

# List of ICR Attachments and Protocol Appendices\*

**Attachment 1** Authorizing Legislation: Public Law No. 110-373

**Attachment 2** 60-Day Federal Register Notice

*Attachment 2a. Public Comments*

**Attachment 3** Summary of Approved Changes since Last ICR Review

**Attachment 4** CDC IRB Approval Memo

**Attachment 5** Privacy Impact Assessment

**Attachment 6 Service Organization Forms**

*Attachment 6A Outreach Reporting Form for Chapters and Districts*

*Attachment 6B Outreach Reporting Form for National Offices*

**Attachment 7** Biorepository Pilot Study Report

**Attachment 8** Survey Burden Table Calculation

**Attachment 9** Prevalence Rates of ALS by State on 4 Year Avg

**ALS Protocol Relevant Appendices** (originally labeled as ICR attachments, are renamed as they appear in the research protocol to facilitate IRB review):

**Appendix B** (org Att4): *Validation Questions*

**Appendix C** (org Att5): *Create an Account Website Page*

**Appendix D** (org Att8): Consent Forms

**App D1** National ALS Registry

**App D2** National ALS Biorepository (Biospecimens)

**App D3** National ALS Biorepository (Postmortem)

**App D4** National ALS Biorepository (Saliva)

**Appendix E** (org Att6): Survey Introduction

**App E1** *Essential Questionnaire*

**App E2** *Disease Progression Survey (ALS FRS)*

**App E3** *Follow-up Questions - Demography*

**App E4** *Follow-up Questions - Lifestyle Information*

**App E5** *Follow-up Questions - Environmental Factors*

**App E6** *Follow-up Questions - ALS-associated Clinical Factors*

**App E7** NCHS Redesign Comments on Follow-up Surveys

**Appendix F** (org Att7): Privacy Act Statement

**Appendix M** (org Att11)

**App M1** (org 11A) *ALS Registry Research Application Form*

**App M2** (org 11B) *Annual Update*

**Appendix S:** Biorepository Protocol

**App S.A-1** (org Att12A) *ALS Biorepository Specimen Processing Form*

**App S.A-2** (org Att12B) *Biorepository Saliva Collection Instructions*

**App S.B-6a.** Biorepository COVID-19 Safety Procedures and Restart Plan

**App S.B-6b.** National ALS Biorepository COVID-19 Safety Information Sheet

\* *Italicized ICR attachments and protocol appendices are information collection forms represented in the burden tables.*