LupusPRO™ (v 1.7)

This questionnaire asks for your views about the effect of lupus or its treatment on your health, quality of life, and the medical care you receive related to your lupus. Answer each question by placing a cross mark (x) in the response box that best describes you. If you are unsure about how to answer a question, please answer as best you can. There is no right or wrong answer. Please select only one response to each question. You may choose the "Not Applicable" option for a question only if a box is provided in that column for that particular question.

A. In the past 4 weeks, how often did you experience the following due to your lupus?

		1	1	1		1	-
		None of	A little	Some of	Most of	All of	Not
		the time	of the	the time	the time	the	Applicable
			time			time	
1.	Loss of hair						
••	2000 of Hall						
2.	New or flare of previous lupus-related						
	skin rashes	Ш		Ш			
3.	Lupus flare						
4.	Poor memory						
	,				Ш		
5.	Lack of concentration						
6.	Lupus medication(s) related bothersome]]
	side effects.		Ц				
7.	Concern about the number of						
	medications being received for lupus.						
8.	Concern that lupus medication(s) will						
0.	affect ability to have a baby.						
_							
9.	Worry about ability to prevent unplanned						П
	pregnancy.						

B. How often were you <u>limited</u> in performing the following daily activities because of your <u>physical health</u> <u>due to your</u> lupus over the past **4 weeks**?

		None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
10.	Taking care of your personal needs (dress, comb hair, toilet, eat, bathe)						
11.	Getting in and out of a bed or chair						
12.	Fulfilling family responsibilities						
13.	Taking care of those who directly depend on me (family, pet).						
14.	A burden to family or friends due to your physical abilities.						

C. How often did you feel the following due to your lupus during the past 4 weeks?									
		None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable		
15.	I woke up feeling worn out								
16.	I felt pain and aching in my body								
17.	I was unable to do my usual activities due to bodily pain								
18.	I was unable to perform usual activities for long periods of time (e.g. around home or at work) because of pain or fatigue								
19.	I was limited in the kinds of tasks or activities I could perform because of pain or fatigue								
D. During the past 4 weeks, how often did you feel because of your lupus that you were									
		None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable		
20.	Worried about lupus' impact on my future								
21.	Worried about losing income								
22.	Anxious								
23.	Depressed								
24.	Concerned that lupus (or its treatment) may lead to more health problems								
25.	Concerned that lupus related health problems will last a long time								
E. [E. During the past 4 weeks, how often did you feel the following due to lupus?								
		None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable		
26.	I disliked my appearance								
27.	I thought less of myself								
28.	I lacked control over my appearance								
29.	I was self conscious about my appearance								
30.	I was embarrassed about how others perceived me								

F. During the **past 4 weeks**, <u>how often did lupus interfere</u> with your:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable	
Ability to plan activities and schedule events							
Overall life satisfaction							
Enjoyment of life							
Fulfillment of career goals							
During the past 4 weeks , how <u>often</u> would y	ou say in <u>re</u>	gards to you	ır lupus?				
	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable	
I received support from my family.							
I focused on making my situation better.							
I learned to live with my lupus.							
I received comfort/strength from my religious or spiritual beliefs.							
H. During the past 3 months, how often did you feel the following about the medical care for lupus you received?							
	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable	
My doctor was accessible when I had a question regarding my lupus.							
My doctor understood the impact of lupus on my life.							
My doctor provided me with the information I need to understand my lupus.							
My doctors discussed/ monitored the side effects of lupus medicine/s.							
	events Overall life satisfaction Enjoyment of life Fulfillment of career goals Ouring the past 4 weeks, how often would youring the past 4 weeks, how often would your life. I received support from my friends. I received support from my family. I focused on making my situation better. I learned to live with my lupus. I received comfort/strength from my religious or spiritual beliefs. Ouring the past 3 months, how often did your my lupus. My doctor was accessible when I had a question regarding my lupus. My doctor understood the impact of lupus on my life. My doctor provided me with the information I need to understand my lupus. My doctors discussed/ monitored the	Ability to plan activities and schedule events Overall life satisfaction Enjoyment of life Fulfillment of career goals Ouring the past 4 weeks, how often would you say in reserved support from my friends. I received support from my friends. I received support from my family. I focused on making my situation better. I learned to live with my lupus. I received comfort/strength from my religious or spiritual beliefs. Ouring the past 3 months, how often did you feel the form the time My doctor was accessible when I had a question regarding my lupus. My doctor understood the impact of lupus on my life. My doctor provided me with the information I need to understand my lupus. My doctors discussed/ monitored the	Ability to plan activities and schedule events Overall life satisfaction Enjoyment of life Fulfillment of career goals Ouring the past 4 weeks, how often would you say in regards to you. I received support from my friends. I received support from my family. I focused on making my situation better. I learned to live with my lupus. I received comfort/strength from my religious or spiritual beliefs. Ouring the past 3 months, how often did you feel the following about the time My doctor was accessible when I had a question regarding my lupus. My doctor understood the impact of lupus on my life. My doctor provided me with the information I need to understand my lupus. My doctors discussed/ monitored the	Ability to plan activities and schedule events	Ability to plan activities and schedule events Overall life satisfaction	the time the time the time the time the time the time the time. Ability to plan activities and schedule events. Overall life satisfaction	

Thank you for completing this questionnaire. Please check to make sure all questions have been answered.

Scoring for LupusPRO v1.7

Items	Construct	Domain	Description	Reverse Coding
1-3	HRQOL	Lupus Symptoms	Lupus Symptoms	Yes
4-5	HRQOL	Cognition	Cognition	Yes
6-7	HRQOL	Lupus Medications	Lupus Medications	Yes
8-9	HRQOL	Procreation	Procreation	Yes
10-14	HRQOL	Physical Health	Physical Function, Role Physical	Yes
15-19	HRQOL	Pain Vitality	Pain Vitality	Yes
20-25	HRQOL	Emotional Health	Emotional function, Role Emotional	Yes
26-30	HRQOL	Body Image	Body Image	Yes
31-34	N-HRQOL	Desires-Goals	Desires, Goals, Plans	Yes
35-36	N-HRQOL	Social support	Support system	No
37-39	N-HRQOL	Coping	Coping	No
40-43	N-HRQOL	Satisfaction with care	Satisfaction with Lupus Care	No

The LupusPRO© has 5 point Likert response format, where 0=None of the time/not applicable, 1= A little of the time, 2= Some of the time, 3=Most of the time, 4= All of the time, 5= Not applicable (recode as 0 for scoring). Reverse scoring for some items is required (as above). There are 12 observed domains. Item scores are totaled for each domain item and the mean domain score is obtained by dividing the total score by the number of items in that domain. The mean raw domain score is transformed to scores ranging from 0 (worst QOL) to 100 (best QOL) by dividing by 4 (the number of Likert responses {5 responses} minus 1) and then multiplying by 100, as below: (Mean raw domain score/4) x 100= Transformed score for the domain.

Transformed domain scores are obtainable when at least 50% of the items are answered. Total HRQOL and N-HRQOL scores are obtained by averaging the transformed domain scores within each construct.