QOL-E V. 3
HEALTH-RELATED QUALITY OF LIFE IN MYELODYSPLASTIC SYNDROME

This is a study of patients with Myelodysplastic syndrome (MDS), which aims to find out how the patients feel about their health and living with their blood disorder.
Your participation is very important to us. You have been selected through a scientific sampling procedure to take part and it is important that everyone who has been chosen should complete this questionnaire so that we can obtain a true picture. The answers you give to the questions will lead to better treatment for all patients who need to be treated for MDS. It will take about 10 minutes to complete the questionnaire. Thank you for your help.

PRIVACY NOTICE

All information which might allow for the identification of the participants in this study will be considered strictly confidential, will be used only for the purpose of evaluation during the study, and will not be disclosed or released for any reason without previous written consent, unless required by law.

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

1. Answer the question by marking the correct answer for you.

For example: (Mark the correct answer)

		YES	NO
a.	Have you been in a submarine?		√

2. If you are not sure how to answer a question, mark the best answer and write a comment next to the answer. We will read all of your comments, so you can write as much as you like.

3. If necessary, you can ask the staff who gave you the questionnaire for assistance.

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY.

INTRODUCTION

1. In general, would you say that your health is:

Excellent	Good	Acceptable	Poor

2. Compared to a month ago, your health is:

Better	The same	Worse	Much worse

PHYSICAL WELL BEING

3. During the last week, your health may have made it difficult for you to do some of the things you do every day:

		I found it very difficult	I found it rather difficult	No difficulties at all
a.	To do heavy exercise, for example running/jumping			
b.	To climb stairs			
c.	To bend over			
d.	To take care of myself (wash myself, get dressed, feed myself).			

FUNCTIONAL WELL BEING

4. During the last week, what problems have you had in your daily activities because of your health?

		Yes	No
a.	I got little done		
b.	I have felt more tired doing my work		

5. During the last week, have you found it difficult to stay awake during the daytime?

All of the time	Most of the time	Some of the time	Never

SOCIAL OR FAMILY LIFE

6. Are the following statements true or false, according to you?

		True	I don't know	False
a.	My current condition interferes too much with my life			
b.	I feel weighed down by my disease			
c.	I feel I am a bother to my family			

7. Your health prevents you from having a paid job, whether you are of retirement age or not:

True	False

8. During the last week, was sexual arousal a problem for you?

Never	Rarely	Sometimes	Often

INCONVENIENCE RELATED TO YOUR ILLNESS

9. During the last week, how much did tiredness get in the way of your daily chores?

Not at all	A little	A lot	Extremely

10. During the last week, how tired did you feel?

Not at all	A little	A lot	Extremely

11. During the last week, how much did the following problems bother you?

		Not at all	A little	A lot	Extremely
a.	Headache				
b.	Palpitations				
c.	Taking care of yourself made you feel tired				
d.	Being bedridden				

12. During the last week, did you get enough sleep?

Always	Often	Rarely	Never

13. During the last week, did shortness of breath disturb you while climbing the stairs?

Never	Sometimes	Often	Always

14. What effects of the illness disturb your daily life?

		Not at all	A little	Extremely
a.	Being dependent on transfusions			
b.	Not being able to do housework			
c.	Not being able to travel either short or long distances			
d.	Being dependent on the hospital, doctors and/or nurses			
e.	Stress and worry because of the illness			
f.	The effect on your sex life			
g.	Side-effects of the treatment			

Notes: