Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Wave 3 Pre-Interview Questionnaire: Confidential

Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

IDS-TILDA ID NUMBER: W 3 ☐ ☐ ☐

GENDER: FEMALE ☐ MALE ☐

FOR OFFICE USE ONLY

INTERVIEW DATE: ☐☐ / ☐☐ / ☐☐

INTERVIEWER ID NUMBER ☐ ☐ ☐ ☐ ☐

IDS-TILDA

Working to Make Ireland the Best Place to Grow Old

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INSTRUCTIONS

This questionnaire is part of WAVE 3 of The Intellectual Disability Supplement to TILDA. Thank you for taking part in this study. Your answers are very important to us to help ensure the needs of people with an intellectual disability are met as they grow older.

WHAT TO DO IF YOU NEED HELP.

If you need support filling in the questionnaire ask a family member, a key worker or a friend who knows you at least 6 months to help.

HOW TO FILL IN THE QUESTIONNAIRE.

Please answer the questions by:

Ticking a box like this ☑

Or writing a number in a box like this **2**

Sometimes you will find an instruction telling you which questions to answer next like this

YES

NO ☑ IF 'NO' GO TO QUESTION **3**

HOW TO RETURN THIS QUESTIONNAIRE

Please give the questionnaire to the interviewer on the day of your interview. If you have any questions about the questionnaire, please call us at 01 8963186 or 01 8963187.

SECTION A: How you spend your free time

1. How often if at all, do you do any of the following activites

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES 

Activity	Daily/ Almost Daily	Once a week or more	Twice a month or more	About once a month	Every few months	About once or twice a year	Don't Know	Never
Go to cinema								
Theatre, Concert, Opera								
Eat Out								
Goto an art Gallery or museum								
Go to church or other place of worship								
Go to pub for a drink								
Go to a coffee shop for light refreshments								
Go Shopping								
Participates in sports activities / events								
Go to sports events								
Go to library								

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES 

Activity	Daily/ Almost Daily	Once a week or more	Twice a month or more	About once a month	Every few months	About once or twice a year	Don't Know	Never
Go to social clubs (i.e. bingo, play cards)								
Go to Hairdressers								
Perform in local art groups and choirs								
Spend time on hobbies or creative activities								
Visit family and friends in their home								
Talk to family and friends on the telephone								
Do voluntary work								
Other activities outside of the home please specify								

Where do you spend your free time

2. Thinking of the activities you ticked in section one, please let us know if you do these activities within the community setting, within an ID service setting or both settings

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES 

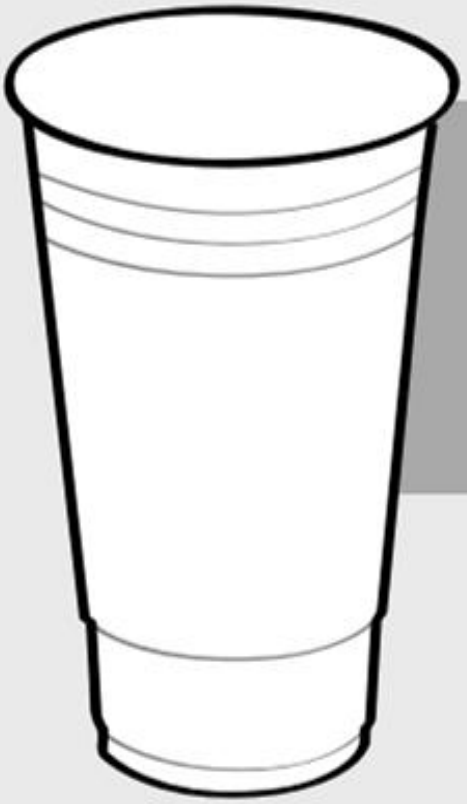
Activity	Within the community setting	Within ID Service Setting	Both within the community and ID setting	Don't Know	Never
Cinema					
Theatre, Concert or Opera					
Eat Out					
Goto an art Gallery or museum					
Go to church or other place of worship					
Go to a pub for a drink					
Go to a coffee shop for light refreshments					
Go Shopping					
Participates in sports activities / event					
Go to Sports events					
Go to Library					
Go to social clubs (e.g. bingo, play cards					
Go to the hairdressers					
Perform in local art groups and choirs					
Spend time on hobbies or creative activities					
Visit family and friends in their home					

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES

Activity	Within the community setting	Within ID Service Setting	Both within the community and ID setting	Don't Know	Never
Talk to family and friends on the telephone					
Do voluntary work					
Other activities outside of your home					

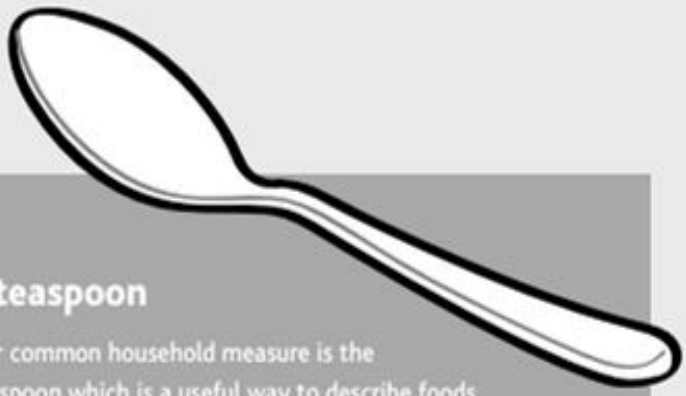
Other (Please Specify)

