

PATH60s Phone Follow Up

Participant Questionnaire

Information and consent module

Q1 Participant's Wave 5 PATH ID: _____

Q2 Date of participant's Wave 4 interview (DD/MM/YYYY): _____

Q3 Interviewer name: _____

Q4 You have read the Information Sheet about the research project. Was this information clear? Do you have any questions about the project? If yes, provide details:

- Yes, Information Sheet read and no further questions
- Yes, Information Sheet read and questions recorded: _____

Q5 Date of script being read (DD/MM/YYYY): _____

Q6 Do you agree to participate in this project?

- Yes (Skip to Q8)
- Yes, but Proxy interview (Skip to Q7)
- No (End of survey)

Q7 If you previously gave us permission, we can contact your relative or close friend to complete this interview on your behalf. Do you agree?

- Yes, I will now confirm the details of your relative or close friend you agreed we could contact. (confirm then End of survey)
- No (End of survey)

Q8 Do you agree for us to ask a relative or close friend some questions about your living situation, daily activities, health (including specific medical conditions), memory, thinking and assistance received in the home (e.g. government care packages)?

- Yes, <Details will be checked/collected after the survey.>
- No

Please note that you can refuse to answer any of these questions.

Relationships and household composition module

Q9 Which of the following best describes your current residence?

- House / townhouse
- Flat / unit / apartment
- Independent living - Residential aged care home (Skip to Q11)
- Hostel - Residential aged care home (Skip to Q11)
- Nursing home - Residential aged care home (Skip to Q11)
- Special care (e.g. Dementia) - Residential aged care home (Skip to Q11)
- Other - Residential aged care home (Skip to Q11)
- Granny flat
- Other, please specify: _____

Q10 Including yourself, how many people usually live in your household? _____

Condition: If answer is 1 then Skip to Q12

Q11 Do any of the following people usually live in your household (or current residence)? <Read out response options, allow for multiple responses>

- Spouse or partner
- Son or daughter (include step, foster, adopted)
- Parent
- Brother or sister
- Grandchild
- Parent in law
- Son or daughter in law
- Brother or sister in law
- Other relative
- Someone who is not a relative (include friend, boarders etc)
- No / Not applicable

Q12 What is your current marital status?

- Married - first and only marriage (Skip to Q13)
- Married - second or later marriage (Skip to Q13)
- Separated from someone you are married to
- Divorced
- Widowed
- Have never married

Q12B Are you currently in a relationship that has lasted for 6 months or more?

- Yes
- No (Skip to Q14)

Ask this Question: If Q11 Spouse or partner Is Not Selected

Q13 Which of the following best describes your spouse or partner's current residence?

- House / townhouse
- Flat / unit / apartment
- Independent living - Residential aged care home
- Hostel - Residential aged care home
- Nursing home - Residential aged care home
- Special care (e.g. Dementia) - Residential aged care home
- Other - Residential aged care home
- Granny flat
- Other, please specify: _____

Q14 Since your last interview, have you been widowed (by a spouse or partner)?

- Yes
- No (Skip to Q16)
- Refused (Skip to Q16)

Q15 In what year? (YYYY)

- Year: _____
- Refused

I am sorry for your loss. I know these questions can be difficult to answer. If you are ready, we will turn now to a different set of questions.

Q16 Do you have an advanced care plan? (Definition: an agreement, often made with doctors and family, about your preferences for future health care)

- Yes
- No
- Don't know

Q17 Have you had an ACAT assessment? (Definition: by a government agency to see if you can get help at home or if you can move into an aged care home)

- Yes
- No
- Don't know

Aged care transitions module

Ask this Module: If in Q9

Independent living - Residential aged care home

Nursing home - Residential aged care home

Special care (e.g.dementia) - Residential aged care home

Hostel - Residential aged care home

Other - Residential aged care home OR

Other, please specify__

Is Selected.

Q18 Did you move into residential aged care since your last interview?

- Yes
- No (Skip to Q24)

Q19 In what year (YYYY)?

