



Wave 4 Pre-Interview Questionnaire: Confidential

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

IDS-TILDA ID NUMBER:

GENDER: FEMALE MALE

FOR OFFICE USE ONLY

INTERVIEW DATE: / /

INTERVIEWER ID NUMBER:

IDS-TILDA would like to convey to the reader that no part of this protocol may be replicated reproduced or copied in any form without the explicit permission of the principal investigator of IDS-TILDA ©



IDS-TILDA

***Working to Make Ireland the Best Place to
Grow Old***

Table of Contents

INSTRUCTIONS	ii
WHAT TO DO IF YOU NEED HELP.....	ii
HOW TO FILL IN THE QUESTIONNAIRE.	ii
HOW TO RETURN THIS QUESTIONNAIRE	ii
Personal Details – For New Participants only	iii
A) Section A: How you spend your free time	1
B) Section B: Height and weight.....	6
C) Section C: Medical Tests and screening.....	7
D) Section D: Women only Questions	8
E) Section E: Health Services You Use.....	11
F) Section F: How happy are you with your health services.....	18
G) Section G: Cognition.....	20
H) Section H: Behaviours that Challenge	23
I) Section I: Medications.....	31
J) Section J: Sources of Income (SI).....	37
K) Section K: Transport	40
L) Section L: Living Circumstances.....	43
M) Section M: I (ADL) & Helpers.....	50
N) Section N: How did you find filling out the questionnaire	63

INSTRUCTIONS

This questionnaire is part of WAVE 4 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.

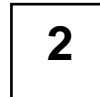
HOW TO FILL IN THE QUESTIONNAIRE.

Please answer the questions by:

Ticking a box like this



Or writing a number in a box like this



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 on 01 8963187.

Personal Details – For New Participants only

NP1

Are you male or female?

Please tick one box only

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

NP2

What is your date of birth?

(e.g. 01/03/66)

		/			/		
--	--	---	--	--	---	--	--

Don't know

NP3

Are you ...?

Please tick one box only

Single (never married)	<input type="checkbox"/>
Living with a partner as if married	<input type="checkbox"/>
With a partner but not living with him/her	<input type="checkbox"/>
Married	<input type="checkbox"/>
Separated	<input type="checkbox"/>
Divorced	<input type="checkbox"/>
Widowed	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

<p>NP4</p>	<p>Do you have any children?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td data-bbox="339 358 726 414">Yes</td> <td data-bbox="726 358 837 414"></td> </tr> <tr> <td data-bbox="339 414 726 470">No</td> <td data-bbox="726 414 837 470"></td> </tr> <tr> <td data-bbox="339 470 726 526">Don't know</td> <td data-bbox="726 470 837 526"></td> </tr> </table>	Yes		No		Don't know							
Yes													
No													
Don't know													
<p>NP5</p>	<p>What is your level of intellectual disability?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td data-bbox="339 685 730 768">Not verified</td> <td data-bbox="730 685 850 768"></td> </tr> <tr> <td data-bbox="339 768 730 851">Mild</td> <td data-bbox="730 768 850 851"></td> </tr> <tr> <td data-bbox="339 851 730 934">Moderate</td> <td data-bbox="730 851 850 934"></td> </tr> <tr> <td data-bbox="339 934 730 1016">Severe</td> <td data-bbox="730 934 850 1016"></td> </tr> <tr> <td data-bbox="339 1016 730 1099">Profound</td> <td data-bbox="730 1016 850 1099"></td> </tr> <tr> <td data-bbox="339 1099 730 1182">Don't know</td> <td data-bbox="730 1099 850 1182"></td> </tr> </table>	Not verified		Mild		Moderate		Severe		Profound		Don't know	
Not verified													
Mild													
Moderate													
Severe													
Profound													
Don't know													
<p>NP6</p>	<p>What is the cause of your intellectual disability?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td data-bbox="339 1357 1091 1440">Down syndrome</td> <td data-bbox="1091 1357 1206 1440"></td> </tr> <tr> <td data-bbox="339 1440 1091 1523">Cause of intellectual disability unknown</td> <td data-bbox="1091 1440 1206 1523"></td> </tr> <tr> <td data-bbox="339 1523 1091 1606">Don't know</td> <td data-bbox="1091 1523 1206 1606"></td> </tr> <tr> <td data-bbox="339 1606 1091 1688">Other</td> <td data-bbox="1091 1606 1206 1688"></td> </tr> </table> <p>Other (please tell us)</p> <div data-bbox="339 1798 1163 1964" style="border: 1px solid black; height: 74px; width: 516px;"></div>	Down syndrome		Cause of intellectual disability unknown		Don't know		Other					
Down syndrome													
Cause of intellectual disability unknown													
Don't know													
Other													

NP7

What is the highest level of education you have completed?

Tick one box only

Some primary (not complete)	<input type="checkbox"/>
Primary or equivalent	<input type="checkbox"/>
Intermediate/junior/group certificate or equivalent	<input type="checkbox"/>
Leaving certificate or equivalent	<input type="checkbox"/>
Diploma/certificate	<input type="checkbox"/>
Primary degree	<input type="checkbox"/>
Postgraduate/higher degree	<input type="checkbox"/>
None	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
Other	<input type="checkbox"/>

Other (please tell us)

NP8

How long have you lived in your current place of residence?

year(s)

month(s)

Don't know

A) Section A: How you spend your free time

Question 1: How often if at all, do you do any of the following activities

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								
Go to 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

Question 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					
Go to 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					

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

Other (Please Specify)

B) Section B: Height and weight

Question 3:

What is your height without shoes?

Centimetres

Or

Feet

Inches

Don't know

Question 4:

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

C) Section C: Medical Tests and screening

Question 5:

Please indicate if you have received any of the following injections.

Please tick one box per line

	YES	NO	Don't know
A flu injection in the last year?			
A Hepatitis B Vaccine in the last 5 years?			

Question 6:

Please indicate if you **have ever** 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
A blood test for cholesterol?				
Your blood pressure measured?				
A thyroid function test?				
A blood glucose test (sugar test)?				
Been screened or assessed from memory impairment / Dementia?				
A bone density test? (e.g. DXA scan)				
A bowel cancer screening test?				
A PSA blood test (men only)?				

D) Section D: Women only Questions



Question 7:

Have you gone through or are you currently going through the menopause?

Please tick one box only

YES, gone through the menopause already	Go to Q. 8
YES, currently going through the menopause	Go to Q. 8
NO	Go to Q. 9
Don't know	Go to Q. 9

Question 8:

About how old were you when it started?

I was years old?

