Generic instruments

E1 Sickness Impact Profile (SIP) [Extract only]

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am confused and start several actions at a time ___
2. I have more minor accidents, for example, drop things, trip and fall, bump into things ___
3. I react slowly to things that are said or done ___
4. I do not finish things I start ___
5. I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things ___
6. I sometimes behave as if I were confused or disorientated in place or time, for example, where I am, who is around, directions, what day it is ___
7. I forget a lot, for example, things that happened recently, where I put things, appointments ___
8. I do not keep my attention on any activity for long ___
9. I make more mistakes than usual ___
10. I have difficulty doing activities involving concentration and thinking ___

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

For permission to use contact: Health Services Research & Development Center, Johns Hopkins School of Hygiene and Public Health, 624 North Broadway, Baltimore, MD 21205-1901, USA

E1 Continued

Sickness Impact Profile (SIP) [Extract only]

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am having trouble writing or typing —
2. I communicate mostly by gestures, for example, moving head, pointing, sign language —
3. My speech is understood only by a few people who know me well —
4. I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly —
5. I don't write except to sign my name —
6. I carry on a conversation only when very close to the other person or looking at him —
7. I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words —
8. I am understood with difficulty —
9. I do not speak clearly when I am under stress —

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

At the end of the SIP, a reminder:

NOW, PLEASE REVIEW THE QUESTIONNAIRE TO BE CERTAIN YOU HAVE FILLED OUT ALL THE INFORMATION. LOOK OVER THE BOXES ON EACH PAGE TO MAKE SURE EACH ONE IS CHECKED SHOWING THAT YOU HAVE READ ALL OF THE STATEMENTS. IF YOU FIND A BOX WITHOUT A CHECK, THEN READ THE STATEMENTS ON THAT PAGE.

E2 Nottingham Health Profile (NHP) [Extract only] *Page 1 of 1*

Nottingham Health Profile

Please do not write in this margin

LISTED BELOW ARE SOME PROBLEMS PEOPLE MIGHT HAVE IN THEIR DAILY LIVES.
READ THE LIST CAREFULLY AND PUT A TICK IN THE BOX ☐ UNDER YES FOR ANY PROBLEM THAT APPLIES TO YOU AT THE MOMENT. TICK THE BOX ☐ UNDER NO FOR ANY PROBLEM THAT DOES NOT APPLY TO YOU. PLEASE ANSWER EVERY QUESTION. IF YOU ARE NOT SURE WHETHER TO ANSWER YES OR NO, TICK WHICHEVER ANSWER YOU THINK IS MOST TRUE AT THE MOMENT.

	YES	NO
I'm tired all the time	☐	☐
I have pain at night	☐	☐
Things are getting me down	☐	☐

	YES	NO
I have unbearable pain	☐	☐
I take tablets to help me sleep	☐	☐
I've forgotten what it's like to enjoy myself	☐	☐

	YES	NO
I'm feeling on edge	☐	☐
I find it painful to change position	☐	☐
I feel lonely	☐	☐

Please turn over the page

For permission to use contact: Dr Stephen McKenna, Galen Research, Enterprise House, Manchester Science Park, Lloyd Street North, Manchester M15 6SU, UK

E3 SF-36v2™ Health survey standard version

Page 1 of 3

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.
Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully, and click on the circle that best describes your answer.
Thank you for completing this survey!

1) In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
O	O	O	O	O

2) Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
O	O	O	O	O

3) The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports	O	O	O
b. Moderate Activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	O	O	O
c. Lifting or carrying groceries	O	O	O
d. Climbing several flights of stairs	O	O	O
e. Climbing one flight of stairs	O	O	O
f. Bending, kneeling, or stooping	O	O	O
g. Walking more than a mile	O	O	O
h. Walking several hundred yards	O	O	O
i. Walking one hundred yards	O	O	O
j. Bathing or dressing yourself	O	O	O

4) During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	O	O	O	O	O
b. Accomplished less than you would like	O	O	O	O	O
c. Were limited in the kind of work or other activities	O	O	O	O	O
d. Had difficulty performing the work or other activities (for example, it took extra effort)	O	O	O	O	O

For permission to use contact: Dr John Ware, Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116–4313, USA

E3 Continued

Page 2 of 3

SF-36v2™ Health survey standard version

5) During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	O	O	O	O	O
b. Accomplished less than you would like	O	O	O	O	O
c. Did work or activities less carefully than usual	O	O	O	O	O

6) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all O Slightly O Moderately O Quite a bit O Extremely O

7) How much bodily pain have you had during the past 4 weeks?

None O Very mild O Mild O Moderate O Severe O Very Severe O

8) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all O A little bit O Moderately O Quite a bit O Extremely O

9) These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks ...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	O	O	O	O	O
b. Have you been very nervous?	O	O	O	O	O
c. Have you felt so down in the dumps that nothing could cheer you up?	O	O	O	O	O
d. Have you felt calm and peaceful?	O	O	O	O	O
e. Did you have a lot of energy?	O	O	O	O	O
f. Have you felt downhearted and depressed?	O	O	O	O	O
g. Did you feel worn out?	O	O	O	O	O
h. Have you been happy?	O	O	O	O	O
i. Did you feel tired?	O	O	O	O	O

For permission to use contact: Dr John Ware, Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116–4313, USA

E3 Continued

SF-36v2™ Health survey standard version

10) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
O	O	O	O	O

11) How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people	O	O	O	O	O
b. I am as healthy as anybody I know	O	O	O	O	O
c. I expect my health to get worse	O	O	O	O	O
d. My health is excellent	O	O	O	O	O

For permission to use contact: Dr John Ware, Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116–4313, USA

E4 EuroQoL(EQ-5D)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care

I have no problems with self-care ☐

I have some problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

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

I have no problems with performing my usual activities ☐

I have some problems with performing my usual activities ☐

I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

Anxiety/Depression

I am not anxious or depressed ☐

I am moderately anxious or depressed ☐

I am extremely anxious or depressed ☐

For permission to use contact: Dr Frank de Charro, EuroQoL Group Business Manager, PO Box 4443, 3006 AK Rotterdam, The Netherlands

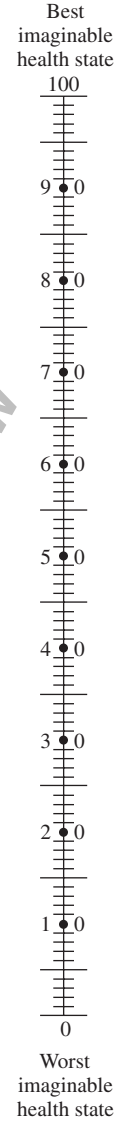
E4 Continued

EuroQoL(EQ-5D)

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by **drawing a line** from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



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E5 A Patient Generated Index© of quality of life (PGI)

Page 1 0f 1

A PATIENT GENERATED INDEX© OF QUALITY OF LIFE

Your answers to the following steps will tell us how your life is affected by your _____ AND ITS TREATMENT.
It will also tell us how you would like to see your life improved.

STEP 1: Identifying areas

We would like you to think of the most important areas of your life that are affected by your _____ AND ITS TREATMENT. Please write up to FIVE areas in the boxes below.

(Please see the reverse side of this form for an example of a completed PGI, and a list of areas mentioned by other patients)

STEP 2: Scoring each area

In this part we would like you to score the areas you mentioned in step 1. This score should show how badly affected you were over the past MONTH. Please score each area out of 10 using this scale:

10 = Exactly as you would like to be
9 = Close to how you would like to be
8 = Very good but not how you would like to be
7 = Good, but not how you would like
6 = Between good and fair
5 = Fair
4 = Between poor and fair
3 = Poor but not the worst you could imagine
2 = Very poor but not the worst you could imagine
1 = Close to the worst you could imagine
0 = The worst you could imagine

STEP 3: Spending points

We want you to 'spend' 14 points to show which areas of your life you feel are most important to your overall quality of life. Spend more points on areas you feel are most important to you and less on areas that you feel are not so important.

You don't have to spend any points on an area.

You can't spend more than 14 points in total.