Section B: What you like to Eat and Drink



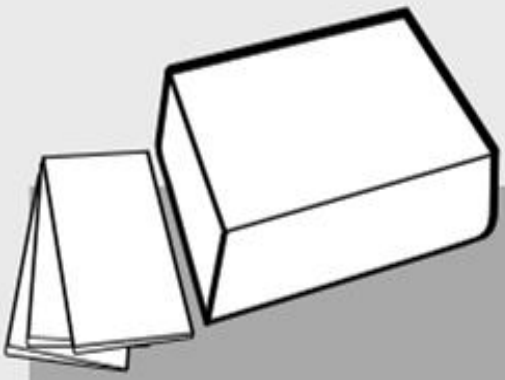
200ml Disposable Cup

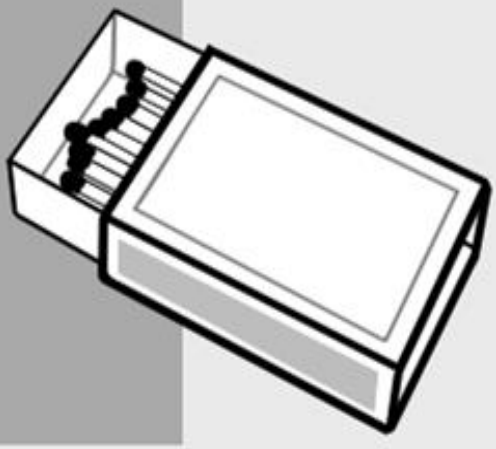
When consumers were shown a plastic disposable cup (200ml), most agreed that this was the best way to describe servings of many foods such as cereal, cooked pasta, cooked rice, cooked or tinned fruit and cooked vegetables and pulses (peas, beans, lentils).



5ml teaspoon

Another common household measure is the 5ml teaspoon which is a useful way to describe foods such as peanut butter which provides a light meal serving from the Meat, Fish and Alternatives Food Group.





Matchbox Size Piece of Cheese

Another simple serving size description that is easy for people to visualise is the matchbox size piece of cheese.

SECTION B: What do you like to eat and drink

THIS IS AN EXAMPLE OF HOW TO COMPLETE THIS SECTION

Thinking about the food that you eat, we would like you to tell us how often you usually eat the following foods.

For each food there is an amount shown, either what we think is a "medium serving" or a common household unit such as a slice or teaspoon. Please put a tick in the box to indicate how often, on average, you have eaten the specified amount of each food (To the nearest whole number) during the past year, i.e. from when you receive this questionnaire to the same month the previous year.

Examples:

The following are examples on how to estimate how often and how much meat/meat alternatives you ate over the past year. Please estimate your food intake for all foodstuffs in the same way.

Meat: if you ate a medium serving of stew once a week over the past year, put a tick in the box "one a week". If you think you usually ate more or less than a medium serving, please try to estimate which box suits best.

EXAMPLE HOW TO COMPLETE THE FOOD SECTION 'WHAT YOU EAT AND DRINK'

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Meat and meat alternatives (medium serving)									
Beef roast									
Beef: steak									
Beef: mince									
Beef: stew			☑						

PLEASE START NOW TO TELL US ABOUT THE FOOD YOU EAT AND WHAT YOU DRINK

3. Please tell us the usual amount of food you eat.
Please answer every question, do not leave any lines blank.

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Meat and meat alternatives (medium serving)									
Beef roast									
Beef: steak									
Beef: mince									
Beef: stew									
Beef burger (1 burger)									
Pork: roast									
Pork: chops									
Pork: slices/steak/escalopes									
Lamb: roast									
Lamb: chops									
Lamb: stew									
Chicken portion OR other poultry e.g. turkey: roast									
Breaded chicken, chicken nuggets, chicken burger									
Bacon									
Ham									
Corned beef									
Luncheon meats									
Sausages, Frankfurters (1 sausage)									

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Savoury pies (e.g. meat pie, pork pie, steak & kidney pie, sausage rolls)									
Heart, kidney									
Fish fried in batter, as in fish and chips									
Fish fried in bread crumbs									
Oven baked/grilled fish (in bread crumbs OR batter)									
Fish fingers/fish cakes									
Other white fish, fresh OR frozen (e.g. cod, haddock, plaice, sole, halibut, coli)									

A. FISH AND POULTRY (Medium serving – the size of a deck of cards OR palm of hands without fingers)

	Never /less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Oily fish (fresh) - (e.g. mackerel, kippers, tuna, salmon, sardines, herring)									
Oily fish (canned) - (e.g. mackerel, kippers, tuna, salmon, sardines, herring)									

	Never /less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Shellfish (e.g. crab, prawns, mussels)									
Canned Sardines									

Please check that you put a tick (√) on every line

B. BREAD AND SAVOURY BISCUITS (One slice OR one biscuit)

	Never /less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
White bread and rolls (including ciabatta and pannini bread)									
Brown bread and rolls									
Wholemeal bread and rolls									
Cream crackers, cheese biscuits									
Crisp bread, e.g. Ryvita									
Pancakes, muffins, oatcakes									
Baguette									