Don't know

Question 9:	<p>Have you been invited for a mammogram in the last 2 years?</p> <p>Please tick one box only</p> <table border="1" data-bbox="373 360 1190 530"> <tr> <td>YES</td> <td></td> </tr> <tr> <td>NO</td> <td></td> </tr> <tr> <td>Don't Know</td> <td></td> </tr> </table>	YES		NO		Don't Know											
YES																	
NO																	
Don't Know																	
Question 10:	<p>If you were invited, did you attend?</p> <p>Please tick one box only</p> <table border="1" data-bbox="373 757 1190 927"> <tr> <td>YES</td> <td></td> </tr> <tr> <td>NO</td> <td></td> </tr> <tr> <td>Don't Know</td> <td></td> </tr> </table>	YES		NO		Don't Know											
YES																	
NO																	
Don't Know																	
Question 11:	<p>If you did not attend, what was the reason</p> <p>Please tick all that apply</p> <table border="1" data-bbox="373 1167 1369 1843"> <tr> <td>Environment not accessible e.g. the machine not suitable, no wheelchair access</td> <td></td> </tr> <tr> <td>Lack of support staff</td> <td></td> </tr> <tr> <td>Lack of transport</td> <td></td> </tr> <tr> <td>Too long in the waiting room</td> <td></td> </tr> <tr> <td>Fear</td> <td></td> </tr> <tr> <td>Cost</td> <td></td> </tr> <tr> <td>Don't know</td> <td></td> </tr> <tr> <td>Other (Please specify)</td> <td></td> </tr> </table>	Environment not accessible e.g. the machine not suitable, no wheelchair access		Lack of support staff		Lack of transport		Too long in the waiting room		Fear		Cost		Don't know		Other (Please specify)	
Environment not accessible e.g. the machine not suitable, no wheelchair access																	
Lack of support staff																	
Lack of transport																	
Too long in the waiting room																	
Fear																	
Cost																	
Don't know																	
Other (Please specify)																	

<p>Question 12:</p>	<p>Have you been invited for a Cervical smear test in the last 2 years?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>YES</td> <td></td> </tr> <tr> <td>NO</td> <td></td> </tr> <tr> <td>Don't Know</td> <td></td> </tr> </table>	YES		NO		Don't Know													
YES																			
NO																			
Don't Know																			
<p>Question 13:</p>	<p>If you were invited, did you attend?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>YES</td> <td></td> </tr> <tr> <td>NO</td> <td></td> </tr> <tr> <td>Don't Know</td> <td></td> </tr> </table>	YES		NO		Don't Know													
YES																			
NO																			
Don't Know																			
<p>Question 14:</p>	<p>If you did not attend, what was the reason?</p> <p>Please tick all that apply</p> <table border="1"> <tr> <td>Environment not accessible e.g. the equipment not suitable, no wheelchair access</td> <td></td> </tr> <tr> <td>Lack of support staff</td> <td></td> </tr> <tr> <td>Lack of transport</td> <td></td> </tr> <tr> <td>Too long in the waiting room</td> <td></td> </tr> <tr> <td>Fear</td> <td></td> </tr> <tr> <td>Cost</td> <td></td> </tr> <tr> <td>No need</td> <td></td> </tr> <tr> <td>Don't know</td> <td></td> </tr> <tr> <td>Other (Please specify)</td> <td></td> </tr> </table>	Environment not accessible e.g. the equipment not suitable, no wheelchair access		Lack of support staff		Lack of transport		Too long in the waiting room		Fear		Cost		No need		Don't know		Other (Please specify)	
Environment not accessible e.g. the equipment not suitable, no wheelchair access																			
Lack of support staff																			
Lack of transport																			
Too long in the waiting room																			
Fear																			
Cost																			
No need																			
Don't know																			
Other (Please specify)																			

E) Section E: Health Services You Use

Question 15:

Are you covered by private medical insurance?

Please tick one box only

YES, covered by private medical insurance	<input type="checkbox"/>
NO, not covered by private medical insurance	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

Question 16:

The next question is about the health services you use, where you use them, and how many times in the last year you attended, It also asks if you paid for any of the services out of your own pocket.

Don't know if any health services used in the last year **Go to Q. 17**


Didn't use any health services in the last year **Go to Q. 17**

If you did use any health services in the last year, tell us how many times you attended the health service in the community or in the service provider / service setting.

For any you didn't attend, please put a '0' in the relevant box.

Also please tell us if you paid for any of these visits out of your own pocket.

ANSWER ALL THAT APPLY

	How many times did you attend in the community setting / mainstream?	How many times did you attend in the service provider setting?	Did you pay for any of these visits out of your own pocket? PLEASE TICK IF APPLICABLE 
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			
	Neurological services			
	Psychological services			
	Endocrinology services			
	Dermatology services			
	Palliative care services			
	Other			
Question 17:	In the last year, about how often did your GP visit you at home?			
	Number of visits	<input type="text"/>		
	Don't know	<input type="text"/>		
Question 18:	In the last year, how many times did you attend a hospital emergency department for treatment?			
	Number of visits	<input type="text"/>		
	Don't know	<input type="text"/>		

<p>Question 19:</p>	<p>This question asks for more information about your visits to a hospital emergency department for treatment in the last year.</p> <p>Didn't visit a hospital emergency department <input type="checkbox"/> Go to Q. 20</p> <p>If you attended a hospital emergency department for treatment in the last year, what was the reason?</p> <p>Please tick all that applies</p> <table border="1"> <tr><td>Multiple injuries</td><td></td></tr> <tr><td>Broken or fractured bone(s)</td><td></td></tr> <tr><td>Burn(s)</td><td></td></tr> <tr><td>Dislocation(s)</td><td></td></tr> <tr><td>Sprain or strain(s)</td><td></td></tr> <tr><td>Cut(s) or Open wound</td><td></td></tr> <tr><td>Scrape, bruise, blister(s)</td><td></td></tr> <tr><td>Concussion or other head/brain injury</td><td></td></tr> <tr><td>Poisoning</td><td></td></tr> <tr><td>Internal injuries(s)</td><td></td></tr> <tr><td>Pneumonia</td><td></td></tr> <tr><td>Epilepsy</td><td></td></tr> <tr><td>Don't know</td><td></td></tr> <tr><td>Other</td><td></td></tr> </table>	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	
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																													
<p>Question 20:</p>	<p>In the last year, about how many visits did you make to a hospital out-patient clinic?</p> <p>Number of visits <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>																												

