

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 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 16. | I felt pain and aching in my body | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 17. | I was unable to do my usual activities due to bodily pain | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 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 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 19. | I was limited in the kinds of tasks or activities I could perform because of pain or fatigue | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

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 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 21. | Worried about losing income | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. | Anxious | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 23. | Depressed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 24. | Concerned that lupus (or its treatment) may lead to more health problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 25. | Concerned that lupus related health problems will last a long time | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

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 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 27. | I thought less of myself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 28. | I lacked control over my appearance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 29. | I was self conscious about my appearance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 30. | I was embarrassed about how others perceived me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

F. During the past 4 weeks, how often did lupus interfere 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 |
|-----|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 31. | Ability to plan activities and schedule events | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 32. | Overall life satisfaction | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 33. | Enjoyment of life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 34. | Fulfillment of career goals | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

G. During the **past 4 weeks**, how often would you say in regards to your lupus?

| | | None of the time | A little of the time | Some of the time | Most of the time | All of the time | Not Applicable |
|-----|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 35. | I received support from my friends. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. | I received support from my family. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. | I focused on making my situation better. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 38. | I learned to live with my lupus. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 39. | I received comfort/strength from my religious or spiritual beliefs. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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 |
|-----|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 40. | My doctor was accessible when I had a question regarding my lupus. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 41. | My doctor understood the impact of lupus on my life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 42. | My doctor provided me with the information I need to understand my lupus. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 43. | My doctors discussed/ monitored the side effects of lupus medicine/s. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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:

$(\text{Mean raw domain score}/4) \times 100 = \text{Transformed score for the domain.}$

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.