

ERN ReCONNET RP-QoL | Quality of life in Relapsing Polychondritis

The following questionnaire is designed to find out **how Relapsing Polychondritis affects your life**.

Please carefully **read each statement** and **then tick the closest answer to how you have felt during the last 28 days** because of relapsing polychondritis, considering the day or days on which polychondritis had the strongest impact on your life. *Please try to answer the questions as honestly as you can. Feel free to not answer any question you feel uncomfortable with.*

Please record your answers (FOR THE LAST 28 DAYS) using the following scale	not at all	a little	moderately	a lot	extremely	Prefer not to answer / not appropriate
Q1. How much has relapsing polychondritis made it harder for you to spend time with your family?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q2. How much has relapsing polychondritis changed the way you feel or act with your partner?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q3. How much has relapsing polychondritis made it harder for you to spend time with your friends?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q4. How much has relapsing polychondritis made it harder for you to do your work or studies?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q5. How much has relapsing polychondritis made it harder for you to do everyday activities , like washing dishes, getting dressed, cleaning the house or preparing food?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q6. How much has relapsing polychondritis made it harder for you to enjoy leisure activities , like reading a book, playing a game, or watching TV?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q7. How much has relapsing polychondritis made it harder for you to move from one place to another , like walking in the house or climbing stairs?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q8. How much has relapsing polychondritis made it harder for you to do light physical activities , like walking outside	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q9. How much has relapsing polychondritis made it harder for you to do more intense physical activities , like running or doing sport?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q10. How much has relapsing polychondritis made it harder for you to sleep well?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q11. How much has relapsing polychondritis made you feel tired or low on energy?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q12. How much has pain and inflammation of cartilages (chondritis of the ears, nose, trachea, chest wall) bothered you?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q13. How much has other types of pain such as joint pain due to relapsing polychondritis bothered you?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q14. How much has relapsing polychondritis made it harder for you to hear sounds or conversations?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}

Please record your answers (FOR THE LAST 28 DAYS) using the following scale	not at all	a little	moderately	a lot	extremely	Prefer not to answer or not appropriate
Q15. How much has relapsing polychondritis made it harder for you to read or see?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q16. How much has relapsing polychondritis made it harder for you to talk or speak clearly?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q17. How much has relapsing polychondritis made it harder to breathe or made you feel short of breath?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q18. How much has relapsing polychondritis made it harder to have a satisfactory intimate/sexual life?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q19. How much has relapsing polychondritis made you need help or support from your family, friends or other relatives?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q20. How much has relapsing polychondritis made you feel that you are asking too much help from others?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q21. How much has your treatment for relapsing polychondritis made things harder for you?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q22. How much has your treatment for relapsing polychondritis made you have negative feelings about your body or gain weight?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q23. How much have changes in your body, like cartilage deformities, affected how you feel about your appearance?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q24. How much has relapsing polychondritis made you lack confidence in yourself?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q25. How much has relapsing polychondritis made it harder to think, remember things, or pay attention?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q26. How much has relapsing polychondritis made you feel worried or stressed?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q27. How much does it worry you not knowing when relapsing polychondritis might get worse or flare?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q28. How much has relapsing polychondritis made it harder to plan things or activities?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q29. How much does it worry you that doctors may not know a lot about relapsing polychondritis?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q30. How much has relapsing polychondritis bothered you because of the need to go to the doctor or take blood tests or other exams?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}
Q31. How has relapsing polychondritis affected your ability to manage expenses like paying for food, medication, rent, or loans?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ _{NA}

Calculation of total RP-QoL score: sum (S) the points (0 to 4) for each question, then subtract the from 124 so that RP-QoL score = 124 – (S). The theoretical RP-QoL score ranges from 0 (worst QoL) to 124 (best QoL). In the initial validation study [1] which included 239 participants from 19 countries, the median RP-QoL score was 55 (Interquartile range: 40–77).