Please check that you put a tick (√) on every line

C. Cereals (One medium sized bowl)

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Porridge, Readybrek									
All Bran, Weetabix, Shredded Wheat									
Branflakes, Bran Buds									
Fortified Oatmeal									
Cornflakes, Rice Krispies									
Muesli (e.g. Country Store, Alpen, sugar coated, Granola)									
Sugar Coated Cereals (e.g. Frosties, Crunchy Nut Cornflakes, Crunchy Sugar Coated Muesli)									
Fortified Cereal									

Please check that you put a tick (√) on every line

D. Potatoes, Rice and Pasta (Medium serving – about a cupful)

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Boiled, instant or jacket potatoes									
Mashed potatoes									
Chips									
Roast potatoes									
Potato Salad									
White rice									
Brown rice									
White/yellow/green pastas (e.g. spaghetti, macaroni, noodles)									
Wholemeal pasta									
Lasagne (meat based)									
Lasagne (vegetarian)									
Moussaka									
Pizza									
Macaroni Cheese									

Please check that you put a tick (√) on every line

E. Dairy Products and Fats

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Cream (1 tablespoon)									
Full-fat yoghurt OR Greek- style Yoghurt (125g carton)									
Dairy desserts (125g carton)									
Cheddar cheese (medium serving)									
Low-fat cheddar cheese (medium serving OR 1 slice - 25g)									
Eggs as boiled, fried, scrambled, poached (1)									
Quiche (medium serving)									
Light salad cream OR light mayonnaise (1 tablespoon)									
Salad cream, mayonnaise (1 tablespoon)									
Other salad dressing									

F: The following on bread OR Vegetables									
	Never/less than once a month	**1-3 per month**	**Once a week**	**2-4 per week**	**5-6 per week**	**Once a day**	**2-3 per day**	**4-5 per day**	**6+ per day**
Butter (1 teaspoon)									
Light Butter e.g. Dawn light, Connacht Gold (teaspoon)									
Sunflower margarine e.g. Flora (1 teaspoon)									
Low-fat margarine e.g. low- low (1 teaspoon)									
Cholesterol lowering spreads e.g. Flora Pro Active, Dairy Gold Heart (1 teaspoon)									
Cream and vegetable oil spread e.g. Golden Pasture, Kerrymaid, Dairy Gold (1 teaspoon)									
Olive oil spread e.g. Golden Olive (1 teaspoon)									

Please check that you put a tick (√) on every line

G: Fruit (1 fruit OR medium serving)

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Apples									
Pears									
Oranges, Satsuma, mandarins									
Grapefruit									
Bananas									
Grapes									
Melon									
Peaches, plums									
Apricots									
Strawberries, raspberries, kiwi fruit									
Tinned fruit									
Dried fruit e.g. raisins									
Frozen fruit									

Please check that you put a tick (√) on every line

H: Vegetables Fresh, frozen OR tinned (Medium serving – 2 tablespoons OR 4 desert spoons)									
	Never/ less than once a month	**1-3 per month**	**Once a week**	**2-4 per week**	**5-6 per week**	**Once a day**	**2-3 per day**	**4-5 per day**	**6+ per day**
Carrots									
Spinach									
Broccoli, spring greens, kale									
Brussel sprouts									
Cabbage									
Peas									
Green beans, broad beans, runner beans									
Courgettes									
Cauliflower									
Parsnips, turnips									
Leeks									
Onions									
Garlic									
Mushrooms									

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Sweet peppers									
Beansprouts									
Green salad, Lettuce									
Cucumber, celery									
Tomatoes									
Sweetcorn									
Beetroot									
Coleslaw									
Baked beans									
Dried lentils, beans, peas									
Tofu, soya meat, TVP, veggieburger									

Please check that you put a tick (√) on every line

I: Sweets and Snacks (Medium serving)

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Chocolate coated sweet biscuits e.g. digestive (1)									
Plain sweet biscuits e.g. Marietta, Digestives, Rich Tea (1)									
Cakes e.g. fruit, sponge									
Buns, pastries e.g. croissants, doughnuts									
Fruit pies, tarts, crumbles									
Sponge puddings									
Milk puddings e.g. rice, custard, trifle									
Ice cream, choc ices, Frozen desserts									
Chocolates, single OR square									
Sweets, toffees, mints									
Sugar added to tea, coffee, cereal (1 teaspoon)									

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Sugar substitute e.g. Canderel added to tea, coffee, cereal (1 teaspoon)									
Crisps OR other packet snacks									
Peanuts OR other nuts									

Please check that you put a tick (√) on every line

J: Soups, Sauces and Spreads

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Vegetable soups: homemade/fresh (1 bowl)									
Vegetable soups: tinned/packet (1 bowl)									
Meat OR cream soups: homemade/fresh (1 bowl)									
Meat OR cream soups: tinned/packet (1 bowl)									
Sauces e.g. white sauce,									
cheese sauce, gravy (1 tablespoon)									

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Tomato based sauces e.g. pasta sauces									
Curry-type sauces									
Pickles, chutney (1 tablespoon)									
Marmite, Bovril (1 tablespoon)									
Jam, marmalade, honey, syrup (1 tablespoon)									
Peanut butter (1 teaspoon)									

Please check that you put a tick (√) on every line

K: Drinks	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Tea (cup)									
Coffee instant (cup)									
Coffee ground (cup)									
Coffee, decaffeinated (cup)									
Coffee whitener e.g. coffee-mate (teaspoon)									

	Never/ less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
Cocoa, Hot Chocolate (cup)									
Horlicks, Ovaltine (cup)									
Low calorie OR diet soft fizzy drinks (glass)									
Fizzy Soft drinks e.g. Cocoa Cola (glass)									
Pure fruit drinks e.g. orange juice (small glass)									
Fruit squash (small glass)									

L: Other food items

It is difficult to ask about all the food you have eaten. Please write down the names of any food items you have eaten and that you have not yet been asked.

