

POMONA II: Health Indicators for People with Intellectual Disability: Using an Indicator Set

Project 2004130 European Commission: Directorate C - Public Health & Risk Assessment

SECTION 1 A1→A11

To be completed by researcher at the beginning of the interview with the person with intellectual disability (& other if requested)

SECTION 2 B1→T15

To be completed by the person with intellectual disability (& other if requested) by interview with a researcher.

In cases where an individual's level of intellectual disability is such that she or he is deemed unable to respond to the questions, the interview should be conducted with a proxy respondent who knows the person well. Questions should be rephrased to accommodate the use of a proxy respondent - that is, the question 'who do you live with?' should be rephrased 'who does (name of person with intellectual disability) live with?'

SECTION 3 REL1→CB58

To be completed in advance of interview by a respondent who knows the person with intellectual disability

SECTION 1

<i>A1</i>	<i>Please allocate a unique random number from 1-100 for this participant and use this as an ID number for the data entry</i>	Random Identification Number:
<i>A2</i>	<i>Please identify the Member State where this survey is being completed</i>	1=Austria 2=Belgium 3=Finland 4=France 5=Germany 6=Ireland 7=Italy 8=Lithuania 9=The Netherlands 10=Norway 11=Romania 12=Slovenia 13=Spain 14=United Kingdom
<i>A3</i>	<i>Please identify the Region the participant resides in from the attached code list</i>	A list of regions will be provided for each participating Member State
<i>A4</i>	<i>Please identify the region where the participant resides as a rural or urban location</i>	1=Rural 2=Urban
<i>A5</i>	<i>Is the residence in a location in the community where the general population reside (e.g. residential street)?</i>	0=No 1=Yes
<i>A6</i>	<i>Please identify the method by which data was collected on behalf of this person</i>	(Circle as many as are relevant) <i>A6A: Specify other method</i> 1=Postal survey 2=Phone survey 3=Face to face interview 4=Other

A7	<i>Who has given written consent for this survey to be undertaken?</i>	(Circle as many as required) 1=Person with intellectual disability (ID) 2=Family member 3=Paid carer 4=Health Professional 5=Other	A7A: Specify other person
A8	<i>Who is attending the interview?</i>	1= Person with ID only 2= Proxy respondent only 3= Person with ID & another person	
A9	<i>If a proxy or another person is assisting in the completion of this interview, please identify their relationship to the person with intellectual disability?</i>	0=Not applicable, person with ID attended interview alone 1=Parent/Guardian of person with ID 2=Other family member (not parent) of person with ID 3=Advocate/volunteer of person with ID 4=Paid carer 5=Health Professional 6=Other person	A9A: Specify other person
A10	<i>How long has the proxy or another person assisting in the completion of this interview known the person with intellectual disability?</i>	Number of Years=	
A11	<i>What is the gender of the person with intellectual disability?</i>	1=Female 2=Male	

C2

What type of residence do you live in? (Circle one response only)

- 1=Independent or semi-independent residence (maximum 2 hours supervision daily (alone or with others)
- 2=In family home (living with both parents, one parent, sibling(s) non-relative (e.g. neighbour, family friend) adopted family, foster family
- 3=In residential setting provided by service provider with over 16 residents
- 4=In residential setting provided by service provider with less than 16 residents
- 5=In nursing home for elderly, psychiatric hospital or other intensive placement with special requirements due to challenging behaviour or profound and or multiple disability.
- 6=Vagrant or homeless
- 7=Unable to answer/unclear response
- 8=Refused

C3	<i>How many people live in your residence? (Live=People who are not paid staff and who reside at least 5 nights a week)</i>	1=No of people= _____ 2=Unable to answer/unclear response 3=Refused
C4	<i>Are there people who are paid supervisors in your house?</i>	1=Yes, 24 hours a day 2=Yes, only at night 3=Yes, only during the day 4=Yes, part time both at day and night 5=No 6=Unable to answer/unclear response 7=Refused
D1	<i>Are you a member of any club or organisation, such as a sport or entertainment club, a local or neighbourhood group, a party, etc?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused
D2	<i>How often do you talk to any of your neighbours? (Neighbours=people who live in the community in houses/apartments near where you live)</i>	1=On most days 2=Once or twice a week 3=Once or twice a month 4=Less often than once a month 5=Never 6=Not applicable - do not have neighbours 7=Unable to answer/unclear response 8=Refused
D3	<i>We would like to ask how often do you meet people, whether here at home, or elsewhere. How often do you meet friends or relatives who are not living with you?</i>	1=On most days 2=Once or twice a week 3=Once or twice a month 4=Less often than once a month 5=Never 6=Unable to answer/unclear response 7=Refused
D4	<i>During the last week, have you spoken, even if only by telephone, to anyone who is not a member of your household?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused

E1	<i>Do you have a job (in paid employment in open or supported market)?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused	
E2	<i>On average, how many hours a week do you spend at your job?</i>	1=No of hours per week _____ 2=Unable to answer/unclear response 3=Refused 99=Does not engage in employment activities	
E3	<i>Do you receive money for working in your job?</i>	0=No 1=Yes, specify 2=Unable to answer/unclear response 3=Refused 99=Does not engage in employment activities	E3A: Specify weekly amount in euro
E4	<i>Do you receive other benefits for working in your job?</i>	0=No 1=Yes, specify 2=Unable to answer/unclear response 3=Refused 99=Does not engage in employment activities	E4A: Specify other benefits
E5	<i>Are you attending an educational or training course?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused	
E6	<i>On average, how many hours a week do you spend at your educational or training course?</i>	1=No of hours per week _____ 2=Unable to answer/unclear response 3=Refused 99=Does not engage in educational or training activities	
E7	<i>Are you attending an alternative daily activity (e.g. volunteering, crafts, arts, club member etc)?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused	

<i>E8 On average, how many hours a week do you spend at this alternative daily activity?</i>	1=No of hours per week _____ 2=Unable to answer/unclear response 3=Refused 99=Does not engage in alternative daily activity	
<i>F1 Do you receive an income from the following sources?</i>	(Circle all answers 1= Yes or 0 =No) 1 0 Unable to answer/unclear response 1 0 Refused 1 0 Don't Know 1 0 Has no income from any sources 1 0 Employee Wage or salary 1 0 Self Employment Wage 1 0 Pension 1 0 Unemployment/Redundancy Benefit 1 0 Social Benefit/Grant 1 0 Income from investment, savings, insurance or property 1 0 Income to purchase care/support 1 0 Income from other source - specify	<i>F1A: Specify other source</i>
<i>F2 If you add up the income from all the sources, do you know what is your total net income per month?</i>	0=No 1=Yes - specify 2=Unable to answer/unclear response 3=Refused	<i>F2A: Specify monthly income in euro</i>
<i>F3 Do you choose how much money you can spend each week for personal spending (e.g. clothes, socializing)? (Or does someone else decide how much money you can have?)</i>	0=No, mostly someone else decides 1=Yes, mostly I decide 2=Unable to answer/unclear response 3=Refused	
<i>F4 Do you choose the things you buy with your personal spending money? (Or does someone else decide the things you buy with your money?)</i>	0=No, mostly someone else decides 1=Yes, mostly I decide 2=Unable to answer/unclear response 3=Refused	

F5 *Sometimes, when money is tight, people have to go without things. In the last year have you always had enough money for these items when you wanted them?* (Circle all answers 1= Yes, 0 =No, NA =Not Applicable (as someone else pays for this))

1 0 NA Unable to answer/unclear response
 1 0 NA Refused
 1 0 NA New Clothes
 1 0 NA New Shoes
 1 0 NA Food
 1 0 NA Heating
 1 0 NA Telephoning friends or family
 1 0 NA Going out
 1 0 NA Visits to the pub or a club
 1 0 NA A hobby or sport
 1 0 NA A holiday

G1 *What is the cause of your disability?* 1=Down's Syndrome 2=Fragile X 3=Other - specify 4=Unknown 5=Unable to answer/unclear response 6=Refused G1A: Specify other cause

