Carer identified	☐ Yes → ☐ Informal ☐ Formal ☐ No
Okay to contact carer	☐ Yes ☐ No
Carer's details completed	☐ Yes ☐ No
Carer consents to Awhina Study	☐ Yes ☐ No
Return questionnaire to participant	☐ Yes ☐ No

Life and Living in Advanced Age: A Cohort Study in New Zealand

Te Puāwaitanga o Ngā Tapuwae Kia Ora Tonu

~ WAVE 4 ~

This questionnaire has been developed by the LiLACS NZ research team and is for the purpose of the LiLACS NZ project. For queries, please contact Professor Ngaire Kerse at the LILACS NZ research base.

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Visit record form

VISIT 1

Date: ☐☐ . ☐☐ . ☐☐☐☐
(dd) (mm) (yyyy)

Start Time: *(24 hour time)* ☐☐☐☐
Finish Time: *(24 hour time)* ☐☐☐☐

Who provided the responses to this questionnaire? ☐
1=Participant 2=Family member 3=Other ....

Reason for proxy completing questionnaire ....

If a proxy completed the questionnaire, who answered most of the questions? ☐
1=Participant told proxy the answers 2=Proxy used their own judgement

Place of interview: ☐
1=Residence 2=Health centre 3=Other ....

Language used to answer questions: ☐
1=English 2=Te reo Māori/bilingual 3=Other ....

VISIT 2

Date: ☐☐ . ☐☐ . ☐☐☐☐
(dd) (mm) (yyyy)

Start Time: *(24 hour time)* ☐☐☐☐
Finish Time: *(24 hour time)* ☐☐☐☐

Who provided the responses to this questionnaire? ☐
1=Participant 2=Family member 3=Other ....

Reason for proxy completing questionnaire ....

If a proxy completed the questionnaire, who answered most of the questions? ☐
1=Participant told proxy the answers 2=Proxy used their own judgement

Place of interview: ☐
1=Residence 2=Health centre 3=Other ....

Language used to answer questions: ☐
1=English 2=Te reo Māori/bilingual 3=Other ....

Visit record form

VISIT 3

Date: ☐☐ . ☐☐ . ☐☐☐☐
(dd) (mm) (yyyy)

Start Time: *(24 hour time)* ☐☐☐☐
Finish Time: *(24 hour time)* ☐☐☐☐

Who provided the responses to this questionnaire? ☐
1=Participant 2=Family member 3=Other ....

Reason for proxy completing questionnaire ....

If a proxy completed the questionnaire, who answered most of the questions? ☐
1=Participant told proxy the answers 2=Proxy used their own judgement

Place of interview: ☐
1=Residence 2=Health centre 3=Other ....

Language used to answer questions: ☐
1=English 2=Te reo Māori/bilingual 3=Other ....

VISIT 4

Date: ☐☐ . ☐☐ . ☐☐☐☐
(dd) (mm) (yyyy)

Start Time: *(24 hour time)* ☐☐☐☐
Finish Time: *(24 hour time)* ☐☐☐☐

Who provided the responses to this questionnaire? ☐
1=Participant 2=Family member 3=Other ....

Reason for proxy completing questionnaire ....

If a proxy completed the questionnaire, who answered most of the questions? ☐
1=Participant told proxy the answers 2=Proxy used their own judgement

Place of interview: ☐
1=Residence 2=Health centre 3=Other ....

Language used to answer questions: ☐
1=English 2=Te reo Māori/bilingual 3=Other ....

Life and Living in Advanced Age: A Cohort Study in New Zealand
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Name ....

Interviewer: ....

Site Number: ....

(1=Opotiki/Te Kaha, 2=Whakatane, 3=Rotorua Māori, 4= Rotorua non-Māori, 5=NMO PHO, 6=WBOP PHO)

Date: ☐☐ . ☐☐ . ☐☐☐☐
(dd) (mm) (yyyy)

---

1. Contact Details

I would like to check some of the details you have previously given us

AA1. Do you still live at ... ***(refer sheet for previous address)***

No = 0 *(Record new address)* Yes = 1 *(Go to AA2)* ☐

Full Address ....
....
.... Phone ....

AA2. Is .... ***(refer sheet)*** **still someone we could contact if we cannot get hold of you? If for example you moved or were away or have died?** *(If not, record new contact details below)*

Name .... Phone ....
Address ....
....
Relationship..

Answer the following for the above or previously named contact

a. Can be contacted if I moved or were away No = 0 Yes = 1 ☐

AA3. Is .... ***(refer sheet)*** **still someone we could contact if we cannot get hold of you?**

If not, record new contact details below. Different household for second contact if possible

Name .... Phone ....
Address ....
....
Relationship..

Answer the following for the above or previously named contact

a. Can be contacted if I moved or were away No = 0 Yes = 1 ☐

Interviewer: *If only one contact recorded please ask if there is anyone else. Record new contact details*

Interviewer: ....

2. Personal History

AB1. Is your GP still ... ***(refer sheet for previous GP)***

No = 0 *(Record new contact)* Yes = 1 *(Go to AB2)* ☐

If no please tell me your GP's name and address:

GP's Name .... Phone ....

GP's Practice ....

....

Interviewer: *If no GP was recorded, please ask and record in the space*

AB2. What is your current marital status?

I have never been married/partnered	Married/ partnered	Widow/Widower	Separated	Divorced	
1	2	3	4	5	☐

AB3. Who do you live with most of the time? ☐

1 = alone *(Go to AB3b)*
2 = with spouse/partner only
3 = with spouse and child/other relative
4 = with spouse and non-relatives
5 = with child (not spouse)
6 = with other(s) not spouse or children
Who? ....

AB3a. If not living alone, how many people, including you, live in your residence/ household most of the time? ☐☐

OR

AB3b. If living alone, how long have you lived alone *(years)* ☐☐

AB4. What best describes your home? ☐

1 = private dwelling, stand-alone house
2 = private unit or apartment – independent
3 = unit or apartment on site with family dwelling
4 = retirement village – villa or own unit
5 = rest home (*Go to AF20*)
6 = private hospital (own or shared room) (*Go to AF20*)
7 = Marae or iwi based housing
8 = other...
....

IA4. I'd like to check how this accommodation is owned or rented. Do you... ☐

1 = Own it outright yourself or with spouse/partner
2 = Still pay a mortgage or loan yourself or with spouse/partner
3 = Rent (Private)
4 = Rent (Public) e.g. State or local council
5 = Pay part rent and part mortgage (shared ownership)
6 = Live here rent free (e.g. relative, friend's property)
8 = Lease to occupy
7 = Other ....
....

AF20. How far away in distance does your nearest: *(record one for each line)*

	Same house / within 1 ½ km	1 ½ - 8 km	8 - 25 ½ km	25 ½ - 80 km	80+ km/ overseas	Not applicable or none living	
a. Child live?	1	2	3	4	5	6	
b. Brother or sister live?	1	2	3	4	5	6	
c. Relative live? (not including your spouse/child/siblings)	1	2	3	4	5	6	

AB12. How much do you disagree or agree with this statement:

"I have a strong sense of belonging to my own ethnic group(s)"

Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
0	1	2	3	4	

AB5. Have you ever been to a Marae? 0 = No *(Go to AB6)* 1 = Yes

AB5a. If yes how often over the last 12 months

Not in the last 12 months	Once	A few times	Several times	More than once a month	
0	1	2	3	4	

This question considers your contacts with people:

AB6. In general, would you say that your contacts are with …

Mainly Māori	Some Māori	Few Māori	No Māori	
1	2	3	4	

Maori only to answer this section, others to go to question AC1

	Not at all	A little	Moderately	Very	Extremely	
AB9. How important is your hapu to your wellbeing?	1	2	3	4	5	
AB10. How important is your iwi to your wellbeing?	1	2	3	4	5	
AB11. How well do you understand your tikanga?	1	2	3	4	5	

LANGUAGE AND CULTURE

AC1. In which language(s) could you have a conversation about a lot of everyday things?

(read all options and mark answers with a 0 = No 1 = Yes)

1 = Maori

2 = English

3 = Samoan

4 = New Zealand Sign Language

5 = Cook Island Maori

6 = Niue

7 = Tokelau

8 = Other Pacific Language

9 = Other language(s), for example GUJARATI, CANTONESE, GREEK ....

If only English is spoken/understood go to AC4
If Maori or other non-English language is spoken or understood answer the following questions for the most significant other language

AC3a. Where do you speak Māori/other language? *0 = No 1 = Yes*

Don't speak it ☐
On the Marae ☐
In my community ☐
At home ☐
In meetings or at work (includes volunteer work) ☐
Other... ☐

AC3b. Do you seek out opportunities to listen to Māori/other language?
0 = No *(Go to AC4)* 1 = Yes ☐

AC3c. If yes, how often do you seek out opportunities to listen to Māori/other language?

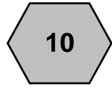
every day	every week	every month	occasionally	
1	2	3	4	☐

AC3d. Where do you listen to Māori/other language? *0 = No 1 = Yes*

On the Marae ☐
In my community ☐
At home ☐
In meetings or at work (includes volunteer work) ☐
On Maori TV ☐
On Maori/iwi radio ☐
Other... ☐

All to answer

	Not at all	A little	Moderately	Very	Extremely	
AC4. How important is your language and culture to your wellbeing?	1	2	3	4	5	☐
AC5. Thinking about the values that you have, how important are your values to your wellbeing?	1	2	3	4	5	☐



AD2. How important is faith to your wellbeing?