	Never/less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day

4 **How often have you had the following meals per week**
Please tick ONE answer on EACH line

(A snack is a smaller meal consisting of for example, a fruit, biscuit, bun, cake, yoghurt or sweets/candy**)**

	Every Day	1-3 times a week	4-6 times a week	Never
Breakfast				
Morning snack				
Lunch				
Afternoon snack				
Dinner				
Night snack				
Any other meal				

5 **How many glasses of water would you say you drink per day/each day (small glass)? See picture on page 6 for sample**

None	
1-2 glasses	
More than 2 and less than 4 glasses	
More than 4 and less than 6 glasses	
More than 6 and less than 8 glasses	
More than 8 and less than 10 glasses	
More than 10 glasses per day	

	Other	
	Other (Please specify)	
6	**What type of milk do you use most often?** **PLEASE TICK ON BOX**	
	None	
	Whole/full fat	
	Low fat	
	Skimmed	
	Super/Fortified	
	Soya	
	Other	
	Other (please specify)	

7	**How much milk do you use each day?** **PLEASE TICK ONE BOX**

Less than half a pint	
250ml (half pint)	
568ml (1 pint)	
One litre	
More than one litre	

8	**How often do you eat fried food (i.e. use of oil or other fats when cooking)?**

Never	
Less than once a month	
One or several times a month	
One or several times a week	
Every day	

9	**How often do you add salt to food while cooking?**

Always	
Usually	
Sometimes	
Rarely	
Never	

10	**How often do you add salt to food while at the table?**

Always	
Usually	
Sometimes	
Rarely	
Never	

11 **What type of spread do you usually use on bread?**
(Please tick all that apply or use the most)

Butter or hard margarine	
A low fat spread	
A Polyunsaturated spread	
None	
Other (Please describe)	

12 **What type of fat/oil would you usually use for cooking?**

(Please tick all that apply OR use most often)

Vegetable oil	
Sunflower oil	
Olive oil	
Coconut oil	
Rapeseed oil	
Lard or dripping	
Butter (or hard margarine)	
None	
Other	

	Other (please specify)

Section C: Weight

Question 13: What is your weight without clothes?

Stones ☐ Pounds ☐

(e.g. 10) (e.g. 2)

Or

Pounds ☐

(e.g. 142)

Or

Kilos ☐

(e.g. 64.4)

Don't know ☐

Section D: The Exercise you do

Rapid Assessment of Physical Activity

Physical Activities are activities where you move and increase your heart rate above its resting rate, whether you do them for pleasure, work, or transportation.

The following questions ask about the amount and intensity of physical activity you usually do. The intensity of the activity is related to the amount of energy you use to do these activities.

Light activities 1. your heart beats slightly faster than normal 2. you can talk and sing	 Walking Leisurely  Stretching  Vacuuming or Light Yard Work
Moderate activities • your heart beats faster than normal • you can talk but not sing	 Fast Walking  Aerobics Class  Strength Training  Swimming Gently
Vigorous activities • your heart rate increases a lot • you can't talk or your talking is broken up by large breaths	 Stair Machine  Jogging Running  Tennis, Racquetball, or Pickleball or Badminton

14. How physically active are you?

(Please circle or tick the answer that applies to you on each line)

I Rarely or never do any physical activities	YES	NO
I do some **light** or **moderate** physical activities, but not every week	YES	NO
I do some light physical activity every week	YES	NO
I do moderate physical activities every week, but less than 30 minutes a day or 5 days a week	YES	NO
I do vigorous physical activities every week, but less than 20 minutes a day or 3 days a week	YES	NO
I do 30 minutes or more a day of moderate physical activities, 5 or more days a week	YES	NO
I do 20 minutes or more a day of vigorous physical activities, 3 or more days a week	YES	NO
I do activities to increase muscle **strength**, such as lifting weights or calisthenics, once a week or more	YES	NO
I do activities to improve flexibility, such as stretching or yoga, once a week or more.	YES	NO

Section E: Medical Tests and screening

15 **Please indicate if you have received any of the following medical tests in the last year.**

Please tick one box per line

	YES	NO	Don't know
Have you had flu injection?			
Have you had a Hepatitis B Vaccine?			

16 **Please indicate if you have received any of the following medical tests**
Please tick one box per line

	YES, within the last 2 years	YES, Over 2 years ago	NO	Don't Know
Have you ever had a blood test for cholesterol?				
Have you ever had your blood pressure measured?				
Have you ever had a thyroid function test?				
Have you ever had a blood glucose test (sugar test)?				
Have you ever been screened or assessed from memory impairment / Dementia?				
Have you had a bone density test? (e.g. DXA scan)				

17	**Did your mother or father ever have any of the following?** **Please tick all that apply**

Osteoporosis (Brittle bone)	
Hip Fracture	
Colon cancer	
Breast cancer	
Dementia	
Diabetes	
Don't know	

18	**Have you ever had any of the following tests?** **Please tick all that apply**

CT Brain Scan		
CT Scan (other than brain)		**Please tell us**
MRI Brain scan		
MRI Scan (other than brain)		**Please tell us**
EEG		
Don't know		