Please use the last two boxes to score all areas affected by other health problems and all other non health areas

AREAS AFFECTED BY OTHER HEALTH PROBLEMS

ALL OTHER NON-HEALTH AREAS OF LIFE

Remember: total must add up to 14

For permission to use contact: Dr Danny Ruta, Department of Epidemiology & Public Health, Ninewells Hospital & Medical School, Dundee DD1 9SY, Scotland

Disease-specific instruments

E6 European Organisation for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30)

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ⌊⌋⌊⌋⌊⌋

Your birthdate (Day, Month, Year): ⌊⌋⌊⌋⌊⌋⌊⌋⌊⌋⌊⌋

Today's date (Day, Month, Year): ⌊⌋⌊⌋⌊⌋⌊⌋⌊⌋⌊⌋

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at all	A little	Quite a bit	Very much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4

Please go on to the next page

E6 Continued

European Organisation for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30)

During the past week:	**Not at all**	**A little**	**Quite a bit**	**Very much**
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

For permission to use contact: Quality of Life Unit, EORTC Data Centre, Avenue E Mounier 83-B11, 1200 Brussels, Belgium

E7 EORTC head and neck module (EORTC QLQ-H&N35)

EORTC QLQ-H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	**Not at all**	**A little**	**Quite a bit**	**Very much**
1. Have you had pain in your mouth?	1	2	3	4
2. Have you had pain in your jaw?	1	2	3	4
3. Have you had soreness in your mouth?	1	2	3	4
4. Have you had a painful throat?	1	2	3	4
5. Have you had problems swallowing liquids?	1	2	3	4
6. Have you had problems swallowing pureed food?	1	2	3	4
7. Have you had problems swallowing solid food?	1	2	3	4
8. Have you choked when swallowing?	1	2	3	4
9. Have you had problems with your teeth?	1	2	3	4
10. Have you had problems opening your mouth wide?	1	2	3	4
11. Have you had a dry mouth?	1	2	3	4
12. Have you had sticky saliva?	1	2	3	4
13. Have you had problems with your sense of smell?	1	2	3	4
14. Have you had problems with your sense of taste?	1	2	3	4
15. Have you coughed?	1	2	3	4
16. Have you been hoarse?	1	2	3	4
17. Have you felt ill?	1	2	3	4
18. Has your appearance bothered you?	1	2	3	4

Please go on to the next page

For permission to use contact: Quality of Life Unit, EORTC Data Centre, Avenue E Mounier 83-B11, 1200 Brussels, Belgium

E7 Continued

EORTC head and neck module (EORTC QLQ-H&N35)

During the past week:	**Not at all**	**A little**	**Quite a bit**	**Very much**
19. Have you had trouble eating?	1	2	3	4
20. Have you had trouble eating in front of your family?	1	2	3	4
21. Have you had trouble eating in front of other people?	1	2	3	4
22. Have you had trouble enjoying your meals?	1	2	3	4
23. Have you had trouble talking to other people?	1	2	3	4
24. Have you had trouble talking on the telephone?	1	2	3	4
25. Have you had trouble having social contact with your family?	1	2	3	4
26. Have you had trouble having social contact with friends?	1	2	3	4
27. Have you had trouble going out in public?	1	2	3	4
28. Have you had trouble having physical contact with family or friends?	1	2	3	4
29. Have you felt less interest in sex?	1	2	3	4
30. Have you felt less sexual enjoyment?	1	2	3	4

During the past week:	**No**	**Yes**
31. Have you used pain-killers?	1	2
32. Have you taken any nutritional supplements (excluding vitamins)?	1	2
33. Have you used a feeding tube?	1	2
34. Have you lost weight?	1	2
35. Have you gained weight?	1	2

For permission to use contact: Quality of Life Unit, EORTC Data Centre, Avenue E Mounier 83-B11, 1200 Brussels, Belgium

E8 Functional Assessment of Cancer – General version (FACT-G)

Page 1 of 2

FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP 1	I have a lack of energy	0	1	2	3	4
GP 2	I have nausea	0	1	2	3	4
GP 3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP 4	I have pain	0	1	2	3	4
GP 5	I am bothered by the side effects of treatment	0	1	2	3	4
GP 6	I feel ill	0	1	2	3	4
GP 7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS 1	I feel close to my friends	0	1	2	3	4
GS 2	I get emotional support from my family	0	1	2	3	4
GS 3	I get support from my friends	0	1	2	3	4
GS 4	My family has accepted my illness	0	1	2	3	4
GS 5	I am satisfied with family communication about my illness	0	1	2	3	4
GS 6	I feel close to my partner (or the person who is my main support	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS 7	I am satisfied with my sex life	0	1	2	3	4

