ACT\_INTRO

ACT\_1

We'd like to know about [CAPI: RESPONDENT NAME]'s activities.

Thinking first about things done around the house, in an average day how many hours does [CAPI: he/she] spend watching television?

ACT\_2

In an average day how many hours does [CAPI: he/she] spend reading?

ACT\_5

In an average day how many hours does [CAPI: he/she] spend doing chores, maintenance, or gardening?

ACT\_7

In an average day how many hours does [CAPI: he/she] spend using a computer or the internet?

ACT\_8

In an average day how many hours does [CAPI: he/she] spend taking naps?

**Response Options:**

- 0= None
- 1 = One-half
- 2 = One
- 3 = Two to three
- 4 = Four to Six
- 5 = Seven or More
- 6 = Never

ACT\_9

Are there any other common activities around the home that [CAPI: he/she] does in an average day?

1 = Yes

5 = No [SKIP TO ACT\_10]

ACT\_9A

Please tell me which other common activities [CAPI: he/she] does **most frequently** around the home?

IWER: Probe for up to three activities.

If the INF mentions activities outside the home say:” Please list only the activities done around the home. We will be asking for activities outside the home later.”

[OPEN ENDED] \_\_\_\_\_

ACT\_10

Does [CAPI: he/she] prepare hot meals?

1 = Yes

5 = No [SKIP TO ACT\_13]

6 = It’s not customary for R to do this.

8 = DK [SKIP TO ACT\_13]

9 = RF [SKIP TO ACT\_13]

ACT\_11

How many days per week does [CAPI: he/she] prepare hot meals?

[IWER: # Days] \_\_\_\_\_

ACT\_12

How many times per day?

[IWER: # TIMES] \_\_\_\_\_

ACT\_13

And now thinking about things away from home, is [CAPI: he/she] able to travel somewhere on [CAPI: his/her] own?

1 = Yes

5 = No

ACT\_14

Can [CAPI: he/she] use public transit on [CAPI: his/her] own?

1 = Yes

5 = No

ACT\_15

How often does [CAPI: he/she] go to work or volunteer? Would you say daily, several times a week, once a week, once a month, rarely, or never?

1 = DAILY

2 = SEVERAL TIMES A WEEK

3 = ONCE A WEEK

4 = ONCE A MONTH

5 = RARELY

6 = NEVER

ACT\_16

How often does [CAPI: he/she] go to the store or market for food or other things? Would you say daily, several times a week, once a week, once a month, rarely, or never?

1 = DAILY

2 = SEVERAL TIMES A WEEK

3 = ONCE A WEEK

4 = ONCE A MONTH

5 = RARELY

6 = NEVER [SKIP TO ACT\_18]

8 = DK [SKIP TO ACT\_18]

9 = RF [SKIP TO ACT\_18]

ACT\_17

Does [CAPI: he/she] usually go alone or with someone?

1 = ALONE

5 = WITH SOMEONE

ACT\_22

How often does [CAPI: he/she] go for walks? Would you say daily, several times a week, once a week, once a month, rarely, or never?

1 = DAILY

2 = SEVERAL TIMES A WEEK

3 = ONCE A WEEK

4 = ONCE A MONTH

5 = RARELY

6 = NEVER [SKIP TO ACT\_24]

8 = DK [SKIP TO ACT\_24]

9 = RF [SKIP TO ACT\_24]

ACT\_23

Does [CAPI: he/she] usually go alone or with someone?

1 = ALONE

5 = WITH SOMEONE

ACT\_24

How often does [CAPI: he/she] do yoga or any other exercise? Would you say daily, several times a week, once a week, once a month, rarely, or never?

1 = DAILY

2 = SEVERAL TIMES A WEEK

3 = ONCE A WEEK

4 = ONCE A MONTH

5 = RARELY

6 = NEVER [SKIP TO ACT\_26]

8 = DK [SKIP TO ACT\_26]

9 = RF [SKIP TO ACT\_26]

ACT\_25

Does [CAPI: he/she] usually go alone or with someone?

1 = ALONE

5 = WITH SOMEONE

ACT\_26

Does [CAPI: he/she] do other common activities outside the home?

1 = YES

5 = NO [SKIP TO ACT\_27]

ACT\_26A

Please tell me which other common activities [CAPI: he/she] does **most frequently** outside the home?

IWER: Probe for up to three activities.