Section F:  Women only questions	
19	**Have you gone through or are you currently going through the menopause?** **Please tick one box** YES, gone through the menopause already ☐ YES, currently going through the menopause ☐ NO ☐ Don't know ☐
20	**About how old were you when it started?** I was ☐☐ years old? Don't know

21	**Since menopause have you used prescription hormone (e.g. HRT, estrogen)** **Please tick one box** YES, currently taking hormones ☐ YES, but no longer taking hormones ☐ NO ☐ Don't know ☐
22	**For how many years have you been taking prescription hormones?** (for example…… 0 3 years) For ☐☐ years Don't know ☐
23	**For how many years did you take prescription hormones?** (for example…… 0 3 years) For ☐☐ years Don't know ☐

24	**Do you check your breasts for lumps regularly?** YES NO Don't Know
25	**Has the GP or nurse checked your Breasts for lumps?** YES NO Don't Know
26	**Have you had a mammogram or x-ray of the breast, to search for cancer?** YES NO Don't Know
27	**Have you had a Cervical smear test?** YES NO Don't Know

Section G:	 Men only questions
29	**Do you check your testicles for lumps regularly?** YES ☐ NO ☐ Don't Know ☐
30	**Has the GP checked your testicles for lumps?** YES ☐ NO ☐ Don't Know ☐
31	**Have you had an examination of your prostate to screen for cancer?** YES ☐ NO ☐ Don't Know ☐
32	**Have you had a blood test (PSA) to screen for prostate cancer?** YES ☐ NO ☐ Don't Know ☐

Section H: Health Services Utilisation

33 **Are you covered by any of the following?**

Please tick one box

Full medical card or equivalent	
GP visit card	
Private medical insurance – in my own name	
Private medical insurance, as the spouse of a subscriber	
Private medical insurance, as the relative of a subscriber	
None of the above	
Don't know	

34 **Do you visit your GP at an office/surgery**

In the community		**Go to Q35**
In service provider setting		**Go to Q36**
GP visits me at home		**Go to Q37**

35	**In the last year, about how often did you visit your GP in the community or did your GP visit you?** Number of visits ☐ Don't know ☐
36	**In the last year, about how often did you visit your GP in Service provider setting or did your GP visit you?** Number of visits ☐ Don't know ☐
37	**In the last year, about how often did your GP visit you at home?** Number of visits ☐ Don't know ☐
38	**In the last year, how many times did you visit a hospital emergency department** Number of visits ☐ **Please write the number of visits in the box** Don't know ☐

39 **If you attended A&E for treatment in the last year, what was the reason?**

Please tick all that apply

Has not visited A&E in last year	
Multiple injuries	
Broken or fractured bone(s)	
Burn(s)	
Dislocation(s)	
Sprain or strain(s)	
Cut(s) or Open wound	
Scrape, bruise, blister(s)	
Concussion or other head/brain injury	
Poisoning	
Internal injuries(s)	
Pneumonia	
Epilepsy	
Don't know	
Other	

40 **In the last year, about how many visits did you make to a hospital out-patient clinic?**

Number of visits		**Please write the number of visits in the box**
Don't know		

41 **In the last year, how many nights did you spend in an Acute/general hospital?**

Number of nights		**Please write the number of nights in the box**
Don't know		

42 **Please tell us the name of the hospital you were in. for example (St James Hospital Dublin OR Louth County, Dundalk)**

Name of Hospital	Location of Hospital
Example: St James Hospital	**Dublin**

43 **In the last year, how many nights did you spend in an acute/psychiatric hospital due to mental health problems?**

Number of nights		**Please write the number of nights in the box**
Don't know		

44 **In the last year, how many nights did you spend in a nursing / convalescent home?**

Number of nights		**Please write the number of nights in the box**
Don't know		

45 **In the last year, how many nights did you spend in respite (excluding nights spent in a nursing home)?**

Number of nights		**Please write the number of nights in the box**
Don't know		

46 **If you have spent nights in respite please tell us where?**

In a community setting	
In a service provider setting	
In both community and service setting	
Don't know	

47 In the last year did you use Meals on wheels?

Service	**Yes**	**No**
Meals on Wheels		

On a typical week, please tell us how many times per week do you receive meals on wheels

_____

48 In the last year did you use Home Help?

Service	Yes	No
Home Help		

On a typical week, please tell us how many hours per week do you receive home help

_____Hours

49 In the last year did you use a Personal Care Attendant?

Service	Yes	No
Home Help		

On a typical week, please tell us how many hours per week did you use a personal care attendant?

_____Hours

50

The next two questions are about the health services you use, where you use them and how many times in the last year you attended. The first one asks you to tell us the services you used that were paid for using your medical card or health insurance, the second question asks you to tell us the services you paid for out of your own pocket.