- Year: _____
- Don't know

Q20 What types of services do you receive? <Allow multiple responses>

- Cooking and meals
- Cleaning
- Activity program (outings, exercises etc)
- Medical / health care - nurse
- Medical / health care - doctor
- Medical / health care - physiotherapy
- Medical / health care - psychologist / counselling
- Medical / health care - medications
- Assisted or supportive living services

Q21 Did you move into residential aged care with your spouse or partner? <Read out response options>

- Yes, at the same time
- Yes, at a different time
- No, self only

	Q22 What were all the reasons you moved? <Allow for multiple responses> Select all reasons:	Q23 Of those you selected, what was the main reason? Select only one:
Age or health problems	<input type="radio"/>	<input type="radio"/>
Mood, anxiety, depression (mental health)	<input type="radio"/>	<input type="radio"/>
Thinking or memory problems	<input type="radio"/>	<input type="radio"/>
Could not care for self	<input type="radio"/>	<input type="radio"/>
For spouse or partner	<input type="radio"/>	<input type="radio"/>
Family thought it was a good idea	<input type="radio"/>	<input type="radio"/>
Closer to family/friends	<input type="radio"/>	<input type="radio"/>
Closer to medical or support services/facilities	<input type="radio"/>	<input type="radio"/>
Closer to other services/facilities (e.g. volunteering, leisure)	<input type="radio"/>	<input type="radio"/>
More/better personal care at new home	<input type="radio"/>	<input type="radio"/>
More suitable for condition(s)	<input type="radio"/>	<input type="radio"/>
Safer environment	<input type="radio"/>	<input type="radio"/>
Family changes/ house was too big	<input type="radio"/>	<input type="radio"/>
Could not get home based support	<input type="radio"/>	<input type="radio"/>
Other, please specify -----	<input type="radio"/>	<input type="radio"/>

Health and wellbeing module

Q24 The next few questions ask for your views about your health, how you feel and how well you are able to do your usual activities on a typical day. If you are unsure about how to answer a question, please give the best answer you can.

In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

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?

Q25 Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q26 Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q27 Lifting or carrying groceries?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q28 Climbing several flights of stairs?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q29 Climbing one flight of stairs?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q30 Bending, kneeling or stooping?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q31 Walking more than one kilometre?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q32 Walking half a kilometre?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q33 Walking 100 metres?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q34 Does your health now limit you in bathing or dressing yourself?

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of your **physical health**:

Q35 Have you accomplished less than you would like as a result of your physical health?

- Yes
- No

Q36 Were you limited in the kind of work or other activities as a result of your physical health?

- Yes
- No

During the PAST 4 WEEKS, 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):

Q37 Have you accomplished less than you would like as a result of any emotional problems?

- Yes
- No

Q38 Did you not do work or other activities as carefully as usual as a result of any emotional problems?

- Yes
- No

Q39 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
- A little bit
- Moderately
- Quite a bit
- Extremely

The next few 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.

Q40 How much of the time during the PAST 4 WEEKS have you felt calm and peaceful?

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

Q41 How much of the time during the PAST 4 WEEKS did you have a lot of energy?

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

Q42 How much of the time during the PAST 4 WEEKS have you felt down?

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

Q43 How much of the time during the PAST 4 WEEKS 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

Q44 In the PAST 4 WEEKS, for how many days were you totally unable to carry out your usual activities or work because of any health condition? Days: _____

Q45 In the PAST 4 WEEKS, for how many days did you cut back or reduce your usual activities or work because of any health condition? (not counting the days that you were totally unable) Days: _____

Thinking and memory module

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We are now going to do some exercises that involve your memory and concentration. Some of these will be easy and some will be harder. Just do the best you can.

So that we can hear each other as clearly as possible, please make sure that you have switched off any televisions or radios. And please do not use or look at any papers, pens, calendars, phones or newspapers during these questions. No one can help you answer these questions either.

Are you ready?

- Participant UNWILLING to proceed – Skip to next module (Q71)

Q46 What is your first name? <cross check with notes>

- Correct
- Incorrect
- Refused

Q47 What is your last name? <cross check with notes>

- Correct
- Incorrect
- Refused

Q48 What month is it?

- Correct
- Incorrect
- Refused

Q49 What date in the month is it?

