Patient Initials		Date of Birth	Day Month Year	Patient ID	Centre No	Trial No

Informal Carer ID:	

Pain Management and Dementia

Carer Health Survey

(friends or family)

The purpose of this questionnaire is to collect information both about your health and the health of the person your provide care or support for, referred to as **the patient.** When answering on behalf of the patient **please do not ask them for information.** This is because we want to find out whether carers can provide accurate information when patients are unable to.

The information you provide will help us understand the impact of pain on the patient and the impact of providing care on your well-being.

Sections 1 and 2 are questions about you. Sections 3, 4 and 5 are questions about the patient.

Please answer all of the questions you feel able to. There are no right or wrong answers. All of your responses are anonymous and confidential and **will not** affect any treatment the patient might receive in the future.

Please enter today's date:

d d	m m	y y y y

Section 1: About you

1. What is your date of birth? ☐☐ ☐☐ ☐☐☐☐ (d d m m y y y y)

2. Are you? (*please tick one*): ❑ Male ❑ Female

3. How many children do you have (under18)? ☐☐

4. Which ethnic group do you belong to? *(please tick only one)*

- ❑ White
- ❑ Asian or Asian British
- ❑ Black or Black British
- ❑ Chinese or Chinese British
- ❑ Mixed ethnicity
- ❑ Gypsy / traveller
- ❑ Other ethnic group

5. Are you….?

- ❑ Married/Cohabiting
- ❑ Single
- ❑ Divorced
- ❑ Widowed

6. Which one of the following best describes your relationship with the patient?

- ❑ Spouse or partner
- ❑ Close friend or companion
- ❑ Other family member
- ❑ Acquaintance, colleague or neighbour

Section 2: Your education and employment

1. What is the highest level of education you have completed? *(please tick only one)*

- ❑ University or college or equivalent
- ❑ Intermediate between secondary level and university (e.g. technical training)
- ❑ Secondary school
- ❑ Primary school (or less)

2. **In the last four weeks, how often have you visited the patient while they were in hospital?**

_____times

If you can't remember or don't know please tick 'don't know'

Don't know ❑

3. **How far away from the hospital do you live?**

_____miles

4. **How did you travel here?**

Please tick all that apply. If you can't remember or don't know please tick 'don't know'
Name only the main mode of transport (for example, if you walked to the bus stop and then got the bus then tick bus).

I walked all the way	*I got the bus*	*I got the train*	*I drove myself*	*I got a taxi*	*I got a minibus*	*Other*	*Don't know*

5. **Which of the following best describes your current situation?**

Please tick only one box. We are interested in which category best describes your employment situation. The first two boxes relate only to ***paid*** *employment. If you are in paid employment but currently on sick leave please complete one of the first two boxes.*
If you feel that none of the categories are applicable please tick other and write a short description on the dotted line underneath the table.

- ❑ Working full time (30 hours or more per week)
- ❑ Working full time (30 hours or more per week)
- ❑ Working part time (less than 30 hours per week)
- ❑ Unemployed and looking for work
- ❑ Volunteer
- ❑ Job training/apprentice

- ❑ Student
- ❑ At home and not looking for work (for example, looking after family)
- ❑ At home, unable to work (for example, due to sickness or disability)
- ❑ Retired
- ❑ Other

Other:……

6. **If you are in paid work, have you been off work because you were sick in the last 4 weeks?**

Only answer this question if you have indicated in question 5 that you are in paid work. If you can't remember or don't know if you were off sick in the last 4 weeks please tick 'don't know'

Yes ❑
No ❑
Don't know ❑

7. **If you have been off work, how long were you off work for?**

Only answer this question if you have indicated in question 5 that you are in paid work. If you can't remember or don't know how many days you were off work due to sickness in the last four weeks please tick don't know.

Total number of days ☐☐
Don't know ❑

The following questions are about the person you care for, the patient.

Section 3: Contact with Health Services

All the questions in Section 3 refer to the **last month**. The first set of questions (questions 1-3) relate to the patient's stay in hospital whilst the second set of questions (questions 4 and 5) relate to any time in the **last month** when they were at home or not in hospital.

1. Which department(s)/ward(s) have they spent their time over the last month on? Please tick each that applies and provide the number of days they have spent in each.

	General Medicine	**General Surgery**	**Orthopaedic**	**Oncology**	**High Dependency Unit**	**Intensive Care Unit**	**Other** (please specify)
Please tick each that applies							
Number of days							

2. In the **last month** whilst they have been in hospital have they had any assessments? please mark a cross in the appropriate box)

Yes ☐ No ☐

If you have answered **Yes to question 2**, please could you tell us what their assessment was for or who they saw?