	<i>All of us need help at times to do things that we find difficult. I now want to ask you some questions about how much help you usually need to do different things.</i>					
	<i>I want you to tell me for each thing whether you can do it on your own, or you need a bit of help, a lot of help or someone to do it for you. So first of all ...</i>	1= You can do it on your own	2= You need a bit of help	3= You need a lot of help / someone to do it for you	4= Unable to answer/unclear response	5=Refused
H1	<i>Getting dressed in the morning</i>	1	2	3	4	5
H2	<i>Putting on a pair of shoes</i>	1	2	3	4	5
H3	<i>Having a shower or a bath</i>	1	2	3	4	5
H4	<i>Ordering something to eat or drink at a cafe</i>	1	2	3	4	5
H5	<i>Drinking a cup of tea</i>	1	2	3	4	5
H6	<i>Washing your clothes</i>	1	2	3	4	5
H7	<i>Making a sandwich</i>	1	2	3	4	5
H8	<i>Filling in a form (for example if you were applying for a job)</i>	1	2	3	4	5
H9	<i>Finding out what is on the TV tonight</i>	1	2	3	4	5
H10	<i>Paying money into your bank or Post Office</i>	1	2	3	4	5
H11	<i>Making an appointment (for example to see your doctor)</i>	1	2	3	4	5

<i>For each condition listed below, can you tell me whether you have ever had the condition in the past and also whether you currently (in the last 12 months) have the condition (tick both options if condition is chronic)</i>	1=Had this condition in the past (over a year ago)	2=Had condition in last 12 months	3=Don't know	4=Unable to answer / unclear	5=Refused
I1 <i>Asthma</i>					
I2 <i>Allergy (excluding allergic asthma)</i>					
I3 <i>Diabetes</i>					
I4 <i>Cataract</i>					
I5 <i>Hypertension (high blood pressure)</i>					
I6 <i>Heart attack</i>					
I7 <i>Stroke, cerebral haemorrhage</i>					
I8 <i>Chronic bronchitis, emphysema</i>					
I9 <i>Osteoarthritis/arthrosis or arthritis/rheumatism</i>					
I10 <i>Osteoporosis</i>					
I11 <i>Gastric or duodenal ulcer</i>					
I12 <i>Malignant tumour (including leukaemia and lymphoma)</i>					
I13 <i>Migraine and frequent headache</i>					
I14 <i>Constipation</i>					
I15 <i>Hypo/Hyperthyroidism</i>					
I16 <i>Other: Specify</i>					
I17 <i>Other: Specify</i>					

J1 *How is your health in general?* 1=Very good
2=Good
3=Fair
4=Bad
5=Very Bad
6=Unable to answer/unclear response
7=Refused

K1 *Do you smoke?* 0=No
1=Yes, now and then
2=Yes, daily
4=Unable to answer/unclear response
5=Refused

K2	<i>How many cigarettes do you smoke on average per day?</i>	0=Do not smoke 1=Less than 20 cigarettes per day 2=20 cigarettes and more per day 3=Unable to answer/unclear response 4=Refused
L1	<i>How often have you drunk alcohol (e.g. beer, wine, spirits, other local beverages) in the past 12 months?</i>	0=Never 1=Every day 2=5-6 days a week 3=3-4 days a week 4=1-2 days a week 5=1-3 days a month 6=5-6 days a year 7=1-2 days a year 8=Unable to answer/unclear response 9=Refused
L2	<i>On a day when you drink alcohol, how much do you usually drink altogether?</i>	0=Do not drink alcohol 1=1-2 drinks 2=3-4 drinks 3=5-6 drinks 4=7-9 drinks 5=10 or more drinks 6=Unable to answer/unclear response 7=Refused
M1	<i>Do you have a diagnosis of epilepsy?</i>	0=No 1=Yes 2=Don't Know 3=Unable to answer/unclear response 4=Refused
M2	<i>Have you had an epileptic seizure in the previous 5 years (since 2001)?</i>	0=No 1=Yes 2=Don't Know 3=Unable to answer/unclear response 4=Refused