For permission to use contact: Dr David F. Cella, Center on Outcomes, Research & Education, Evanston Northwestern Healthcare, 1000 Central Street, Suite 101, Evanston, IL 60201, USA

E8 Continued

Functional Assessment of Cancer – General version (FACT-G)

FACT-G (Version 4)

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE 1	I feel sad	0	1	2	3	4
GE 2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE 3	I am losing hope in the fight against my illness	0	1	2	3	4
GE 4	I feel nervous	0	1	2	3	4
GE 5	I worry about dying	0	1	2	3	4
GE 6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF 1	I am able to work (include work at home)	0	1	2	3	4
GF 2	My work (include work at home) is fulfilling	0	1	2	3	4
GF 3	I am able to enjoy life	0	1	2	3	4
GF 4	I have accepted my illness	0	1	2	3	4
GF 5	I am sleeping well	0	1	2	3	4
GF 6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF 7	I am content with the quality of my life right now	0	1	2	3	4

For permission to use contact: Dr David F. Cella, Center on Outcomes, Research & Education, Evanston Northwestern Healthcare, 1000 Central Street, Suite 101, Evanston, IL 60201, USA

E9 Rotterdam Symptom Checklist© (RSCL)

Rotterdam Symptom Checklist **Confidential**

date of completion _____19___

In this questionnaire you will be asked about your symptoms. Would you please, for all symptoms mentioned, indicate to what extent you have been bothered by it, by circling the answer most applicable to you. The questions are related to the past week.

Example: *Have you been bothered, during the past week, by*

headaches	not at all	a little	quite a bit	very much

Have you, during the past week, been bothered by

lack of appetite	not at all	a little	quite a bit	very much
irritability	not at all	a little	quite a bit	very much
tiredness	not at all	a little	quite a bit	very much
worrying	not at all	a little	quite a bit	very much
sore muscles	not at all	a little	quite a bit	very much
depressed mood	not at all	a little	quite a bit	very much
lack of energy	not at all	a little	quite a bit	very much
low back pain	not at all	a little	quite a bit	very much
nervousness	not at all	a little	quite a bit	very much
nausea	not at all	a little	quite a bit	very much
despairing about the future	not at all	a little	quite a bit	very much
difficulty sleeping	not at all	a little	quite a bit	very much
headaches	not at all	a little	quite a bit	very much
vomiting	not at all	a little	quite a bit	very much
dizziness	not at all	a little	quite a bit	very much
decreased sexual interest	not at all	a little	quite a bit	very much
tension	not at all	a little	quite a bit	very much
abdominal (stomach) aches	not at all	a little	quite a bit	very much
anxiety	not at all	a little	quite a bit	very much
constipation	not at all	a little	quite a bit	very much

For permission to use contact: Professor J.C.J.M. de Haes, Acadmisch Medisch Centrum, Universiteit van Amsterdam, Meibergdreef 9 Postbus 22660, 1100 DD Amsterdam, The Netherlands

E9 Continued

Rotterdam Symptom Checklist© (RSCL)

diarrhoea	not at all	a little	quite a bit	very much
acid indigestion	not at all	a little	quite a bit	very much
shivering	not at all	a little	quite a bit	very much
tingling hands or feet	not at all	a little	quite a bit	very much
difficulty concentrating	not at all	a little	quite a bit	very much
sore mouth/pain when swallowing	not at all	a little	quite a bit	very much
loss of hair	not at all	a little	quite a bit	very much
burning/sore eyes	not at all	a little	quite a bit	very much
shortness of breath	not at all	a little	quite a bit	very much
dry mouth	not at all	a little	quite a bit	very much

A number of activities is listed below. *We do not want to know whether you actually do these, but only whether you are able to perform them presently. Would you please mark the answer that applies most to your condition of the past week.*

	unable	only with help	without help, with difficulty	without help
care for myself (wash etc)	O	O	O	O
walk about the house	O	O	O	O
light housework/household jobs	O	O	O	O
climb stairs	O	O	O	O
heavy housework/household jobs	O	O	O	O
walk out of doors	O	O	O	O
go shopping	O	O	O	O
go to work	O	O	O	O

All things considered, how would you describe your quality of life during the past week?

