

Attachment 3  
Revisions to Data Collection

Revision or New	Change	Rationale
Revision	Attachment 6A or Appendix E - Existing set of questions, reorganized into Essential Questionnaire and 4 Follow-Up Modules	The existing set of questions are being reorganized and streamlined to make the surveys more user friendly for patients. This new design is created to increase completion rates for the surveys. The new design will also decrease the time burden on the patients.
New	Attachment 17 - Releasing state level data on a 4-year rolling average.	ATSDR proposes to release state level data as four-year rolling averages for ALS incidence, prevalence, and mortality. Case counts for the four-year moving average will only be released for states with more than 16 ALS cases and is consistent with United States Cancer Statistics practices where cases or deaths are small and tend to have poor reliability.
New	Addition of new data sources to existing ALS cases.	Achieving more complete ALS case ascertainment by adding new data sources (totaling less than 9), including state ALS registries and non-profit ALS organizations. These new data sources will be added to cases already identified through Registry enrollment and three large national administrative databases (Medicare, Veterans Health Administration, and Veterans Benefits Administration).
New	Restructuring list of attachments into attachments and appendices	The list of attachments has been restructured into attachments and appendices to allow for ease of documentation between OMB approved documents and IRB approved documents.