Not at all	A little	Moderately	Very	Extremely	
0	1	2	3	4	☐

MODIFIED MINI MENTAL STATE EXAMINATION (3MS)

I'd like to ask some questions that measure your attention, memory and ability to understand instructions. Some of the questions will be easy; others may be more difficult.

> ***Interviewer:*** *Even if a proxy is in attendance, remember to ask this section of the participant themselves. Remind them they do not have to answer all the questions.*
>
> *Use the PAGE 13 to help answer AE12, AE13, AE14 and the Clock Drawing Test*

AE1. When were you born?

(Score 1 point for each correct answer)

Where were you born?

Year	/1
Month	/1
Day	/1
Town	/1
Province/Region	/1

AE2. I would like to test your memory. I am going to say 3 words. Repeat them after I have said all three. Now keep those words in mind. I'm going to ask you to say them again in a few minutes.

Shirt	/1
Brown	/1
Honesty	/1

(When repeating back, allow up to 6 tries to remember, score 1 point for each correct answer)

AE3. Please count from 1 to 5. Now count backwards from 5 to 1. /2

(Accurate – score 2; I or 2 errors – score 1)

AE4. Please spell the word 'WORLD' backwards.

(Give only one chance, score 1 point for each letter in correct order)

D	/1
L	/1
R	/1
O	/1
W	/1

SUB SCORE /15

AE5. Please repeat back the three words I asked you to remember.

Shirt	/3
Brown	/3
Honesty	/3

(For each word: spontaneous recall – score 3, prompt – score 2, multiple choice – score 1)

AE6. What year is this? *(Accurate = 8, miss by 1 = 4, miss by 2-5 = 2)* Year /8

What season is it? *(Accurate or within 1 month = 1)* Season /1

What month is it? *(Accurate or within 5 days = 2, miss by 1 month = 1)* Month /2

What is the date? *(Accurate = 3, miss by 1-2 days = 2, miss by 3-5 days = 1)* Date /3

What day of the week is it? *(Accurate = 1)* Day /1

SUB SCORE /24

AE7. Where are we now? (Or what room are we in?) *(Accurate - score 1)* Room /1

What region are we in? *(Accurate - score 2)* Province/Region /2

What district is this? *(Accurate - score 1)* District /1

What city (town) is this? *(Accurate - score 1)* City /1

AE8. What is this?

(Point to the item or body part. Score 1 for each correct answer, approximate answers such as 'pen', 'arm', 'hand' are not acceptable)

pencil /1

watch /1

shoulder /1

elbow /1

knuckle /1

SUB SCORE /10

AE9. You have thirty seconds to answer this next question. Naming as many as you can, what animals have 4 legs? *(I point each. Discontinue after 30 seconds)*

....

....

....

SUB SCORE /10

AE10. In what way are an arm and a leg alike? e.g. Body part, limb /2

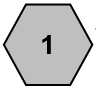
In what way are laughing and crying alike? e.g. feeling, emotion /2

In what way are eating and sleeping alike? e.g. essential for life /2

(Accurate - score 2 each example, less correct - score 1 for each)

AE11. Please repeat the following - "no ifs, ands or buts" correct /5

Allow only 1 trial



AE12. Please read this and do what it says. /3
(Obeys without prompt – score 3, prompt – score 2, can read aloud and obey – score 1)

AE13. Please write a sentence – it can say anything you like. /5
The sentence must contain a subject, a verb and be sensible. Correct grammar and punctuation are not necessary. Prompts permitted if necessary. Score 5 for a complete sentence.

SUB SCORE /19

AE14. Please copy this drawing exactly as it is. *(Ignore tremor and rotation)* /10

- *For each figure: approximately equal sides = 4, 5 unequal sides = 3, other enclosed figure = 2, 2 or more lines = 1)*
- *4 corner enclosure: 4 corners = 2, not 4 corners = 1 or 0*

Hold out a piece of paper (use the blank side of diagram page) to the participant. **AE15. Take this paper in your right hand, fold it in half, and hand it back to me**

R hand	/1
fold	/1
Gave back	/1

AE16. What three words did I ask you to remember earlier?

(Spontaneous recall = 3, prompt = 2, multiple choice =1)

Shirt	/3
Brown	/3
Honesty	/3

SUB SCORE /22

TOTAL 3MS SCORE /100

CLOCK DRAWING

AE17. Please imagine this circle is a clock. I would like you to place the numbers in the correct position then place the hands to indicate a time of 'ten past eleven'

0 =No errors 1 = minor spacing errors 2 = other errors ☐

Comments ....
....
....

Interviewers: *For those who have a score of less than 65 on the 3MSE it is strongly recommended that they are supported by a family member or friend to help answer the questions. If no-one is available and the interview is going well, please continue.*

Tear along dotted line

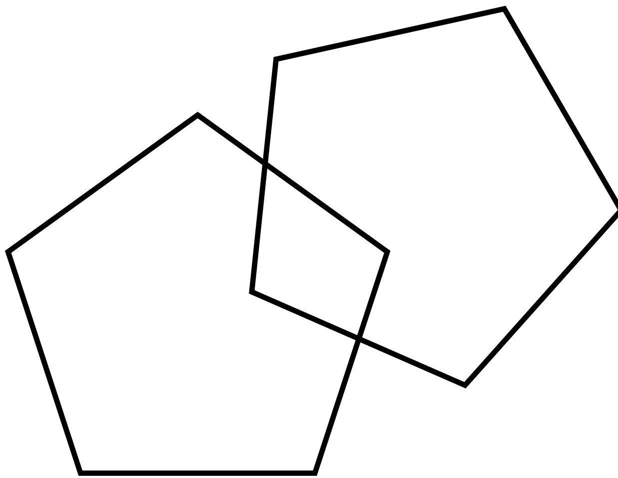
Please write a sentence about anything.

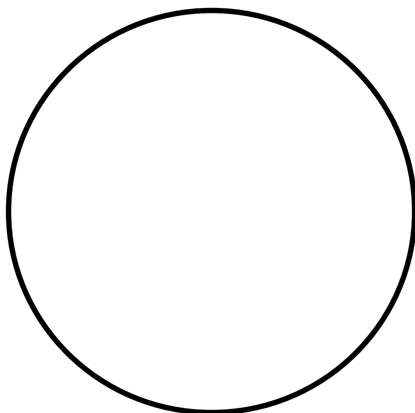
....

....

....

....





Score 777 if don't know, score 888 if refuse to answer, score 999 if not applicable

OCCUPATION

The next questions ask about the work you may have done, both paid and unpaid.

AG10. During the past 7 days, did you work for pay or as a volunteer?

Neither *(Go to AG11)*	Yes, for pay	Yes, as a volunteer	Yes, both for pay and as a volunteer
1	2	3	4

AG10a. How many hours in the last 7 days did you work for pay or as a volunteer?

a. Hours in the last 7 days worked for pay

b. Hours in the last 7 days worked as a volunteer

TOTAL hours in the last 7 days *(Go to next section)*

AG10b. Which of the following categories best describes the amount of physical activity required on your job/volunteer work?

(Answer this for the job you do spend most hours doing)

1= Mainly sitting with slight arm movements. (E.g. office worker, watchmaker, seated assembly worker, bus driver, marae spokesperson).

2= Sitting or standing with some walking. (E.g. cashier, general office worker).

3= Walking, with some handling of materials weighing less than 50 pounds/20kg. (E.g. postie, waiter / waitress).

4= Walking and heavy manual work often requiring handling of materials weighing over 50 pounds/20kg. (E.g. forestry, farm or general labourer).

AG11. If you haven't worked for pay or as a volunteer in the last week, during the past MONTH, did you work for pay or as a volunteer?

Neither *(Go to next section)*	Yes, for pay	Yes, as a volunteer	Yes, both for pay and as a volunteer
1	2	3	4

AG11a. How many hours in the last month did you work for pay or as a volunteer?

a. Hours in the last month worked for pay

b. Hours in the last month worked as a volunteer

TOTAL hours in the last month

Comments

3. Physical Health

SF-12

These next questions ask for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.

BA1. In general, would you say your health is:

2

Excellent	Very Good	Good	Fair	Poor	
1	2	3	4	5	

BA2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all	
a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3	
b. Climbing several flights of stairs	1	2	3	

BA3. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?

3

	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
a. Accomplished less than you would like	1	2	4	5	6	
b. Were limited in the kind of work or other activities	1	2	4	5	6	

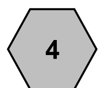
BA4. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
a. Accomplished less than you would like	1	2	4	5	6	
b. Did work or activities less carefully than usual	1	2	4	5	6	

BA5. These questions are about how you feel and how things have been with you DURING THE PAST 4 WEEKS For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS.

	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
a. Have you felt calm and peaceful?	1	2	4	5	6	☐
b. Did you have a lot of energy?	1	2	4	5	6	☐
c. Have you felt downhearted and depressed?	1	2	4	5	6	☐

BA6. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?



Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	☐

BA7. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time	
1	2	3	4	5	☐

SLEEPING AND HEALTH PROBLEMS

CD1. Do you have trouble with your sleeping (on at least 3 nights per week) such that it interferes with your activities the following day (e.g. un-refreshed in the morning, fatigue, poor concentration or irritability)? No = 0 *(Go to BB1)* Yes = 1 ☐

CD2. Do you have any of these sleeping problems? *(read all options)*

(No = 0 Yes = 1)

Waking up in the early hours of the morning ☐
Lying awake for most of the night ☐
Taking a long time to get to sleep ☐
Worry keeping you awake at night ☐
Sleep walking/ sleep talking ☐
Snoring ☐
Getting up at night to go to the toilet ☐
On average, how many times a night ....
Other sleeping problem .... ☐

The next questions ask about conditions you have had for 6 months or more

BB1. Does a HEALTH PROBLEM, or a condition you have (lasting SIX MONTHS or more) cause you difficulty with, or stop you doing: *(No = 0 Yes = 1)*

Everyday activities that people your age can usually do	☐
Communicating, mixing with others or socialising	☐
Any other activity that people your age can usually do	☐

BB3. In general, compared with other people your age, would you say your health is:

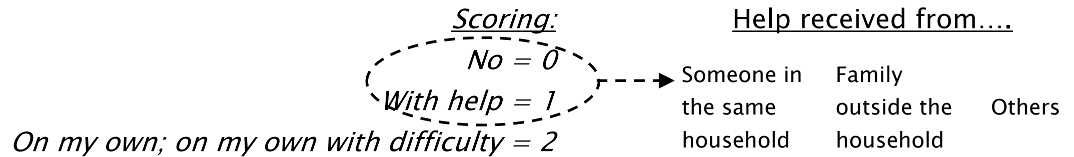
2

Excellent	Very Good	Good	Fair	Poor	
1	2	3	4	5	☐

NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING

The next questions ask about a few more common everyday activities. For each question please tell me whether you do the activity on your own, on your own with difficulty, with help from someone else, or whether you don't do the activity at all. We are interested in whether you have actually DONE the activity in the last few weeks, not whether you CAN do it.

Interviewer: *ask all the questions first. Then go back to all activities the person said they have help to do. For each activity they said they have help to do, find out who helps.*



		Score	Someone in the same household	Family outside the household	Others
BC1.	Mobility				
	a. Do you walk around outside?				
	b. Do you climb stairs?				
	c. Do you get in and out of the car?				
	d. Do you walk over uneven ground?				
	e. Do you cross roads?				
	f. Do you travel on public transport?				
BC2.	In the kitchen				
	a. Do you manage to feed yourself?				
	b. Do you manage to make yourself a hot drink?				
	c. Do you take hot drinks from one room to another?				
	d. Do you do the washing up?				
	e. Do you make yourself a hot snack?				
BC3.	Domestic tasks				
	a. Do you manage your own money when you are out?				
	b. Do you wash small items of clothing?				
	c. Do you do your own housework?				
	d. Do you do your own shopping?				
	e. Do you do a full clothes wash?				
BC4.	Leisure activities				
	a. Do you read newspapers or books?				
	b. Do you use the telephone?				
	c. Do you write letters?				
	d. Do you go out socially?				
	e. Do you manage your own garden?				
	f. Do you drive a car?				
BC5.	Other				
	a. Do you manage your personal care for instance brushing your teeth and hair, washing your hands and face?				
	b. Do you manage to go to the toilet?				
	c. Do you get in/out of bed?				
	d. Do you shower/bath yourself?				
	e. Do you dress yourself?				

Score 777 if don't know, score 888 if refuse to answer, score 999 if not applicable

We are interested in any aids you use to help you get around

BC7. How often do you use any of the following mobility aids?

	None of the time	Some of the time	Most of the time	All of the time	
a. Cane or stick?	0	1	2	3	
b. Walking frame?	0	1	2	3	
c. Wheelchair?	0	1	2	3	
d. Mobility scooter	0	1	2	3	
e. Other (specify)	0	1	2	3	

4. Medical History

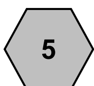
In this section I would like to find out about things to do with medication and your medical history.

MEDICATIONS

The first questions are about medications and non-prescribed products you might use as well as any health problems you may have. Remember that any question you are not happy to answer, you may leave.

Interviewer:
Ask the following questions and record all medications and health products, whether they are prescribed or not, in the table to the right. Include inhalers, suppositories, creams, eye drops and fortified foods such as fortisip, complan etc. You may need to prompt the participant about these more unusual products.
Ask if you can look at the medication packets and fill in as much information as you can. See the procedure manual for further guidance on completing this section.

CA1. Do you currently take any medications prescribed by the doctor?



No = 0 *(Go to CA3)* Yes = 1 ☐

		Never	Rarely	Sometimes	Often	Very often	
CA1a.	**Sometimes people forget to take their medicines. How often do *you* forget to take your medication(s)?**	1	2	3	4	5	
CA1b.	**Sometimes people alter the way they take their medication, that is take them at a different time or take less or more of a medication. How often do *you* alter you medication(s)?**	1	2	3	4	5	

CA3. Do you currently take any over the counter medicines that are not prescribed?

No = 0 Yes = 1 ☐

CA4. Do you currently take any nutritional supplements? No = 0 Yes = 1 ☐

CA5. Do you take any "natural" or "herbal" products or traditional medicines? No = 0 Yes = 1 ☐

CA6c. Do you use Rongoa Māori healing practices? No = 0 *(Go to CA7)* Yes = 1 ☐

CA6d. How much do Māori healing practices contribute to your quality of life? 4

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

CA6. Do you take any Rongoa Māori medicines? No = 0 Yes = 1 ☐

PLEASE RECORD ALL MEDICATIONS AND HEALTH-RELATED PRODUCTS IN THE TABLE BELOW

MEDICATION TABLE *List prescription medications first leave a line, then over the counter medications* Generic name	Strength	** How is this taken?	Number of tablets				* Other Frequency	*** How do you get this medication
			Breakfast	Lunch	Dinner	Bedtime		

FREQUENCIES: 1xDay code under breakfast; 2xDay code breakfast and dinner; 3xDay code breakfast, lunch and dinner

***Other frequency:** D = day M = month Y = year W = Week (use the most relevant denominator and add a number to identify how often in a D, M, W or Y e.g. 5D = 5 times a day)

**** Code for "How is it taken"?** 1 = by mouth (swallowed) 2 = by mouth (not swallowed) 3 = skin patch 4 = ointment/cream 5 = injection 6 = eye drops 7 = ear drops 8 = inhaled/nasally 9 = per rectum

***** Codes for "How do you get this medication"?** 1 = prescription 2 = bought, no script 3 = other

MEDICATION TABLE *List prescription medications first leave a line, then over the counter medications* Generic name	Strength	**How is this taken?	Number of tablets				*Other Frequency	***How do you get this medication
			Breakfast	Lunch	Dinner	Bedtime		

FREQUENCIES: 1xDay code under breakfast; 2xDay code breakfast and dinner; 3xDay code breakfast, lunch and dinner

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***** Codes for "How do you get this medication"?** 1 = prescription 2 = bought, no script 3 = other

MEDICATION ASSISTANCE AND HEART HEALTH

CA7. Do you use any aids to help you take your *prescribed* medication?

No = 0 *(Go to CA8)* Yes = 1 (*Go to CA7a*) ☐

CA8. Do you think an aid to help you take your *prescribed* medication would be useful?

No = 0 *(Go to CA9)* Yes = 1 ☐

CA8a. What would be useful?

....

....

CA7a. What type of aid do you use? *(No = 0 Yes = 1)*		**CA7b. How useful is this aid?** *0 = not at all, 1 = somewhat, 2 = moderately, 3 = very, 4 = extremely*
Blister pack	☐	☐
Weekly medication boxes	☐	☐
Yellow card	☐	☐
Other................................	☐	☐

CA7c. What else would be useful?

....

....

CA9. Does anyone give you advice about your medication? No = 0 Yes = 1

General Practitioner ☐ Pharmacist ☐

District nurse ☐ Practice Nurse ☐

Other .... ☐

CA10. Does anyone help you take your medication? No = 0 *(Go to CB1)* Yes = 1 ☐

CA10a. Who helps you take your medication?	*(No = 0 Yes = 1)*	**CA10b. How do they help?** Give the medication	Reminder to take the medication	Fill the medication box
a. General Practitioner/Practice Nurse	☐	☐	☐	☐
b. Whanau or Family member	☐	☐	☐	☐
c. Formal Carer	☐	☐	☐	☐
d. Friend or neighbour	☐	☐	☐	☐
e. District Nurse	☐	☐	☐	☐
f. Other	☐	☐	☐	☐

CB1. Since your last LILACS NZ interview about a year ago, have you been told by a doctor that you have had: *No = 0 Yes = 1 Don't Know = 2*		**CB3. Were you in hospital for this?** *No = 0 Yes = 1*
a. Heart attack/myocardial infarction	☐	☐
b. Angina	☐	☐
c. Stroke	☐	☐
d. Transient Ischemic Attack / mini stroke	☐	☐
f. Atrial fibrillation or irregular heartbeat	☐	☐
g. Congestive heart failure	☐	☐
h. Intermittent claudication (pain in calves when walking), peripheral vascular disease	☐	☐

MAJOR LIFE EVENTS

These next two questions ask about major health events you may have experienced

FD1. Have you had a major injury or health event that has affected you since your last LILACS NZ interview about a year ago?

