

Carer identified	<input type="checkbox"/> Yes	<input type="checkbox"/> Informal	<input type="checkbox"/> Formal
	<input type="checkbox"/> No	→	
Okay to contact carer		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Carer's details completed		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Carer consents to Kai Āwhina Study		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Return questionnaire to participant		<input type="checkbox"/> Yes	<input type="checkbox"/> No

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

### Te Puāwaitanga o Ngā Tapuwae Kia Ora Tonu

#### Wave 5

#### *Partial participation/brief interview*



Date:   .   .      
(dd) (mm) (yyyy)

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

Interviewer: .....

Site Number: .....

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

*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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Name .....

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 (own home)      2=Medical Centre      3=Research Centre      4= Other.....

# 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?

No = 0 (Record new details below)      Yes = 1

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

Answer the following for the above or previously named contact

AA2a. 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?

No = 0 (Record new details below)      Yes = 1

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

Answer the following for the above or previously named contact

AA3a. 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

A1. Is your GP still ... (refer sheet for previous GP)

No = 0 (Record new contact) Yes = 1 (Go to A9)

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

A9. What is your current marital status?

Married/ partnered	Widow/Widower	Separated	Divorced	<input type="checkbox"/>
2	3	4	5	

A10. Do you live in a rest home/private hospital?

No = 0 Yes = 1 (Go to A12)

A11. 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 .....

A12. In the last year have you been admitted to a hospital?

No=0; Yes=1

A13. In the last year have you been admitted to a care facility?

No=0; Yes=1

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 A15) Yes=1

**FD2a. What was it?**

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

**A15. 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

- a. Heart attack/myocardial infarction
- b. Angina
- c. Stroke
- d. Transient Ischemic Attack / mini stroke
- e. High Blood Pressure
- f. Atrial fibrillation or irregular heartbeat
- g. Congestive heart failure
- h. Intermittent claudication (pain in calves when walking),  
peripheral vascular disease
- i. Rheumatic Fever
- j. Other heart or circulatory problem

**A17. Were you in hospital for this?**

No = 0 Yes = 1

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Specify.....

**A18. Do you smoke cigarettes?**

No=0; Yes=1

**A21. How many times have you fallen in the last 12 months?**

None 0	One 1	Two or three 2	Four or more 3	<input type="checkbox"/>
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**A22. How much does your eyesight interfere with normal day-to-day functioning?**

10 Not at all 1	Somewhat 2	Moderately 3	Very 4	Extremely 5	<input type="checkbox"/>
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**A23. How much does your hearing interfere with normal day-to-day functioning?**

10 Not at all 1	Somewhat 2	Moderately 3	Very 4	Extremely 5	<input type="checkbox"/>
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A24. During the past month have you often been bothered by feeling down, depressed or hopeless? No=0; Yes=1

A25. During the past month have you often been bothered by having little interest or pleasure in doing things? No=0; Yes=1

A26. In general, would you say your health is:
Excellent 1 | Very Good 2 | Good 3 | Fair 4 | Poor 5

A27. Compared to one year ago, how would you rate your health in general NOW?
1 = Much better now than one year ago
2 = Somewhat better now than one year ago
3 = About the same as one year ago
4 = Somewhat worse now than one year ago
5 = Much worse now than one year ago

A28. Do you have any DISABILITY or HANDICAP that is long-term (lasting six months or more)? No=0; Yes=1

A29. What is the main medical problem that interferes with you living well e.g. heart failure, arthritis, mention up to three?
Record:
.....
.....
.....

A30. 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

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 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.