Medical assessment (excluding daily ward rounds):	**Please tick each assessment they had**	**Number of times**
Surgical		
Orthopaedic		
Oncology		
Cardiology		
Respiratory		
Radiography		
CT scan		
MRI Scan		
X Ray		
Pathology		
Blood tests		
Other assessments, meetings or sessions		
Physiotherapist		
Occupational therapist		
Psychologist		
Dietician		
Speech and language therapist		
Social worker		
Other:		

3. In the **last month** whilst they have been in hospital have they had an operation or any other procedure? (please mark a cross in the appropriate box)

   Yes ☐ No ☐

If you have answered **Yes to question 3**, please could you tell us what their operation or procedure was for? We have left space for up to four but if there are more please put the details at the end of the form

Details of operation (for example, hip replacement) of procedure (for example, laryngosophy)
I. Details:
II. Details:
III. Details:
IV. Details:

4. Over the **last month**, when they were not in hospital did they use any of the following health and social services?

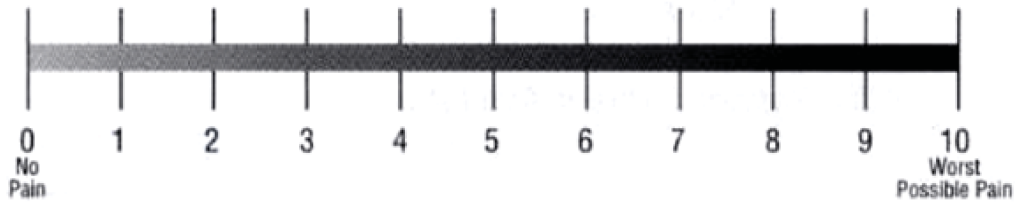
Type of service	Have they used the service during the last month? Please tick (✓) yes or no	Total number of face to face contacts during the last month	Total number of contacts by telephone or email during the last month
a. GP, surgery visit	Yes ☐ No ☐		
b. GP, home visit	Yes ☐ No ☐		
c. District nurse, health visitor or member of community health team	Yes ☐ No ☐		
d. Have they had contact with other health or social care staff such as a psychologist or home help? (please specify which type below): …… …… ……	Yes ☐ No ☐	Number contacts with each: …… …… ……	Number contacts with each: …… …… ……

5. Over the **last month**, when they were not in hospital did they use any of the following? (Please do not complete the shaded squares).

Type of service	**Which service have you used during the last month?**		**Number of days spent in hospital/ hospice in last month**	**Number of visits in last month**
Hospital day centre	Yes ☐	No ☐		
Hospital outpatient clinic	Yes ☐	No ☐		
Hospital accident and emergency	Yes ☐	No ☐		
Nursing home/ hospice stay	Yes ☐	No ☐		

Section 4: Pain Assessments

1. Thinking about the patient, please mark on the rating scale below (with an **X**) what you think their average level of pain over the last 24 hours has been. Please make sure your **X** is visible. Please do not ask the patient about their pain level while completing this.



2. Is the patient currently taking pain medication? (please tick)

   - ❑ Yes (please go to Question 3)
   - ❑ No (please go to the next section)

3. Again, thinking about the patient, in the last 24 hours, how much relief have pain treatments or medications provided? Please circle the percentage that most shows how much relief you think they have received.

	0%	**10%**	**20%**	**30%**	**40%**	**50%**	**60%**	**70%**	**80%**	**90%**	**100%**	
No Relief												Complete

Section 5: EQ-5D – Proxy & DEMQOL Proxy

Health-Related Quality of Life – The person you provide care for

Thinking about the patient, place a tick in **one** box in each group below, indicating which statement best describes **their** health state **today.**

Mobility

- They have no problems in walking about ❑
- They have some problems walking about ❑
- They are confined to bed ❑

Self Care

- They have no problems with self care ❑
- They have some problems washing or dressing himself/herself ❑
- They are unable to wash or dress himself/herself ❑

Usual Activities

(e.g. work, study, housework, family or leisure activities)

- They have no problems with performing usual activities ❑
- They have some problems with performing usual activities ❑
- They are unable to perform usual activities ❑

Pain/Discomfort

- They have no pain or discomfort ❑
- They have moderate pain or discomfort ❑
- They have extreme pain or discomfort ❑

Anxiety/Depression

- They are not anxious or depressed ❑
- They are moderately anxious or depressed ❑
- They are extremely anxious or depressed ❑

We would like to know how good or bad **the patient's** health is TODAY

This scale is numbered from 0 to 100.

100 means the best health you can imagine.

0 means the worst health you can imagine.

Mark an X on the scale to indicate how **their** health is TODAY.

Now, please write the number you marked on the scale in the box below:

THEIR HEALTH TODAY: [ ]

The best health you can imagine

The worst health you can imagine