- Correct
- Incorrect
- Refused

Q50 What year is it?

- Correct
- Incorrect
- Refused

Q51 What day of the week is it?

- Correct
- Incorrect
- Refused

Q52 What season is it?

- Correct
- Incorrect
- Refused

Q53 What is your age? <cross check with notes>

- Correct
- Incorrect
- Refused

Q54 What is your phone number? <cross check with notes>

- Correct
- Incorrect
- Refused

Q55 Please count backwards from 20 to 1. <If the participant makes an error on their first trial, ask them to try again.>

- Correct on first trial
- Correct on second trial
- Incorrect on both trials
- Refused

Q56 I'm going to read you a list of 10 words. Please listen carefully and try to remember them. When I am done, tell me as many as you can in any order. I am not allowed to repeat any of these words.

Ready? <Read words at a 1 second pace.>

Cabin
Pipe
Elephant
Chest
Silk
Theatre
Watch
Whip
Pillow
Giant

Now tell me all the words you can remember.

<input type="radio"/> Cabin	<input type="radio"/> Silk	<input type="radio"/> Whip
<input type="radio"/> Pipe	<input type="radio"/> Theatre	<input type="radio"/> Pillow
<input type="radio"/> Elephant	<input type="radio"/> Watch	<input type="radio"/> Giant
<input type="radio"/> Chest		

Q56b continued

Refused

Q57 Please take 7 away from 100. <Pause for a response>

Now continue to take 7 away from what you have left over until I ask you to stop.

<No further prompts or instructions are given, except to "keep going".>

<Stop after 5 numbers.>

<input type="radio"/> 99	<input type="radio"/> 89	<input type="radio"/> 79	<input type="radio"/> 69	<input type="radio"/> 59
<input type="radio"/> 98	<input type="radio"/> 88	<input type="radio"/> 78	<input type="radio"/> 68	<input type="radio"/> 58
<input type="radio"/> 97	<input type="radio"/> 87	<input type="radio"/> 77	<input type="radio"/> 67	<input type="radio"/> 57
<input type="radio"/> 96	<input type="radio"/> 86	<input type="radio"/> 76	<input type="radio"/> 66	<input type="radio"/> 56
<input type="radio"/> 95	<input type="radio"/> 85	<input type="radio"/> 75	<input type="radio"/> 65	<input type="radio"/> 55
<input type="radio"/> 94	<input type="radio"/> 84	<input type="radio"/> 74	<input type="radio"/> 64	<input type="radio"/> 54
<input type="radio"/> 93	<input type="radio"/> 83	<input type="radio"/> 73	<input type="radio"/> 63	<input type="radio"/> 53
<input type="radio"/> 92	<input type="radio"/> 82	<input type="radio"/> 72	<input type="radio"/> 62	<input type="radio"/> 52
<input type="radio"/> 91	<input type="radio"/> 81	<input type="radio"/> 71	<input type="radio"/> 61	<input type="radio"/> 51
<input type="radio"/> 90	<input type="radio"/> 80	<input type="radio"/> 70	<input type="radio"/> 60	<input type="radio"/> 50

Q57b continued:

- Refused
- Interviewer notes: _____

Q58 What do people usually use to cut paper?

- Correct = Scissors or shears
- Incorrect = Knife
- Refused

Q59 What number is in a dozen?

- Correct = 12
- Incorrect
- Refused

Q60 What is the prickly green plant found in the desert?

- Correct = Cactus
- Incorrect = Prickly pear, don't know
- Refused

Q61 What animal does wool come from?

- Correct = Sheep, lamb
- Incorrect = Llama, alpaca, don't know
- Refused
- Needed to spell 'wool'

Q62 Please repeat: 'No ifs ands or buts' <Do not repeat this instruction.>

- Correct = Must be exact
- Incorrect
- Refused

Q63 Please say this: 'Methodist Episcopal' <Do not repeat this instruction.>

- Correct = Must be exact
- Incorrect
- Refused

Q64 What is the Prime minister's first name?

- Correct = Malcolm, must be exact
- Incorrect
- Refused

Q65 What is the Prime minister's last name?