If the INF mentions activities inside the home say: "Please list only the activities done outside the home."

[OPEN ENDED ACTIVITY] \_\_\_\_\_

## SECTION. FEELINGS

ACT\_27

We'd also like to know a little about how you think [CAPI: he/she] feeling during the day.

Thinking about yesterday (or the most recent day you observed [CAPI: him/her] most of the day), how much would you say [CAPI: he/she] felt happy? Would you say Not at all, A little, Somewhat, Quite a bit, or Very much?

ACT\_29

Thinking about yesterday (or the most recent day you observed [CAPI: him/her] most of the day), how much would you say [CAPI: he/she] felt engaged? Would you say Not at all, A little, Somewhat, Quite a bit, or Very much?

ACT\_30

Thinking about yesterday (or the most recent day you observed [CAPI: him/her] most of the day), how much would you say [CAPI: he/she] felt alert? Would you say Not at all, A little, Somewhat, Quite a bit, or Very much?

ACT\_31

Thinking about yesterday (or the most recent day you observed [CAPI: him/her] most of the day), how much would you say [CAPI: he/she] felt interested? Would you say Not at all, A little, Somewhat, Quite a bit, or Very much?

ACT\_36

Thinking about yesterday (or the most recent day you observed [CAPI: him/her] most of the day), how much would you say [CAPI: he/she] felt confused? Would you say Not at all, A little, Somewhat, Quite a bit, or Very much?

ACT\_37

Thinking about yesterday (or the most recent day you observed [CAPI: him/her] most of the day), how much would you say [CAPI: he/she] felt withdrawn? Would you say Not at all, A little, Somewhat, Quite a bit, or Very much?

### RESPONSE OPTIONS:

1 = NOT AT ALL

2 = A LITTLE

3 = SOMEWHAT

4 = QUITE A BIT

5 = VERY MUCH

ACT\_38

Have you seen a change in [CAPI: his/her] daily activities in the past few years? Has there been no change, is [CAPI: he/she] slowing down, or have the activities decreased or discontinued?

1= No change

2= Slowing down

3= Activities decreased or discontinued

## SECTION CSI – Community Screening Interview

CSI\_COGACT1

Has there been a general decline in [CAPI: he/she] mental functioning?

1= Yes

5= No [GO TO CSI\_COGACT2]

8 = DK [GO TO CSI\_COGACT2]

9 = RF [GO TO CSI\_COGACT2]

CSI\_COGACT1a\_Month

When did you first notice this? Please estimate the date: Month, Year.

[ENTER MONTH]

IWER: PROBE for month and year

CSI\_COGACT1a\_Year

[ENTER YEAR]

CSI\_COGACT1a\_ME

CALCULATE # months elapsed: \_\_\_\_ months.

CSI\_COGACT1b.

Did this happen slowly or suddenly?

1 = Slowly

2 = Suddenly

CSI\_COGACT1c.

Has the course of the decline been a steady downhill progression or have there been abrupt declines?

1 = steady,

2 = abrupt,

8 = DK

9 = RF

CSI\_COGACT2

We all have slight difficulties with remembering things as we get older. Has this been a serious problem for [R NAME]?

1 = yes

5 = no [GO TO CSI\_COGACT3]

CSI\_COGACT2a.

Did this happen slowly or suddenly?

1 = slowly

2 = suddenly

CSI\_COGACT2b.

Has the course of the memory problems been a steady downhill progression or have there been abrupt declines?

1 = steady



2 = abrupt

CSI\_COGACT3

Now I would like to ask about other changes you may have noticed in [CAPI: RESPONDENT NAME].

Does [CAPI: he/she] forget where [CAPI: he/she] has put things? Would you say Yes, No, or Sometimes?

CSI\_COGACT4

Does [CAPI: he/she] forget where things are usually kept? Would you say Yes, No, or Sometimes?

CSI\_COGACT5

Does [CAPI: he/she] forget the names of friends? Would you say Yes, No, or Sometimes?

CSI\_COGACT6

Or, members of the family? Would you say Yes, No, or Sometimes?

CSI\_COGACT7

Does [CAPI: he/she] forget what [CAPI: he/she] wanted to say in the middle of a conversation? Would you say Yes, No, or Sometimes?

CSI\_COGACT8

When speaking does [CAPI: he/she] have difficulty finding the right words? Would you say Yes, No, or Sometimes?