No = 0 *(Go to FD2)* Yes = 1 ☐

FD1a. What was it? ....

....

....

FD2. Have you had a major psychological stress event that has affected you since your last LILACS NZ interview about a year ago? For example the unexpected loss of a family member or moving house.

No = 0 *(Go to CF1)* Yes = 1 ☐

FD2a. What was it? ....

....

....

FALLS, CONTINENCE, AND HEALTH HABITS

The next questions are about falls

CF1. How many times have you fallen in the last 12 months?

None *(Go to CF11)*	One	Two or three	Four or more	
0	1	2	3	☐

CF1a. Have you sought medical attention because of your fall/s?

No = 0 Yes = 1 ☐

CF1b. When you fell during the last 12 months? No = 0 Yes = 1

a. Did you have a fracture

b. Did you have some other kind of injury (please describe)

....

c. Were you admitted to hospital?

CF11. Have you had any fracture not from a fall since your last LILACS NZ interview about a year ago? No = 0 *(Go to CF2)* Yes = 1

CF11a. Cause of fracture

CF2. How confident are you that you can do all your daily activities without falling?

Not at all confident	Quite confident	Completely confident
0	1	2

I want to ask you about any bladder and bowel problems you might have

CF3. Do you have a problem with losing control of urine when you don't want to?

No = 0 *(Go to CF4)* Yes = 1

CF3a. How much of a problem would you say you have with losing control of urine?

Severe problem	Moderate problem	Mild problem *(Go to CF4)*	No problem *(Go to CF4)*
1	2	3	4

CF3b. Have you sought help for this? No = 0 Yes = 1

Your GP

District nurse

Pharmacy

Other ....

CF4. Do you have a problem with losing control of your bowels when you don't want to?

No = 0 Yes = 1

CC1. Do you smoke cigarettes? No = 0 *(Go to DE1)* Yes = 1

CC1c. On average, how many cigarettes do you smoke per day?
One pack is 20 cigarettes

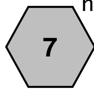
DE1. How often do you have a drink containing alcohol?

Never	Monthly or less	Two to four times a MONTH	Two to three times a WEEK	Four or more times a WEEK
0	1	2	3	4

PAIN

I'd like to ask a few questions about pain now. I'm going to ask for some detail about each area that you have pain in. Use the following scale to determine the level of pain.

Example



no pain ____ worst possible pain

0 1 2 3 4 5 6 7 8 9 10

CG0. Do you have any pain now? No = 0 *(Go to CG6)* Yes = 1 ☐

Where is it? *(**Interviewer:** Use the scale and map supplied to code all pain mentioned by area and write each area in the table below)*

Area		CG1	CG2	CG3	CG4	CG5
a.						
b.						
c.						
d.						
e.						
f.						
g.						
h.						

Interviewer *– ask these questions about each area before you go on to the next*

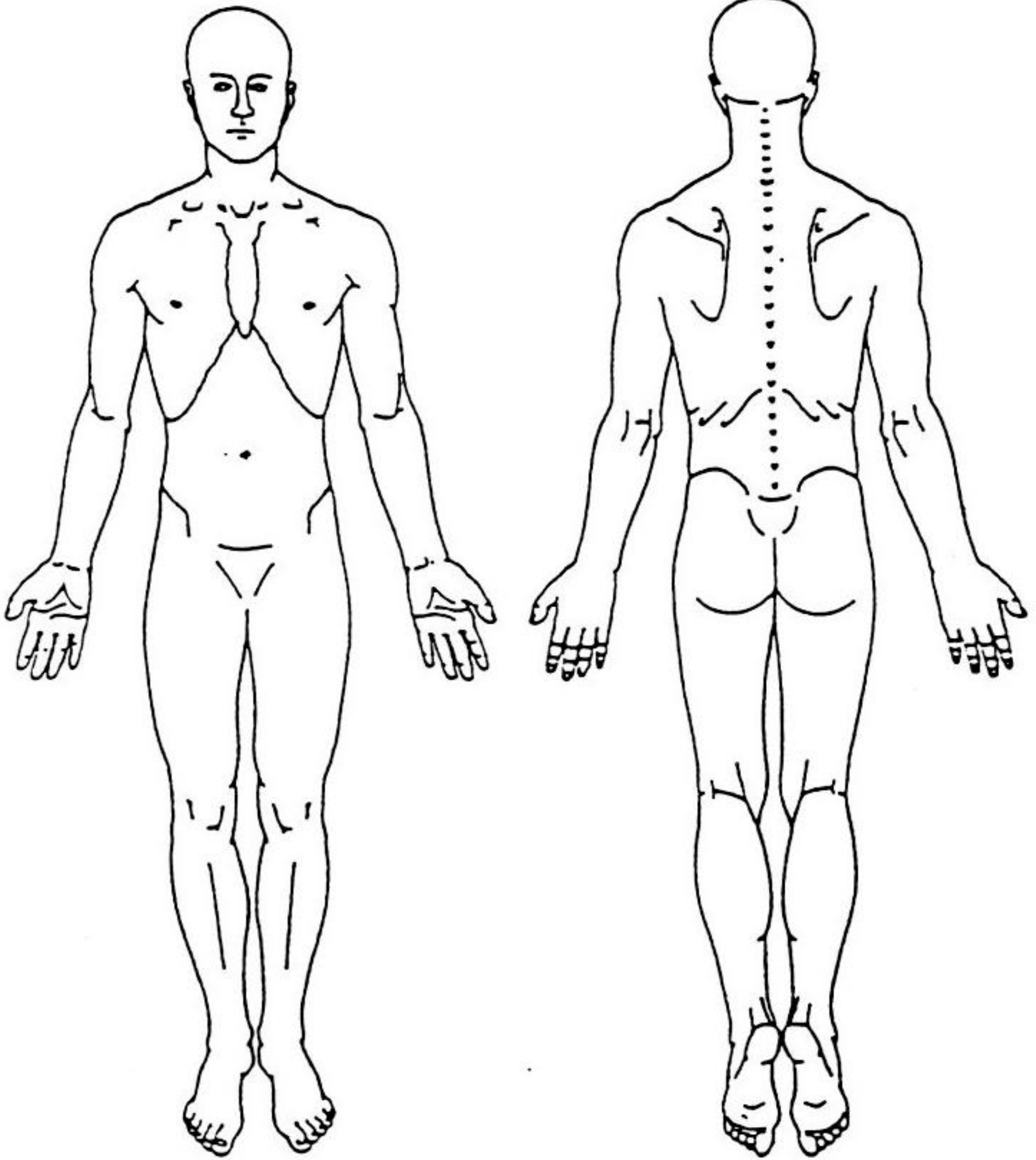
CG1. What is your pain RIGHT NOW?
CG2. What is your TYPICAL or AVERAGE pain?
CG3. What is your pain level AT ITS BEST (How close to '0' does your pain get at its best)?
CG4. What is your pain level AT ITS WORST (How close to '10' does your pain get at its worst)?
CG5. How many days over the last month have you had this pain?

CG6. Are there any other areas you sometimes have pain but do not have pain right now?
No = 0 *(Go to next section)* Yes = 1 ☐

Interviewer, *code other areas of pain and ask CG2–CG5 above for each area mentioned*

Area		CG1	CG2	CG3	CG4	CG5
i.		**0**				
j.		**0**				
k.		**0**				
l.		**0**				
m.		**0**				
n.		**0**				
o.		**0**				

Ask participant to shade or circle the location of each area of pain. Place letter of area (a – o) beside shading or circle.



SCREEN II (14 items)

I'm now going to ask you some questions about your eating habits. I want to find out about your normal eating habits – so we'll talk about a TYPICAL day. There are no right or wrong answers to any of these questions

DB1. Has your weight changed in the past 6 months?

No, my weight has stayed within a few kilos *(Go to DB2)*	Yes	I don't know how much I weigh or if my weight has changed *(Go to DB2)*	
0	1	2	☐

DB1a. How much has it changed?

I gained			I lost			
More than 5kg	2½ – 5kg	About 2–2½ kg	More than 5kg	2½ – 5kg	About 2–2½ kg	
1	2	3	4	5	6	☐

DB2. Have you been trying to change your weight in the past 6 months?

No	Yes	No, but it changed anyway	
0	1	2	☐

DB3. Do you think your weight is…

More than it should be	Just right	Less than it should be	
1	2	3	☐

DB4. Do you skip meals?

Never or rarely	Sometimes	Often	Almost every day	
1	2	3	4	☐

DB5. Do you limit or avoid certain foods?

I eat most foods	I limit some foods and I am managing fine	I limit some foods and I am finding it difficult to manage	
1	2	3	☐

DB6. How would you describe your appetite?

