

Surrogate ID#

**GOALS OF CARE BASELINE INTERVIEW**  
**KEEP THIS PAGE SEPARATE FROM INTERVIEW**

INTERVIEWER ID#:

**DECISION MAKER CONTACT INFORMATION:**

Last Name: \_\_\_\_\_

First Name: \_\_\_\_\_

MI: \_\_\_\_\_

Street Address 1: \_\_\_\_\_

Street Address 2: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_

ZIP: \_\_\_\_\_

Primary Phone # : \_\_\_\_\_

Phone Type: \_\_\_\_\_ Best time to call: \_\_\_\_\_

Secondary Phone # : \_\_\_\_\_

Phone Type: \_\_\_\_\_ Best time to call: \_\_\_\_\_

Email (if best way to schedule): \_\_\_\_\_

DATE OF INTERVIEW: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**BEGIN INTERVIEW AFTER INFORMED CONSENT**

Surrogate ID#

Surrogate ID#

INTERVIEW DATE:

INTERVIEWER:

**HOW WOULD YOU LIKE ME TO REFER TO YOUR FAMILY MEMBER DURING THIS INTERVIEW:** \_\_\_\_\_

A-10. [QB\_A10] Tell me about your loved ones memory loss and how it effects their daily life.

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A-20. [QB\_A20] On approximately how many days during the **last month** were you able to visit [RESIDENT]?

\_\_\_\_ **NUMBER OF DAYS**  
77 = DON'T KNOW  
88 = REFUSED

A-30. [QB\_A30] On approximately how many days **in a typical week** are you able to visit [RESIDENT]?

\_\_\_\_ **NUMBER OF DAYS**  
77 = DON'T KNOW  
88 = REFUSED

A-40. [QB\_A40] On approximately how many days **in a typical week** do **other family and friends** visit [RESIDENT]?

\_\_\_\_ **NUMBER OF DAYS**  
77 = DON'T KNOW  
88 = REFUSED

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**Alzheimer Disease Related Quality of Life™  
(ADRQL™)**

Now I'd like to ask you a series of questions to help me know more about [RESIDENT] and their experience living with dementia. I'll make some statements about living with dementia, and you can simply Agree or Disagree based on what you observed of [RESIDENT] in the past 2 weeks:

B-10. The next statements are about relating to and being around other people. After each statement, please answer "Agree" if the statement describes [RESIDENT] in the last 2 weeks or answer "Disagree" if it does not.

	<b>Agree</b>	<b>Disagree</b>	<b>Don't Know</b>	<b>REFUSED</b>
[QB_B10_1] He/She smiles or laughs when around other people	1	2	7	8
[QB_B10_2] He/She does <u>not</u> pay attention to the presence of others	1	2	7	8
[QB_B10_3] He/She will stay around other people	1	2	7	8
[QB_B10_4] He/She seeks contact with others by greeting people or joining in conversations.	1	2	7	8
[QB_B10_5] He/She talks with people	1	2	7	8
[QB_B10_6] He/She touches or allows touching such as handshakes, hugs, kisses, pats.	1	2	7	8
[QB_B10_7] He/She can be comforted or reassured by others	1	2	7	8
[QB_B10_8] He/She is <u>not</u> comfortable with strangers or people he/she doesn't recognize	1	2	7	8
[QB_B10_9] He/She reacts with pleasure to pets or small children	1	2	7	8
[QB_B10_10] He/She talks with people on the telephone	1	2	7	8
[QB_B10_11] He/She becomes upset or angry when approached by another person.	1	2	7	8
[QB_B10_12] He/She pushes, grabs or hits people	1	2	7	8

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B-20. The next statements are about special identity and important relationships. After each statement, please answer “Agree” if the statement describes [RESIDENT] in the last 2 weeks or answer “Disagree” if it does not.