<p>Question 21:</p>	<p>In the last year, how many times were you admitted to hospital overnight?</p> <p>Note: These are sometimes called in-patient admissions.</p> <p>Number of admissions <input type="text"/></p> <p>Don't know <input type="text"/></p>																												
<p>Question 22:</p>	<p>In the last year, how many nights did you spend in an Acute/general hospital?</p> <p>Number of nights <input type="text"/></p> <p>Don't know <input type="text"/></p>																												
<p>Question 23:</p>	<p>Please tell us the names of the hospitals you were in over the last year. For example (St James Hospital Dublin OR Louth County, Dundalk)</p> <table border="1" data-bbox="379 1182 1417 1948"> <thead> <tr> <th data-bbox="379 1182 898 1238">Name of Hospital</th> <th data-bbox="898 1182 1417 1238">Location of Hospital</th> </tr> </thead> <tbody> <tr> <td data-bbox="379 1238 898 1294">Example: St James Hospital</td> <td data-bbox="898 1238 1417 1294">Dublin</td> </tr> <tr> <td data-bbox="379 1294 898 1350"></td> <td data-bbox="898 1294 1417 1350"></td> </tr> <tr> <td data-bbox="379 1350 898 1406"></td> <td data-bbox="898 1350 1417 1406"></td> </tr> <tr> <td data-bbox="379 1406 898 1462"></td> <td data-bbox="898 1406 1417 1462"></td> </tr> <tr> <td data-bbox="379 1462 898 1518"></td> <td data-bbox="898 1462 1417 1518"></td> </tr> <tr> <td data-bbox="379 1518 898 1574"></td> <td data-bbox="898 1518 1417 1574"></td> </tr> <tr> <td data-bbox="379 1574 898 1630"></td> <td data-bbox="898 1574 1417 1630"></td> </tr> <tr> <td data-bbox="379 1630 898 1686"></td> <td data-bbox="898 1630 1417 1686"></td> </tr> <tr> <td data-bbox="379 1686 898 1742"></td> <td data-bbox="898 1686 1417 1742"></td> </tr> <tr> <td data-bbox="379 1742 898 1798"></td> <td data-bbox="898 1742 1417 1798"></td> </tr> <tr> <td data-bbox="379 1798 898 1854"></td> <td data-bbox="898 1798 1417 1854"></td> </tr> <tr> <td data-bbox="379 1854 898 1910"></td> <td data-bbox="898 1854 1417 1910"></td> </tr> <tr> <td data-bbox="379 1910 898 1948"></td> <td data-bbox="898 1910 1417 1948"></td> </tr> </tbody> </table>	Name of Hospital	Location of Hospital	Example: St James Hospital	Dublin																								
Name of Hospital	Location of Hospital																												
Example: St James Hospital	Dublin																												

<p>Question 24:</p>	<p>In the last year, how many nights did you spend in an acute/psychiatric hospital due to mental health problems?</p> <p>Number of nights <input data-bbox="671 663 751 741" type="text"/></p> <p>Don't know <input data-bbox="671 846 751 925" type="text"/></p>		
<p>Question 25:</p>	<p>In the last year, how many nights did you spend in respite?</p> <p>Number of nights <input data-bbox="730 1171 810 1249" type="text"/></p> <p>Don't know <input data-bbox="735 1312 815 1391" type="text"/></p>		

<p>Question 26:</p>	<p>This question asks for more information about your nights spent in respite in the last year.</p> <p>Didn't spend any nights in respite <input type="checkbox"/> Go to Q. 27</p> <p>If you have spent nights in respite in the last year, please tell us how many nights you have spent in each of the following:</p> <table border="1" data-bbox="379 577 1362 801"> <tr> <td>In a community setting</td> <td></td> </tr> <tr> <td>In a service provider setting</td> <td></td> </tr> <tr> <td>In a nursing/convalescent home</td> <td></td> </tr> <tr> <td>Don't know</td> <td></td> </tr> </table>	In a community setting		In a service provider setting		In a nursing/convalescent home		Don't know	
In a community setting									
In a service provider setting									
In a nursing/convalescent home									
Don't know									
<p>Question 27:</p>	<p>In the last year how many hours per week did you use a personal care attendant on a typical week?</p> <p>Number of nights <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p>								
<p>Question 28:</p>	<p>Are there any services that you think you would benefit from that you are not receiving at present?</p> <p>Please tick one box only</p> <table border="1" data-bbox="379 1541 1198 1709"> <tr> <td>YES</td> <td></td> </tr> <tr> <td>NO</td> <td></td> </tr> <tr> <td>Don't Know</td> <td></td> </tr> </table> <p>If YES, please specify</p>	YES		NO		Don't Know			
YES									
NO									
Don't Know									

F) Section F: 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 health care providers.

Question 29: Are all staff at the health services nice and polite to you?

Please tick one box on every line

	Yes, all staff	Yes, some staff	No	Don't know	Does not apply
Doctors/GP surgery					
Dentist's office					
General hospital					

Question 30: When you go to the health services, do you have the support (family/staff) to get there?

Please tick one box on every line

	Almost always	Sometimes	Almost never	Don't know	Does not apply
Doctors/GP surgery					
Dentist's office					
General hospital					

<p>Question 31:</p>	<p>When you go to the health services, do you have the transport to get there?</p> <p>Please tick one box on every line</p> <table border="1"> <thead> <tr> <th></th> <th>Almost always</th> <th>Sometimes</th> <th>Almost never</th> <th>Don't know</th> <th>Does not apply</th> </tr> </thead> <tbody> <tr> <td>Doctors/GP surgery</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Dentist's office</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>General hospital</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		Almost always	Sometimes	Almost never	Don't know	Does not apply	Doctors/GP surgery						Dentist's office						General hospital					
	Almost always	Sometimes	Almost never	Don't know	Does not apply																				
Doctors/GP surgery																									
Dentist's office																									
General hospital																									
<p>Question 32:</p>	<p>Can you think of anything you asked for help with but didn't get?</p> <p>Please tick one box only</p> <table border="1"> <tbody> <tr> <td>Yes</td> <td></td> <td>Go to Q. 33</td> </tr> <tr> <td>No</td> <td></td> <td>Go to Q. 34</td> </tr> <tr> <td>Don't know</td> <td></td> <td>Go to Q. 34</td> </tr> </tbody> </table> <p>IF YES (Please specify)</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div>	Yes		Go to Q. 33	No		Go to Q. 34	Don't know		Go to Q. 34															
Yes		Go to Q. 33																							
No		Go to Q. 34																							
Don't know		Go to Q. 34																							
<p>Question 33:</p>	<p>Please tell us the main thing that stops/prevents you from getting this service or services?</p> <div style="border: 1px solid black; height: 60px; width: 100%;"></div> <p>Don't know <input type="checkbox"/></p>																								

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

G) Section G: Cognition

Please indicate how long you know the participant: _____ Years

The following section should ideally be completed by a person who knows the participant 2 years or more, if you don't know the participant 2 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 2 years ago and to compare it with what he/she is like now. Two 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 2 years.

Note the importance of comparing his/her present performance with 2 years ago.

So, if 2 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".

Question 34: PLEASE INDICATE THE CHANGES YOU HAVE OBSERVED BY CIRCLING THE APPROPRIATE ANSWER.