- Correct = Turnbull, must be exact
- Incorrect
- Refused

Q66 What is the name of the Monarch of the Commonwealth?

- Correct = Queen Elizabeth, Elizabeth II, Elizabeth of Windsor, Elizabeth Regina
- Partially correct = Queen or Elizabeth
- Incorrect
- Refused

Q67 Please tap five times on the phone.

<If person is using a mobile phone, ask them to tap on something hard nearby such as a counter or table.>

<Do not repeat this instruction.>

- Correct = 5 taps are heard
- Partially correct = More or less than 5 taps are heard
- Incorrect = No taps are heard
- Refused

Q68 What is the opposite of 'West'?

- Correct = East
- Incorrect
- Refused
- Needed to spell 'West'

Q69 What is the opposite of 'generous'?

- Correct = Selfish, greedy, tight, mean, meagre, skimpy etc
- Incorrect = Not very nice, degenerate, don't know
- Refused
- Needed to spell 'generous'

Q70 Please repeat the list of 10 words I read earlier

- Refused
- Cabin
- Pipe
- Elephant
- Chest
- Silk
- Theatre
- Watch
- Whip
- Pillow
- Giant

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Okay, thank you for your answers.

Emotional wellbeing module

Choose the best answer for how you have felt over the past week:

Q71 Are you basically satisfied with your life?

- Yes
- No

Q72 Have you dropped many of your activities and interests?

- Yes
- No

Q73 Do you feel that your life is empty?

- Yes
- No

Q74 Do you often get bored?

- Yes
- No

Q75 Are you in good spirits most of the time?

- Yes
- No

Q76 Are you afraid that something bad is going to happen to you?

- Yes
- No

Q77 Do you feel happy most of the time?

- Yes
- No

Q78 Do you often feel helpless?

- Yes
- No

Q79 Do you prefer to stay at home, rather than going out and doing new things?

- Yes
- No

Q80 Do you feel you have more problems with memory than most?

- Yes
- No

Q81 Do you think it is wonderful to be alive now?

- Yes
- No

Q82 Do you feel pretty worthless the way you are now?

- Yes
- No

Q83 Do you feel full of energy?

- Yes
- No

Q84 Do you feel that your situation is hopeless?

- Yes
- No

Q85 Do you think that most people are better off than you are?

- Yes
- No

Medical events and hospitalisations module

The next few questions are about recent medical or health problems you may have experienced since your last interview. We want to know about NEW events, not those you have previously told us about.

Since your last interview, have you been told by a doctor that you have any of the following:

Q86 Alzheimer's disease?

- Yes
- No (Skip to Q88)

Q87 In what year were you told (YYYY)? _____

Q88 Vascular Dementia?

- Yes
- No (Skip to Q90)

Q89 In what year were you told (YYYY)? _____

Q90 Any other form of Dementia (not Alzheimer's Disease or Vascular Dementia)?

- Yes
- No (Skip to Q93)

Q91 What type of Dementia?

- Record answer: _____
- Don't know

Q92 In what year were you told (YYYY)? _____

Q93 A stroke?

- Yes
- No (Skip to Q95)

Q94 In what year were you told (YYYY)? _____

Q95 Transient Ischemic Attack (TIA or mini stroke)?

- Yes
- No (Skip to Q97)

Q96 In what year were you told (YYYY)? _____

Q97 Depression?

- Yes
- No (Skip to Q99)

Q98 In what year were you told (YYYY)? _____

Q99 Cancer or leukaemia?

- Yes
- No (Skip to Q101)

Q100 In what year were you told (YYYY)? _____

Q101 Parkinson's Disease?

- Yes
- No (Skip to Q103)

Q102 In what year were you told (YYYY)? _____

Q103 Since your last interview, have you consulted a doctor about problems with your memory or thinking?

- Yes
- No (Skip to Q105)
- Don't know (Skip to Q105)
- Refused (Skip to Q105)

Q104 In what year (YYYY)?

- Record year: _____
- Don't know

Q105 In the last 12 months how many times have you been admitted to any hospital for at least one night?

