

Study ID
completing:.....

Researcher

Today's date:

Patient Initials:

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%E2%80%93state_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

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

C. EQ5D quality of life. Some more questions about everyday activities.

Questions answered by:	
Patient	<input type="checkbox"/>
Proxy	<input type="checkbox"/>
Patient and Proxy together	<input type="checkbox"/>

1. Mobility. Please tick one box		
	<i>Patient</i>	<i>Proxy</i>
I am confined to bed.....	<input type="checkbox"/>	<input type="checkbox"/>
I have some problems in walking about.....	<input type="checkbox"/>	<input type="checkbox"/>
I have no problems walking about.....	<input type="checkbox"/>	<input type="checkbox"/>
2. Self care. Please tick one box		
	<i>Patient</i>	<i>Proxy</i>
I am unable to wash or dress myself.....	<input type="checkbox"/>	<input type="checkbox"/>
I have some problems in washing or dressing.....	<input type="checkbox"/>	<input type="checkbox"/>
I have no-problems with looking after myself.....	<input type="checkbox"/>	<input type="checkbox"/>
3. Usual activities (e.g. housework, leisure, family)? Please tick one box		
	<i>Patient</i>	<i>Proxy</i>
I am unable to perform my usual activities.....	<input type="checkbox"/>	<input type="checkbox"/>
I have some problems performing my usual activities.....	<input type="checkbox"/>	<input type="checkbox"/>
I have no problems performing my usual activities.....	<input type="checkbox"/>	<input type="checkbox"/>
4. Pain/Discomfort: Do you currently have pain or discomfort? Please tick one box		
	<i>Patient</i>	<i>Proxy</i>
I have no pain or discomfort.....	<input type="checkbox"/>	<input type="checkbox"/>
I have moderate pain or discomfort.....	<input type="checkbox"/>	<input type="checkbox"/>
I have extreme pain or discomfort.....	<input type="checkbox"/>	<input type="checkbox"/>
5. Anxiety / Depression. Please tick one box		
	<i>Patient</i>	<i>Proxy</i>
I am not anxious or depressed.....	<input type="checkbox"/>	<input type="checkbox"/>
I am moderately anxious or depressed.....	<input type="checkbox"/>	<input type="checkbox"/>
I am extremely anxious or depressed.....	<input type="checkbox"/>	<input type="checkbox"/>

D. Activities of daily living.

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 grooming?	Needs help with personal care	0	
	Independent face/hair/teeth/shaving (implements provided)	1	
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	Unable - no sitting balance	0	

transferring?	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, stair lift)	1
	Independent up and down	2

E. Client Service Receipt Inventory

1. Have you been in hospital during the past 3 months? (include index admission)		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>		

2. Have you been in a care home, either for respite or permanent care during the past 3 months?		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>
<i>From</i>	<i>To</i>		

Part One: Participant Schedule

A. PARTICIPANT ACCOMMODATION

1.	Usual place of residence during the last three months?	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	No	0

during the last three months?	Yes	1
<i>If yes, Accommodation type:</i> 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 _____	Code	Approximate number of nights spent

Only complete if Question 1 is coded 4 to 10			
3a.	Organisation managing facility	Local authority social services	1
		NHS	2
		Private (for-profit)	3
		Voluntary (non-profit)	4
		Other: _____	5
3b.	(Participants)'s total contribution to weekly charge for facility	£□□□□□.□□	
3c.	Who contributes towards placement (circle all that apply)	NHS	1
		Local authority	2
		Voluntary organisation	3
		Participant	4
		Participant's family	5
		Insurance policy	6
		Other: _____	7

B. PARTICIPANT SERVICE RECEIPT

4a.	Hospital services used over the last three months (include normal accommodation given in Question 1)				
	Service	Name of ward / clinic / hospital / centre	Reason for using service (eg nature of illness, regular respite arrangement)	Unit of measurement	Total number of units received
	Day hospital			Day attendance	□□
	Accident and Emergency			Days Attended	□□
	Outpatient services			No of Appointments	□□
	Other : _____			_____	□□
	Ambulance				□□

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

4c.	Community – based services used over the last three months <i>(do not include services provided by people employed directly by the accommodation facility in which the participant is currently living)</i>								
	Service <i>(do not include outpatient services)</i>	Type of visit		Paid for by				Total number of contacts <i>(Round to nearest whole number)</i>	Average duration of each contact (minutes) <i>(Round to nearest whole number)</i>
		Domiciliary	Office	Health or social services	Self	Both	Voluntary 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)	CPN/CMHN	0	1	1	2	3	4		
vi)	Continence nurse	0	1	1	2	3	4		
vii)	Occupational therapist	0	1	1	2	3	4		
viii)	Community psychiatrist	0	1	1	2	3	4		
ix)	Psychologist	0	1	1	2	3	4		
x)	Social worker	0	1	1	2	3	4		
xi)	Community Matron	0	1	1	2	3	4		
xii)	Care assistant	0	1	1	2	3	4		
xiii)	Chiropodist	0	1	1	2	3	4		
xiv)	Sitting scheme	0	1	1	2	3	4		
xv)	Self-help group	0	1	1	2	3	4		

xvi)	Specialist nurse	0	1	1	2	3	4		
xvii)	Meals on wheels	0	1	1	2	3	4		No of days
xviii)	Dentist	0	1	1	2	3	4		
xix)	Optician	0	1	1	2	3	4		
xx)	Counsellor	0	1	1	2	3	4		
xxi)	Physiotherapist	0	1	1	2	3	4		
xxii)	Other doctor	0	1	1	2	3	4		
Other community-based services:									
xxiii)	_____	0	1	1	2	3	4		
xxiv)	_____	0	1	1	2	3	4		
xxv)	_____	0	1	1	2	3	4		
xxvi)	_____	0	1	1	2	3	4		

The end - thank you