Compared with 2 years ago how is this person at:

	1	2	3	4	5	6
Remembering things about family and friends e.g. occupations, birthdays, addresses	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
Remembering things that have happened recently	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
Recalling conversations a few days later	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable

	Remembering his/her address and telephone number	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Remembering what day and month it is	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Remembering where things are usually kept	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	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	Not applicable
	Knowing how to work familiar machines around the house	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Learning to use a new gadget or machine around the house	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Learning new things in general	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Following a story in a book or on TV	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Making decisions on everyday matters	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Handling money for shopping	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
	Handling financial matters e.g. the pension, dealing with the bank	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable

	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	Not applicable
	Using his/her intelligence to understand what's going on and to reason things through	Much Improved	A bit improved	Not much change	A bit worse	Much worse	Not applicable
Question 35:	Any other Information (Cognition):						

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

H) Section H: Behaviours that Challenge

Question

36:

Below you will find broad definitions followed by specific items for three types of behaviour problems:

1. Self-injurious behaviours (items 1-8),
2. Aggressive/destructive behaviours (items 9-18), and
3. 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
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.

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 behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.		Never / no problem	Average Frequency of Occurrence				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 or with any other body part	0	1	2	3	4	1	2	3
4.	Self-scratching	0	1	2	3	4	1	2	3
5.	Pica (ingesting non-food items)	0	1	2	3	4	1	2	3
6.	Inserting objects in nose, ears, anus, etc.	0	1	2	3	4	1	2	3
7.	Hair pulling (tearing out patches of hair)	0	1	2	3	4	1	2	3
8.	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3

Is there a psychological or non-pharmacological intervention in place to address this behavior?

Please tick one box only

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

If 'Yes' please describe this intervention

AGGRESSIVE/DESTRUCTIVE BEHAVIOUR

Mild Problem	Moderate Problem	Severe Problem
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	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.

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

Is there a psychological or non-pharmacological intervention in place to address this behavior?

Please tick one box only

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

If 'Yes' please describe this intervention

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.

Average Frequency of Occurrence

		Never /no problem	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) objects	0	1	2	3	4
23.	Repetitive hand and/or finger movements	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

Is there a psychological or non-pharmacological intervention in place to address this behavior?

Please tick one box only

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

If 'Yes' please describe this intervention

I) Section I: Medications

Question 37: 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 medicines.

Don't take any medication

Go to Question 38

Don't know what medication I take, record by proxy

PLEASE COMPLETE MEDICATION FORM

Medicines verified from Kardex /case record

PLEASE WRITE DOWN DETAILS OF ALL MEDICATIONS/TABLETS. USE ONE LINE PER MEDICATION AND FOLLOW THE EXAMPLE GIVEN BELOW

Name of Medication	Dosage Strength	Frequency	Route	Date first Prescribed
Epilim Chrono tablets	200mgs	Twice a day (BD)	Orally (PO)	Sept 2009
One touch ultra test strip(blood glucose)	1 strip	Before meals	-	June 2015
Neo-cytamen Injection(hydroxycobalamin)	1000mgs	Monthly	IM	Nov 2010
Xalatan eye drops	2 drops (left eye)	Nocte (At night)	Instill	June 2010
Emulsifying Ointment		PRN	Topically	Jan 2009
Evening Primrose Oil capsules	1000mg	1 daily	PO	June 2005
Ensure Plus Drinks		1 daily	PO	Oct 2007

	Name of Medication	Dosage Strength	Frequency	Route	Date first Prescribed
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					
11.					
12.					
13.					
14.					
15.					
16.					

17.					
18.					
19.					
20.					
21.					
22.					
23.					
24.					

Question 38: Some studies like TILDA link the information they collect with official health records to provide a complete picture about the health and treatment history of the participant.

Please note we are interested in linking with official health records from this Wave 4 study period (September 2019-February 2020).
If you took part in Wave 3 of the study (October 2016-February 2017) we are also interested in this study period.

Would you be happy to provide us with your medical card number/ Drugs Payment Scheme (DPS) number for this purpose?

Please tick one box only

Yes		
No		Go to Q. 39
Don't know		Go to Q. 39

If yes, please write your medical card number/Drugs Payment Scheme number in the box below.

Question 39: **Have you ever received any easy to read information leaflets about your medication?**

Please tick one box only

Yes		Go to Q. 40
No		Go to Q. 41
Don't know		Go to Q. 41

Question 40:

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	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>
Public Health Nurse	<input type="checkbox"/>
RNID	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
Other	<input type="checkbox"/>

Other (please tell us)

J) Section J: Sources of Income (SI)

Question 41:

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

Didn't receive any payments in the last year

Go to Q. 42

Don't know if received payments in the last year

Go to Q. 42

If you did, please tick all the types of payments that you have received in the last year.

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	
Don't know	
Other (please specify)	

<p>Question 42:</p>	<p>Once you have paid all of your bills, how much money do you have every week?</p> <p>€ _____ Total amount</p> <p>(From CAPI SI_30.3 new q)</p>									
<p>Question 43:</p>	<p>Have you ever had an assessment of financial capacity undertaken with you?</p> <p>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?</p> <p>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</p> <p>Please tick one box only</p> <table border="1" data-bbox="360 1238 860 1408"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Don't know	<input type="checkbox"/>			
Yes	<input type="checkbox"/>									
No	<input type="checkbox"/>									
Don't know	<input type="checkbox"/>									
<p>Question 44:</p>	<p>Do you have your own bank account?</p> <p>Please tick one box only</p> <table border="1" data-bbox="360 1621 1184 1792"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> <td>Go to Q. 45</td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> <td>Go to Q. 46</td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> <td>Go to Q. 46</td> </tr> </table>	Yes	<input type="checkbox"/>	Go to Q. 45	No	<input type="checkbox"/>	Go to Q. 46	Don't know	<input type="checkbox"/>	Go to Q. 46
Yes	<input type="checkbox"/>	Go to Q. 45								
No	<input type="checkbox"/>	Go to Q. 46								
Don't know	<input type="checkbox"/>	Go to Q. 46								

Question 45: **Who has access to your bank card?**
Tick all that apply

Myself	<input type="checkbox"/>
Family	<input type="checkbox"/>
Keyworker	<input type="checkbox"/>
Service provider	<input type="checkbox"/>
Friend(s)	<input type="checkbox"/>

K) Section K: Transport

Question 46:

Within the last year, have you used any of the following means of transport?

Didn't use any transport in the last year

Go to Q. 52

Don't know if any transport used in the last year

Go to Q. 52

If you did, tick all that apply

Bicycle/motorbike	
Drive myself	
Driven as a passenger by family	
Driven as a passenger by friends	
Driven as a passenger by service staff	
Public bus (city or urban)	
Public bus (intercity)	
Public buses (rural)	
Taxi/hackney	
DART/Luas	
Train (commuter)	
Bus operating as part of the rural transport scheme	
Don't know	
Other (please specify)	

(Adapted from ELSA/TILDA)

Question 47:

Which of these methods of transport do you use most often?