		<u>Scoring:</u>		<u>Help received from....</u>		
		No = 0		Someone in the same household	Family outside the household	Others
		With help = 1				
		On my own; on my own with difficulty = 2				

  

A31.	Mobility				
	a. Do you walk around outside?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A32.	In the kitchen				
	a. Do you manage to feed yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b. Do you manage to make yourself a hot drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c. Do you take hot drinks from one room to another?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A33.	Domestic tasks				
	c. Do you do your own housework?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d. Do you do your own shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	e. Do you do a full clothes wash?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A34.	Leisure activities				
	b. Do you use the telephone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A35.	Other				
	a. Do you manage your personal care for instance brushing your teeth and hair, washing your hands and face?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b. Do you manage to go to the toilet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c. Do you get in/out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Now I'd like to ask you some questions about help and support you may be receiving.

**GC15. In the last 3 months, who has provided you the most help, care and support? (You can identify up to two persons)**

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 (Go to A37) | 777 = Don't Know (Go to A37)                     |                     |

1.	<input type="text"/>
2.	<input type="text"/>

*If no Kai Āwhina carer was interviewed prior, 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 A37*); Yes=1

*If prior Kai Āwhina 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 ( <i>Go to CG15c</i> )	Yes	Don't know details	<input type="checkbox"/>
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 A37*); Yes=1

**GC15d. If 'Yes', can I have his/her contact details?**

No ( <i>Go to A37</i> )	Yes	Don't know details	<input type="checkbox"/>
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.**

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*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 is identified, 2) participant agrees for us to contact the carer, and 3) carer's contact details are available.

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

Th  
older and what you have thought about this questionnaire.

**A37. 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	<input type="checkbox"/>
	1	2	3	4	5	

**A36. 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	<input type="checkbox"/>
	1	2	3	4	5	6	



**CONTACT FOR END OF LIFE STUDIES**

Discuss the EEL and TPS Studies and show the PIS

EL24. Have you already nominated someone for the end of life study?

No=0 *(Go to EL21)* Yes=1

EL25. Are you still comfortable for your nominees to be contacted?

a. Primary nominee No=0 Yes=1

b. Secondary nominee No=0 Yes=1

c. Tertiary nominee No=0 Yes=1

For nominees that are the same check if their contact details have changed and enter below, for nominees that are dropped enter their replacements on the next page EL22a,b,c.

<b>Primary Nominee</b>	<p><b>EL25a. Have your Primary nominee's details changed?</b></p> <p style="text-align: center;"><input type="checkbox"/></p> <p style="text-align: center;">No = 0    Yes = 1</p>	<p><b>IF YES, please record any new details below</b></p> <p>Name.....</p> <p>Phone.....</p> <p>Address.....</p> <p>.....</p> <p>Relationship.....</p> <p>....</p>
<b>Secondary Nominee</b>	<p><b>EL25b. Have your Secondary nominee's details changed?</b></p> <p style="text-align: center;"><input type="checkbox"/></p> <p style="text-align: center;">No = 0    Yes = 1</p>	<p><b>IF YES, please record any new details below</b></p> <p>Name.....</p> <p>Phone.....</p> <p>Address.....</p> <p>.....</p> <p>Relationship.....</p>
<b>Tertiary Nominee</b>	<p><b>EL25c. Have your Tertiary nominee's details changed?</b></p> <p style="text-align: center;"><input type="checkbox"/></p> <p style="text-align: center;">No = 0    Yes = 1</p>	<p><b>IF YES, please record any new details below</b></p> <p>Name.....</p> <p>Phone.....</p> <p>Address.....</p> <p>.....</p> <p>Relationship.....</p>

**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

**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*

<b>EL22a Primary nominee</b>	<b>EL22b Secondary nominee</b>	<b>EL22c Tertiary nominee</b>
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 .....	Date contacted .....	Date contacted .....
<b>EL22a-1</b> The person above consents to be contacted for EEL/TPS (No=0 Yes=1) <input type="checkbox"/>	<b>EL22b-1</b> The person above consents to be contacted for EEL/TPS (No=0 Yes=1) <input type="checkbox"/>	<b>EL22c-1</b> The person above consents to be contacted for EEL/TPS (No=0 Yes=1) <input type="checkbox"/>

**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.*