

## Condition area

# Living with the disease: symptoms and daily impacts

### 1. How much does your disease interfere with daily life in general?

- a. Not at all
- b. Minimally
- c. Moderately
- d. Significant amount

### 2. Have you experienced any of the following difficulties? (Select all that apply)

Options are symptoms typical of the disease

### 3. Which THREE of the following symptoms most negatively impact your daily life?

Options are symptoms typical of the disease

### 4. Which have you experienced while coping with your Disease? (Select all that apply)

- a. Depression
- b. Anxiety
- c. Low self esteem
- d. Social isolation
- e. Difficulty with relationships outside of family
- f. Hopelessness
- g. None of the above

### 5. Which of the following statements is true for you as related to living with Disease?

(Select all that apply)

- a. I miss work or school more than I'm comfortable with
- b. Family stress is common in my life
- c. Others don't know what it's like live with Disease
- d. I cannot participate in sports or other physical activities I enjoy
- e. My general daily function is limited by Disease
- f. None of the above

### 6. Are there specific activities that are important to you but that you cannot do at all, or as fully as you would like, because of your condition?

### 7. How do your symptoms and their negative impacts affect your daily life on the best days? On the worst days?



**8. What are the symptoms that matter most to you?**

**9. How has your condition and its symptoms changed over time?**

**10. What worries you most about your condition?**

**11. What additional questions should we ask you to understand your experience with [disease]?**

## **Therapy area**

### **Challenges in treating the disease**

**1. What medications do you use for your disease?**

**2. How well does your current treatment reduce the most significant symptoms of your disease?**

**3. Which symptoms do you have that are NOT addressed fully by your current treatments?**

**4. If the side effect profile of a new drug was more severe than you currently experience with your treatments, but clinical evidence indicated that the drug would significantly slow the progression of your disease and/or improve your quality of life, how likely would you be to take this drug?**

**5. Without considering side effects of a drug, which ONE of the following would be most important to you in a future therapy?**

Evidence that the drug will:

- a. Reverse decline in organ function (i.e., halt progression of disease, delay need for organ transplant)
- b. Improve your quality of life or prevent future reduction in quality of life prolong your life

**6. What are the most significant downsides to your current treatments and how do they affect your daily life?**

**7. Assuming there is no complete cure for your condition, what specific things would you look for in an ideal treatment for your condition?**

**8. What additional questions should we ask you to understand your preferences on and aspirations for treatments for [disease]?**