Tick all that apply

Bicycle/motorbike	<input type="checkbox"/>
Drive myself	<input type="checkbox"/>
Driven as a passenger by family	<input type="checkbox"/>
Driven as a passenger by friends	<input type="checkbox"/>
Driven as a passenger by service staff	<input type="checkbox"/>
Public bus (city or urban)	<input type="checkbox"/>
Public bus (intercity)	<input type="checkbox"/>
Public buses (rural)	<input type="checkbox"/>
Taxi/hackney	<input type="checkbox"/>
DART/Luas	<input type="checkbox"/>
Train (commuter)	<input type="checkbox"/>
Bus operating as part of the rural transport scheme	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

(TILDA)

Question 48:	<p>Do you feel there is a lack of transport facilities in your area?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> <td>Go to Q. 49</td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> <td>Go to Q. 50</td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> <td>Go to Q. 50</td> </tr> </table>	Yes	<input type="checkbox"/>	Go to Q. 49	No	<input type="checkbox"/>	Go to Q. 50	Don't know	<input type="checkbox"/>	Go to Q. 50
Yes	<input type="checkbox"/>	Go to Q. 49								
No	<input type="checkbox"/>	Go to Q. 50								
Don't know	<input type="checkbox"/>	Go to Q. 50								
Question 49:	<p>Does the lack of transport facilities in your area affect your lifestyle?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>A great deal</td> <td><input type="checkbox"/></td> </tr> <tr> <td>To some extent</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Not at all</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	A great deal	<input type="checkbox"/>	To some extent	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	Don't know	<input type="checkbox"/>	
A great deal	<input type="checkbox"/>									
To some extent	<input type="checkbox"/>									
Not at all	<input type="checkbox"/>									
Don't know	<input type="checkbox"/>									
Question 50:	<p>What would you consider are the most important improvements that could be made to the transport options available to you?</p> <div data-bbox="368 1256 1370 1532" style="border: 1px solid black; height: 123px; width: 628px;"></div>									
Question 51:	<p>Any other Information (Transport)</p> <div data-bbox="368 1615 1370 1778" style="border: 1px solid black; height: 73px; width: 628px;"></div>									

L) Section L: Living Circumstances

Question 52: Do you have a key to your own home?

Please tick one box only

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

(McConkey et al. 2016)

Question 53: How many people live under the same roof as you?

By live we mean people who are NOT paid staff and who reside at this residence for the majority of the week (e.g. family members, other people with ID).

Number of People	<input style="width: 95%;" type="text"/>
------------------	--

Don't know	<input style="width: 95%;" type="text"/>
------------	--

(Adapted POMONA)

Question 54: Do you have your own bedroom for yourself?

Please tick one box only

Yes	<input type="checkbox"/>	Go to Q. 57
No	<input type="checkbox"/>	Go to Q. 56
Don't know	<input type="checkbox"/>	Go to Q. 57

<p>Question 55:</p>	<p>How many people do you share a bedroom with? (other than with a partner)</p> <table border="1" data-bbox="352 302 1150 414"> <tr> <td data-bbox="352 302 788 414">Number of People</td> <td data-bbox="788 302 1150 414"></td> </tr> </table> <table border="1" data-bbox="352 472 738 528"> <tr> <td data-bbox="352 472 660 528">Don't know</td> <td data-bbox="660 472 738 528"></td> </tr> </table> <p>(National Quality standards HIQA/IDS-TILDA)</p>	Number of People		Don't know										
Number of People														
Don't know														
<p>Question 56:</p>	<p>Would you prefer to have your own bedroom?</p> <p>Please tick one box only</p> <table border="1" data-bbox="352 719 940 965"> <tr> <td data-bbox="352 719 863 775">Yes</td> <td data-bbox="863 719 940 775"></td> </tr> <tr> <td data-bbox="352 775 863 831">No</td> <td data-bbox="863 775 940 831"></td> </tr> <tr> <td data-bbox="352 831 863 887">Not applicable</td> <td data-bbox="863 831 940 887"></td> </tr> <tr> <td data-bbox="352 887 863 965">Don't know</td> <td data-bbox="863 887 940 965"></td> </tr> </table> <p>(National Quality Standards HIQA/IDS-TILDA)</p>	Yes		No		Not applicable		Don't know						
Yes														
No														
Not applicable														
Don't know														
<p>Question 57:</p>	<p>Do you receive support from nursing staff in your residence?</p> <p>Please tick one box only</p> <table border="1" data-bbox="352 1171 1074 1697"> <tr> <td data-bbox="352 1171 810 1227">24 Hours a day</td> <td data-bbox="810 1171 1074 1227"></td> </tr> <tr> <td data-bbox="352 1227 810 1283">Only at night</td> <td data-bbox="810 1227 1074 1283"></td> </tr> <tr> <td data-bbox="352 1283 810 1339">Only during the day</td> <td data-bbox="810 1283 1074 1339"></td> </tr> <tr> <td data-bbox="352 1339 810 1462">Part time both at day and night</td> <td data-bbox="810 1339 1074 1462"></td> </tr> <tr> <td data-bbox="352 1462 810 1630">Not applicable (no paid nursing staff in your house day or night)</td> <td data-bbox="810 1462 1074 1630"></td> </tr> <tr> <td data-bbox="352 1630 810 1697">Don't know</td> <td data-bbox="810 1630 1074 1697"></td> </tr> </table> <p>Other, (Please specify)</p> <table border="1" data-bbox="352 1809 1337 1977"> <tr> <td data-bbox="352 1809 1337 1977"></td> </tr> </table> <p>(Adapted from POMONA)</p>	24 Hours a day		Only at night		Only during the day		Part time both at day and night		Not applicable (no paid nursing staff in your house day or night)		Don't know		
24 Hours a day														
Only at night														
Only during the day														
Part time both at day and night														
Not applicable (no paid nursing staff in your house day or night)														
Don't know														

Question 58:

Do you receive support from other staff (e.g. key worker, support worker) in your residence (excluding nursing staff)?