	Agree	Disagree	Don't Know	REFUSED
[QB_B20_1] He/She talks about or still does things related to his/her previous work or daily activities	1	2	7	8
[QB_B20_2] He/She is aware of his/her place in the family such as being a husband/wife, parent, or grandparent	1	2	7	8
[QB_B20_3] He/She makes or indicates choices in routine daily activities such as what to wear, what to eat, or where to sit	1	2	7	8
[QB_B20_4] He/She becomes upset by personal limitations such as forgetting, losing things, or getting confused in familiar places	1	2	7	8
[QB_B20_5] He/She shows interest in events, places or habits from his/her past such as old friends, former residences, church or prayer	1	2	7	8
[QB_B20_6] He/She does <u>not</u> respond to his/her own name	1	2	7	8
[QB_B20_7] He/She does <u>not</u> express beliefs or attitudes that he/she always had	1	2	7	8
[QB_B20_8] He/She indicates “yes” or “no” by gesturing, nodding or talking	1	2	7	8

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B-30. The next statements are about different types of behavior in the last 2 weeks. After each statement, please answer "Agree" if the statement describes [RESIDENT] in the last 2 weeks or answer "Disagree" if it does not.

	Agree	Disagree	Don't Know	REFUSED
[QB_B30_1] He/She smiles or laughs or is cheerful	1	2	7	8
[QB_B30_2 ] He/She squeezes, twists or wrings his/her hands	1	2	7	8
[QB_B30_3 ] He/She throws, hits, kicks or bangs objects....	1	2	7	8
[QB_B30_4 ] He/She calls out, yells, curses or makes accusations	1	2	7	8
[QB_B30_5 ] He/She locks or barricades himself/herself in his/her room/house/apartment	1	2	7	8
[QB_B30_6] He/She is irritable or easily angered	1	2	7	8
[QB_B30_7 ] He/She says he/she wants to die	1	2	7	8
[QB_B30_8 ] He/She cries, wails, or frowns	1	2	7	8
[QB_B30_9 ] He/She shows delight	1	2	7	8
[QB_B30_10] He/She is restless and wound up, or repeats actions such as rocking, pacing, or banging against walls	1	2	7	8
[QB_B30_11] He/She resists help in different ways such as with dressing, eating or bathing, or by refusing to move	1	2	7	8
[QB_B30_12 ] He/She clings to people or follows people around	1	2	7	8
[QB_B30_13] He/She appears to be content or satisfied	1	2	7	8
[QB_B30_14 ] He/She talks of "feeling sick", "having pain" or "being cold"	1	2	7	8
[QB_B30_15 ] He/She shows a sense of humor	1	2	7	8

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B-40. The next statements are about usual activities in the last 2 weeks. After each statement, please answer “Agree” if the statement describes [RESIDENT] in the last 2 weeks or answer “Disagree” if it does not.

	Agree	Disagree	Don't Know	REFUSED
[QB_B40_1] He/She enjoys doing activities alone such as listening to music or watching TV	1	2	7	8
[QB_B40_2] He/She does <u>not</u> take part in activities he/she used to enjoy, even when encouraged to take part	1	2	7	8
[QB_B40_3] He/She sits quietly and appears to enjoy the activity of others even though he/she is not actively participating	1	2	7	8
[QB_B40_4] He/She shows <u>no</u> signs of pleasure or enjoyment when taking part in leisure activities or recreation	1	2	7	8
[QB_B40_5] He/She dozes off or does nothing most of the time	1	2	7	8

B-50. Now I'll ask about behavior in the facility. After each statement, please answer “Agree” if the statement describes [RESIDENT] in the last 2 weeks or answer “Disagree” if it does not [BL\_B50].

	Agree	Disagree	Don't Know	REFUSED
[QB_B50_1] He/She gets enjoyment from or is calmed by his/her possessions or belongings	1	2	7	8
[QB_B50_2] He/She talks about feeling <u>unsafe</u> or says his/her belongings are <u>not</u> safe	1	2	7	8
[QB_B50_3] He/She is upset or unsettled when in places other than where he/she lives	1	2	7	8
[QB_B50_4] He/She makes repeated attempts to leave	1	2	7	8
[QB_B50_5] He/She is upset or unsettled in his/her living environment	1	2	7	8
[QB_B50_6] He/She is comfortable moving around where he/she lives	1	2	7	8
[QB_B50_7] He/She talks about wanting to leave or go home	1	2	7	8

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C-10. [QB\_C10] During the **next 6 months**, what do you expect may happen to [RESIDENT], based on what you know about (HIS/HER) health?

