

## Appendix 1: A list of interview questions for ALS patients

- 1) Which symptoms of ALS have the greatest impact on a person's quality-of-life and disease burden?
- 2) How is an individual's life altered by having ALS?
- 3) What changes would greatly improve your overall satisfaction with life?

### Physical

- 4) Could you give examples of how a person with ALS is affected physically by the disease?
- 5) Has pain or fatigue interfered with your life?
- 6) Has weakness or difficulty walking interfered with your life?
- 7) What type of physical function limitations are most important to a patient with ALS?
- 8) Do you have problems with your swallowing or eating?
- 9) Do you experience weakness at your hands or arms? How does this affect your life?
- 9a) What other activities do you now have difficulty doing?

### Mental

- 10) Do you have difficulty concentrating, reading, remembering, or thinking? How has this affected you?

### Emotional

- 11) Could you give examples of how a person with ALS is affected emotionally by the disease?

### Social

- 12) How does ALS affect the social health of a person? (e.g. their relationship with family, work colleagues, or friends)
- 13) What ways does ALS affect family life?
- 14) Has ALS interfered with how you interact with others?
- 15) What activities with your friends do you have difficulty participating in?
- 16) How has ALS interfered with how you communicate with others?

### Everyday

- 17) What is the most troubling problem a person with ALS has to face?
- 18) What are the "little-things" that are affected by and important to people with ALS?
- 19) What are the most important questions a healthcare provider should ask someone with ALS?
- 20) What are the ways that ALS affects someone's everyday life?
- 21) What areas of your life would you most like to improve?
- 22) How does ALS interfere with your job or your ability to get a job?
- 23) What type of activities around the house do you have difficulty with?
- 24) What ways is a patient's independence affected by ALS?
- 25) Has ALS changed how you view yourself or your perceived body image?
- 26) What areas of your life would you most like to improve?
- 27) Do you have any problems with your sleep or with daytime sleepiness?
- 28) Do you have problems breathing? If so how does this affect you?
- 29) Do cramps or fasciculations affect your life? How about spasticity of the limbs?
- 30) How is your bladder and bowel function? Does this interfere with your life?
- 31) If a successful therapy was developed, what would it do for you?
- 32) Are there other areas that have a major impact on your quality-of-life or disease burden that we did not mention?