Please tick one box only

24 Hours a day	<input type="checkbox"/>
Only at night	<input type="checkbox"/>
Only during the day	<input type="checkbox"/>
Part time both at day and night	<input type="checkbox"/>
Not applicable (no paid nursing staff in your/his/her] house day or night)	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

Other, please specify

(Adapted from POMONA)

<p>Question 59:</p>	<p>Thinking about your current home do you ...?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>Own this residence/have mortgage</td> <td><input type="checkbox"/></td> <td>Go to Q. 61</td> </tr> <tr> <td>Family own the residence</td> <td><input type="checkbox"/></td> <td>Go to Q. 61</td> </tr> <tr> <td>Rent – From service provider</td> <td><input type="checkbox"/></td> <td>Go to Q. 60</td> </tr> <tr> <td>Rent – From private landlord</td> <td><input type="checkbox"/></td> <td>Go to Q. 60</td> </tr> <tr> <td>Rent – From local authority / social housing</td> <td><input type="checkbox"/></td> <td>Go to Q. 60</td> </tr> <tr> <td>Does not pay rent / Not applicable</td> <td><input type="checkbox"/></td> <td>Go to Q. 61</td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> <td>Go to Q. 61</td> </tr> <tr> <td>Rent - Other (Please specify)</td> <td><input type="checkbox"/></td> <td>Go to Q. 60</td> </tr> </table>	Own this residence/have mortgage	<input type="checkbox"/>	Go to Q. 61	Family own the residence	<input type="checkbox"/>	Go to Q. 61	Rent – From service provider	<input type="checkbox"/>	Go to Q. 60	Rent – From private landlord	<input type="checkbox"/>	Go to Q. 60	Rent – From local authority / social housing	<input type="checkbox"/>	Go to Q. 60	Does not pay rent / Not applicable	<input type="checkbox"/>	Go to Q. 61	Don't know	<input type="checkbox"/>	Go to Q. 61	Rent - Other (Please specify)	<input type="checkbox"/>	Go to Q. 60
Own this residence/have mortgage	<input type="checkbox"/>	Go to Q. 61																							
Family own the residence	<input type="checkbox"/>	Go to Q. 61																							
Rent – From service provider	<input type="checkbox"/>	Go to Q. 60																							
Rent – From private landlord	<input type="checkbox"/>	Go to Q. 60																							
Rent – From local authority / social housing	<input type="checkbox"/>	Go to Q. 60																							
Does not pay rent / Not applicable	<input type="checkbox"/>	Go to Q. 61																							
Don't know	<input type="checkbox"/>	Go to Q. 61																							
Rent - Other (Please specify)	<input type="checkbox"/>	Go to Q. 60																							
<p>Question 60:</p>	<p>Do you have a tenancy agreement between you and the person you rent from?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Don't know	<input type="checkbox"/>																		
Yes	<input type="checkbox"/>																								
No	<input type="checkbox"/>																								
Don't know	<input type="checkbox"/>																								
<p>Question 61:</p>	<p>Is your residence...?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>A bungalow or 1 storey house</td> <td><input type="checkbox"/></td> </tr> <tr> <td>A house with 2 or more stories</td> <td><input type="checkbox"/></td> </tr> <tr> <td>A ground floor flat</td> <td><input type="checkbox"/></td> </tr> <tr> <td>A flat/apartment/maisonette on upper storey, with lift</td> <td><input type="checkbox"/></td> </tr> <tr> <td>A flat/apartment/maisonette on upper storey, with no lift</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table> <p>Other (Please specify)</p> <div style="border: 1px solid black; height: 60px; width: 100%;"></div> <p>(NDS/IDS-TILDA)</p>	A bungalow or 1 storey house	<input type="checkbox"/>	A house with 2 or more stories	<input type="checkbox"/>	A ground floor flat	<input type="checkbox"/>	A flat/apartment/maisonette on upper storey, with lift	<input type="checkbox"/>	A flat/apartment/maisonette on upper storey, with no lift	<input type="checkbox"/>	Don't know	<input type="checkbox"/>												
A bungalow or 1 storey house	<input type="checkbox"/>																								
A house with 2 or more stories	<input type="checkbox"/>																								
A ground floor flat	<input type="checkbox"/>																								
A flat/apartment/maisonette on upper storey, with lift	<input type="checkbox"/>																								
A flat/apartment/maisonette on upper storey, with no lift	<input type="checkbox"/>																								
Don't know	<input type="checkbox"/>																								

<p>Question 62:</p>	<p>Is your residence adapted or not adapted to meet your needs?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>Adapted</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Not adapted</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	Adapted	<input type="checkbox"/>	Not adapted	<input type="checkbox"/>	Don't know	<input type="checkbox"/>		
Adapted	<input type="checkbox"/>								
Not adapted	<input type="checkbox"/>								
Don't know	<input type="checkbox"/>								
<p>Question 63:</p>	<p>Does your residence have a bathroom, bedroom and kitchen all on the same floor or level?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Not applicable</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table> <p>(Adapted from Disability Follow back Survey)</p>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not applicable	<input type="checkbox"/>	Don't know	<input type="checkbox"/>
Yes	<input type="checkbox"/>								
No	<input type="checkbox"/>								
Not applicable	<input type="checkbox"/>								
Don't know	<input type="checkbox"/>								
<p>Question 64:</p>	<p>Do you have any difficulty getting around inside your home for example, getting to and from the toilet, going from room to room, such as your bedroom to the living room?</p> <p>Please tick one box only</p> <table border="1"> <tr> <td>No difficulty</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Some difficulty</td> <td><input type="checkbox"/></td> </tr> <tr> <td>A lot of difficulty</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Cannot do at all</td> <td><input type="checkbox"/></td> </tr> </table> <p>(Adapted from NDS)</p>	No difficulty	<input type="checkbox"/>	Some difficulty	<input type="checkbox"/>	A lot of difficulty	<input type="checkbox"/>	Cannot do at all	<input type="checkbox"/>
No difficulty	<input type="checkbox"/>								
Some difficulty	<input type="checkbox"/>								
A lot of difficulty	<input type="checkbox"/>								
Cannot do at all	<input type="checkbox"/>								

<p>Question 65:</p>	<p>Have any modifications been made to your home to help you get around?</p> <p>Please tick one box only</p> <table border="1" data-bbox="352 300 1302 584"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> <td>Go to Q. 66</td> </tr> <tr> <td>No – but modifications are needed</td> <td><input type="checkbox"/></td> <td>Go to Q. 66</td> </tr> <tr> <td>No – and modifications are not needed</td> <td><input type="checkbox"/></td> <td>Go to Q. 70</td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> <td>Go to Q. 66</td> </tr> </table> <p>(IDS-TILDA)</p>	Yes	<input type="checkbox"/>	Go to Q. 66	No – but modifications are needed	<input type="checkbox"/>	Go to Q. 66	No – and modifications are not needed	<input type="checkbox"/>	Go to Q. 70	Don't know	<input type="checkbox"/>	Go to Q. 66						
Yes	<input type="checkbox"/>	Go to Q. 66																	
No – but modifications are needed	<input type="checkbox"/>	Go to Q. 66																	
No – and modifications are not needed	<input type="checkbox"/>	Go to Q. 70																	
Don't know	<input type="checkbox"/>	Go to Q. 66																	
<p>Question 66:</p>	<p>What modifications have been (need to be) made?</p> <p>Please tick all that apply</p> <table border="1" data-bbox="352 801 1190 1368"> <tr> <td>Ramps on street level entrances</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Automatic or easy to open doors (includes lever handles)</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Widened doorways or hallways</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Lift device</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Visual alarms or audio warning devices</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Grab bars or a bath lift (in the bathroom)</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Lowered counters in the kitchen</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Other (please specify)</td> <td><input type="checkbox"/></td> </tr> </table> <p>(NDS Adapted by IDS-TILDA)</p>	Ramps on street level entrances	<input type="checkbox"/>	Automatic or easy to open doors (includes lever handles)	<input type="checkbox"/>	Widened doorways or hallways	<input type="checkbox"/>	Lift device	<input type="checkbox"/>	Visual alarms or audio warning devices	<input type="checkbox"/>	Grab bars or a bath lift (in the bathroom)	<input type="checkbox"/>	Lowered counters in the kitchen	<input type="checkbox"/>	Don't know	<input type="checkbox"/>	Other (please specify)	<input type="checkbox"/>
Ramps on street level entrances	<input type="checkbox"/>																		
Automatic or easy to open doors (includes lever handles)	<input type="checkbox"/>																		
Widened doorways or hallways	<input type="checkbox"/>																		
Lift device	<input type="checkbox"/>																		
Visual alarms or audio warning devices	<input type="checkbox"/>																		
Grab bars or a bath lift (in the bathroom)	<input type="checkbox"/>																		
Lowered counters in the kitchen	<input type="checkbox"/>																		
Don't know	<input type="checkbox"/>																		
Other (please specify)	<input type="checkbox"/>																		
<p>Question 67:</p>	<p>What was the total cost of modifications made to [your/his/her] home?</p> <p>Please write the amount to the nearest €100</p> <table border="1" data-bbox="352 1585 852 1648"> <tr> <td>Don't know</td> <td><input type="text"/></td> </tr> </table> <p>(TILDA)</p>	Don't know	<input type="text"/>																
Don't know	<input type="text"/>																		

<p>Question 68:</p>	<p>Were any of the costs of the modifications covered by the State?</p> <p>Please tick one box only</p> <table border="1" data-bbox="352 356 1102 584"> <tr> <td>Yes, all of the costs</td> <td><input type="checkbox"/></td> <td>Go to Q. 70</td> </tr> <tr> <td>Yes, some of the costs</td> <td><input type="checkbox"/></td> <td></td> </tr> <tr> <td>No, none of the costs</td> <td><input type="checkbox"/></td> <td></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> <td></td> </tr> </table> <p>(TILDA)</p>	Yes, all of the costs	<input type="checkbox"/>	Go to Q. 70	Yes, some of the costs	<input type="checkbox"/>		No, none of the costs	<input type="checkbox"/>		Don't know	<input type="checkbox"/>	
Yes, all of the costs	<input type="checkbox"/>	Go to Q. 70											
Yes, some of the costs	<input type="checkbox"/>												
No, none of the costs	<input type="checkbox"/>												
Don't know	<input type="checkbox"/>												
<p>Question 69:</p>	<p>How much did you pay for the home modifications?</p> <p>Please write the amount to the nearest €100</p> <table border="1" data-bbox="352 748 850 808"> <tr> <td>Don't know</td> <td><input type="text"/></td> </tr> </table> <p>(TILDA)</p>	Don't know	<input type="text"/>										
Don't know	<input type="text"/>												
<p>Question 70:</p>	<p>Any other information (Living Circumstances)</p> <div data-bbox="352 925 1289 1205" style="border: 1px solid black; height: 125px; width: 587px;"></div>												

M) Section M: I (ADL) & Helpers

Activities of daily living

Question 71: Please indicate the level of difficulty, if any, you have with each of the following activities –

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES

Level of difficulty	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking across room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing/showering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bed – in and out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using toilet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 72: Does anyone ever help you with each of the following –

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES

Help	Yes	No	Not applicable
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking across room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing/showering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bed – in and out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using toilet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 73: This question asks for more information about help you may receive from other people with any of these activities.

Not applicable/No help needed **Go to Q. 75**

If you do receive help, who supports you with this activity/these activities?

Please tick all that apply

Spouse/Partner/Boyfriend/Girlfriend	
Parent	
Sibling	
Grandparent	
Aunt / Uncle	
Cousin	
Key worker / Support worker	
Friend	
Neighbour	
Home help	
Public health nurse	
Nurse	
Health care worker	

Question 74: How much help do you receive from this person (in hours and minutes per week) in a typical week?

Please record to the nearest 15-minute interval for each person who helps you (continue to the next page)

	Hrs	Mins
Spouse/Partner/Boyfriend/Girlfriend		
Parent		
Sibling		
Grandparent		

	Aunt / Uncle		
	Cousin		
	Key worker / Support worker		
	Friend		
	Neighbour		
	Home help		
	Public health nurse		
	Nurse		
	Nurse		
	Health care worker		
	Don't know		
	Other (Please specify)		

Question 75:

This question asks about any equipment or devices you might use to help you with dressing.

Don't use any equipment/devices

Go to Q. 76

If you do, please tick all the equipment/devices that you use to help you with dressing

Velcro fastenings on clothes	
Shoe horn	
Pick-up stick	
Device for putting on socks	
Other (please specify)	

Question 76:

This question asks about any equipment or devices you might use to help you with walking across a room.

Don't use any equipment/devices

Go to Q. 77

If you do, please tick all the equipment/devices that you use to help you with walking across a room

Walking stick	
Walking frame	
Crutches	
Railing	
Orthopedic shoes	
Brace (leg or neck)	
Limb prosthesis	
Oxygen / Respirator	
Furniture or walls	
Wheelchair	
Other (please specify)	

Question 77:

This question asks about any equipment or devices you might use to help you with bathing/showering

Don't use any equipment/devices

Go to Q. 78

If you do, please tick all the equipment/devices that you use with bathing/showering

Shower seat	
Grab rails	
Hand-held shower	
Walking frame or stick	
Rubber mat	
Hoist	
Other (please specify)	

Question 78:

This question asks about any equipment or devices you might use to help you with eating and drinking.

Don't use any equipment/devices

Go to Q. 79

If you do, please tick all the equipment/devices that you use to help you with eating and drinking

Beakers	
Grip mats	
Modified utensils e.g. spoons, forks	
Plate guards	
Other (please specify)	

Question 79:

This question asks about any equipment or devices you might use to help you with getting in and out of bed.

Don't use any equipment/devices

Go to Q. 80

If you do, please tick all the equipment/devices that you use to help you with getting in and out of bed

Walking stick	
Walking frame	
Bed rail	
Crutches	
Orthopaedic Shoes	
Brace (leg or back)	
Prosthesis	
Oxygen Respirator	
Furniture / walls	
Wheelchair	
Bed level	
Hoist	
Other (please specify)	

Question 80:

This question asks about any equipment or devices you might use to help you with using the toilet.