0 = GET BETTER

1 = STAY ABOUT THE SAME

2 = GET WORSE

3 = GET MUCH WORSE AND POSSIBLY EVEN DIE

7 = DK

8 = REFUSED

D-10. [QB\_D10] In health care, when people have a serious illness like dementia, doctors and nurses will sometimes ask about the most important goal we are trying to achieve with treatment. The most common medical goals for treatment are prolonging life, supporting the person's ability to function, and improving comfort. Choosing the most important goal helps doctors and nurses choose treatments that are best for the individual, and fit with their and their family's values. I will ask you about [RESIDENT]'s choice first, then about your choice. If [RESIDENT] could be involved in this conversation, which of these goals do you think (HE/SHE) would say was most important right now in (HIS/HER) care and medical treatments?

1= PROLONGING LIFE

2= SUPPORTING FUNCTION

3= IMPROVING COMFORT

4= OTHER, SPECIFY

\_\_\_\_\_ [QB\_D10\_SP\_G1] \_\_\_\_\_

7= DON'T KNOW

8= REFUSED

D-20. [QB\_D20] Which goal would YOU say is the best goal to guide (HIS / HER) care and medical treatments?

1= PROLONGING LIFE

2= SUPPORTING FUNCTION

3= IMPROVING COMFORT

4= OTHER, SPECIFY

\_\_\_\_\_ [QB\_D20\_SP\_G1] \_\_\_\_\_

7= DON'T KNOW

8= REFUSED

D-30. [QB\_D30] Based on your discussions with the nursing home staff and physician, which of these goals is their top priority for (HIS / HER) care and medical treatment?

1 = PROLONGING LIFE

2 = SUPPORTING FUNCTION

3 = IMPROVING COMFORT

4= OTHER, SPECIFY

\_\_\_\_\_ [QB\_D30\_SP\_G1] \_\_\_\_\_

7 = DON'T KNOW

8 = REFUSED

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Prolonging life: prolong life as much as possible with medical treatment

Supporting function: keeping (him/her) as independent as possible, holding on to (his/her) function as much as possible with treatments they choose

Improving comfort: to improve the level of comfort with treatments as much as possible

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D-40. [QB\_D40] Can you talk about a recent incident that was challenging in regard to healthcare for your loved one.

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### **\*\*\*\*\*Read Script for the Video**

For B group: You will now view an excerpt of a video describing dementia and dementia care. The video is designed as a training tool for professional caregivers, but the information is also valuable for family members.

For A group: Next, you will view the decision aid that discusses Goals of Care for patients with memory loss. The decision aid is a resource tool which provides information to decision makers. It provides education about dementia, describes three medical goals of care, and clarifies what issues need to be considered when making healthcare decisions for someone with memory loss.

**REVIEW DVD HERE**

Surrogate ID#

Now, since you have reviewed the video about dementia and dementia care, I will ask you a few questions about caring for people with dementia, and your role helping to make decisions about their healthcare. For each statement please tell me if you think it is true or false.

#### KNOWLEDGE QUESTIONS ABOUT **DEMENTIA**

**TRUE FALSE UNSURE REFUSED**

E-10. [QB_E10] Dementia can be treated, but not cured	1	0	7	8
E-20. [QB_E20] People with dementia can improve over time	1	0	7	8
E-30. [QB_E30] People with advanced dementia have trouble doing simple tasks but they can always talk in full sentences	1	0	7	8
E-40. [QB_E40] The two most common complications of advanced dementia are infections and heart problems	1	0	7	8

#### KNOWLEDGE QUESTIONS ABOUT **DECISION-MAKING FOR SOMEONE WITH DEMENTIA**

**TRUE FALSE UNSURE REFUSED**

E-50. [QB_E50] The first step in decision-making is to consider the values of the patient	1	0	7	8
E-60. [QB_E60] I should make decisions based on what I would want for myself if I had dementia	1	0	7	8
E-70. [QB_E70] The family decision-maker is the only one involved in treatment decisions for someone with dementia.	1	0	7	8
E-80. [QB_E80] Personal, religious and cultural values should be considered in deciding about goals of care for someone with dementia.	1	0	7	8

**Now that you've reviewed the video, I'd like to ask you again about the idea of goals of medical care. You might answer the very same way as before, or the video might have made you consider the goals of medical care and treatments for [RESIDENT] somewhat differently – any answer is fine.**

F-10. [QB\_F10] In health care, when people have a serious illness like dementia, doctors and nurses will sometimes ask about the most important goal we are trying to achieve with treatment. The most common medical goals for treatment are prolonging life, supporting the person's ability to function, and improving comfort. Choosing the most important goal helps doctors and nurses choose treatments that are best for the individual, and fit with their and their family's values. I will ask you about [RESIDENT]'s choice first, then about your choice. If [RESIDENT] could be involved in this conversation, which of these goals do you think (HE/SHE) would say was most important right now in (HIS/HER) care and medical treatments?

1= PROLONGING LIFE

2= SUPPORTING FUNCTION

3= IMPROVING COMFORT

4= OTHER, SPECIFY

\_\_\_\_\_ [QB\_F10\_SP\_G1] \_\_\_\_\_

7= DON'T KNOW

8= REFUSED

Surrogate ID#

F-20. [QB\_F20] Which goal would you say is the best goal to guide (HIS / HER) care and medical treatments?

1= PROLONGING LIFE

2= SUPPORTING FUNCTION

3= IMPROVING COMFORT

4= OTHER, SPECIFY

\_\_\_\_\_ [QB\_F20\_SP\_G1] \_\_\_\_\_

7= DON'T KNOW

8= REFUSED

F-30. [QB\_F30] Based on your discussions with the nursing home staff and physician, which of these goals is their top priority for (HIS / HER) care and medical treatment?

1 = PROLONGING LIFE

2 = SUPPORTING FUNCTION

3 = IMPROVING COMFORT

4= OTHER, SPECIFY

\_\_\_\_\_ [QB\_F30\_SP\_G1] \_\_\_\_\_

7 = DON'T KNOW

8 = REFUSED

G-10. [QB\_G10] What are personal goals for [RESIDENT]? By this question I mean what do you see as enhancing (HIS / HER) quality of life or meaning in life? What does (HE / SHE) look forward to or get pleasure from? \_\_\_\_\_

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You told me that you think \_\_\_\_\_[ANSWER TO F20]\_\_\_\_\_ is the best goal to guide [RESIDENT's] care and medical treatments now. Now I'd like to ask you about a series of treatments and see if you think these should or should not be used if care is focused on the primary goal of PROLONGING LIFE, SUPPORTING FUNCTION, OR IMPROVING COMFORT (START WITH THE GOAL THEY CHOSE; ANSWER ALL)

If the primary goal of care and medical treatment for [RESIDENT] was prolonging life, would you use [specify treatment] in the prolonging life goal?

Prolonging Life		Definitely Use	Probably Use	Probably Not Use	Definitely Not Use	Don't Know
H-10 [QB_H10]	Life support with CPR and breathing machine use	1	2	3	4	7
H-20 [QB_H20]	Hospice	1	2	3	4	7
H-30 [QB_H30]	Hospital Admission	1	2	3	4	7
H-40 [QB_H40]	IV medicines and fluids	1	2	3	4	7
H-50 [QB_H50]	Tube feeding	1	2	3	4	7
H-60 [QB_H60]	Activities and therapies to strengthen movement	1	2	3	4	7
H-70 [QB_H70]	Emotional and spiritual support	1	2	3	4	7
H-80 [QB_H80]	Medicine for pain	1	2	3	4	7

H-90 [QB\_H90] Other treatments you can think of for this goal:

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Surrogate ID#

The next questions are focused on treatments for the supporting function goal. Would you use [specify treatment] in the supporting function goal?

Supporting Function		Definitely Use	Probably Use	Probably Not Use	Definitely Not Use	Don't Know
H-100 [QB_H100]	Life support with CPR and breathing machine use	1	2	3	4	7
H-110 [QB_H110]	Hospice	1	2	3	4	7
H-120 [QB_H120]	Hospital Admission	1	2	3	4	7
H-130 [QB_H130]	IV medicines and fluids	1	2	3	4	7
H-140 [QB_H140]	Tube feeding	1	2	3	4	7
H-150 [QB_H150]	Activities and therapies to strengthen movement	1	2	3	4	7
H-160 [QB_H160]	Emotional and spiritual support	1	2	3	4	7
H-170 [QB_H170]	Medicine for pain	1	2	3	4	7

H-180 [QB\_H180] Other treatments you can think of for this goal:

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Surrogate ID#

The next questions are focused on treatments for the improving comfort goal. Would you use [specify treatment] in the improving comfort goal?

Improving Comfort		Definitely Use	Probably Use	Probably Not Use	Definitely Not Use	Don't Know
H-190 [QB_H190]	Life support with CPR and breathing machine use	1	2	3	4	7
H-200 [QB_H200]	Hospice	1	2	3	4	7
H-210 [QB_H210]	Hospital Admission	1	2	3	4	7
H-220 [QB_H220]	IV medicines and fluids	1	2	3	4	7
H-230 [QB_H230]	Tube feeding	1	2	3	4	7
H-240 [QB_H240]	Activities and therapies to strengthen movement	1	2	3	4	7
H-250 [QB_H250]	Emotional and spiritual support	1	2	3	4	7
H-260 [QB_H260]	Medicine for pain	1	2	3	4	7

H-270 [QB\_H270] Other treatments you can think of for this goal:

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## DECISIONAL CONFLICT SCALE

The video you watched gave you some more information about dementia and dementia care. In addition, you have experience watching [RESIDENT] live with dementia, and helping to make choices about what care is best for (HIM / HER). Sometimes just thinking about a choice, like the choice to focus on a primary medical goal of prolonging life, supporting function, or promoting comfort in dementia care for a loved one, can be difficult. Please listen to the following comments that some people make when deciding about medical goals and treatments. I'd like for you to consider each statement based on choosing a main goal of care to guide treatment choices for [RESIDENT]. I'm going to give you this card that shows the choices. For each question I ask, please show me how strongly you agree or disagree with these comments, from 1 (strongly agree) to 5 (strongly disagree).

### I-10. UNCERTAINTY

**SA A N D SD DK R**

a. [QB_I10_a] This decision between a medical goal of care is easy for me to make	1	2	3	4	5	7	8
b. [QB_I10_b] I feel sure about what to choose	1	2	3	4	5	7	8
c. [QB_I10_c] I am clear about the best choice for [RESIDENT]	1	2	3	4	5	7	8

### I-20. INFORMED

**SA A N D SD DK R**

a. [QB_I20_a] I know the options available to choose a main goal of care to guide treatment choices for [RESIDENT]	1	2	3	4	5	7	8
b. [QB_I20_b] I know the benefits of each possible option	1	2	3	4	5	7	8
c. [QB_I20_c] I know the risks of each possible option	1	2	3	4	5	7	8

### I-30. VALUES CLARITY

**SA A N D SD DK R**

a. [QB_I30_a] I am clear about which benefits matter most for [RESIDENT]	1	2	3	4	5	7	8
b. [QB_I30_b] I am clear which risks matter most for [RESIDENT]	1	2	3	4	5	7	8
c. [QB_I30_c] I am clear about which is more important, the benefits or the risks	1	2	3	4	5	7	8

### I-40. SUPPORT

**SA A N D SD DK R**

a. [QB_I40_a] I have enough advice to make a choice	1	2	3	4	5	7	8
b. [QB_I40_b] I am choosing without pressure from others	1	2	3	4	5	7	8
c. [QB_I40_c] I have enough support from others to make this choice	1	2	3	4	5	7	8

### I-50 EFFECTIVE DECISION

(If no decision has been made, put DK)

**SA A N D SD DK R**

a. [QB_I50_a] I feel I have made an informed choice	1	2	3	4	5	7	8
b. [QB_I50_b] My decision shows what is most important for [RESIDENT]	1	2	3	4	5	7	8
c. [QB_I50_c] I expect to stick with my decision	1	2	3	4	5	7	8
d. [QB_I50_d] I am satisfied with my decision	1	2	3	4	5	7	8

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## ADVANCE DIRECTIVES AND FREQUENCY OF COMMUNICATION

I will now focus on Advance Directives and frequency of communication. I'd like to know if [RESIDENT] expressed any previous opinion about goals of care or treatments.

J-10. [QB\_J10] Does [RESIDENT] have a signed document about end-of-life care, like a living will, giving directions for the kind of medical treatment (HE/SHE) would want if (HE/SHE) had a serious illness and could not speak for (HIMSELF/HERSELF)?