In the last year, did you receive any of the following services? (WITH YOUR MEDICAL CARD or YOUR PRIVATE HEALTH INSURANCE)

Tell us if you attended the health service in the community or in the service provider / service setting or both

PLEASE TELL US TO THE BEST OF YOUR ABILITY HOW MANY TIMES YOU ATTENDED

TICK ALL THAT APPLY

	Community setting / mainstream	Service provider setting	Both		How many times did you attend
General Practitioner (GP)					
Public Health or community nurse					
Occupational therapy					
Chiropody services					
Physiotherapy services					
Social work services					
Psychological / counselling services					
Home Help					
Optician services					
Hearing services					
Dental Services					
Pharmacist					
Dietician Services					
Speech & Language services					
Day centre services					
Neurological services					
Psychological services					
Endocrinology services					
Dermatology services					
Palliative home care services					
Palliative day care services					
Don't know					
Other					
Other (please tell us)					

51 **In the last year, did you receive any of the following services?**
(WHICH YOU PAID FOR YOURSELF OUT OF YOUR OWN POCKET)

Tell us if you attended the health service in the community or in the service provider / service setting or both

PLEASE TELL US TO THE BEST OF YOUR ABILITY HOW MANY TIMES YOU ATTENDED

TICK ALL THAT APPLY

	Community setting / mainstream	Service provider setting	Both		How many times did you attend
General Practitioner (GP)					
Public Health or community nurse					
Occupational therapy					
Chiropody services					
Physiotherapy services					
Social work services					
Psychological / counselling services					
Home Help					
Optician services					
Hearing services					
Dental Services					
Pharmacist					
Dietician Services					
Speech & Language services					
Day centre services					
Neurological services					
Psychological services					
Endocrinology services					
Dermatology services					
Palliative home care services					
Palliative day care services					
Don't know					
Other					

Other (please tell us)

52	**Are there any services that you think you would benefit from that you are not receiving at present?** **Please tick one box**

YES	
NO	
Don't Know	
If YES please specify	

Section I: How happy are you with your health services

The next few questions ask how satisfied or happy you are with the service you get from your doctor and dentist and the people who work there.

53 **Are the staff at the doctors/GP surgery (including the doctor) nice and polite to you?**

Please tick one box

Yes, all staff	☐
Yes, some staff	☐
No	☐

54 **Do you like your GP and the way you are treated in appointments?**

Please tick one box

Yes	☐
No	☐
Not sure	☐

55 **When you want to go to the GP surgery, do you have the support and transport to get there?**
PLEASE TICK ONE BOX

A. Support

Almost never	☐
Sometimes	☐
Almost always	☐

B Transport

Almost never	☐
Sometimes	☐
Almost always	☐

56 **Are the staff at the dentist office (including dentist) nice and polite to you?**

PLEASE TICK ONE BOX

Yes, all staff	
Yes, some staff	
No	

57 **Do you like your dentist and the way you are treated in appointments?**

PLEASE TICK ONE BOX

Yes	
No	
Not sure	

58 **When you want to go to the dentist, do you have a way to get there?**
PLEASE TICK ONE BOX

A Support

Almost never	
Sometimes	
Almost always	

B Transport

Almost never	
Sometimes	
Almost always	

59 **Are the staff in the General Hospital (including Doctors/Nurses, other staff such as reception/security) nice and polite to you?**

Please tick one box

Yes, all staff	
Yes, some staff	
No	

60	**Do you like the staff in the General Hospital (including Doctors/Nurses, Other staff such as reception/security) and the way you are treated in appointments?** **Please tick one box** Yes ☐ No ☐ Not sure ☐
61	**When you want to go to the General Hospital, do you have a way to get there?** **Please tick one box** Almost never ☐ Sometimes ☐ Almost always ☐
62	**Can you think of anything you asked for help with but didn't get?** **Please tick one box** Yes ☐ No ☐ IF YES (Please specify)

63	**Please tell us the main thing that stops/prevents you from getting this service or services?** Don't know ☐

Section J: Information on Health

64 Have you ever received any information on the following…….?

Please tick all that apply

	Easy Read (written health promotion document)	Education / guidance / seminar (Verbal information)
Exercise		
Counselling		
Diabetes		
Epilepsy		
Hearth Health		
Bone Health		
Bowel Cancer		
Diabetic Retinopathy		
Breast check		
Prostate check		
Cervical check		
Nutrition/Healthy eating		
Sexually transmitted infection check		
Lung Health Test (Spirometry)		
None of the above		
Don't know		

65 **Please tell us who you received easy to read information from.**

Other may include family, friends, support or key workers or any other person or group not listed here.

Please tick all that apply

	Specialist	GP	Pharmacist	Public Health Nurse	RNID	Other
Bone Health						
Bowel Cancer						
Diabetic Retinopathy						
Breast Check						
Prostrate Check						
Cervical Check						
Nutrition/Healthy Eating						
Sexually transmitted infection check						

Other (Please specify)

Please get your Carer/Key worker/Support person to complete this section

Section K: IQ Code

Please indicate how long you know the participant: _____ Years

The following section should ideally be completed by a person who knows the participant 10 years or more, if you don't know the participant 10 years or more please refer to someone who does, otherwise complete to the best of your knowledge.

Now we want you to remember what your friend or relative was like 10 years ago and to compare it with what he/she is like now. 10 years ago was in 20___.

Below are situations where this person has to use his/her memory and we want you to indicate whether this has improved, stayed the same or got worse in that situation over the past 10 years.

Note the importance of comparing his/her present performance with 10 years ago. So if 10 years ago this person always forgot where he/she had left things, and he/she still does, then this would be considered "Hasn't changed much".

66

PLEASE INDICATE THE CHANGES YOU HAVE OBSERVED BY CIRCLING THE APPROPRIATE ANSWER.