CSI\_COGACT9

Does [CAPI: he/she] use the wrong words? Would you say Yes, No, or Sometimes?

CSI\_COGACT10

Does [CAPI: he/she] tend to talk about what happened long ago, rather than the present? Would you say Yes, No, or Sometimes?

CSI\_COGACT11

Does [CAPI: he/she] forget when [CAPI: he/she] last saw you? Would you say Yes, No, or Sometimes?

CSI\_COGACT12

Does [CAPI: he/she] forget what happened the day before? Would you say Yes, No, or Sometimes?

CSI\_COGACT13

Does [CAPI: he/she] forget where [CAPI: he/she] is? Would you say Yes, No, or Sometimes?

CSI\_COGACT14

Does [CAPI: he/she] get lost in the community, such as when finding the post office or friends' houses? Would you say Yes, No, or Sometimes?

CSI\_COGACT15

Does [CAPI: he/she] get lost in [CAPI: his/her] own home, such as when finding the toilet? Would you say Yes, No, or Sometimes?

**RESPONSE OPTIONS:**

1 = Yes

2 = Sometimes

5 = No

## SECTION 10-66

TEN\_1 Does [CAPI: he/she] have difficulty performing household chores that [CAPI: he/she] used to do, such as preparing food or boiling a pot of tea? Would you say yes, sometimes, or no?

1=Yes

2=Sometimes

5= No

TEN\_1a [Ask if TEN\_1==1 or 2]. DO YOU THINK THAT THE PROBLEM IS PRIMARILY DUE TO PHYSICAL DISABILITY?

1=Yes

5=No

TEN\_2. Has there been a **loss of a special skill or hobby** [CAPI: he/she] could manage before?

1=Yes

5=No

TEN\_3. Has there been a change in [CAPI: his/her] ability to handle money? Would you say [CAPI: he/she] has no difficulty, some difficulty, or cannot handle money?

0= No difficulty

1= Some difficulty

2= Cannot handle money

TEN\_4. Does [CAPI: he/she] have difficulty in adjusting to change in [CAPI: his/her] daily routine? Would you say yes, sometimes, or no?

1= Yes

2= Sometimes

5= No

TEN\_5. Have you noticed a change in [CAPI: his/her] ability to think and reason?

1=Yes

5=No

## SECTION BLESSED – Blessed Test—Part 1

BL1\_1

Next I am going to ask you for some information about how well [CAPI: RESPONDENT NAME] is able to do some additional activities.

Performing household tasks.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_2

BL1\_1A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_2

Coping with small sums of money.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_3

BL1\_2A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_3

Remembering a short list of items such as a shopping list.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_4

BL1\_3A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_4

Finding her/his way about indoors at home or other familiar locations.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_5

BL1\_4A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_5

Finding his/her way around familiar streets.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_6

BL1\_5A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_6

Grasping situations or explanations.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_7

BL1\_6A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_7

Recalling recent events.

Would you say [CAPI: RESPONDENT NAME] has no loss, some loss, or severe loss?

1 = NO LOSS

2 = SOME LOSS

3 = SEVERE LOSS

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO BL1\_8

BL1\_7A

Would you say this loss is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

BL1\_8

Tending to dwell on the past.

Would you say [CAPI: RESPONDENT NAME] does none of the time, sometimes, or frequently?

1 = NONE

2 = SOMETIMES

3 = FREQUENTLY

8 = DK

9 = RF

IF = 1, 8, OR 9 THEN SKIP TO END\_INFORMANT

BL1\_8A

Would you say this is due to physical reasons, mental reasons, or both?

1 = PHYSICAL

2 = MENTAL

3 = BOTH

## SECTION JSI – Judgement and Problem Solving - Informant

### Social Behaviour

JSI\_BE.A. Does respondent talk rudely to people which he/she never did before?

1. Yes
2. No

JSI\_BE.B. Does respondent laugh or cry for no reason?

1. Yes
2. No

### Following questions are from CDR informant questionnaire

JSI\_5. In general, if you had to rate his/her abilities to solve problems at the present time, would you consider them:

- a. As good as they have ever been?
- b. Good, but not as good as before?
- c. Fair?
- d. Poor?
- e. No ability at all?

JSI\_6. Can he/she handle a household emergency (e.g., water leak, small fire)?

- a. As well as before
- b. Worse than before because of trouble thinking
- c. Worse than before, another reason



JSI\_7. Can he/she understand situations or explanations?

