

## Appendix R - Key Informant Interview Guide

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Study Name: Promotion of the National ALS Registry in Non-referral Centers

### Key Informant Interview Guide

Interviewer's Name: \_\_\_\_\_

Date/Time: \_\_\_\_\_

Location: \_\_\_\_\_

#### **General Information for Interviewer**

*All headings as well as everything in italics are intended to guide the interviewer only and should not be read to or asked of the interviewees. All questions/probes are noted for suggestion and guidance only.*

*Be aware of word choice and phrasing. Discussions with this population should begin at a ninth-grade reading level.*

*Before to the start of each interview, check that the digital recorder is in working order. Review the informed consent before turning on the tape recorder. Do not forget to turn on the tape recorder prior to the start of the interview.*

*Things to bring to each interview session:*

- Business cards/contact information for research team members when appropriate*
- Extra copies of the interview guide*
- Paper and pen (and/or laptop when it will not impact respondents' preference) for note-taking*
- Digital recorder and extra batteries*
- Copies of informed consent forms*
- Copies of the Infographic and Provider Guide*
- Screenshots of ATSDR website and Registry web portal or iPad to show web portal*
- Gift cards and gift card sheet*
- Thank you letters; two per interview- one for participant to take home and one for project records*
- Envelopes for completed informed consent forms and completed thank you letters*

Public reporting burden of this collection of information is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0923-XXXX).

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### **Part 1:**

10-15 Minutes: Introduction

*Interviewer reads aloud:* Thank you for taking time out of your busy schedule to speak with me today about the National ALS Registry. This interview may last approximately 45-60 minutes. I will try to keep us on track so we do not go over 60 minutes.

*Interviewer reads aloud:* My name is [Heather Jordan/Lindsay Rechtman]. I work for McKing Consulting Corporation. McKing has been contracted by the Agency for Toxic Substances and Disease Registry (ATSDR) to conduct a pilot study of educational and promotional outreach activities at non-referral/non-specialty center neurology practices in the US to increase self-enrollment of persons with ALS in the National ALS Registry. Our goals in this interview are to learn about your knowledge, attitudes, and beliefs about the National ALS Registry. We would also like to hear your thoughts and opinions about some of the materials ATSDR currently uses to promote the Registry and the process of self-enrollment in the Registry. I have an outline for this interview that I will try to follow so we can try to talk about the things that will help us meet our goals.

*Interviewer reads aloud:* Your participation in this interview is completely voluntary. You have the right to not participate and you may choose not to answer any particular question. If at any time during our conversation you wish to stop participating, you are completely free to do so. Interviews will be recorded to ensure the research team has record of your responses. However no personal information will be included on the recording. Your participation is confidential and anonymous. Confidential means that only our research team members will see the focus group transcripts. Your name will not be associated with this interview or its transcription. You will be identified only by our Interviewee Project Number. Recordings will be destroyed after the information has been transcribed. If a report of this study is published or if the results are presented at a conference, only group results will be described. There are minimal risks to taking part in this project. Risks might include feeling uncomfortable or anxious while answering questions.

*Interviewer reads aloud:* At the conclusion of this interview, you will receive a \$100 gift card for your time and effort today.

*Interview readers aloud:* Do you have any questions at this time?

*Interviewer reads aloud:* Is it okay to get started now?

*Interviewer:* Turn on recorder.

### **Part 2:**

45-60 Minutes

*Interviewer reads each of the following questions aloud.*

#### A. Current Patients

1. Are you currently diagnosing and/or caring for patients with ALS? Please explain.
2. Have you diagnosed and/or cared for patients with ALS since the self-enrollment web portal went live October 2010? Please explain.

#### B. Knowledge, Attitudes, Beliefs, and Practices Related to the National ALS Registry

1. Have you ever heard of the National ALS Registry? What can you tell me about the National ALS Registry?  
**Public reporting burden of this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clinton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).**
2. How does the National ALS Registry collect information about persons with ALS?
3. What is your opinion about the National ALS Registry? Please explain.
4. Do you have any concerns about the National ALS Registry? Please explain.
5. What do you think the benefits of the National ALS Registry are? For patients? Doctors? Researchers?

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6. Have you ever attended a meeting and seen the National ALS Registry booth? What do you remember about the booth?
7. Have you ever received a packet of information in the mail or over the fax machine about the National ALS Registry? Please explain.
8. If you received a packet of information about the Registry, what do you remember from the packet of materials? Can you tell me how you used the materials?
9. Have you completed the National ALS Registry Continuing Medical Education module? Please explain. (Probe: Did you complete the module because you saw information about it in the packet?)
10. Have you ever seen the National ALS Registry poster? Have you hung it up? Where and why that location? Why not? Can you describe the feedback/questions/comments you received from the poster? (Probe: Did you see it/hang it because you received a copy in the mail?)
11. Have you ever handed out the Patient Guide to one of your patients? Did you hand out the Guide because you received a copy in the mail? Can you describe your interaction with a patient when giving them the guide? (Probes: What did you say? Who you typically give it to?)
12. Can you describe a situation when you would hand out the Guide?
13. Can you describe a situation when you wouldn't hand out the Guide?
14. Have you ever told a patient about the National ALS Registry? At what point in their care do you tell them about the Registry? Can you tell me about these types of conversations? Please explain.
15. Have you ever advised a patient to self-enroll in the Registry? Please explain. What criteria do you use to determine when you will advise a patient to enroll in the Registry? (Probes: Will you wait until you have EMG results? Wait until they are definite ALS as per the El Escorial criteria?)
16. Are you aware of any of your patients enrolling in the Registry? If so, what did they tell you about that experience?
17. Have you ever helped a patient with ALS self-enroll through the web portal? What was that experience like for you? For the patient?
18. Have you ever ordered promotional materials through the National ALS Registry web site? Can you describe that experience?

### C. *Review and Critique of National ALS Registry Promotional Materials*

1. *Interviewer: Hand-out Provider Guide and allow time for Interviewee to read the document.*
  - a. Let's first look at the front cover of the Guide.
    - i. What do you think this Guide will be about?
    - ii. Who runs the National ALS Registry?
    - iii. Is the picture inviting/relatable/interesting/offensive?
    - iv. Do you like the cover? Why or why not?
    - v. What would you change about the cover?
  - b. Now let's open the Guide and look at the inside panels.
    - i. What are the goals of the National ALS Registry?
    - ii. According to this Guide, what is ALS?
    - iii. How does the National ALS Registry collect information about persons with ALS?
    - iv. What are some of the resources available through the National ALS Registry?
    - v. Do you like the pictures used in the inside panels? Why or why not?
    - vi. Is the font and font size appropriate? Why or why not?
    - vii. Do you like the inside panels in this Guide? Why or why not?
    - viii. What would you change about the inside panels of this Guide?
  - c. Now let's look at the back cover of the Guide.
    - i. What is ATSDR?
    - ii. How would you obtain for information about the National ALS Registry?
    - iii. Do you like the outside panel of this Guide? Why or why not?
    - iv. What would you change about the outside panel of this Guide?

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- d. Do you have any additional comments about the Guide?
2. *Interviewer: Hand-out Infographic and allow time for Interviewee to read the document.*
    - a. What do you think this Infographic is about?
    - b. Who runs the National ALS Registry?
    - c. What is the National ALS Registry?
    - d. How do I obtain more information?
    - e. How does a person with ALS sign up for the Registry?
    - f. What does “Will my information be private” mean as it is written on this Infographic?
    - g. Do you think this infographic is clear/concise? Why or why not?
    - h. What do you like about this Infographic?
    - i. What don't you like about this Infographic?
    - j. What would you change about this Infographic?
    - k. Do you have any additional comments about the Infographic?
  3. Are you aware of the National ALS Registry web site? Have you ever visited it?
  4. *Interviewer: Show the Registry website on iPad (or screenshots) and allow time for Interviewee to see the website.*
    - a. What are your initial thoughts of this website?
    - b. What do you like about the self-enrollment process of this website?
    - c. What don't you like about the self-enrollment process of this website?
    - d. What would you change about this website?
    - e. What would you keep on this website?
    - f. Putting yourself in a patient's perspective, how do you feel their experience with the website may be?
    - g. Can you demonstrate to me how you would walk a patient through this website?
    - h. Have any patients commented to you about the website?

### **Part 3:**

10-15 Minutes: *Wrap-up*

*Interviewer reads aloud:* This has been a really great conversation. The information you told me is very useful. We covered a lot of information today, but is there anything we didn't address that you would like to comment on? If you have any questions or think of something else you want to tell me, please call me or email me. Also, if you are interested in receiving a copy of the key informant interview write-up, please let us know. Again, thank you for your time today!

*Interviewer:* Turn off recorder. Hand interviewee a thank you letter and a gift card. Record gift card number. Make sure to collect all belongings and make sure the meeting space is tidy. Thank the neurology practice point-of-contact, if available.