0 = NO [SKIP TO J-30]

1 = YES

7 = DK [SKIP TO Q B-30]

8 = REFUSED [SKIP TO J-30]

J-20. [QB\_J20] Does this living will give information about whether or not [RESIDENT] would want life-sustaining treatment in the event of a life-threatening illness? *(If subject needs definition for life sustaining treatment use this one: Life sustaining treatments are any medical device or procedure that increases your life expectancy by restoring or taking over a vital bodily function. The medical device or procedure can be a drug, ventilator (breathing machine), surgery, therapy, or artificially provided fluids and nutrition.)*

0 = NO

1 = YES, INDICATES REFUSAL \_\_\_\_\_[QB\_J20\_SP\_1]\_\_\_\_\_

2 = YES, INDICATES ACCEPTANCE OF \_\_\_\_\_[QB\_J20\_SP\_2]\_\_\_\_\_

7 = DK

8 = REFUSED

J-30. [QB\_J30] Has [RESIDENT] ever expressed an opinion about whether or not (HE/SHE) would want life sustaining treatments in the event of a life-threatening illness?

0 = NO

1 = YES, INDICATES REFUSAL \_\_\_\_\_[QB\_J30\_SP\_1]\_\_\_\_\_

2 = YES, INDICATES ACCEPTANCE OF \_\_\_\_\_[QB\_J30\_SP\_2]\_\_\_\_\_

7 = DK

8 = REFUSED



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**Now I'd like to ask you some questions about your experience communicating with the nursing home staff and other health care providers about care for [RESIDENT]**

K-10. [QB\_K10] Please tell me how involved overall you feel you have been in making decisions related to [RESIDENT's ] treatment plan during resident's stay at the nursing home?

- 1 = NOT AT ALL INVOLVED; I MOSTLY RELIED ON THE PHYSICIAN AND CARE TEAM TO MAKE THESE DECISIONS
- 2 = SOMEWHAT INVOLVED; I CONTRIBUTED TO SOME OF THE DECISIONS MADE BY A PHYSICIAN OR MEMBERS OF THE CARE TEAM
- 3 = VERY INVOLVED; I HAD DETAILED DISCUSSIONS WITH THE PHYSICIAN OR MEMBERS OF THE CARE TEAM
- 7 = DK
- 8 = REFUSED

K-20. [QB\_K20] Did you participate in a Care Plan meeting in the last three months?

- 0 = No
- 1 = Yes
- 7 = DK
- 8 = Refused

FOR THE NEXT SET OF QUESTIONS, PLEASE THINK ABOUT ANY DISCUSSIONS CONCERNING **IMPORTANT** MEDICAL TREATMENTS OR HEALTH CARE GOALS, NOT JUST ROUTINE COMMUNICATION YOU HAVE WITH NURSING HOME STAFF.

K-30: [QB\_K30] At any point in [Resident's] stay at the nursing home, have you had a discussion with the nursing home staff [including nursing staff, social workers, administrative staff, etc.] about decisions regarding important medical treatments and health care goals for [RESIDENT]?

- 0 = No
- 1 = Yes SPECIFY STAFF ROLE \_\_\_\_\_[QB\_K30\_SP]\_\_\_\_\_
- 7 = DK
- 8 = Refused

K-40. [QB\_K40] At any point in [Resident's] stay at the nursing home, have you had any discussion with the nursing home physician who is taking care of [RESIDENT] about decisions regarding important medical treatments and health care goals for [RESIDENT]?

- 0= NO
- 1= YES
- 7= DK
- 8= REFUSED

K-50. [QB\_K50] At any point in [Resident's] stay at the nursing home, have you had any discussion with a nursing home Nurse Practitioner or Physician's Assistant who is taking care of [RESIDENT] about decisions regarding important medical treatments and health care goals for [RESIDENT]?

- 0 = NO / NOT PRESENT
- 1 = YES
- 7 = DK
- 8 = REFUSED

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K-60. [QB\_K60] At any point in [Resident's] stay at the nursing home, have you had a discussion with another physician– for example a physician in a hospital -- who was also taking care of [RESIDENT] about decisions regarding important medical treatments and health care goals for [RESIDENT]?

0 = NO

1 = YES, SPECIFY WHERE PHYSICIAN PRACTICES \_\_\_\_\_[QB\_K60\_SP]\_\_\_\_\_

7 = DK

8= REFUSED

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NOW, I'm going to ask a few more questions about communication with health care providers.

