

# Study ID .....

Today's date: .....

## Is this form being completed by interview with the patient participant directly?

*Please tick one box*

- Yes, by interview with patient participant alone .....
- Yes, by interview with patient participant and carer jointly .....
- No, it is being completed by interview with:
- Patient's husband or wife .....
- Another relative (please specify in the box below).....
- 
- A friend.....
- A paid carer.....
- Any other (please specify in the box below).....
- 

## This section is to be completed by direct interview with the patient participant only

### A. Cognition: Will you do a memory test for me?

[MMSE]; not replicated in this text due to copyright reasons, but see [http://en.wikipedia.org/wiki/Mini%2080%93mental\\_state\\_examination](http://en.wikipedia.org/wiki/Mini%2080%93mental_state_examination)

### B. DEMQoL Quality of life. Now I would like to ask about how you find life at present. Look at the card to choose which answer describes how you feel.

First, I'm going to ask you about **your feelings**. In the last week, have you felt.....

#### Have you felt...

1.	Cheerful? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
2.	Worried or anxious?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
3.	That you are enjoying life? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
4.	Frustrated?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
5.	Confident? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
6.	Full of energy? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
7.	Sad?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
8.	Lonely?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
9.	Distressed?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
10.	Lively? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
11.	Irritable?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
12.	Fed-up?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
13.	That there are things that you wanted to do but couldn't?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

Now, I'm going to ask you about **your memory**. In the last week, how worried have you been about...

**How worried have you been about...**

14.	Forgetting things that happened recently?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
15.	Forgetting who people are?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
16.	Forgetting what day it is?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
17.	Your thoughts being muddled?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
18.	Difficulty making decisions?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
19.	Poor concentration?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

Now, I'm going to ask you about your **everyday life**. In the last week, how worried have you been about....

**How worried have you been about...**

20.	Not having enough money?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
21.	How you get on with people close to you?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
22.	Getting the affection you want?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
23.	People not listening to you?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
24.	Making yourself understood?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
25.	Getting help when you need it?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
26.	Getting to the toilet in time?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
27.	How you feel in yourself?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
28.	Your health overall?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate ....

29.	Your quality of life overall? **	Very good <input type="checkbox"/>	Good <input type="checkbox"/>	Fair <input type="checkbox"/>	Poor <input type="checkbox"/>
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\*\*items that need to be reversed before scoring

**C. Some questions about things that make life worthwhile (use cue cards)**

**[ICECAP]**

1. Thinking about love & friendship, which describes you?

I can have all of the love and friendship that I want  
 ... a lot of the love and friendship that I want  
 ... a little of the love and friendship that I want  
 I cannot have any of the love and friendship that I want

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

2. Thinking about the future, which describes you?

I can think about the future without any concern  
 ... with only a little concern  
 ... with some concern  
 ... with a lot of concern

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

3. Are you able to do things that make you feel valued?

I am able to do all of the things that make me feel valued  
 ... many of the things that make me feel valued  
 ... a few of the things that make me feel valued  
 I am unable to do any of the things that make me feel valued

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4. Thinking about enjoyment and pleasure, which describes you?

I can have all of the enjoyment and pleasure that I want  
 ... a lot of the enjoyment and pleasure that I want  
 ... a little of the enjoyment and pleasure that I want  
 I cannot have any of the enjoyment and pleasure that I want

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

5. Thinking about independence, which describes you?

I am able to be completely independent  
 ... independent in many things  
 ... independent in a few things  
 I am unable to be at all independent

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

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**This section is to be completed by interview with the patient participant and/or carer on their behalf**

**D. Activities of daily living. Some questions about everyday activities.**  
 Please score what the person has actually done in the last week or so.

**[Barthel index]**

How do they manage with grooming?	Needs help with personal care	0	
	Independent face/hair/teeth/shaving (implements provided)	1	
How do they manage with eating?	Unable	0	
	Needs help cutting, spreading butter etc.	1	
	Independent (food provided in reach)	2	
How do they manage with dressing?	Dependent	0	
	Needs help but can do about half unaided	1	
	Independent (including buttons, zips, laces etc.)	2	
How do they manage with bathing?	Dependent	0	
	Independent (or in shower)	1	

