Appendix 1:

New ALS Patient Questionnaire

1. Patient Demographics:
   a. Age: _______
   b. Gender: [ ] M  [ ] F
   c. Race:  [ ] Hispanic  [ ] Caucasian  [ ] African American  [ ] Other:_________

2. Health Care Utilization:
   a. Where did you receive medical care for ALS prior to coming to the VA?

   b. What type of doctor did you see?  [ ] Primary care  [ ] Family  [ ] Neurologist  [ ] Other

   c. Have you been seen by a Neurologist since you had ALS?  [ ] Yes  [ ] No

3. Health Information/Care:
   During your previous medical care:

   1. Was education about ALS Management provided to you?  [ ] Yes  [ ] No
      *If yes, please indicate how satisfied you were with the ALS management education that you received:
      [ ] Very satisfied  [ ] Satisfied  [ ] Neutral  [ ] Dissatisfied  [ ] Very dissatisfied

   2. Where you evaluated by a Speech Therapist?  [ ] Yes  [ ] No
      *If yes, please indicate how satisfied you were with the ALS management education that you received:
      [ ] Very satisfied  [ ] Satisfied  [ ] Neutral  [ ] Dissatisfied  [ ] Very dissatisfied

   3. Was Tracheostomy placement discussed with you?  [ ] Yes  [ ] No
      *If yes, please indicate how satisfied you were with the ALS management education that you received:
      [ ] Very satisfied  [ ] Satisfied  [ ] Neutral  [ ] Dissatisfied  [ ] Very dissatisfied

   4. Was a PEG Tube Placement discussed with you?  [ ] Yes  [ ] No
      *If yes, please indicate how satisfied you were with the ALS management education that you received:
      [ ] Very satisfied  [ ] Satisfied  [ ] Neutral  [ ] Dissatisfied  [ ] Very dissatisfied
5. Were you evaluated by an **Occupational Therapist** for Equipment Needs? □ Yes □ No
   
   *If yes, please indicate how satisfied you were with the **ALS management** education that you received:*

   □ Very satisfied   □ Satisfied   □ Neutral   □ Dissatisfied   □ Very dissatisfied

6. Was a **Home Evaluation** done? □ Yes □ No
   
   *If yes, please indicate how satisfied you were with the **ALS management** education that you received:*

   □ Very satisfied   □ Satisfied   □ Neutral   □ Dissatisfied   □ Very dissatisfied

7. Was the prognosis of ALS (disease course & outcomes) discussed with you? □ Yes □ No
   
   *If yes, please indicate how satisfied you were with the **ALS management** education that you received:*

   □ Very satisfied   □ Satisfied   □ Neutral   □ Dissatisfied   □ Very dissatisfied

8. Was the **End of Life care** discussed with you? □ Yes □ No
   
   *If yes, please indicate how satisfied you were with the **ALS management** education that you received:*

   □ Very satisfied   □ Satisfied   □ Neutral   □ Dissatisfied   □ Very dissatisfied
Appendix 2:

Established ALS Patient Questionnaire

4. **Patient Demographics:**
   a. Age: _______
   b. Gender: [ ] M [ ] F
   c. Race: [ ] Hispanic [ ] Caucasian [ ] African American [ ] Other:_________

5. **Health Care Utilization:**
   a. What type of care did you receive? [ ] Outpatient [ ] Inpatient

6. **Health Information/Care:**
   During your care at The Cleveland VA:
   9. Was education about ALS Management provided to you? [ ] Yes [ ] No
      *If yes, please indicate how satisfied you were with the ALS management education that you received:*
      [ ] Very satisfied [ ] Satisfied [ ] Neutral [ ] Dissatisfied [ ] Very dissatisfied
   10. Where you evaluated by a Speech Therapist? [ ] Yes [ ] No
       *If yes, please indicate how satisfied you were with the ALS management education that you received:*
       [ ] Very satisfied [ ] Satisfied [ ] Neutral [ ] Dissatisfied [ ] Very dissatisfied
   11. Was Tracheostomy placement discussed with you? [ ] Yes [ ] No
       *If yes, please indicate how satisfied you were with the ALS management education that you received:*
       [ ] Very satisfied [ ] Satisfied [ ] Neutral [ ] Dissatisfied [ ] Very dissatisfied
   12. Was a PEG Tube Placement discussed with you? [ ] Yes [ ] No
       *If yes, please indicate how satisfied you were with the ALS management education that you received:*
       [ ] Very satisfied [ ] Satisfied [ ] Neutral [ ] Dissatisfied [ ] Very dissatisfied
13. Were you evaluated by an Occupational Therapist for Equipment Needs? □ Yes □ No

*If yes, please indicate how satisfied you were with the ALS management education that you received:*

□ Very satisfied □ Satisfied □ Neutral □ Dissatisfied □ Very dissatisfied

14. Was a Home Evaluation done? □ Yes □ No

*If yes, please indicate how satisfied you were with the ALS management education that you received:*

□ Very satisfied □ Satisfied □ Neutral □ Dissatisfied □ Very dissatisfied

15. Was the prognosis of ALS (disease course & outcomes) discussed with you? □ Yes □ No

*If yes, please indicate how satisfied you were with the ALS management education that you received:*

□ Very satisfied □ Satisfied □ Neutral □ Dissatisfied □ Very dissatisfied

16. Was the End of Life care discussed with you? □ Yes □ No

*If yes, please indicate how satisfied you were with the ALS management education that you received:*

□ Very satisfied □ Satisfied □ Neutral □ Dissatisfied □ Very dissatisfied