

\* 1. Which of the conditions under review are you commenting on?

ICER lists all ongoing assessments here

\* 2. ICER gathers input from a variety of perspectives. Which perspective are you representing with your feedback? If you wish to represent more than one perspective, please fill out the survey again for each perspective.

Patient

Caregiver/family

Patient advocate

Other (please describe)

## Populations

3. Are you living with a specific type of {{ Q1 }} (such as a certain genotype or subtype)?

- No
- I don't know
- Yes, please describe

4. Which groups of people living with {{ Q1 }} do you think ICER should focus on for this review (for example: genotypes, ages, gender, or race/ethnicity)?

## Interventions and Comparators

5. How do you currently manage your {{ Q1 }} (any treatments such as medications, diet, exercise, other)?

6. What treatments for {{ Q1 }} do you think ICER should review? A list of the treatments currently being considered are available [here](#) under {{ Q1 }}.

7. If you are not actively treating your {{ Q1 }}, why not?

8. Do you or anyone you know have any difficulty getting treatment (such as lack of specialists, insurance coverage, costs, travel)? if so, please describe.

## Outcomes

9. How does {{ Q1 }} affect your day-to-day life?

10. How well do your treatment(s) work?

11. Are you bothered by any side effects of your treatment(s)?

12. Do your current treatment(s) provide any benefits beyond treating your condition itself (such as your ability to work or go to school, to follow your care plan, or perform daily tasks)?

13. Are there any downsides to these treatment(s) that are important to you (such as your ability to work or go to school, more difficulty following your care plan, or inability to perform daily tasks)?

14. What impact might these treatment(s) have on your caregivers (such as increasing or decreasing the time needed to care for a loved one)?

## Timing and setting

15. Is there anything about the length of the study/studies of these treatments that you would like us to consider?

16. Is there anything about where your care is given that you would like us to consider?

## Populations

17. Is the person you are caring for living with a specific type of {{Q1}} (such as a certain genotype or subtype)?

- No
- I don't know
- Yes (please describe)

18. Which group of people living with {{Q1}} do you think ICER should focus on for this review (for example: certain genotypes, ages, gender, or race/ethnicity)?

## Interventions and Comparators

19. How does the person you care for manage their {{Q1}} (any treatments such as medications, diet, exercise, other)?

20. What treatments for {{Q1}} do you think ICER should review? A list of the treatments currently being considered are available [here](#) under {{ Q1 }}.

21. If the person you are caring for is not actively treating their {{Q1}}, why not?

22. Does the person you care for have any difficulty getting treatment (such as lack of specialists, insurance coverage, costs, travel)? If so, please describe.

## Outcomes

23. How does {{Q1}} affect the day-to-day life of the person you care for?

24. How does caring for a person with {{Q1}} affect your life as a caregiver?



## Timing and Setting

25. Is there anything about the length of the study/studies of these treatments you would like us to consider?

26. Is there anything about where care is given that you would like us to consider?

**FOR PATIENT ADVOCATES**

27. Are you representing an organization that advocates for people with {{ Q1 }}? If yes, please describe the name, size, and location of the organization along with its mission and key activities.

## Populations

28. Which groups of people living with {{Q1}} do you think ICER should focus on for this review (for example: certain genotypes, ages, gender, or race/ethnicity)?

29. Are there any groups of people living with {{Q1}} that are often overlooked that you want us to know about?

## Interventions and Comparators

30. How do the people you advocate for currently manage {{Q1}} (any treatments such as medications, diet, exercise, other)?

31. What treatments for {{Q1}} do you think ICER should review? A list of the treatments currently under consideration are available [here](#) under {{ Q1 }}.

32. If some of the people you advocate for are not actively treating {{Q1}}, why not?

33. Do people that you advocate for have any difficulty getting treatment (such as lack of specialists, insurance coverage, costs, travel)? If so, please describe.

## Outcomes

34. How does {{Q1}} affect the day-to-day life of the people you advocate for?

35. How well do treatment(s) work for the people you advocate for?

36. Are any of the people you advocate for bothered by side effects of treatment(s)?

37. Do current treatment(s) provide any benefits beyond treating the condition itself (such as ability to work or go to school, to follow a care plan, or preform daily tasks)?

38. Are there any downsides to these treatment(s) (such as inability to work or go to school, more difficulty following your care plan, or inability to preform daily tasks)?

39. What impact might these treatment(s) have on caregivers (such as increasing or decreasing the time needed to care for a loved one)?

## Conclusion

40. Is there anything else ICER should know that we haven't asked?

41. Would you like to be updated on ICER's work on {{ Q1 }}?

- No thanks
- Yes, please use this email address

42. Would you be willing to be contacted if we have any questions about the feedback you provided?

- No thanks
- Yes, please use this email address