Very good	Good	Fair	Poor	
1	2	3	4	☐

DB7. How many pieces or servings of fruit and vegetables do you eat in a day?

Can be canned, fresh, frozen or juice. A handful is a serving, count each vegetable as a separate serving.

Five or more	Four	Three	Two	Less than two	
1	2	3	4	5	☐

DB8. How often do you eat meat, eggs, fish, poultry or meat alternatives?
Meat alternatives are dried peas, beans, lentils, nuts, peanut butter or tofu.

Two or more times a day	One to two times a day	Once a day	Less than once a day	
1	2	3	4	☐

DB9. How often do you have milk products?
Includes fluid milk, cooking with milk, milk puddings, ice cream, cheese, yoghurt and milk alternatives like soy beverages.

Three or more times a day	Two to three times a day	One to two times a day	Usually once a day	Less than once a day	
1	2	3	4	5	☐

DB10. How much fluid do you drink in a day?
Includes: water tea, coffee, herbal drinks, juice, and soft-drinks but not alcohol

Eight or more cups	Five to seven cups	Three to four cups	About two cups	Less than two cups	
1	2	3	4	5	☐

Use blank pages at end of questionnaire to work out typical daily intake

DB10a. Do you cough, choke or have pain when swallowing food or fluids?

Never	Rarely	Sometimes	Often or always	
1	2	3	4	☐

DB11. Do you suffer from dry mouth or reduced salivation? 0 = No 1 = Yes ☐

DB12. Is biting or chewing food difficult for you?

Never (Go to DB13)	Rarely	Sometimes	Often or always	
1	2	3	4	☐

DB12a. If yes, why is chewing difficult? ***(Main reason first)***

Pain in mouth (other than gums or teeth)	Gum disease	Teeth sore	Dentures don't fit	Other	☐ ☐
1	2	3	4	5	☐

Specify other ....

DB13. Do you use commercial meal replacements or supplements? ***(protein shakes, energy bars, Complan, Ensure)***

Never or rarely	Sometimes	Often or always	
1	2	3	☐

DB14. Do you eat one or more meals a day with someone?

Never or rarely	Sometimes	Often	Almost always	
1	2	3	4	☐

DB15. Who usually prepares your meals?

I do	I share my cooking with someone else	Someone else cooks most of my meals	
1	2	3	☐

DB16. Which statement best describes meal preparation for you?

I enjoy cooking most of my meals	I sometimes find cooking a chore	I usually find cooking a chore	I'm satisfied with the quality of food prepared by others	I'm not satisfied with the quality of food prepared by others	
1	2	3	4	5	☐

DB17. Do you have any problems getting your groceries?

Can be poor health or disability, limited income, lack of transportation, weather conditions, or finding someone to shop

Never or rarely	Sometimes	Often	Always	
1	2	3	4	☐

5. Mental Health

GERIATRIC DEPRESSION SCALE (15-items)

The next questions are from a scale used in many studies and are about how you have been feeling lately. Please choose the best answer to describe how you have felt over the past WEEK.

	No = 0 Yes = 1
EA1. Are you basically satisfied with your life?	
EA2. Have you dropped many of your activities and interests?	
EA3. Do you feel that your life is empty?	
EA4. Do you often get bored?	
EA5. Are you in good spirits most of the time?	
EA6. Are you afraid that something bad is going to happen to you?	
EA7. Do you feel happy most of the time?	
EA8. Do you often feel helpless?	
EA9. Do you prefer to stay at home, rather than going out and doing new things?	
EA10. Do you feel you have more problems with memory than most?	
EA11. Do you think it is wonderful to be alive now?	
EA12. Do you feel pretty worthless the way you are now?	
EA13. Do you feel full of energy?	
EA14. Do you feel that your situation is hopeless?	
EA15. Do you think that most people are better off than you are?	

6. Support needs

VISITS TO HEALTH PROFESSIONALS

Thank you for answering the questions about medical conditions. I'd now like to ask you about visits to health professionals.

GA1. If you have any health problems, which one would you most like to be fixed?

....

(if no problems Go to GA4)

GA1b. Who is helping /trying to help you with this problem? No = 0 Yes = 1

General Practitioner		Practice Nurse	
Pharmacist		Carer	
Dentist		Whanau or family member	
Friend or neighbour		Other	

GA4. When you have a health problem, how easy is it for you to get help with it?

10

Not at all	Somewhat	Moderately	Very	Extremely	
1	2	3	4	5	

GA2. Since your last LILACS NZ interview about a year ago, have you visited, or had a visit from, any of the following health professionals? How many times in the last 12 months?

8

	Not at all	About once a year	About every 6 months	About every 3 months	About every month	About every week	Don't know	
a. General practitioner	0	1	2	3	4	5	6	
b. Hospital based doctor or private specialist	0	1	2	3	4	5	6	
c. After hours medical clinic	0	1	2	3	4	5	6	
d. Practice nurse	0	1	2	3	4	5	6	
e. Pharmacist/chemist	0	1	2	3	4	5	6	
f. Dentist	0	1	2	3	4	5	6	
g. Podiatrist – feet	0	1	2	3	4	5	6	
h. Audiologist – ears/hearing	0	1	2	3	4	5	6	
i. Optometrist – eyes glasses	0	1	2	3	4	5	6	
j. District Nurse	0	1	2	3	4	5	6	
k. Physiotherapist	0	1	2	3	4	5	6	
l. Occupational Therapist	0	1	2	3	4	5	6	
m. Dietician	0	1	2	3	4	5	6	
n. Social worker	0	1	2	3	4	5	6	
o. Community worker	0	1	2	3	4	5	6	

p. Whanau ora worker	0	1	2	3	4	5	6	
q. Alternative health professional e.g. Naturopath / Homeopath	0	1	2	3	4	5	6	
r. Tohunga / Maori healer	0	1	2	3	4	5	6	
s. Other health professional. Specify	0	1	2	3	4	5	6	

LA3. Have you ever been treated unfairly (e.g. treated differently, kept waiting) by a health professional (e.g. doctor, nurse, dentist etc.) because of your ethnicity in New Zealand?

(0 = No 1 = Yes)

Within the past 12 months ☐ More than 12 months ago ☐

An important thing for older people is the way they get on with their doctor. Would you now please answer the following questions? Thinking about when you have last consulted your GP, How do you rate the following?

9

	Very Poor	Poor	Fair	Good	Very Good	Excellent	
DR3a. How well the doctor listens to what you have to say?	0	1	2	3	4	5	
DR3c. How well the doctor explains your problems or any treatment that you need?	0	1	2	3	4	5	
DR3e. The doctor's care and concern for you?	0	1	2	3	4	5	
DR3f. The doctor's respect for your culture	0	1	2	3	4	5	

I'd like to ask you about things which might help you understand your health better

GA5. When you are seeing the doctor what method have you used and is it useful?
Have you used...

No = 0 Yes = 1

	Used	Useful
Written medical information from the doctor?		
GP follow-up (phone or visit)?		
Taking a whanau or family member or advocate with you?		
Practice Nurse follow-up (phone or visit)?		
Other		

if no methods used go to GB1

GA6. Which method was most useful? ☐

1 = Written medical information from the doctor
2 = GP follow-up (phone or visit)
3 = Taking a whanau or family member or advocate with you
4 = Practice Nurse follow-up (phone or visit)
5 = Other ....

HEARING/VISION/TEETH

I'd like to ask a couple of questions about your hearing and your eyesight now.

GB1. How much does your hearing interfere with normal day-to-day functioning?

10

Not at all	Somewhat	Moderately	Very	Extremely
1	2	3	4	5

GB2. Do you have a hearing aid? No = 0 *(Go to GB3)* Yes = 1

GB2a. How often do you use it?

None of the time	Some of the time	Most of the time	All of the time
0	1	2	3

GB3. How much does your eyesight interfere with normal day-to-day functioning?

10

Not at all	Somewhat	Moderately	Very	Extremely
1	2	3	4	5

GB4. How much do your teeth interfere with normal day-to-day functioning?

Not at all	Somewhat	Moderately	Very	Extremely
1	2	3	4	5

SOCIAL SUPPORT

Now I'd like to ask you some questions about your social network and social relationships.

GC1. When you need some extra help, can you count on anyone to help with daily tasks like grocery shopping, cooking, house cleaning, telephoning, give you a ride?

No (*Go to GC3*)	Yes	I don't need help
0	1	2

GC2. In the last year who has been most helpful with these daily tasks?

1 = Spouse
2 = Daughter
3 = Son
4 = Sibling
5 = Other relative
6 = Your neighbours
7 = Co-workers
8 = Church members
9 = Club members
10 = Professionals
11 = Any friend not included in these categories
12 = No-one
777 = Don't Know

GC3. Could you have used more help with daily tasks than you received? Would you say...

A lot	A little help	Some	None at all (received sufficient help)
1	2	3	4

Score 777 if don't know, score 888 if refuse to answer, score 999 if not applicable

GC4. Can you count on anyone to provide you with emotional support? (e.g. talking over problems or helping you make a difficult decision)

No (*Go to GC6)*	Yes	I don't need help
0	1	2

GC5. In the last year who has been most helpful in providing you with emotional support?

