

Participant ID: |_| - |_|_| - |_| - |_|_|_|

FORM H

ACTION study

1st follow up interview (3 months after inclusion)

1. Date and type of assessment		
1.01	Interviewer code	_
1.02	Date of assessment (i.e. the date the information was collected)	_ _ _ _ 20_ _ _
1.03	Type of assessment	<input type="checkbox"/> Clinic <input type="checkbox"/> At participant's home <input type="checkbox"/> Telephone <input type="checkbox"/> Did not attend <input type="checkbox"/> Proxy <input type="checkbox"/> Other

2. Study withdrawal and vital status		
2.01	Participant alive on scheduled assessment date?	<input type="checkbox"/> Yes (go to Q2.02) <input type="checkbox"/> No (go to Q2.04) <input type="checkbox"/> Unknown (go to Q2.06)
2.02	Participant withdrew before scheduled assessment date?	<input type="checkbox"/> Yes (go to Q2.03) <input type="checkbox"/> No (go section 3)
2.03	Enter reason for withdrawal	<input type="checkbox"/> No reason provided

	<i>(go to section 3)</i>	<input type="checkbox"/> Do not want to participate in follow-up interviews <input type="checkbox"/> Too ill to continue participation <input type="checkbox"/> Other
2.04	Enter date of death	 _ _ _ _ _ _ _ _ _ _ 20_ _ _ _ _
2.05	Enter Underlying Cause of Death	
2.06	How was Cause of Death determined?	<input type="checkbox"/> Verbally (go to section 3) <input type="checkbox"/> Medical records (go to section 3)
2.07	Enter date patient was last known to be alive	 _ _ _ _ _ _ _ _ _ _ 20_ _ _ _ _

3. Quality of life (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 around PLEASE TICK
- I have some problems in walking around ONE BOX
- I am confined to bed

Personal Care

- I have no problems with personal care PLEASE TICK
- I have some problems washing or dressing myself ONE BOX
- 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 PLEASE TICK
- I have some problems with performing my usual activities ONE BOX
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort PLEASE TICK
- I have moderate pain or discomfort ONE BOX
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed PLEASE TICK
- I am moderately anxious or depressed ONE BOX
- I am extremely anxious or depressed

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**

Best
imaginable
health state

100

90

80

70

60

50

40

30

20

10

0

0

0

0

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Worst
imaginable
health state

4. **Quality of Life
(EORTC)**



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):

31

 | | | | | | | | | | | |

	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
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

Please go on to the next page

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
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 <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> 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

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5. Psycho-social (HADS)

Hospital Anxiety and Depression Scale (HADS)

Please tick or circle the most correct answer. Don't spend too long thinking about each answer. Answer as you are feeling now.

I feel tense or 'wound up':	Most of the time	3	A
	A lot of the time	2	
	From time to time, occasionally	1	
	Not at all	0	
I still enjoy the things I used to enjoy:	Definitely as much	0	D
	Not quite so much	1	
	Only a little	2	
	Hardly at all	3	
I get a sort of frightened feeling as if something awful is about to happen:	Very definitely and quite badly	3	A
	Yes, but not too badly	2	
	A little, but it doesn't worry me	1	
	Not at all	0	
I can laugh and see the funny side of things:	As much as I always could	0	D
	Not quite so much now	1	
	Definitely not so much now	2	
	Not at all	3	
Worrying thoughts go through my mind:	A great deal of the time	3	A
	A lot of the time	2	
	From time to time, but not too often	1	
	Only occasionally	0	
I feel cheerful:	Not at all	3	D
	Not often	2	
	Sometimes	1	
	Most of the time	0	
I can sit at ease and feel relaxed:	Definitely	0	A
	Usually	1	
	Not Often	2	
	Not at all	3	

I feel as if I am slowed down	Nearly all the time	3	D
	Very often	2	
	Sometimes	1	
	Not at all	0	
I get a sort of frightened feeling like 'butterflies' in the stomach:	Not at all	0	A
	Occasionally	1	
	Quite Often	2	
	Very Often	3	
I have lost interest in my appearance:	Definitely	3	D
	I don't take as much care as I should	2	
	I may not take quite as much care	1	
	I take just as much care as ever	0	
I feel restless as I have to be on the move:	Very much indeed	3	A
	Quite a lot	2	
	Not very much	1	
	Not at all	0	
I look forward with enjoyment to things:	As much as I ever did	0	D
	Rather less than I used to	1	
	Definitely less than I used to	2	
	Hardly at all	3	
I get sudden feelings of panic:	Very often indeed	3	A
	Quite often	2	
	Not very often	1	
	Not at all	0	
I can enjoy a good book or radio or TV program:	Often	0	D
	Sometimes	1	
	Not often	2	
	Very seldom	3	

7. Help from your family or friends when you were in hospital

A carer is someone who helps you with your day-to-day needs. Carers may be friends or family members.

7.01 While in hospital for your surgery, did you need regular help from a carer (not a hospital staff member) with the following tasks?		If yes, who provided this help?				
	YES	NO	Spouse/ partner	Child(ren)	Outside help	Other
Personal care (bathing, using the toilet, brushing teeth)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting around (walking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provision of meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care (e.g. taking drugs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.02	During your stay in hospital, how many hours a day did you receive help?		_ _ hours			
7.03	Who provided most help?		<input type="checkbox"/> Spouse/partner <input type="checkbox"/> Child(ren) <input type="checkbox"/> Outside paid help <input type="checkbox"/> Other			
7.04	Has this carer's involvement in your care affected his or her: <i>(tick all that apply)</i>		<input type="checkbox"/> Employment (i.e. has he or she had to stop working or reduce the number of hours of paid work per week)? <input type="checkbox"/> Education (i.e. has he or she had to stop school or reduce the number of hours attending school each week)? <input type="checkbox"/> Friendships or ability to participate in social activities?			

8. Cost diary		
8.01	Was cost diary provided at baseline interview?	<input type="checkbox"/> Yes <input type="checkbox"/> No (If no, go to Q8.02)
8.02	Cost diary provided to participant today, with explanation	<input type="checkbox"/> Yes <input type="checkbox"/> No
8.03	If not, please provide reason	

9. Signature of person completing the form		
9.01	Signature	_____
9.02	Date form signed	____ ____ ____ ____ 20____ ____