

Quality of Life Questionnaire

Trial Number.....

Date.....

Patient initials.....

3 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.

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

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Fever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Weight gain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Change in your sense of taste	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Change in your sense of smell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Pain in abdomen (belly)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Sores in mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Mouth dryness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Eye dryness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Difficulty in swallowing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Dental problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Cough	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Skin itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Skin dryness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Hair loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Abnormal hair growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Changes in your appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Stiff joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Combing your hair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Shaving or making up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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 probably 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

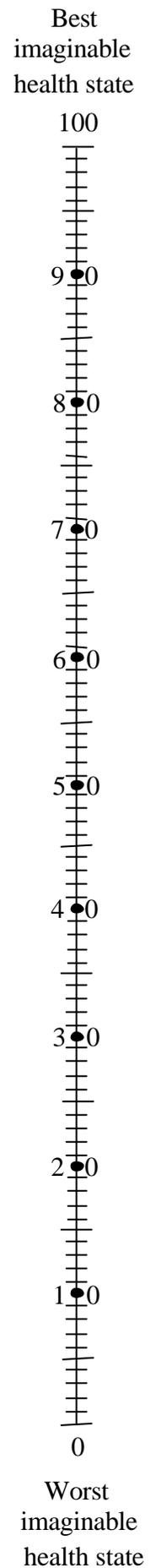
Anxiety/Depression

- 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	<input type="checkbox"/>
Widowed	<input type="checkbox"/>
Divorced/separated	<input type="checkbox"/>
Single	<input type="checkbox"/>

78 **Present Employment Status**

Full-time	<input type="checkbox"/>
Part-time	<input type="checkbox"/>
On sick-leave	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Other	<input type="checkbox"/>

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.