22

1 = Spouse 2 = Daughter 3 = Son
4 = Sibling 5 = Other relative 6 = Your neighbours
7 = Co-workers 8 = Church members 9 = Club members
10 = Professionals 11 = Any friend not included in these categories
12 = No-one 777 = Don't Know

GC6. Could you have used more emotional support than you received? Would you say…

A lot	A little help	Some	None at all (received sufficient help)
1	2	3	4

22

GC15. Regardless of how you answered the previous questions, who has provided you the most help, care and support in the last 3 months? (You can identify up to two persons)

1 = Spouse 2 = Daughter 3 = Son **1.**
4 = Sibling 5 = Other relative 6 = Your neighbours **2.**
7 = Co-workers 8 = Church members 9 = Club members
10 = Professionals 11 = Any friend not included in these categories
12 = No-one (*Go to GC18)* 777 = Don't Know *Go to GC18)*

If no Awhina carer was interviewed in wave 3, ask GC15a

GC15a. Are you comfortable for us to contact this person to speak to about the ways he/she has given you the help, care and support in the last 3 months?

No=0 *(Go to GC8);* Yes=1

If prior Awhina carer was interviewed;

GC15e. Last year we contacted …………. (*refer to participant detail sheet*). **Is this the same person?**

No=0 Yes=1

GC15b. Can I have his/her contact details to ask if he/she would be willing to take part in a study of their experience of providing this help, care and support to you?

(check that we already have them in the system)

No (*Go to GC15c)*	Yes	Don't know details
0	1	2

GC15b-1 Name of the carer: ....

Address: ....

Phone: ....

Other comments: ....

GC15b-2.
Record previous Kai Āwhina ID No. or assign a new ID No. ☐☐☐☐☐☐☐

Refer to participant detail sheet to check previous Carer ID number

GC15c. Is there anyone else you would like to name (particularly if the first named carer is a paid "formal care worker")?

No=0 *(Go to GC18);* Yes=1 ☐

GC15d. If 'yes", can I have his/her contact details?

No *Go to GC18)*	Yes	Don't know details	
0	1	2	☐

GC15d-1 Name of the carer: ....

Address: ....

Phone: ....

Other comments: ....

GC15d-2.
Record previous Kai Āwhina ID No. or assign a new ID No. ☐☐☐☐☐☐☐

Refer to participant detail sheet to check previous Carer ID number

Instruction for interviewer:

(I) Please tick boxes "☑" on the front page whether 1) a carer (formal or informal) is identified, 2) participant agrees for us to contact the carer and 3) carer's contact details are provided.

(II) Remember to contact the identified carer if they are not present to inform them about the AWHINA (LOVE & SUPPORT) STUDY and to obtain a written informed consent.

GC18. How well informed are those providing care for you about your healthcare needs?

4	Not at all	Slightly	Moderately	Quite a bit	Extremely	
	1	2	3	4	5	☐

GC7. Does it seem that your family and friends (i.e. people who are important to you) understand you?

None of the time	Hardly ever	Some of the time	Most of the time	All of the time	
1	2	3	4	5	☐

GC8. How satisfied are you with the kinds of relationships you have with your family? 11

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Satisfied most of the time	Satisfied all of the time	
1	2	3	4	5	☐

GC9. How satisfied are you with the kinds of relationships you have with your friends?

Extremely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Satisfied most of the time	Satisfied all of the time	
1	2	3	4	5	☐

GC16. What funded/subsidised government/community services are available for older people in your area? *(Do not prompt for answers)* *(No=0; Yes=1)*

Buses/taxis	☐	Meal support	☐
Home help (cleaning)	☐	Age Concern	☐
Home Help (shopping)	☐	Stroke Foundation	☐
Home Help (gardening)	☐	Foundation of the Blind	☐
Home Help (lawn mowing)	☐	Alzheimer's Association	☐
Personal Care (bathing/dressing etc.)	☐	Other	☐
Other	☐	Other	☐

GC19. How well informed are those providing care for you about what is available to assist you? 4

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	☐

GC20. What are the most useful sources of information about services for older people?

(No=0; Yes=1)

1 = Medical Practice	☐	2 = General Practitioner	☐
3 = Friends	☐	4 = Whanau or family	☐
5 = Paid caregiver or home help	☐	6 = The internet	☐
7 = Written material	☐	Other	☐

GC21. How well informed are you about accessing services to assist you? 4

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	☐

GC22. How confident are you about accessing services to assist you? 4

Not at all	Slightly	Moderately	Quite a bit	Extremely	
1	2	3	4	5	☐

GC23. How confident are you filling out forms by yourself?

Always	Often	Sometimes	Occasionally	Never	
1	2	3	4	5	☐

Comments ....
....
....

GC17. Do you use a medical alarm? No=0; Yes=1 ☐

If living in a rest home or private hospital Go to GC12

GC10. Do you receive any regular support service, such as home help?

No = 0 *(Go to GC12)* Yes = 1 ☐

GC11. Do you receive any of the following support services?

IF Yes: **How often? Who funds this help?**

Interviewer: *For each service received, ask who the support is received from. Record the frequency in the appropriate column – there may be more than one service provider*

	A. Receive No = 0 Yes = 1	B. Frequency 1 = Several times a day 2 = Once a day 3 = One or more times a week 4 = Less than once a week	C. Support provided by 1 = public system 2 = part of accommodation cost 3 = respondent pays 4 = family pays
a. Any meal service			
b. Home Help (cleaning)			
c. Home Help (shopping)			
d. Home Help (gardening)			
g. Home Help (lawns)			
e. Personal Care (bathing/dressing etc.)			
h. Bus/taxi			
i. Age Concern			
j. Stroke Foundation			
k. Foundation for the Blind			
l. Alzheimers Foundation			
f. Other			

GC12. How often do you currently provide care or assistance for other people?

Never	Occasionally (less than weekly)	Once a week	Two to five times weekly	Daily (six to seven times weekly)	
0	1	2	3	4	☐

FA1. All things considered, how satisfied are you with your life as a whole these days

12

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
1	2	3	4	5	☐

7. End of life

Interviewer: *Remind the participant that he/she has the right not answer or not to proceed with this section at any time*

Now I want to ask you about your plan for the end of your life.

EL1. Are you comfortable talking about this?

No=0 *(Go to Contacts for End of Life Studies)* Yes=1 ☐

EL18. How important would the following be for you at the end of your life?

10

		Not at all	Somewhat	Moderately	Very	Extremely	
a.	To have my pain/symptoms well controlled	1	2	3	4	5	
b.	To not be a burden to my family	1	2	3	4	5	
c.	To feel my life is complete	1	2	3	4	5	
d.	To be at peace with my God	1	2	3	4	5	
e.	To have sorted out my personal affairs	1	2	3	4	5	
f.	To die at home	1	2	3	4	5	
g.	To be mentally alert (until death)	1	2	3	4	5	
h.	To be involved in decisions about my care	1	2	3	4	5	
i.	To have sorted out my funeral arrangements	1	2	3	4	5	
j.	To not be a burden to society	1	2	3	4	5	
k.	To have specific cultural practices undertaken	1	2	3	4	5	
l.	To have sorted out the continuing care of my pet(s)	1	2	3	4	5	
m.	Other, specify	1	2	3	4	5	

....

EL12. Where would you like to die (what place)? (you can choose more than one) (No=0; Yes=1)

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	At home	☐
	In a public hospital	☐
	In a whānau/family room in a public hospital	☐
	In a rest home/private hospital	☐
Some other place:	At a family member home (not where you live now)	☐
	At your turangawaewae (tribal home)	☐
	At a spiritual place that is special for you	☐
	In a hospice	☐
	Other, specify	☐

EL4. Do you have a Living Will or Advanced Care Plan?

No=0 *(Go to Contacts for End of Life Studies)* Yes=1 ☐

EL4a. If yes,

	No	Yes	
a. Do you have an Enduring Power of Attorney?	0	1	
b. Do you wish for major surgery or medical intervention if you are seriously ill?	0	1	
c. Do you wish to be resuscitated?	0	1	
d. Other	0	1	

EL5. Have you talked to a friend or family member about your wishes?

No=0 Yes=1 ☐

CONTACT FOR END OF LIFE STUDIES

EL21. Are you comfortable for us to contact a family member, whānau or a close friend of yours after your death to find out how things went?

No=0 *(Go to Section 8)* Yes=1 ☐

If yes, discuss the EEL questionnaire and TPS and show the EEL PIS

EL22. Can I have contact details for your family member, whānau or friend to ask if he/she would be willing to take part in a study about how things were for you at the end of your life? *Record contact details below*

The person you have just chosen will be the first person we contact. If this person is not available is there anyone else we could contact to talk to about how things were for you at the end of your life? *Record details for other contacts below*

EL22a Primary nominee	EL22b Secondary nominee	EL22c Tertiary nominee
Name	Name	Name
Address	Address	Address
Phone	Phone	Phone
Relationship to LiLACS NZ participant	Relationship to LiLACS NZ participant	Relationship to LiLACS NZ participant
Date contacted ……………………………………… **EL22a-1** The person above consents to be contacted for EEL/TPS (No=0 Yes=1) ☐	Date contacted ……………………………………… **EL22b-1** The person above consents to be contacted for EEL/TPS (No=0 Yes=1) ☐	Date contacted ……………………………………… **EL22c-1** The person above consents to be contacted for EEL/TPS (No=0 Yes=1) ☐

EL23. I have been given an explanation of what is involved in the Experiences at the End of Life and Te Pākeketanga studies and I understand what the data will be used for. I agree that the person(s) I nominated may be invited to answer questions or complete a longer qualitative interview after I die.

