Quality of Life Questionnaire

Trial Number……..……..

Date……..……..

Patient initials……

12 Month

AML17 Trial

QUALITY OF LIFE STUDY

This booklet contains a set of questions which have been developed to study any possible long-term effects of your illness and treatment. The aim of the study is to improve our knowledge about any physical and psychosocial side effects of leukaemia therapy in order to identify areas where more help could be offered to patients. We would be grateful if you could help us in our research by completing this questionnaire**. The information you provide will be kept strictly confidential and used only for medical research.**

Please note that your doctor will not see the answers you give and, if you have specific symptoms or problems as indicated here, you may need to discuss these with your doctor in person.

If you find any of the questions are irrelevant or difficult please make a note of this on the last page.

Please answer all the questions yourself by ticking the box that best applies to you.

There are no "right" or "wrong" answers.

Please enter the date on which you completed this questionnaire: ……/……/…….

Section 1: Current Health Condition

		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 suitcase?	☐	☐	☐	☐
2.	Do you have any trouble taking a long walk	☐	☐	☐	☐
3.	Do you have any trouble taking a short walk outside of the house?	☐	☐	☐	☐
4.	Do you have to stay in a bed or a chair most of the day?	☐	☐	☐	☐
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	☐	☐	☐	☐

For the next two questions please circle the number between 1 and 7 that best applies to you.

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

1	2	3	4	5	6	7
Very Poor						**Excellent**

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

1	2	3	4	5	6	7
Very Poor						**Excellent**

During the Past Week

		Not at all	A little	Quite a bit	Very much
8.	Were you limited in doing either your work or other daily activities?	☐	☐	☐	☐
9.	Were you limited in pursuing your hobbies or other leisure time activities?	☐	☐	☐	☐

10.	Were you short of breath?	☐	☐	☐	☐
11.	Have you had pain?	☐	☐	☐	☐
12.	Did you need to rest?	☐	☐	☐	☐
13.	Have you had trouble sleeping?	☐	☐	☐	☐
14.	Have you felt weak?	☐	☐	☐	☐
15.	Have you lacked an appetite?	☐	☐	☐	☐
16.	Have you felt nauseated?	☐	☐	☐	☐
17.	Have you vomited?	☐	☐	☐	☐
18.	Have you been constipated?	☐	☐	☐	☐
19.	Have you had diarrhoea?	☐	☐	☐	☐
20.	Were you tired?	☐	☐	☐	☐
21.	Did pain interfere with your daily activities?	☐	☐	☐	☐
22.	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	☐	☐	☐	☐
23.	Did you feel tense?	☐	☐	☐	☐
24.	Did you worry?	☐	☐	☐	☐
25.	Did you feel irritable?	☐	☐	☐	☐
26.	Did you feel depressed?	☐	☐	☐	☐
27.	Have you had difficulty remembering things?	☐	☐	☐	☐
28.	Has your physical condition or medical treatment interfered with your family life?	☐	☐	☐	☐
29.	Has your physical condition or medical treatment interfered with your social activities?	☐	☐	☐	☐
30.	Has your physical condition or medical treatment caused you financial difficulties?	☐	☐	☐	☐

Patients sometimes report that they have some of the following symptoms. This time we would like to know whether you have experienced any of these symptoms during the **past month**.

During the **PAST MONTH**, have you had problems with:

		Not at all	A little	Quite a bit	Very much
31.	Chills	☐	☐	☐	☐
32.	Fever	☐	☐	☐	☐
33.	Infection	☐	☐	☐	☐
34.	Weight loss	☐	☐	☐	☐
35.	Weight gain	☐	☐	☐	☐
36.	Change in your sense of taste	☐	☐	☐	☐
37.	Change in your sense of smell	☐	☐	☐	☐
38.	Pain in abdomen (belly)	☐	☐	☐	☐
39.	Sores in mouth	☐	☐	☐	☐
40.	Mouth dryness	☐	☐	☐	☐
41.	Eye dryness	☐	☐	☐	☐
42.	Difficulty in swallowing	☐	☐	☐	☐
43.	Dental problems	☐	☐	☐	☐
44.	Cough	☐	☐	☐	☐
45.	Skin itching	☐	☐	☐	☐
46.	Skin dryness	☐	☐	☐	☐
47.	Hair loss	☐	☐	☐	☐
48.	Abnormal hair growth	☐	☐	☐	☐
49.	Changes in your appearance	☐	☐	☐	☐
50.	Stiff joints	☐	☐	☐	☐
51.	Combing your hair	☐	☐	☐	☐
52.	Shaving or making up	☐	☐	☐	☐

	Not at all	A little	Quite a bit	Very much
53. Dizziness	☐	☐	☐	☐
54. Feeling cold	☐	☐	☐	☐
55. Flushes	☐	☐	☐	☐
56. Headaches	☐	☐	☐	☐
57. Blurred vision	☐	☐	☐	☐
58. Hearing loss	☐	☐	☐	☐
59. Pain during sexual intercourse	☐	☐	☐	☐
60. Anal pain	☐	☐	☐	☐
61. Painful urination	☐	☐	☐	☐
62. Blood in urine	☐	☐	☐	☐

Please continue to Section 2: Emotions, on the next page

Section 2: Emotions

This section of the questionnaire is designed to help us know how you feel. Please read each item and place a 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 our replies: your immediate reaction to each item will propably be more accurate than a long thought-out response.

Tick only one box
for each question

63 **I feel tense or 'wound up':**

- Most of the time ☐
- A lot of the time ☐
- Time to time, occasionally ☐
- Not at all ☐

64 **I still enjoy the things I used to enjoy:**

- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

65 **I get a sort of frightened feeling as if something awful is about to happen:**

- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

66 **I can laugh and see the funny side of things:**

- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

67 **Worrying thoughts go through my mind:**

- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

68 **I feel cheerful:**

- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

69 **I can sit at ease and feel relaxed:**

- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

70 **I feel as if I am slowed down:**

- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

71 **I get a sort of frightened feeling like 'butterflies' in the stomach:**

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

72 **I have lost interest in my appearance:**

- Definitely ☐
- I don't take so much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

73 **I feel restless as if I have to be on the move:**

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

74 **I look forward with enjoyment to things:**

- As much as ever I did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

75 **I get sudden feelings of panic:**

- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

76 **I can enjoy a good book or radio or TV programme:**

- Often ☐
- Sometimes ☐
- Not often ☐
- Seldom ☐

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 ❑

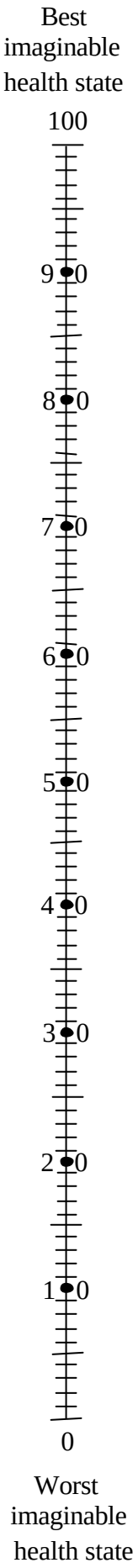
I am moderately anxious or depressed ❑

I am extremely anxious or depressed ❑

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



Personal Details

77a **Sex** Male ☐ Female ☐

77b **Date of Birth** ……..

77c **Marital Status**

Married/living together ☐
Widowed ☐
Divorced/separated ☐
Single ☐

78 **Present Employment Status**

Full-time ☐
Part-time ☐
On sick-leave ☐
Unemployed ☐
Retired ☐
Other ☐

If 'Other' please specify…….

If now unemployed, was this as a direct result of your illness:

Yes ☐ **No** ☐

Please continue to Patient's Evaluation of the Questionnaire on the next page.

Patient's evaluation of questionnaire

79 Did anyone help you to complete the questionnaire?

No ☐ Yes ☐

If YES, who helped you?…….

80 Were there any questions that you found confusing or difficult to answer?

No ☐ Yes ☐

If YES, please list the question number(s)……

81 Were there any questions that you found upsetting?

No ☐ Yes ☐

If YES, please list the question number(s)……

Please use the space below if you have other comments:

……..

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Thank you for your time and co-operation in answering these questions.

Please return the questionnaire to the AML Trials Office in the reply paid envelope provided.