### Toolkit – Decision-Making Problem Score

<b>L-10.</b> [QB_L10]	In the past 3 months, how much information did the doctor and nursing home team provide you about [RESIDENT'S] medical condition – would you say less information than was needed, just the right amount, or more than was needed? (C1c)	<b>1 =</b> Less than was needed <b>2 =</b> Just the right amount <b>3 =</b> More than was needed <b>4 =</b> N/A <b>7 =</b> Don't Know
<b>L-20.</b> [QB_L20]	Does [RESIDENT] have, <u>or ever has had</u> , specific wishes or plans about the types of medical treatment (HE/SHE) does or does not want while dying? (D1)	<b>0 =</b> No <b>1 =</b> Yes <b>7 =</b> Don't know
<b>L-30.</b> [QB_L30]	To the best of your knowledge, did [RESIDENT'S] doctor or the nursing home staff speak to (HIM/HER) or you about (HIS/HER) wishes about medical treatment <u>since they have lived in the nursing home?</u> (D2)	<b>0 =</b> No <b>1 =</b> Yes <b>7 =</b> Don't Know
<b>L-40.</b> [QB_L40]	Did (HIS/HER) doctor or the nursing home staff speak to (HIM/HER) or you about making sure (HIS/HER) care was consistent with (HIS/HER) wishes <u>since they have lived in the nursing home?</u> (D3)	<b>0 =</b> No <b>1 =</b> Yes <b>7 =</b> Don't Know
<b>L-50.</b> [QB_L50]	In the past 3 months, was there any medical procedure or treatment that happened to (HIM/HER) that was inconsistent with (HIS/HER) previously stated wishes? (D4)	<b>0 =</b> No <b>1 =</b> Yes <b>7 =</b> Don't Know

Surrogate ID#

## QUALITY OF COMMUNICATION

NOW I'm going to ask you some questions about the QUALITY of communication you have experienced with health care providers. I'll ask you some questions about how good they are at talking with you about RESIDENT's illness and the types of care that he / she would want. We know that many people think highly of their doctors and nurses; so to help us improve communication please be critical.

FIRST I'm going to ask ONLY about the nursing home staff – including nurses, social workers, and any other staff members you usually communicate with about [RESIDENT]. Questions concerning the doctor are next. Using the following scale, where “0” is the worst you could imagine and “10” is the best you could imagine, please tell me the best number for each statement.

**When talking with the nursing home staff about important issues, how good are they at:**

M-10	Worst										Best	Didn't Do	Don't Know
a. [QB_M10_a] Using words that you can understand.	0	1	2	3	4	5	6	7	8	9	10	888	999
b. [QB_M10_b] Looking you in the eye.	0	1	2	3	4	5	6	7	8	9	10	888	999
c. [QB_M10_c] Answering all your questions about (RESIDENT'S) illness and treatment.	0	1	2	3	4	5	6	7	8	9	10	888	999
d. [QB_M10_d] Listening to what you have to say.	0	1	2	3	4	5	6	7	8	9	10	888	999
e. [QB_M10_e] Caring about (RESIDENT) as a person.	0	1	2	3	4	5	6	7	8	9	10	888	999
f. [QB_M10_f] Giving you his or her full attention.	0	1	2	3	4	5	6	7	8	9	10	888	999
g. [QB_M10_g] Talking with you about your feelings concerning the possibility that (RESIDENT) might get sicker.	0	1	2	3	4	5	6	7	8	9	10	888	999
h. [QB_M10_h] Talking to you about the details concerning the possibility that (RESIDENT) might get sicker.	0	1	2	3	4	5	6	7	8	9	10	888	999
i. [QB_M10_i] Talking to you about how long (RESIDENT) might live.	0	1	2	3	4	5	6	7	8	9	10	888	999
j. [QB_M10_j] Talking to you about what (RESIDENT'S) dying might be like.	0	1	2	3	4	5	6	7	8	9	10	888	999
k. [QB_M10_k] Involving you in the decisions about the treatments that (RESIDENT) would want.	0	1	2	3	4	5	6	7	8	9	10	888	999
l. [QB_M10_l] Asking about the things in life that are important to (RESIDENT).	0	1	2	3	4	5	6	7	8	9	10	888	999
m. [QB_M10_m] Asking about (RESIDENT'S) spiritual or religious beliefs.	0	1	2	3	4	5	6	7	8	9	10	888	999

Surrogate ID#

The next question has a different rating scale, 0 is the nursing home staff is not comfortable at all and 10 is they are extremely comfortable. Please tell me a number for the following statement.