LiLACS NZ participant, or proxy, to sign

***Interviewer**: inform the LiLACS NZ participant or their proxy that you will let the primary nominee know that they have been nominated to be contacted in the event of their death.*

8. Physical performance measures

SHORT PHYSICAL PERFORMANCE BATTERY

Reason not attempted or not completed

	CODE		*CODE*
Tried but unable	1	Participant unable to understand instructions	5
Participant could not hold position unassisted	2	Other (specify)	6
Not attempted, you felt unsafe	3	Participant refused	7
Not attempted, participant felt unsafe	4		

Now I'd like to ask you to do some physical performance tests. I will first describe and show each movement to you. Then I'd like you to try to do it. If you cannot do a particular movement or you feel it would be unsafe to try to do it, tell me and we'll move on to the next one. Let me emphasise that I do not want you to try to do any exercise that you feel might be unsafe.

BALANCE TEST

***Instructions**: Start with B: Semi-tandem stand. If the person cannot hold the position for 10 seconds, ask them to attempt A: Side-by-side stand. If they manage the semi-tandem stand for 10 seconds, go straight to C: Tandem stand.*

	Number of seconds held:	Held for 10 sec No = 0 Yes = 1	If not attempted or failed, enter reason: *(Code box above)*
A. Side-by-side stand **I want you to try to stand with your feet together, side by side, for about 10 seconds.**	☐☐.☐☐	☐	☐ ....

If not attempted or not held for 10 seconds, end balance tests and go to gait speed test

	Number of seconds held:	Held for 10 sec No = 0 Yes = 1	If not attempted or failed, enter reason: *(Code box above)*
B. Semi-Tandem Stand **Now I want you to try to stand with the side of the heel of one foot touching the big toe of the other foot for about 10 seconds. You may put either foot in front, whichever is more comfortable for you.**	☐☐.☐☐	☐	☐ ....

If not attempted or not held for 10 seconds, end balance tests and go to gait speed test

	Number of seconds held:	Held for 10 sec No = 0 Yes = 1	If not attempted or failed, enter reason: *(Code box above)*
C. Tandem Stand **Now I want you to try to stand with the heel of one foot in front of and touching the toes of the other foot for about 10 seconds. You may put either foot in front, whichever is more comfortable for you.**	☐☐.☐☐	☐	☐ ....

GAIT SPEED TEST

Now I am going to observe how you normally walk. This is our walking course. I want you to walk to the other end of the course at your usual speed, just as if you were walking down the street to go to the store. Walk all the way past the other end of the tape before you stop.

		First walk	Second walk
Test was attempted	No = 0 Yes = 1	☐	☐
Time for 3 metres (seconds)		☐☐☐ . ☐☐	☐☐☐ . ☐☐
Aids for walk (None = 1, Cane = 2, Walker = 3, Other = 4)		☐	☐
If not attempted or failed, enter reason		☐ ……………	☐ ……………..

(Code box above) *If not attempted or failed, go to chair stand test*

CHAIR STAND TEST

Let's do the last movement test. Do you think it would be safe for you to try to stand up from a chair without using your arms?

So let's do the test. This test measures the strength in your legs. First, fold your arms across your chest and sit so that your feet are on the floor; then stand up keeping your arms folded across your chest.

(Single Chair Stand Test)

Safe to stand without help (No = 0, Yes = 1) ☐

Results ☐
- Participant stood without using arms — *Go to Repeated Chair Stand Test*
- Participant used arms to stand — *End test*
- Test not completed — *End test*

If not attempted or failed, code reason ☐ …………………………………………..

(Code box above)

Please stand up as QUICKLY as you can 5 times without stopping in between. After standing up each time, sit down and then stand up again. Keep your arms folded across your chest. I'll be timing you with a stopwatch.

(Repeated Chair Stand Test)

Safe to stand five times (No = 0, Yes = 1) ☐

Time to complete five stands (in seconds) ☐☐ . ☐☐

If not attempted or failed, code reason ☐ ………………………………………………

(Code box above)

9. Housing and Environment

We know that people's living environments are closely related to their health and well-being. We also know that people often move as they get older. The next questions now are about your house and about changing where you live.

IB1. Has your place of residence changed since your last LILACS NZ interview about a year ago?

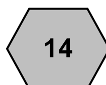
No = 0 *(Go to IB6)* Yes = 1 ☐

If 'Yes' to question IB1… and if more than one move, ask about last move only

IB2. When did you move? Date or best estimate ☐☐ . ☐☐ . ☐☐☐☐

(dd) (mm) (yyyy)

IB3. Why did you choose your current residence? No = 0 Yes = 1



Size of home	☐
Better safety and security	☐
To free up money or equity	☐
Easier maintenance of house and or gardens	☐
Closer to shops, post office, or other amenities	☐
Closer to health services eg. your GP	☐
Nicer environment eg view, climate, weather	☐
To be near or with children	☐
To be near or with other relatives	☐
To be near or with friends	☐
Returning to family/whanau land	☐
Other	☐

IB4. Was there any one event that made it important to move? No = 0 Yes = 1 ☐

If 'No', go to IB14

If 'Yes' to question IB4:

IB5. What event was that? *Do <u>not</u> read, Do <u>not</u> prompt but put a 1 for each event identified*

Death or illness of spouse or partner	☐
Death or illness of another family member	☐
Sudden worsening of health e.g. stroke	☐
Gradual worsening of health or function	☐
Fear, e.g. of criminal behaviour	☐
Something else	☐
Something else	☐

Then go to IB14

Ask the following questions only if 'No' to Question IB1

IB6. Since your last LILACS NZ interview about a year ago, have you seriously considered moving house?
No = 0 *(Go to IB19)* Yes = 1 ☐

IB7. Was there any one event that made it important to move?
No = 0 *(Go to IB9)* Yes = 1 ☐

If 'Yes' in question IB7:

IB8. What event was that? *Do not read, Do not prompt but put a 1 for each event identified*

- Death or illness of spouse or partner ☐
- Death or illness of another family member ☐
- Sudden worsening of health e.g. stroke ☐
- Gradual worsening of health or function ☐
- Fear, e.g. of criminal behaviour ☐
- Something else .... ☐
- Something else .... ☐

IB9. Was a decision made about moving?

No, still considering	Yes, will stay here for now *(Go to IB14)*	Yes, will move soon but haven't decided where to *(Go to IB14)*	Yes, will move soon *(Go to IB11)*	
1	2	3	4	☐

Only those still considering

15

IB10. Who was it that *first raised* the issue of a move? *(No = 0 Yes = 1)*

- You ☐
- Your child or close family ☐
- Your GP ☐
- Other care providers ☐
- Your spouse/partner ☐
- Neighbour or friend ☐
- Hospital doctors ☐
- Someone else...................................... ☐

Now go to IB15

IB11. Where will you move to? ☐

1 = private dwelling, stand-alone house
2 = private unit or apartment – independent
3 = granny flat unit or apartment on site with family dwelling
4 = retirement village – villa or own unit
5 = rest home *(Go to IB13)*
6 = private hospital *(Go to IB13)*
7 = marae or iwi based housing
8 = other..

If not 'rest home' or 'private hospital' in question IB11:

IB12. Who will you live with most of the time after moving?

1 = alone
2 = with spouse/partner only
3 = with spouse and child/other relative
4 = with spouse and non-relatives
5 = with child (not spouse)
6 = with other(s) not spouse or children
Who? ....

IB13. Why did you choose to move to there? *No = 0 Yes = 1*

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- For smaller home
- For larger home
- Better safety and security
- To free up money or equity
- Easier maintenance of house and or gardens
- Closer to shops, post office, or other amenities
- Closer to health services eg. your GP
- Nicer environment eg view, climate, weather
- To be near or with children
- To be near or with other relatives
- To be near or with friends
- To receive the care that I need
- Returning to family/whanau land
- **Other** ....

IB14. Who was it that *first raised* the issue of a move? *No = 0 Yes = 1*

15

- You
- Your child or close family
- Your GP
- Other care providers
- Your spouse/partner
- Neighbour or friend
- Hospital doctors
- Someone else...

IB15. Who has contributed to the decision (*to stay or move*)? *Yes =1 for all that apply*

15

- You
- Your child or close family
- Your GP
- Other care providers
- Your spouse/partner
- Neighbour or friend
- Hospital doctors
- Someone else...

IB16. How much was it your decision (*to stay or move*)?

17

Wholly my decision	Mostly my decision	About half my decision	Not really my decision	Not at all my decision
1	2	3	4	5

IB17. How satisfied are you now with the decision *(to stay or move)*?

12

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
5	4	3	2	1	☐

10

IB18. Did you consider any of the following as alternatives to moving?