- None (Skip to Q113)
- Record answer: _____

Ask the following for maximum of 6 times admitted to hospital:

Q106 How many nights did you stay on the first visit? _____

Q107 How many nights did you stay on visit 2? _____

Q108 How many nights did you stay on visit 3? _____

Q109 How many nights did you stay on visit 4? _____

Q110 How many nights did you stay on visit 5? _____

Q111 How many nights did you stay on visit 6? _____

Q112 During the last 12 months, were you admitted to hospital for any of the following: <Read out options, allow multiple responses>

- Injury
- Illness
- Mental health issue such as stress, anxiety or depression
- Dependence on alcohol or drugs
- Refused
- None of the above

Care at home module

Ask this Module if in Q9:

House / townhouse

Flat / unit/ apartment

Granny flat

Other, please specify__

Is Selected

Q113 Do you currently receive assistance at home with activities such as transport, cleaning, meal preparation or shopping?

- Yes
- No (Skip to Q117)

Q114 Is any of this assistance from a paid service provider or organisation (not a volunteer or an unpaid family member or friend)?

- Yes
- No (Skip to Q117)
- Don't know

Q115 Is this care provided as part of a Home Care package (Home Care agreement or Home Care plan) arranged with the government?

- Yes
- No (Skip to Q117)
- Don't know (Skip to Q117)

Q116 Which type of package or support do you receive?

- Commonwealth Home Support (entry level)
- Home Care Package Programme
- Transitional or flexible care
- Other
- Don't know

Falls module

Q117 How many falls did you have in the last 12 months? (Definition: A fall is unexpectedly coming to rest on the ground, floor or a lower level).

- None (Skip to Q122)
- Record number: _____

Q118 Were you injured as a result of (this fall / these falls)?

- Yes
- No (Skip to Q121)

Q119 What parts of your body were injured? <Read out response options, allow multiple responses>

- Head
- Neck or back
- Wrist or hand
- Hip

Q120 Did you suffer from any of the following: <Read out response options, allow multiple responses>

- Broken bone or fracture
- Dislocation
- Lost consciousness

Q121 Where did the fall(s) take place? <Read out response options, allow multiple responses>

- At your home: inside
- At your home: outside (entrance to house or in the garden)
- In a hospital
- In a public place (shopping centre, doctors, on the street)
- At someone else's home (inside or outside)

Driving module

Q122 Do you have a current driver's licence?

- Yes
- No
- Refused

Q123 For the purpose of the next few questions, a 'current driver' means someone who has driven a car within the last 12 months and someone who would drive a car today if they needed to. Using that definition, do you consider yourself a current driver?

- Yes
- No (Skip to Q128)

Q124 Have you personally driven a car at least once in the last week?

- Yes
- No

Q125 How many days would you personally drive in an average week? _____

Q126 How many kilometres would you personally drive in an average week?

- 5 - 50 kilometres
- 51 - 150 kilometres
- 151 - 200 kilometres
- More than 200 kilometres

Q127 How many more years do you expect to drive? _____ (Skip to Q130)

Q128 Have you stopped driving since your last interview?

- Yes, stopped since last interview
- No, stopped before last interview or never drove (Skip to Q131)

Q129 When did you stop driving?

- In the last 12 months
- Between 1 and 2 years ago (Skip to Q131)
- Over 2 years ago (Skip to Q131)

Q130 How many accidents you have been involved in when you were the driver, whether or not you were at fault, in the past 12 months?

- Enter number _____
- Refused

Final module

Q131 What activities do you enjoy most in your daily life? <Allow multiple responses - only read response options if prompting is required>

- Volunteering
- Being with family
- Being with friends
- Child minding or babysitting
- Pets
- Gardening
- Craft, artwork or sewing
- Exercise or sport
- Shopping
- Driving
- Games
- Reading
- Cooking
- Bushwalking or bird watching
- Holidays, day trips, travel or sight seeing
- Paid work
- Watching television, computer or internet
- Other, please specify _____

Q132 And just to confirm, could you please tell me your current age in years? _____

Thank you for participating in the PATH study. Your time and cooperation are greatly appreciated.

For those who agreed for us to contact their Informant (If Q8 Yes Is Selected):

I will now confirm the details of your relative or close friend you agreed we could contact.