

## Appendix O – Key Informant Interview Informed Consent

### Promotion of the National ALS Registry to Non-referral Centers Informed Consent Form

#### **Background**

It had been estimated that 5,000 individuals are diagnosed with Amyotrophic Lateral Sclerosis (ALS) annually, and that roughly 12,000 individuals in the US have the disease at any given time. In October 2008, the ALS Registry Act was signed into law. The Agency for Toxic Substances and Disease Registry (ATSDR) was designated to develop the National ALS Registry (Registry). The main goals of the Registry are to better describe the incidence and prevalence of ALS; to better outline demographic factors associated with the disease; and to examine risk factors that might be associated with the disease. The Registry was developed by applying an algorithm to existing national administrative datasets. These datasets come from the Centers for Medicare and Medicaid Services (CMS), Veterans Health Administration (VHA), and Veterans Benefits Administration (VBA). In 2010 self-registration was added. The proportion of cases identified via self-enrollment is lower than those identified in the administrative datasets. On-going self-registration is critical because not all persons with ALS can be identified through the algorithm. In addition, only self-registering persons with ALS can complete the risk-factor surveys.

#### **Purpose**

The purpose of this project is to gain a better understanding of neurologists' and their staffs' knowledge, attitudes, and beliefs about the Registry. It will also characterize opinions of Registry promotional materials.

#### **What do I have to do?**

If you agree to take part, you will be asked to complete a 45-60 minute interview. There are no costs to you to take part except for your time. You will receive a \$100 gift card at the end of the interview.

#### **Risks**

There are minimal risks to taking part in this project. Risks might include feeling uncomfortable or anxious while answering questions. Interviews will be digitally recorded. However no personal information will be included on the recording.

#### **Benefits**

It is unlikely that you will directly benefit from this research. However, the information you provide may help to improve the Registry's promotional materials. It may also be used improve outreach strategies to healthcare providers.

#### **Confidentiality**

Your personal information, including your name will not be collected. If you agree to the interview, you will be assigned a number and this number will be references in the interview transcript and analyses. Digital recordings will be destroyed after the information has been transcribed.

#### **Voluntary**

You do not have to take part in this project and you can stop the interview at any time. If you have any questions about this project you can contact Dr. Wendy Kaye at 770-488-3699.