Yes =1 for all that were considered or received

	Considered	*Received*
Modifications to the home eg ramps or rails		Don't Ask
More support from family		
More support from neighbours &/or friends		
Start home help &/or personal care		
Increase home help &/or personal care		
Better treatment for health conditions, e.g. surgery, therapy or medications		
Something else		
None, no other options considered		

IB19. How likely are you to move (again) in the near future?

10

Not at all	Somewhat	Moderately	Very	Extremely	
1	2	3	4	5	☐

Ask of those not in rest home or private hospital, otherwise Go to IC6

IB20. Have there been any renovations or changes to your current home since your last LILACS NZ interview about a year ago? No = 0 *(Go to IC6)* Yes = 1 ☐

IB20a. Please look at this list. Tell me what was done

	No = 0 Yes = 1
Redecorated	☐
Added or extended rooms	☐
Improved access e.g. rails, ramps, flooring	☐
Improved heating or insulation	☐
Improved bathroom	☐
Outside garden / fencing improvements	☐
Other? (Please describe)	☐

Ask of everyone:

	IC6. In the area where you live, do you have access to the following?		IC7. Are you satisfied with the access you have to ...?
		No = 0 Yes = 1	No = 0 Yes = 1
a.	Safe footpaths and streets to get around		
b.	Safety from personal and property crime or disturbance		
c.	Public or appropriate transportation		
d.	Shops and services		
e.	Medical and related healthcare		
f.	Options for entertainment, recreation and learning		
g.	Private transport provided by someone else		

Specify: ....
....
....

IC5. How difficult is it for you to get to the shops?

10

Not at all	Somewhat	Moderately	Very	Extremely	
1	2	3	4	5	

IC2. Thinking about your current neighbourhood, how well do you like it?

10

Not at all	Somewhat	Moderately	Very	Extremely	
1	2	3	4	5	

AB7. Do you live in the same area as your Hapu /extended family / where you come from?

No = 0 Yes = 1 Don't know = 2

10. Everyday Interests and Activities

We are interested in activities that you spend time doing. First I want to ask you about activities you have done over the last week, that is since last ....
(Interviewer substitute the day of the week).

18

Over the past 7 days, how often did you....	0 = Never 1 = Seldom (1-2 days) 2 = Sometimes (3-4 days) 3 = Often (5-7 days)	A. What were these activities?	B. On average, how many hours per day did you engage in these activities? 1 = Less than one hour 2 = 1 - 2 hours 3 = 2 - 4 hours 4 = More than 4 hours
JA1...participate in sitting activities such as reading, watching TV or doing handicraft?	☐		☐
JA2...take a walk outside your home or yard for any reason? For example, for fun or exercise, walking to work, walking the dog etc.?	☐		☐
JA3...engage in light sport or recreational activities such as light gardening e.g. using a ride-on mower, bowling, golf with a cart, shuffleboard, fishing from a boat or pier or similar activities?	☐		☐
JA4...engage in moderate sport and recreational activities such as moderate gardening e.g. using a motor mower, double tennis, ballroom dancing, hunting, ice skating, golf without a cart, softball or other similar activities?	☐		☐
JA5...engage in strenuous sport and recreational activities such as heavy gardening e.g. using a hand mower, jogging, swimming, cycling, singles tennis, aerobic dance, skiing or other similar activities?	☐		☐
JA6...do any exercises specifically to increase muscle strength and endurance, such as lifting weights or push ups etc?	☐		☐

JA7. How often do you speak or do something with:

	Daily	2-3 times a week	At least weekly	At least monthly	Less often	Never/ I have none	
e. Your spouse	1	2	3	4	5	6	
a. Any of your children or other relatives?	1	2	3	4	5	6	
b. Any friends in your community/neighbourhood?	1	2	3	4	5	6	
c. Any of your neighbours?	1	2	3	4	5	6	
d. Any friends living outside your community/neighbourhood?	1	2	3	4	5	6	

HOUSEHOLD ACTIVITIES AND INTERESTS

Now I'd like to know about household activities you've done over the last 7 days

BC6. During the past 7 days, did you engage in any of the following activities?
(Please answer '*Yes*' or '*No*' for each item)

No = 0 Yes = 1

a. Any light housework, such as dusting or washing dishes

b. Heavy housework or chores, such as vacuuming, scrubbing floors, washing windows or carrying wood

c. Home repairs like painting, wall papering, electrical work etc.

d. Lawn work or yard care, including snow or leaf removal, wood chopping, etc.

e. Outdoor gardening

f. Caring for another person, such as children, dependent spouse or another adult.

JA10. What kind of interests have you dropped during the last 12 months? Have there been any?

0 = No interests dropped *(Go to JA11)*

1 = One or more interests dropped *(list below)*

....

....

....

JA10a. Which of these were reasons for dropping some of your interests?

(Code all that apply No = 0 Yes = 1)

a. Personal capacity; such as reduced strength or energy, limited mobility, vision impairment, hearing impairment, health or other limitation ☐

b. Motivation; such as lack of motivation, “it was time to give up”, not appropriate or proper to continue ☐

c. Time use; such as lack of time, doing it takes longer ☐

d. Security; such as not confident about own limits or abilities, fear of doing things outside the home ☐

e. Physical environment; such as limited accessibility (e.g. Steps, seating, toilets, parking), or restricted environment (e.g. age limited, car access only) ☐

f. Social circumstance; such as caring for other/s, loss of partner or friend, relocation ☐

g. Economic conditions; such as restricted finances or cost ☐

h. Other .... ☐

JA11. During the last 4 weeks how often have you .....?

19

	Every day	Every week	Once	Not at all	If less than monthly Occasionally	
a) Spent time on a hobby (including handcrafts)	1	2	3	4	5	☐
b) Gone to the shops	1	2	3	4	5	☐
c) Visited or been visited by family and friends						☐
d) Gone to the doctor	1	2	3	4	5	☐
e) Taken care of pets?	1	2	3	4	5	☐
f) Attended meetings of any community /neighbourhood or social groups, such as old people’s clubs, lectures or anything like that?	1	2	3	4	5	☐
g) Attended any religious meetings?	1	2	3	4	5	☐
h) Been a spectator at a sports event	1	2	3	4	5	☐
i) Gone to an entertainment or arts event (such as concert, theatre or cinema)	1	2	3	4	5	☐
j) Gone to a restaurant, café, pub or bar	1	2	3	4	5	☐
k) Gone to a TAB (betting shop) or casino	1	2	3	4	5	☐
l) Attended a family event	1	2	3	4	5	☐
m) Attended a social occasion (such as a barbeque or hangi)	1	2	3	4	5	☐
n) Gone to the library or museum	1	2	3	4	5	☐
o) Participated in an outdoor activity (such as cycling, walking or gardening)	1	2	3	4	5	☐

JA12. Thinking of how you spend your time, would you say, "Most days I..............."

Don't have enough to do	Just keep busy enough	Always have more than enough to do	
1	2	3	☐

JA13. How many hours have you spent outside in the *last 4 weeks?*

Thinking about the last 4 weeks, how many hours on a week day (average) Hours ☐

Thinking about the last 4 weeks, how many hours on a weekend day (average) Hours ☐

JA14. How much time do you spend by yourself? Are you …

Always alone	Often alone	Seldom alone	Never alone	
1	2	3	4	☐

JA14a. And would you say that you …

Always feel lonely	Often feel lonely	Sometimes feel lonely	Never feel lonely	
1	2	3	4	☐

11. Financial Situation

The next couple of questions will ask you about your income and how you manage your money. I will not ask you how MUCH money you have. Remember that any information you give to us will be treated in strictest confidence.

KA6. Thinking of your money situation right now, would you say:

I can't make ends meet	I have just enough to get along on	I am comfortable	
1	2	3	☐

KA7. Thinking of your money situation in the future, would you say, I expect that:

I will not have enough to make ends meet	I will have just enough to get along on	I will be comfortable	
1	2	3	☐

KA10. Do you receive any of the following financial assistance?

	No = 0 Yes = 1
Living Alone allowance	☐
Disability allowance	☐
Discount on your rates	☐
Discount on your electricity	☐
Total Mobility card	☐
Disability parking card	☐
Other financial aid	☐

12. Overall Views about growing older

The final questions I want to ask you are about your overall views about growing older and what you have thought about this questionnaire.

MA2. On the whole has growing older been a positive or negative experience for you? 20

Very positive	Mainly positive	Neither positive nor negative	Mainly negative	Very negative	
1	2	3	4	5	☐

MA1. How much do you agree or disagree with the statement "There is a lot you can do to keep healthy in old age? " 21

Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Don't know	
1	2	3	4	5	6	☐

Anything that you would like to say or areas of your way of life that have not been covered?

....
....
....
....

THANK YOU

Thank you for being part of this study. The information you have shared is much appreciated and is very important as it will help us find out how life is now for older New Zealanders.

Interviewer to answer the following:

How well do you rate the…	Very poor	Poor	Neither good nor poor	Good	Very good	
Reliability of the respondent's responses?	1	2	3	4	5	
Participant's understanding of the questions	1	2	3	4	5	
Participant's level of interest?	1	2	3	4	5	
Participant's level of stamina	1	2	3	4	5	

Other comments the Interviewer would like to make: