**Supplementary Materials – Appendix A2**

**Development of Survey: Pilot Phase of Study**

Prior to the initiation of the multicenter study, the investigators at Johns Hopkins University designed and evaluated the survey that would be implemented. The aims of the pilot study were to (1) design a survey that would cover all the relevant topics for examining knowledge about dementia, and knowledge about and attitudes toward advance care planning, (2) to assure that the survey used phrasing that was readily understandable and relevant to caregivers of persons with dementia, and (3) to establish that the items flowed in a logical order. This pilot study was approved by the Johns Hopkins Institutional Review Board, and informed consent was obtained from all participants.

The survey was developed by study investigators based on their knowledge and expertise on Alzheimer disease and related dementias, their knowledge of advance care planning and end of life care for persons with dementia, and prior literature relevant to topics included in the survey. The survey was designed to determine caregivers’ understanding and perceptions about dementia and its stages, and their attitudes about medical decision making and end of life care for persons with dementia. Survey items were also included to determine the extent to which religious or spiritual beliefs might influence medical care decisions, whether additional information on the survey topics would be helpful to respondents and, if so, their preferences for how that information should be provided. The survey tested in the pilot study was a 43-item questionnaire designed as either true/false or multiple choices questions. Questions were formatted for participants to mark their responses on the 10-page document.

The pilot study included a convenience sample of six caregivers of persons with dementia who were enrolled in the Johns Hopkins Alzheimer Disease Research Center (JHADRC) and had either mild, moderate or severe dementia. The JHADRC Clinical Coordinator asked potential participants about their willingness to be contacted about this pilot study. Those who agreed were called by one of the study investigators (BB), who described the study and asked them to participate in a one-hour study visit conducted at the JHADRC or in their home. After informed consent was obtained, participation involved completing the questionnaire and participating in an audio-recorded qualitative interview designed to obtain the individual’s perspectives on the experience of completing the questionnaire, their understanding of questionnaire items, and any challenges faced when responding to the survey questions. As interviews were completed, the qualitative data were summarized and analyzed to identify similarities and differences in responses across participants, and to determine how the questionnaire might be modified for use in the subsequent multicenter study.

In general, the pilot study participants thought that the questionnaire items were good, the content was relevant and understandable, and they were not uncomfortable with the topic. In a few instances, participants noted that the questionnaire made them realize that there are some things that they did not know very much about or that they had not previously discussed with the person with dementia, some of whom were no longer capable of having such a discussion. Some participants suggested changes to a few terms or phrases used in the questionnaire and changes in the order of some response choices.

Based on feedback from the pilot study participants, a few modifications were made to the survey questionnaire. For example, some items were re-formatted or the wording was changed slightly for clarity, and a few response choices were added or re-ordered. The final questionnaire used in the multicenter survey includes 41 items and sub-items.