M3	<i>If you have experienced seizures in the last five years, how often do you have seizures?</i>	0=Have not had a seizure in 5 years 1=Daily 2=Weekly (but not daily) 3=More than once a month (but not weekly) 4=Less than one month 5=Unable to answer/unclear response 6=Refused
N1	<i>Do you have pain inside your mouth?</i>	0=No 1=Yes 2=Don't Know 3=Unable to answer/unclear response 4=Refused
N2	<i>If you do have a pain inside your mouth, is the pain in your teeth or other areas?</i>	0=Do not have a pain inside mouth 1=Teeth 2=Other areas 3=Don't Know 4=Unable to answer/unclear response 5=Refused
N3	<i>During the past 12 months about how many times have you visited a dentist?</i>	0=Never 1=specify number of visits _____ 97=Don't know 98=Unable to answer / unclear response 99=Refused
N4	<i>Could you visit a dentist if you needed to?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
O1	<i>Do you use a visual aid (e.g. glasses)?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused

O2	<i>Are you normally able to read ordinary newspaper print (with glasses if normally worn)?</i>	0=Not at all 1=With great difficulty 2=With some difficulty 3=Without any problem 4=Unable to answer / unclear response 5=Refused 99=Don't know
O3	<i>Can you see well enough to recognise a friend at a distance of one metre (arms length) (with glasses if normally worn)?</i>	0=With great difficulty 1=With some difficulty 2=Without any problem 3=Unable to answer / unclear response 4=Refused 99=Don't know
O4	<i>Can you see well enough to recognise a friend at a distance of four metres (across a road) (with glasses if normally worn)?</i>	0=With great difficulty 1=With some difficulty 2=Without any problem 3=Unable to answer / unclear response 4=Refused 99=Don't know
P1	<i>Do you use a hearing aid?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused
P2	<i>Are you normally able to hear what is said in a normal conversation between 3 people or more (with hearing aid if normally worn)?</i>	0=Not at all 1=With major difficulty 2=With minor difficulty 3=Without difficulty 4=Unable to answer / unclear response 5=Refused 99=Don't know

Q1	<i>How far can you walk on a flat ground without a pause or feeling discomfort?</i>	0=Can't walk 1=Use a wheelchair or frame 2=Walk only a few metres 3=Walk less than 200 metres 4=Walk 200 metres or more 5=Unable to answer / unclear response 6=Refused 99=Don't know
R1	<i>What describes best your leisure time activities during the last year?</i>	6=Hard training and competitive sport more than once a week 5=Jogging and other recreational sports or heavy gardening, at least four hours a week 4=Walking, bicycling or other light activities at least four hours a week. 3=Reading, watching TV or other sedentary activities 2=Unable to answer/unclear response 1=Refused
R2	<i>At least once a week do you engage in any regular activity, such as jogging, cycling, etc., long enough to work up a sweat?</i>	0=No 1=Yes 2=Unable to answer/unclear response 3=Refused
R3	<i>Do you experience any difficulties in engaging in physical activity because of the following reasons?</i>	<i>(Circle all answers 1= Yes, it is a problem or 0 =No, it is not a problem)</i> 1 0 Unable to answer/unclear response 1 0 Refused 1 0 Wheelchair user 1 0 I don't have enough money 1 0 I can't get a lift 1 0 I can't use public transport 1 0 I have no one to go with 1 0 I'm not allowed to go 1 0 I need help but there is no one to help me 1 0 I get too tired 1 0 I don't have enough time 1 0 There is nothing I can do at the leisure centre 1 0 I don't like exercise