Compared with 10 years ago how is this person at:

	1	2	3	4	5
Remembering things about family and friends e.g. occupations, birthdays, addresses	Much Improved	A bit improved	Not much change	A bit worse	Much worse
Remembering things that have happened recently	Much Improved	A bit improved	Not much change	A bit worse	Much worse
Recalling conversations a few days later	Much Improved	A bit improved	Not much change	A bit worse	Much worse
Remembering his/her address and telephone number	Much Improved	A bit improved	Not much change	A bit worse	Much worse
Remembering what day and month it is	Much Improved	A bit improved	Not much change	A bit worse	Much worse

	1	2	3	4	5
Remembering where things are usually kept	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Remembering where to find things which have been put in a different place from usual	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Knowing how to work familiar machines around the house	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Learning to use a new gadget or machine around the house	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Learning new things in general	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Following a story in a book or on TV	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Making decisions on everyday matters	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Handling money for shopping	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Handling financial matters e.g. the pension, dealing with the bank	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
Handling other everyday arithmetic problems e.g. knowing how much food to buy, knowing how long between visits from family or friends	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**

		1	2	3	4	5
	Using his/her intelligence to understand wht's going on and to reason things through	Much Improved	A bit improved	Not much change	A bit worse	Much worse
67	Any other Information (Cognitive Domains):					

Please get your Carer/Key worker/Support person to complete this section	
Section L: Behaviours that Challenge	
68	**IWER: TO BE COMPLETED BY INTERVIEWER** **Instructions** **Below you will find broad definitions followed by specific items for three types of behaviour problems:** • **self-injurious behaviours (items 1-8),** • **aggressive/destructive behaviours (items 9-18), and** • **stereotyped behaviours (items 19-30).** **Indicate which behaviours you have observed in this individual *during the past two months* by circling the number in the appropriate boxes (1) how often a described behaviour typically occurs and (2) how serious a problem the behaviour is. If the behaviour has not occurred during the past two months and therefore poses no problem check "never/no problem" ("0"). If the behaviour has occurred, rate the approximate frequency of its occurrence and its severity (use the definitions below; note, no severity scale is provided for stereotyped behaviour.)**

SELF-INJURIOUS BEHAVIOUR

	Mild Problem	Moderate Problem	Severe Problem
Self-Injurious Behavior	Behaviour occurs but does not inflict significant damage on the individual (e.g., temporary reddening of the skin, very light bruising)	Behaviour may inflict moderate damage on the individual (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs	Behaviour may inflict moderate to severe damage on the individual (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required
Aggression/ Destruction	Behaviour occurs but does not inflict significant damage on other people (e.g., temporary reddening of the skin, very light bruising); or disruption or mild damage to property, e.g., objects thrown, furniture tipped, doors slammed, meals spoiled, paint scratched. Item does not	The behaviour may inflict moderate damage on other people (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs; or moderate damage to property (e.g., curtains torn, furniture partly broken). Item requires repair but can be used.	The behaviour may inflict moderate to severe damage on other people (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required; or significant damage to property. Item requires repair and cannot be used.

	Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the	Never /no problem	Average Frequency of				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
1	Self-biting	0	1	2	3	4	1	2	3
2	Head hitting	0	1	2	3	4	1	2	3
3	Body hitting (except for the head) with own hand	0	1	2	3	4	1	2	3
4	Self-scratching	0	1	2	3	4	1	2	3
5	Pica (ingesting non-food	0	1	2	3	4	1	2	3
6	Inserting objects in nose,	0	1	2	3	4	1	2	3
7	Hair pulling (tearing out	0	1	2	3	4	1	2	3
8	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3

AGGRESSIVE/DESTRUCTIVE BEHAVIOUR

	Aggressive or destructive behaviors are deliberate overt attacks directed towards other individuals or property.	Never /no problem	Average Frequency of Occurrence				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
9	Hitting others	0	1	2	3	4	1	2	3
10	Kicking others	0	1	2	3	4	1	2	3
11	Pushing others	0	1	2	3	4	1	2	3
12	Biting others	0	1	2	3	4	1	2	3
13	Grabbing and pulling others	0	1	2	3	4	1	2	3
14	Scratching others	0	1	2	3	4	1	2	3
15	Pinching others	0	1	2	3	4	1	2	3
16	Verbally abusive with others	0	1	2	3	4	1	2	3
17	Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	1	2	3
18	Bullying - being mean or cruel (e.g., grabbing toys or food from others)	0	1	2	3	4	1	2	3

STEREOTYPED BEHAVIOUR

	Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.	**Never /no problem**	Average Frequency of Occurrence			
			Monthly	Weekly	Daily	Hourly
19	Rocking, repetitive body movements	**0**	1	2	3	4
20	Sniffing objects, own body	0	1	2	3	4
21	Waving or shaking arms	0	1	2	3	4
22	Manipulating (e.g., twirling, spinning)	0	1	2	3	4
23	Repetitive hand and/or finger	0	1	2	3	4
24	Yelling and screaming	0	1	2	3	4
25	Pacing, jumping, bouncing, running	0	1	2	3	4
26	Rubbing self	0	1	2	3	4
27	Gazing at hands or objects	0	1	2	3	4
28	Bizarre body postures	0	1	2	3	4
29	Clapping hands	0	1	2	3	4
30	Grimacing	0	1	2	3	4

Section M: Medications

69. We would like to record all medications that you take on a regular basis, take every day or every week. This will include prescription and non-prescription medications, over –the- counter medicines, vitamins and herbal and alternative

PLEASE WRITE DOWN ALL MEDICATIONS/TABLETS YOU TAKE AND HOW OFTEN YOU TAKE THEM, PLEASE

USE ONE LINE PER MEDICATION

Don't know what medication I take, record by proxy PLEASE COMPLETE MEDICATION FORM