How do they manage using the toilet?	Dependent	0	
	Needs some help but can do something alone	1	
	Independent (on and off, dressing, wiping)	2	
How do they manage with their bladder?	Incontinent or catheterised and unable to manage	0	
	Occasional accident (max once per 24 hours)	1	
	Continent (for over 7 days)	2	
How do they manage with their bowels?	Incontinent (or needs to be given enema)	0	
	Occasional accident (once per week)	1	
	Continent	2	
How do they manage with transferring?	Unable - no sitting balance	0	
	Major help (one or two people, physical) can sit	1	
	Minor help (verbal or physical)	2	
	Independent	3	
How do they manage with mobility?	Immobile	0	
	Wheelchair independent including corners etc.	1	
	Walks with help of one person (verbal or physical)	2	
	Independent (but may use any aid e.g. stick)	3	
How do they manage with stairs?	Unable	0	
	Needs help (verbal, physical, carrying aid)	1	
	Independent up and down	2	

**E. EQ5D quality of life. Some more questions about everyday activities.** Rate as far as possible using information already collected.

**1. Mobility**

*Please tick one box*

- I am confined to bed.....
- I have some problems in walking about.....
- I have no problems walking about.....

**2. Self care**

*Please tick one box*

- I am unable to wash or dress myself.....
- I have some problems in washing or dressing.....
- I have no-problems with looking after myself.....

**3. Usual activities (e.g. housework, leisure, family)?**

*Please tick one box*

- I am unable to perform my usual activities.....
- I have some problems performing my usual activities.....
- I have no problems performing my usual activities.....

**4. Pain / Discomfort: Do you currently have any pain or discomfort?**

*Please tick one box*

- I have no pain or discomfort.....
- I have moderate pain or discomfort.....
- I have extreme pain or discomfort.....

## 5. Anxiety / Depression

Please tick one box

- |   |                          |
|---|--------------------------|
| I am not anxious or depressed.....        | <input type="checkbox"/> |
| I am moderately anxious or depressed..... | <input type="checkbox"/> |
| I am extremely anxious or depressed.....  | <input type="checkbox"/> |

## F. Questions about the effect of health problems on everyday life

I am going to ask some questions about how health problems affect your everyday life.

I want to know about:

- what you do in practice,
- with any kind of help you usually have available,
- compared with other people of your age and background.

[Tick one level for each section, stop when you have identified the right level. If necessary, ask supplementary questions to clarify. A proxy can answer if the subject is unable to do so. In that case 'you' should be read as 'he/ she'. We are interested in 'usual' recent ability, which can be taken as over the last month]

### [London Handicap Scale; mobility]

#### 1. How well are you able to go where you want to go, using any help or means of transport you usually have available? Exclude journeys to hospital.

Please tick one box

- |  |              |                          |
|--|--------------|--------------------------|
| A. Can you go everywhere you want to, no matter how far away?<br>If no, ask question B | Yes, Level 1 | <input type="checkbox"/> |
| B. Do you get out of the house?  | Yes, Level 2 | <input type="checkbox"/> |
|  | No, Level 3  | <input type="checkbox"/> |

### [Physical independence]

#### 2. How well are you able to look after yourself? Include things like shopping, housework, cooking, getting to the toilet and getting dressed.

Please tick one box

- |  |              |                          |
|--|--------------|--------------------------|
| A. Do you do almost everything to look after yourself that someone like you would be expected to do? You need no more than a little help now and again.<br>If no, ask question B | Yes, Level 1 | <input type="checkbox"/> |
| B. Do you need help to be available all the time? You cannot be left alone safely.   | No, Level 2  | <input type="checkbox"/> |
|  | Yes, Level 3 | <input type="checkbox"/> |

### [Occupation].

#### 3. Next, I am interested in work and leisure activities, which includes any paid work, housework, gardening, visiting people, hobbies, watching TV; anything you do to occupy your time.

Please tick one box

- |   |              |                          |
|---|--------------|--------------------------|
| A. Do you do everything you want or need to do, that someone like you would be able to do?<br>If no, ask question B | Yes, Level 1 | <input type="checkbox"/> |
| B. Are there are times, when you would like to be occupied, that you do nothing?                                    | No, Level 2  | <input type="checkbox"/> |
|   | Yes, Level 3 | <input type="checkbox"/> |

**[Social integration].**

**4. Next, I want to know if your health stops you getting on with people, including family, friends, and people you might meet during a normal day.**

*Please tick one box*

- A. Do you get on well with people, see everyone you want to see, and meet new people?  
If no, ask question B Yes, Level 1
- B. Do you find it difficult to get on with people who you don't know well? Maybe you see no-one except close family or the people who look after you. No, Level 2
- Yes, Level 3

**[Awareness]**

**5. Next, awareness of your surroundings. Assume you are using your usual glasses or hearing aid**

*Please tick one box*

- A. Do you see, hear, speak and think clearly, and have a good memory?  
If no, ask question B Yes, Level 1
- B. Do you have problems with hearing, speaking, seeing or your memory, which makes life difficult most of the time? No, Level 2
- Yes, Level 3

**[Economic self sufficiency]**

**6. Finally, affording things you need.**

*Please tick one box*

- A. Can you afford everything you need, including anything you need to buy because of ill-health or disability?  
If no, ask question B Yes, Level 1
- B. Do you find it difficult to afford your most basic needs? You cannot afford things you need because of ill health. No, Level 2
- Yes, Level 3

**G. Client Service Receipt Inventory**

<b>1. Have you been in hospital during the past 6 months? (include index admission)</b>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, please list the dates and hospital		
<i>Dates</i>		<i>Hospital</i>
<i>From</i>	<i>To</i>	

<b>2. Have you been in a care home, either for respite or permanent care during the past 6 months?</b>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, please list the dates, place and whether for respite or permanent care		
<i>Dates</i>	<i>Care Home</i>	<i>Respite / Permanent</i>

From	To		

## Part One: Participant Schedule

### A. PARTICIPANT ACCOMMODATION

1.	Usual place of residence during the <u>last six months</u> ?	Owner occupied house/flat	1
		Privately rented house/flat	2
		House/flat rented from housing associated/local authority	3
	<i>(Also complete Question 3)</i>	Sheltered housing/warden control	4
		Residential home	5
		Nursing home	6
		Acute psychiatric ward	7
		Rehabilitation ward	8
		General medical ward	9
		Other: _____	10

2.	Has ( <i>participant</i> ) lived anywhere else during the <u>last six months</u> ?	No	0
		Yes	1
<i>If yes, Accommodation type:</i>		<b>Code</b>	<b>Approximate number of nights spent</b>
1=Owner occupied house/flat			
2=Privately rented house/flat			
3=House/flat rented from housing associated/local authority			
4=Sheltered housing/warden control			
5=Residential home			
6=Nursing home			
7=Other			

<b>Only complete if Question 1 is coded 4 to 10</b>			
3a.	Organisation managing facility	Local authority social services	1
		NHS	2
		Private (for-profit)	3
		Voluntary (non-profit)	4
		Other: _____	5
3b.	<i>(Participants)</i> 's total contribution to weekly charge for facility	£□□□□.□□	
3c.	Who contributes towards placement ( <i>circle all that apply</i> )	DSS	1
		NHS	2
		Local authority	3
		Voluntary organisation	4
		Participant	5
		Participant's family	6

	Insurance policy	7
	Other: _____	8

### B. PARTICIPANT SERVICE RECEIPT

4a.	<b>Hospital services</b> used over the last six months (include normal accommodation given in Question 1)				
	<b>Service</b>	<b>Name of ward/clinic /hospital/centre</b>	<b>Reason for using service</b> (eg nature of illness, regular respite arrangement)	<b>Unit of measurement</b>	<b>Total number of units received</b>
	Day hospital			Day attendance	<input type="text"/> <input type="text"/>
	Accident and Emergency			Attendance	<input type="text"/> <input type="text"/>
	Outpatient services			Appointment	<input type="text"/> <input type="text"/>
	Psychiatric inpatient ward			Inpatient day	<input type="text"/> <input type="text"/>
	Other inpatient ward			Inpatient day	<input type="text"/> <input type="text"/>
	Other : _____				<input type="text"/> <input type="text"/>

4b.	<b>Day services</b> used over the last six months (do not include any day service provided by the accommodation facility in which the participant is currently living)				
	<b>Service</b>	<b>Name of centre/service</b>	<b>Unit of measurement</b>	<b>Total number of units received</b>	
	Day care:	Local authority social services department	Days	<input type="text"/> <input type="text"/>	
	Day care:	Voluntary organisation	Days	<input type="text"/> <input type="text"/>	
	Lunch club		Visits	<input type="text"/> <input type="text"/>	
	Social club		Visits	<input type="text"/> <input type="text"/>	
	Other : _____			<input type="text"/> <input type="text"/>	