S1	<i>Did you stay in a hospital or clinic for one night or more during the past year, i.e. since '12 months ago'?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused	S1A: <i>If yes, how many times:</i>
S2	<i>During the last year, have you been in hospital for treatment as a day-patient, i.e. admitted to a hospital bed or day ward, but not to stay overnight?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused	S2A: <i>If yes, how many times:</i>
S3	<i>Have you been to Accident & Emergency/ Casualty during the last 12 months?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused	S3A: <i>If yes, how many times:</i>
S4	<i>Have you been to Accident & Emergency/ Casualty during the last 12 months because of epilepsy?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused	S4A: <i>If yes, how many times:</i>
T1	<i>During the past 12 months, about how many times have you visited a family doctor/physician?</i>	0=Never 1=specify number of visits _____ 97=Don't know 98=Unable to answer / unclear response 99=Refused	
T2	<i>During the past 12 months, about how many times have you visited a mental health professional (e.g. a psychiatrist, a psychologist, a therapist)?</i>	0=Never 1=specify number of visits _____ 97=Don't know 98=Unable to answer / unclear response 99=Refused	

T3	<i>During the past 12 months, about how many times have you visited a physiotherapist?</i>	0=Never 1=specify number of visits _____ 97=Don't know 98=Unable to answer / unclear response 99=Refused
T4	<i>During the past 12 months, about how many times have you visited an occupational therapist?</i>	0=Never 1=specify number of visits _____ 97=Don't know 98=Unable to answer / unclear response 99=Refused
T5	<i>During the past 12 months, about how many times have you visited a speech therapist?</i>	0=Never 1=specify number of visits _____ 97=Don't know 98=Unable to answer / unclear response 99=Refused
T6	<i>When have you last had a check up (that is, saw a doctor or nurse for a full physical medical examination)?</i>	1=During the last 6 months 2=6 months - 1 year ago 3=1 year - 5 years ago 4=over 5 years ago 5=Never 6=Don't know 7=Unable to answer / unclear response 8=Refused
T7	<i>Have you been vaccinated against influenza in the last 10 years?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
T8	<i>Have you been vaccinated against tetanus in the last 10 years?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused

T9	<i>Have you been vaccinated against hepatitis B in the last 10 years?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
T10	<i>Have you had your blood pressure measured in the past 5 years?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
T11	<i>Have you had your cholesterol measured in the last 5 years?</i>	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
T12	<i>Have you had a breast examination (excluding a mammogram) by a doctor or nurse in the past year?</i> FOR WOMEN ONLY	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
T13	<i>When was the last time you had a mammogram?</i> FOR WOMEN ONLY	0=Never 1=In the last year 2=In the last 1-2 years 3=Over 2 years ago 4=Don't know 5=Unable to answer / unclear response 6=Refused
T14	<i>Have you had cervical cancer screening in the past 3 years?</i> FOR WOMEN ONLY	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused
T15	<i>Have you had testicular cancer screening in the past 3 years?</i> FOR MEN ONLY	0=No 1=Yes 2=Don't know 3=Unable to answer/unclear response 4=Refused

ADL3	<i>Does the person have difficulty with feeding?</i>	0=No 1=Yes 2=Don't know
ADL4	<i>Does the person have difficulty with toileting?</i>	0=No 1=Yes 2=Don't know
ADL5	<i>Does the person have difficulty moving in and out of bed and moving in and out of a chair?</i>	0=No 1=Yes 2=Don't know
ADL6	<i>Is the person blind or visual impaired?</i>	0=No 1=Yes 2=Don't know
ADL7	<i>Is the person deaf or hearing-impaired?</i>	0=No 1=Yes 2=Don't know
BMI1	<i>How much does the person weigh without clothes and shoes?</i>	1=Weight (in Kg) = _____ 2=Unable to answer/unclear response 3=Refused
BMI2	<i>What is the person's height without shoes?</i>	1=Height (in cm) = _____ 2=Unable to answer/unclear response 3=Refused

MEDICATION

Please write down all medication prescribed for the person

Name & Type of Drug	Brief reason for medication (e.g. control aggression, epilepsy etc.)	Dosage (e.g. 100 mg)	Frequency (e.g. twice daily, depot monthly, as required)	Code ¹ Name	Code Type	Code Reason	Code Dosage	Code Freq
MED1								
MED2								
MED3								
MED4								
MED5								
MED6								
MED7								
MED8								
MED9								
MED10								
MED11								
MED12								
MED13								
MED14								
MED15								
MED16								
MED17								
MED18								

¹ Coding for name and type of drug from national formulary