Don't take any medication ☐ **Go to Question 53**

Name of Medication	Dosage strength	Frequency	Route	Date Prescribed	Doctors	Others

Name of Medication	Dosage strength	Frequency	Route	Date Prescribed	Doctors	Others

70 **Have you ever received any easy to read information leaflets about your medication?**

Please tick one box

Yes	
No	
Don't know	

71 **If you have received information leaflets about your medication, please tell us who gave you these leaflets from the list below.**

PLEASE TICK ALL THAT APPLY

General Practitioner	
Pharmacist	
Public Health Nurse	
RNID	
Don't know	
Other	

Other (please tell us)

SECTION N: Sources of Income (SI)

This section asks questions about the money you get and how much money you have to spend on things you like to do.

72 **Did you receive any of these payments in the last year?**

PLEASE TICK ALL THE PAYMENTS THAT YOU HAVE RECEIVED.

Disability allowance	
Mobility allowance	
Disability benefit (previously known as illness benefit)	
Retirement pension from former employment	
Contributory state pension (previously known as Non-Contributory old age pension)	
Transition state pension (previously known as retirement pension)	
Invalidity pension	
Widow's or Widower's contributory pension	
Private pension	
Jobseeker's allowance (previously known as unemployment assistance)	
Jobseeker's benefit (previously known as unemployment benefit)	
Supplementary welfare allowance	
Other (please specify)	
Not applicable – did not receive any of these payments	

73 **Do you receive money from any other sources (not previously mentioned)?**

Yes	
No	

(IDS-TILDA)

(From CAPI SI_9.3)

74 **Once you have paid all of your bills, how much money do you have every week?**

€_____Total amount

(From CAPI SI_30.3 new q)

75 **Thinking about the last year could you tell us, if you had or did any of the nine things listed below.**

If you did not have or could not do any of these items, was this because you could not afford these things or because you did not want them.

Please indicate an answer for the item on each line in the table

	I had this item	I did not have as I could not afford it	I did not have as I did not want it	Don't know / not sure / not applicable
New clothes				
New shoes				
Food				
Heating				
Telephone friends and family				
Going out				
Visits to pub or club				
A hobby or sport				
A holiday				

(Emerson's the measurement of poverty and socioeconomic position in research involving people with intellectual disability)

76	**Have you ever had an assessment of financial capacity undertaken with you?** **Financial capacity is when someone asks you questions about how you manage your money and how you make decision about spending or saving your money to check if you would need some support with making these decisions?** **These may be decisions about how to spend your money on everyday items like buying food and drink, as well as decisions about buying bigger things such as television, a care, a house** Yes ☐ No ☐ Don't know ☐
77	**Do you have your own bank account?** Yes ☐ No ☐ Don't know ☐
78	**Who has access to your bank card?** **Tick all that apply** Myself ☐ Family ☐ Keyworker ☐ Service provider ☐ Friend(s) ☐

Section O: Transport

79 **Within a typical month, have you used any of the following means of transport?**

Please tells us to the best you can remember how many times you used that means of transport

TICK ALL THAT APPLY

	Yes	How many times
Bicycle / Motorbike		
Drive myself		
Driven as a passenger by family		
Driven as a passenger by friends		
Driven as a passenger by staff service		
Public bus (city or urban)		
Public bus (intercity)		
Public bus (rural)		
Taxi/Hackney		
Dart/Luas		
Train (commuter train)		
Train (intercity)		
Bus operating as part of the rural transport scheme		
Not applicable – haven't used any forms of transport in the last year		
Don't know		
Other (please specify)		

80	**On a typical journey how many kilometres do you travel?** _____Metres/Kilometres
81	**Would you like to use more public transport?** Yes ☐ No ☐ Don't know ☐
82	**Do you feel there is a lack of transport facilities in your area?** Yes ☐ No ☐ Don't know ☐
83	**Does the lack of transport facilities in your area affect your lifestyle?** **Code ONE that applies** A great deal ☐ To some extent ☐ Not at all ☐ Don't know ☐

84	**What would you consider are the most important improvements that could be made to the transport options available to you?**
85	**Any other Information (Transport)**

Section P: How did you find filling out the questionnaire

86 **How long did it take you to fill out this questionnaire?**

Please tick one box

Less than 30 minutes	
30 minutes – 1 hour	
1 – 2 hours	
2 -3	

87 **In general, did you find it easy to understand the questions?**

Please tick one Box

Yes	
No	
Don't know	

88 **Please tell us which questions did you find most difficult to understand?**

89 **Please tell us if you have any other comments about the questionnaire?**

90	**Has anyone supported you to fill out this questionnaire?** **Please tick one box** Yes ☐ No ☐ Don't know ☐
91	**Name of the person supporting you** First Name _____ Surname _____
92	**Is this the same person who gave you support in the previous interview?** Yes ☐ No ☐ Don't know ☐

93 **What is their relationship to you?**

Boyfriend/Girlfriend/Partner	
Parent	
Sibling	
Key worker/Support worker	
Friend	

Other (Please tell us)

94 **How long do you know the person supporting you?**

Less than 6 months	
Between 6 months & a year	
More than a year	
Don't know	

THANK YOU VERY MUCH FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE.

PLEASE BRING IT WITH YOU TO YOUR INTERVIEW AND GIVE IT TO THE INTERVIEWER.