4c.	<b>Community – based services</b> used over the last six months <i>(do not include services provided by people employed directly by the accommodation facility in which the participant is currently living)</i>									
	<b>Service</b> <i>(do not include outpatient services)</i>	<b>Type of visit</b>		<b>Provider agency</b>				<b>Total number of contacts</b> <i>(Round to nearest whole number)</i>	<b>Average duration of each contact (minutes)</b> <i>(Round to nearest whole number)</i>	
		Domiciliary	Office	Health service	Local authority	Voluntary organisation	Private organisation			
i)	Consultant, non psychiatrist	0		1	2	3	4			
ii)	General practitioner	0	1	1	2	3	4			
iii)	Practice nurse (GP clinic)	0	1	1	2	3	4			
iv)	District Nurse	0	1	1	2	3	4			
v)	Health visitor	0	1	1	2	3	4			
vi)	CPN/CMHN	0	1	1	2	3	4			
vii)	Cardiac nurse	0	1	1	2	3	4			
viii)	Continence nurse	0	1	1	2	3	4			
ix)	Occupational therapist	0	1	1	2	3	4			
x)	Community psychiatrist	0	1	1	2	3	4			
xi)	Psychologist	0	1	1	2	3	4			
xii)	Care manager	0	1	1	2	3	4			
xiii)	Social worker	0	1	1	2	3	4			
xv)	Care assistant	0	1	1	2	3	4			
xvi)	Chiropodist	0	1	1	2	3	4			
xvii)	Sitting scheme	0	1	1	2	3	4			
xviii)	Self-help group	0	1	1	2	3	4			
xix)	Meals on wheels	0	1	1	2	3	4		No of days	
xx)	Laundry service	0	1	1	2	3	4			
xxi)	Dentist	0	1	1	2	3	4			
xxii)	Optician	0	1	1	2	3	4			
xxiii)	Counsellor	0	1	1	2	3	4			
xxiv)	Physiotherapist	0	1	1	2	3	4			
xxv)	Other doctor	0	1	1	2	3	4			
<b>Other community-based services:</b>										
xxvi)	_____	0	1	1	2	3	4			
xxvii)	_____	0	1	1	2	3	4			
xxviii)	_____	0	1	1	2	3	4			
xxix)	_____	0	1	1	2	3	4			

## Part Two: Carer Schedule

All the questions below relate only to the last six months.

### C. CARER'S EMPLOYMENT

5.	Regular employment status (Circle one only)	Paid employment	1
		Retired	2
		Housewife / husband	3
		Unemployed / Student	4
		Full time carer	5

6.	Cut down on paid work in order to provide care for (participant). (Also complete Question 7 and 8)	No	0
		Reduced hours	1
		Given up work	2
	By how many hours per week? (Only if reduced hours or given up work)	□ □	

#### Only complete if in "Paid Employment"

7.	Most recent occupation type (State main type if more than one)	Manager / administrator	1
		Professional	2
		Associate professional	3
		Clerical worker / Secretary	4
		Skilled labourer	5
		Services / Sales	6
		Factory worker	7
		Other: _____	8

#### Only complete if in "Paid Employment"

8.	Total number of paid hours per week (Round to the nearest whole number)	□ □
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### D. CARER'S ACCOMMODATION

9.	Usual place of residence during the <u>last six months</u> ?	Owner occupied house/flat	1
		Privately rented house/flat	2
		House/flat rented from housing associated/local authority	3
		Sheltered housing/warden control	4
		Residential home	5
		Nursing home	6
		Other: _____	7

**E. TIME SPENT WITH PARTICIPANT BY PRINCIPAL CARER (i.e. Informant)**

10a.	Normally live with the participant	No	0
		Yes	1
10b.	<b>If No:</b> How many hours are spent giving care to the participant each week? <i>(Round to the nearest whole number)</i>	<input type="text"/> <input type="text"/>	
10c.	<b>If Yes:</b> On a typical day, how much of the time can you leave the participant at home alone?	Less than 25% of the time	1
		Between 25% and 49% of the time	2
		Between 50% and 74% of the time	3
		Between 75% and 100% of the time	4

**F. TIME SPENT WITH PARTICIPANT BY OTHER INFORMAL CARERS**

11a.	Do any other people (eg friends and relatives) regularly provide help for the participant	No	0
		Yes	1
11b.	<b>If Yes:</b> In an average/typical week, what is the total number of hours these people spend caring for the participant? <i>(Round to the nearest whole number)</i>	<input type="text"/> <input type="text"/>	
12a.	Have any friends or relatives taken time off paid work (over the past three months) to help with care giving?	No	0
		Yes	1
12b.	<b>If Yes:</b> Estimate the total number of days taken off work? <i>(Round to the nearest whole number)</i>	<input type="text"/> <input type="text"/>	