- a. Usually
- b. Sometimes
- c. Rarely

JSI\_8. In social situations and when interacting with other people, does he/she behave\* appropriately

- a. Usually
- b. Sometimes
- c. Rarely

## SECTION CB – Caregiver Stress and Burden

CG001. Are you currently providing care on an on-going basis to a family member, friend, or neighbour with a chronic illness or a disability? This would include any kind of regular help with basic activities such as dressing, bathing, grooming this person, managing bills, arranging for medical care, watching or supervising this person, or providing transportation?

0 = No

1 = Yes

CG002. Are you primarily responsible for helping assist {RNAME} with their daily activities or is there someone else in the home who is the primary person assisting?

1 = I am the primary caretaker

2 = Someone else in the home is the primary person caring for {respondent}'s needs.

3 = I share the responsibility with other family members.

4 = { RNAME } cares primarily for themselves.

CG003 [ask if CG001=1] How many people are you caring for on a daily basis?

\_\_\_\_\_ number of people

CG004 [ask if CG001=1] In a typical day, how many hours do you spend caregiving?

\_\_\_\_\_ hours

**Current perceived stress.** These items come from the Perceived Stress Scale (PSS) four item version.

CG005. In the last month, how often have you felt that you were unable to control the important things in your life?

CG006. In the last month, how often have you felt confident about your ability to handle your personal problems?

CG007. In the last month, how often have you felt that things were going your way?

CG008. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Response scale:

0=Never

1=Almost never

2=Sometimes

3=Fairly often

4=Very often

**Depressive symptoms.** These items are from the CESD and are matched exactly to the items in the main LASI Survey Instrument pg. 83 (FS701-FS710).

During the past week...

CG009. How often did you feel depressed?

CG010. How often did you feel tired or low in energy?

CG011. How often did you feel you were overall satisfied?

CG012. How often did you feel alone?

CG013. How often did you feel happy?

Response scale:

1 = Rarely or never (less than 1 day)

2 = Sometimes (1 or 2 days)

3 = Often (3 or 4 days)

4 = Most or all of the time (5-7 days)

**Psychological overload.**

CG014. [Ask if CG001=1] Do you feel that because of the time you spend caring for members of your household you don't have enough time for yourself?

CG015. [Ask if CG001=1] Do you feel stressed between caring for members of your household, and trying to meet other responsibilities in your life such as work?

Response scale:

0 = never

1 = rarely

2 = sometimes

3 = quite frequently

4 = nearly always

**Positive affect.**

CG016. Thinking about the last month, how often did you feel cheerful? +<sup>NSOC</sup>

CG017. Thinking about the last month, how often did you feel calm and peaceful? +<sup>NSOC</sup>

Response scale

1= every day

2= most days

3= some days

4= rarely

5= never

CG018. [Ask if CG001=1] How much do you agree with the following statement: Caring for members of my household is deeply meaningful to me.

Response scale:

1 = strongly disagree

2 = disagree

3 = neither agree nor disagree

4 = agree

5 = strongly agree

6 = not applicable

**Spirituality/ religiosity.** These are the same items as the LASI Survey Instrument FS611.

CG019. How often do you have a feeling of deep inner peace?

CG020. How often do you feel you are spiritually touched by the beauty of creation?

CG021. How often are you thankful for whatever you received in your life?

Response scale:

1 = every day in a week

2 = some days in a week

3 = once in a week

4 = occasionally

5 = never

## END\_INFORMANT

We have now finished your interview. Thank you for your participation.

## INTERVIEWER CHECKPOINT 1

LANGUAGE\_IW What language was the interview administered in?

1. English
2. Hindi
3. Kashmiri
4. Urdu
5. Rajasthani
6. Bhojpuri
7. Marathi
8. Kannada
9. Telugu
10. Tamil
11. Bengali
12. Oriya
13. Assamese
14. Punjabi
15. Gujarati

INF\_Respondent. Is this informant also a respondent for LASI DAD study?

1. Yes

2. No

INTERVIEWER CHECKPOINT 2

IWMODE What was the mode of this interview?

1. Face-to-face
2. Over the telephone

INTERVIEWER CHECKPOINT 3

INF\_STATE. What was the emotional state of the informant?

1. Normal
2. Depressed
3. Can't say

INTERVIEWER CHECKPOINT 4

INF\_PLACE: Where was the informant interview conducted?

1. At respondent's home
2. Telephone