Don't use any equipment/devices

Go to Q. 81

If you do, please tick all the equipment/devices that you use to help you with using the toilet

Raised toilet seat	
Portable toilet / commode	
Grab rails	
Other (please specify)	

Question 81:

Any Other Information (Activities of Daily Living):

Instrumental Activities of daily living

Question 82: Please indicate the level of difficulty, if any, you have with each of the following activities –

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES

Level of difficulty	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all
Preparing a hot meal				
Shopping for groceries				
Making phone calls				
Managing money				
Doing household chores				

Question 83: Does anyone ever help you with each of the following –
FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES

Help	Yes	No	Not applicable
Preparing a hot meal			
Shopping for groceries			
Making phone calls			
Managing money			
Doing household chores			

Question 84: This question asks for more information about help you may receive with any of these activities.

Not applicable/No help needed **Go to Q. 88**

If you do receive help, **who supports** you with this activity/these activities?

Please tick all that apply

Spouse/Partner/Boyfriend/Girlfriend	
Parent	
Sibling	
Grandparent	
Aunt / Uncle	
Cousin	
Key worker / Support worker	
Friend	
Neighbour	
Home help	
Public health nurse	
Nurse	
Health care worker	

Question 85: How much help did [you/he/she] receive from this person (in hours and minutes per week) in a typical week?

Please record to the nearest 15 minute interval for each person who helps you

	Hrs	Mins
Spouse/Partner/Boyfriend/Girlfriend		
Parent		
Sibling		
Grandparent		

	Aunt / Uncle		
	Cousin		
	Key worker / Support worker		
	Friend		
	Neighbour		
	Home help		
	Public health nurse		
	Nurse		
	Health care worker		
	Don't know		
	Other (Please specify)		

Question 86: **Do you feel you need more help with any of these activities, e.g. preparing a hot meal; shopping for groceries; making a telephone call; managing money and paying bills?**

Please tick one box only

Yes		Go to Q. 87
No		Go to Q. 88
Don't know		Go to Q. 88

Question 87: **What help do you feel you need?**

Don't know

Question 88:	Any Other Information (Instrumental Activities of Daily Living): <div data-bbox="379 264 1369 497" style="border: 1px solid black; height: 100px;"></div>
---------------------	---

Functional limitations

Question 89:

You may not be able to do some of the activities listed below but please try to answer each question as best you can. Exclude any difficulties that you expect to last less than three months.

Please indicate the level of difficulty, if any, you have with each of the following activities –

FOR EACH ACTIVITY TICK ONE BOX THAT APPLIES

Level of difficulty	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all
Walking 100 yards				
Running or jogging about 1.5 kilometres (1 mile)				
Sitting for about 2 hours				
Getting up from a chair after sitting for long periods				
Climbing several flights of stairs without resting				
Climbing one flight of stairs without resting				
Stooping, kneeling or crouching				
Reaching or extending your arms above shoulder level				
Pulling or pushing large objects like a living room chair				
Lifting or carrying weights over 10 pounds (5 kilos) like a heavy bag of groceries				
Picking up a small coin from a table				

Question 90:

Any Other Information (Functional limitations)

--

N) Section N: How did you find filling out the questionnaire

<p>Question 91:</p>	<p>How long did it take you to fill out this questionnaire?</p> <p>Please tick one box</p> <table border="1"> <tr> <td>Less than 30 minutes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>30 minutes – 1 hour</td> <td><input type="checkbox"/></td> </tr> <tr> <td>1 – 2 hours</td> <td><input type="checkbox"/></td> </tr> <tr> <td>2 -3</td> <td><input type="checkbox"/></td> </tr> </table>	Less than 30 minutes	<input type="checkbox"/>	30 minutes – 1 hour	<input type="checkbox"/>	1 – 2 hours	<input type="checkbox"/>	2 -3	<input type="checkbox"/>
Less than 30 minutes	<input type="checkbox"/>								
30 minutes – 1 hour	<input type="checkbox"/>								
1 – 2 hours	<input type="checkbox"/>								
2 -3	<input type="checkbox"/>								
<p>Question 92:</p>	<p>In general, did you find it easy to understand the questions?</p> <p>Please tick one box</p> <table border="1"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Don't know	<input type="checkbox"/>		
Yes	<input type="checkbox"/>								
No	<input type="checkbox"/>								
Don't know	<input type="checkbox"/>								
<p>Question 93:</p>	<p>Please tell us which questions did you find most difficult to understand?</p> <div data-bbox="395 1025 1332 1216" style="border: 1px solid black; height: 85px; width: 100%;"></div>								
<p>Question 94:</p>	<p>Please tell us if you have any other comments about the questionnaire?</p> <div data-bbox="395 1413 1332 1603" style="border: 1px solid black; height: 85px; width: 100%;"></div>								

Question 95:	Has anyone supported you to fill out this questionnaire? Please tick one box <table border="1" data-bbox="395 300 895 472"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Don't know	<input type="checkbox"/>				
Yes	<input type="checkbox"/>										
No	<input type="checkbox"/>										
Don't know	<input type="checkbox"/>										
Question 96:	Name of the person supporting you First Name _____ Surname _____										
Question 97:	Is this the same person who gave you support in the previous interview? <table border="1" data-bbox="395 882 895 1055"> <tr> <td>Yes</td> <td><input type="checkbox"/></td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Don't know</td> <td><input type="checkbox"/></td> </tr> </table>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Don't know	<input type="checkbox"/>				
Yes	<input type="checkbox"/>										
No	<input type="checkbox"/>										
Don't know	<input type="checkbox"/>										
Question 98:	What is their relationship to you? <table border="1" data-bbox="395 1189 895 1473"> <tr> <td>Boyfriend/Girlfriend/Partner</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Parent</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Sibling</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Key worker/Support worker</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Friend</td> <td><input type="checkbox"/></td> </tr> </table> <div data-bbox="395 1529 1394 1715" style="border: 1px solid black; padding: 5px; min-height: 80px;"> Other (Please tell us) </div>	Boyfriend/Girlfriend/Partner	<input type="checkbox"/>	Parent	<input type="checkbox"/>	Sibling	<input type="checkbox"/>	Key worker/Support worker	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Boyfriend/Girlfriend/Partner	<input type="checkbox"/>										
Parent	<input type="checkbox"/>										
Sibling	<input type="checkbox"/>										
Key worker/Support worker	<input type="checkbox"/>										
Friend	<input type="checkbox"/>										

Question 99:	How long do you know the person supporting you?								
	<table border="1"><tr><td>Less than 6 months</td><td></td></tr><tr><td>Between 6 months & a year</td><td></td></tr><tr><td>More than a year</td><td></td></tr><tr><td>Don't know</td><td></td></tr></table>	Less than 6 months		Between 6 months & a year		More than a year		Don't know	
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.