- O excellent
- O good
- O moderately good
- O neither good nor bad
- O rather poor
- O poor
- O extremely poor

Would you please check whether you answered all questions?

Thank you for your help.

patient number____

For permission to use contact: Professor J.C.J.M. de Haes, Academisch Medisch Centrum, Universiteit van Amsterdam, Meibergdreef 9 Postbus 22660, 1100 DD Amsterdam, The Netherlands

E10 Quality of Life in Epilepsy (QOLIE-89) [Extract only]

Do Not Write in This Space

QUALITY OF LIFE IN EPILEPSY QUOLIE-89 *(Version 1.0)*

Patient Inventory

Today's date __/__/__

Patient's name _____

Patient's ID # _____

Gender: ☐ **Male** ☐ **Female** Birthdate __/__/__

INSTRUCTIONS

This survey asks you about your health and daily activities. Answer every question by circling the appropriate number (1, 2, . . .).

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

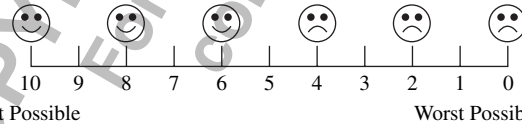
Please feel free to ask someone to assist you if you need help reading or marking the form.

1. In general, would you say your health is: (Circle one number)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Overall, how would you rate your quality of life?

(Circle one number on the scale below)



Best Possible Quality of Life

Worst Possible Quality of Life (as bad as or worse than being dead)

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E10 Continued

Quality of Life in Epilepsy (QOLIE-89) [Extract only]

Do Not Write in This Space

Compared to 1 year ago, how would you rate your health in general **now**?

	(Circle one number)
Much better now than 1 year ago	1
Somewhat better now than 1 year ago	2
About the same as 1 year ago	3
Somewhat worse now than 1 year ago	4
Much worse now than 1 year ago	5

4–13: The following questions are about activities you might do during a typical day. Does **your health** limit you in these activities? If so, **how much**?

	(Circle 1, 2, or 3 on each line) Yes, limited a lot	Yes, limited a little	No, not limited at all
4. *Vigorous activities*, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
5. *Moderate activities*, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
6. Lifting or carrying groceries	1	2	3
7. Climbing *several* flights of stairs	1	2	3
8. Climbing *one* flight of stairs	1	2	3
9. Bending, kneeling, or stooping	1	2	3
10. Walking *more than one mile*	1	2	3
11. Walking *several* blocks	1	2	3
12. Walking *one block*	1	2	3
13. Bathing or dressing yourself	1	2	3

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E10 Continued

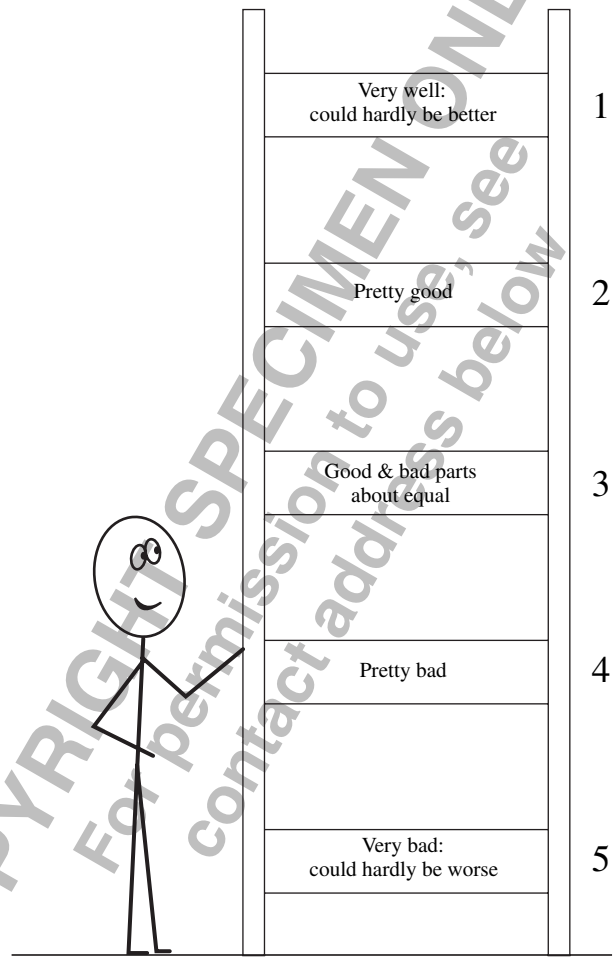
Page 3 of 4

Quality of Life in Epilepsy (QOLIE-89) [Extract only]

49. How has the QUALITY OF YOUR LIFE been during the past 4 weeks (that is, how have things been going for you)?

Do not Write in This Space

(Circle one number)



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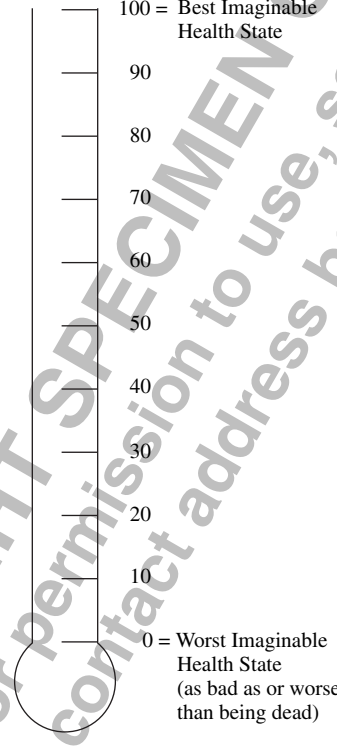
E10 Continued

Quality of Life in Epilepsy (QOLIE-89) [Extract only]

89. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question.**

Do Not Write in This Space



For permission to use contact: Dr O. Devinsky, Office of Contract and Grant Services, RAND, 1700 Main Street, PO Box 2138, Santa Monica, CA 90407-2138, USA

E11 Paediatric Asthma Quality of Life Questionnaire (PAQLQ) [Extract only]

PAEDIATRIC ASTHMA QUALITY OF LIFE QUESTIONNAIRE

PATIENT ID _____

SELF-ADMINISTERED

DATE _____

ACTIVITIES

Because you have asthma, you may have found some of the things you like doing difficult or not much fun.

We want you to think about all the things that you do in which you have been bothered by your asthma.

Some people are bothered by asthma when doing some of the following activities. Please read through the list. Think about how your asthma has bothered you during the last week.

On the next page, write down the **three** (3) things in which you have been bothered **most** by your asthma during the last week. These things must be activities that you will be doing regularly during the study. The three activities you choose can be from this list or you can think of other activities as long as you do them regularly.

1. BALL HOCKEY	19. WALKING UPSTAIRS
2. BASEBALL	20. LAUGHING
3. BASKETBALL	21. STUDYING
4. DANCING (BALLET/JAZZ)	22. DOING HOUSEHOLD CHORES
5. FOOTBALL	23. SINGING
6. PLAYING AT RECESS	24. DOING CRAFTS OR HOBBIES
7. PLAYING WITH PETS	25. SHOUTING
8. PLAYING WITH FRIENDS	26. GYMNASTICS
9. RIDING A BICYCLE	27. ROLLERBLADING/ROLLERSKATING
10. RUNNING	28. SKATEBOARDING
11. SKIPPING ROPE	29. TRACK AND FIELD
12. SHOPPING	30. TOBOGGANING
13. SLEEPING	31. SKIING
14. SOCCER	32. ICE SKATING
15. SWIMMING	33. CLIMBING
16. VOLLEYBALL	34. GETTING UP IN THE MORNING
17. WALKING	35. TALKING
18. WALKING UPHILL	

Write your 3 activities on the next page.

For permission to use contact: Professor E. Juniper, Department of Clinical Epidemiology & Biostatistics, McMaster University Medical Centre, Room 2C10, 1200 Main Street West, Hamilton, Ontario, Canada L8N 3Z5

E11 Continued

Paediatric Asthma Quality of Life Questionnaire (PAQLQ) [Extract only]

On the lines below, please write down the 3 activities in which you have been bothered **most** by your asthma. We then want you to tell us how much you have been bothered doing these things **during the last week because of your asthma.**

Put an x in the box that best describes how bothered you have been.

HOW **BOTHERED** HAVE YOU BEEN DURING THE LAST WEEK?

	Extremely bothered	Very bothered	Quite bothered	Somewhat bothered	Bothered a bit	Hardly bothered at all	Not bothered	Activity not done
	1	2	3	4	5	6	7	
1. _____	☐	☐	☐	☐	☐	☐	☐	☐
2. _____	☐	☐	☐	☐	☐	☐	☐	☐
3. _____	☐	☐	☐	☐	☐	☐	☐	☐
4. COUGHING	☐	☐	☐	☐	☐	☐	☐	☐

IN GENERAL, **HOW OFTEN** DURING THE LAST WEEK DID YOU

	All of the time	Most of the time	Quite often	Some of the time	Once in a while	Hardly any of the time	None of the time
	1	2	3	4	5	6	7
5. Feel FRUSTRATED because of your asthma?	☐	☐	☐	☐	☐	☐	☐
6. Feel TIRED because of your asthma?	☐	☐	☐	☐	☐	☐	☐
7. Feel WORRIED, CONCERNED OR TROUBLED because of your asthma?	☐	☐	☐	☐	☐	☐	☐

Example of a later question

THINK ABOUT ALL THE ACTIVITIES THAT YOU DID IN THE PAST WEEK:

	Extremely bothered	Very bothered	Quite bothered	Somewhat bothered	Bothered a bit	Hardly bothered at all	Not bothered
	1	2	3	4	5	6	7
22. How much were you bothered by your asthma during these activities?	☐	☐	☐	☐	☐	☐	☐

For permission to use contact: Professor E. Juniper, Department of Clinical Epidemiology & Biostatistics, McMaster University Medical Centre, Room 2C10, 1200 Main Street West, Hamilton, Ontario, Canada L8N 3Z5

Domain-specific instruments

E12 Hosptial Anxiety and Depression Scale (HADS) [Extract only]

Hospital Anxiety and Depression (HAD) Scale

Name: _____ Trial No: ☐☐☐☐

Hospital: _____ Date of Completion: ☐☐ ☐☐ ☐☐ (*d* *m* *y*)

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':
- Most of the time . . . . . ☐
- A lot of the time . . . . . ☐
- Time to time, occasionally . . . . . ☐
- Not at all . . . . . ☐

I still enjoy the things I used to enjoy:
- Definitely as much . . . . . ☐
- Not quite as much . . . . . ☐
- Only a little . . . . . ☐
- Hardly at all . . . . . ☐

I feel as if I am slowed down:
- Nearly all the time . . . . . ☐
- Very often . . . . . ☐
- Sometimes. . . . . ☐
- Not at all . . . . . ☐

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all . . . . . ☐
- Occasionally . . . . . ☐
- Quite often . . . . . ☐
- Very often . . . . . ☐

For permission to use contact: NFER-NELSON, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK

E13 Short-form McGill Pain Questionnaire (SF-MPQ)

SHORT-FORM McGILL PAIN QUESTIONNAIRE
RONALD MELZACK

PATIENT'S NAME: _____ **DATE:** _____

	NONE	MILD	MODERATE	SEVERE
THROBBING	0) _____	1) _____	2) _____	3) _____
SHOOTING	0) _____	1) _____	2) _____	3) _____
STABBING	0) _____	1) _____	2) _____	3) _____
SHARP	0) _____	1) _____	2) _____	3) _____
CRAMPING	0) _____	1) _____	2) _____	3) _____
GNAWING	0) _____	1) _____	2) _____	3) _____
HOT-BURNING	0) _____	1) _____	2) _____	3) _____
ACHING	0) _____	1) _____	2) _____	3) _____
HEAVY	0) _____	1) _____	2) _____	3) _____
TENDER	0) _____	1) _____	2) _____	3) _____
SPLITTING	0) _____	1) _____	2) _____	3) _____
TIRING-EXHAUSTING	0) _____	1) _____	2) _____	3) _____
SICKENING	0) _____	1) _____	2) _____	3) _____
FEARFUL	0) _____	1) _____	2) _____	3) _____
PUNISHING-CRUEL	0) _____	1) _____	2) _____	3) _____

NO PAIN ⊢——————————⊣ **WORST POSSIBLE PAIN**

P P I	
0 NO PAIN	_____
1 MILD	_____
2 DISCOMFORTING	_____
3 DISTRESSING	_____
4 HORRIBLE	_____
5 EXCRUCIATING	_____

For permission to use contact: Dr Ronald Melzack, Department of Psychology, McGill University, 1205 Dr Penfield Avenue, Montreal, Quebec, Canada H3A 1B1

E14 Multidimensional Fatigue Inventory (MFI-20)

MULTIDIMENSIONAL FATIGUE INVENTORY
MFI-20

Instructions:

By means of the following statements we would like to get an idea of how you have been feeling lately. There is, for example, the statement:

"I FEEL RELAXED"

If you think that this is entirely true, that indeed you have been feeling relaxed lately, please place an X in the extreme left box; like this:

yes, that is true [X][ ][ ][ ][ ] no, that is not true

The more you disagree with the statement, the more you can place an X in the direction of "no, that is not true". Please, do not miss out a statement, and place one X next to each statement.

1. I feel fit — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
2. Physically I feel only able to do a little — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
3. I feel very active — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
4. I feel like doing all sorts of nice things — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
5. I feel tired — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
6. I think I do a lot in a day — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
7. When I am doing something, I can keep my thoughts on it — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
8. Physically I can take on a lot — yes, that is true [ ][ ][ ][ ][ ] no, that is not true
9. I dread having to do things — yes, that is true [ ][ ][ ][ ][ ] no, that is not true

For permission to use contact: Dr Ellen Smets, Academisch Medisch Centrum, Universiteit van Amsterdam, Meibergdreef 9, Postbus 22660, 1100 DD Amsterdam, The Netherlands

E14 Continued

Multidimensional Fatigue Inventory (MFI-20)

10. I think I do very little in a day	yes, that is true	no, that is not true
11. I can concentrate well	yes, that is true	no, that is not true
12. I am rested	yes, that is true	no, that is not true
13. It takes a lot of effort to concentrate on things	yes, that is true	no, that is not true
14. Physically I feel I am in a bad condition	yes, that is true	no, that is not true
15. I have a lot of plans	yes, that is true	no, that is not true
16. I tire easily	yes, that is true	no, that is not true
17. I get little done	yes, that is true	no, that is not true
18. I don't feel like doing anything	yes, that is true	no, that is not true
19. My thoughts easily wander	yes, that is true	no, that is not true
20. Physically I feel I am in an excellent condition	yes, that is true	no, that is not true

Thank you very much for your cooperation

For permission to use contact: Dr Ellen Smets, Academisch Medisch Centrum, Universiteit van Amsterdam, Meibergdreef 9, Postbus 22660, 1100 DD Amsterdam, The Netherlands

ADL and disability

E15 Barthel Index of Disability (modified) (BI)

Activities of Daily Living–Modified Barthel Index

	Unable to perform task	Substantial help required	Moderate help required	Minimal help required	Fully independent	Score
Personal hygiene	0	1	3	4	5	
Bathing self	0	1	3	4	5	
Feeding	0	2	5	8	10	
Toilet	0	2	5	8	10	
Stair climbing	0	2	5	8	10	
Dressing	0	2	5	8	10	
Bowel control	0	2	5	8	10	
Bladder control	0	2	5	8	10	
Ambulation	0	3	8	12	15	
or Wheelchair*	0	1	3	4	5	
Chair/Bed transfers	0	3	8	12	15	
Total (0–100)						

*Score only if patient is unable to ambulate and is trained in wheelchair management.

For permission to use contact: Dr Surya Shah, School of Health Sciences, University of Teesside, Middlesbrough TS1 3BA, UK