	Not comfortable At all										Extremely comfortable	Hasn't Happened	Don't Know
<b>M-20</b> [QB_M20] How comfortable do you feel the nursing home staff is talking about dying?	0	1	2	3	4	5	6	7	8	9	10	888	999

**NOW, let's talk about the quality of communication you experience when talking with the [Resident's] doctor, or with the nurse practitioner or physician's assistant who also takes care of [RESIDENT]. Do you have someone in mind? When talking about important issues, how good are they at:**

<b>M-30</b>	<b>Worst</b>										<b>Best</b>	<b>Didn't Do</b>	<b>Don't Know</b>
a. [QB_M30_a] Using words that you can understand.	0	1	2	3	4	5	6	7	8	9	10	888	999
b. [QB_M30_b] Looking you in the eye.	0	1	2	3	4	5	6	7	8	9	10	888	999
c. [QB_M30_c] Answering all your questions about (RESIDENT'S) illness and treatment.	0	1	2	3	4	5	6	7	8	9	10	888	999
d. [QB_M30_d] Listening to what you have to say.	0	1	2	3	4	5	6	7	8	9	10	888	999
e. [QB_M30_e] Caring about (RESIDENT) as a person.	0	1	2	3	4	5	6	7	8	9	10	888	999
f. [QB_M30_f] Giving you his or her full attention.	0	1	2	3	4	5	6	7	8	9	10	888	999
g. [QB_M30_g] Talking with you about your feelings concerning the possibility that (RESIDENT) might get sicker.	0	1	2	3	4	5	6	7	8	9	10	888	999
h. [QB_M30_h] Talking to you about the details concerning the possibility that (RESIDENT) might get sicker.	0	1	2	3	4	5	6	7	8	9	10	888	999
i. [QB_M30_i] Talking to you about how long (RESIDENT) might live.	0	1	2	3	4	5	6	7	8	9	10	888	999
j. [QB_M30_j] Talking to you about what (RESIDENT'S) dying might be like.	0	1	2	3	4	5	6	7	8	9	10	888	999
k. [QB_M30_k] Involving you in the decisions about the treatments that (RESIDENT) would want.	0	1	2	3	4	5	6	7	8	9	10	888	999
l. [QB_M30_l] Asking about the things in life that are important to (RESIDENT).	0	1	2	3	4	5	6	7	8	9	10	888	999
m. [QB_M30_m] Asking about (RESIDENT'S) spiritual or religious beliefs.	0	1	2	3	4	5	6	7	8	9	10	888	999

Surrogate ID#

The next question has a different rating scale, 0 is the doctor, physician's assistant or nurse practitioner is not comfortable at all and 10 is they are extremely comfortable. Please tell me a number for the following statement.

	Not comfortable At all											Extremely comfortable	Hasn't Happened	Don't Know
M-40 [QB_M40] How comfortable do you feel the nursing home doctor, physician's assistant or nurse practitioner is talking about dying?	0	1	2	3	4	5	6	7	8	9	10		888	999

M-50. [QB\_M50] Who– including the doctor, nurse practitioner, physician's assistant, nurses, social workers – do you most often depend on for communication about the questions I've just asked?

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M-60. [QB\_M60] Who– including the doctor, nurse practitioner, physician's assistant, nurses, social workers – are you least likely to communicate with about the questions I've just asked?

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M-70. [QB\_M70] Who– including the doctor, nurse practitioner, physician's assistant, nurses, and social workers – would you most like to have improved communication with?

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M-80. [QB\_M80] When is the best time and best way for you and the nursing home team to communicate about the questions I've just asked? [PROBE: Is the Care Plan Meeting a good time? If so, why? If not, when would you prefer?]

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Surrogate ID#

## End-of-Life in Dementia (EOLD) Scales

### N. Satisfaction with Care (SWC-EOLD)

Now we'll move onto the next section. This will focus on your satisfaction with care during **the last month**. Think about the doctors, nurses and other staff at the nursing home that you came into contact with during [RESIDENT'S] **last month**. How strongly do you feel these statements reflect your experience? For each please tell me if you strongly disagree, disagree, agree, or strongly agree.

		Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know
N-10. [QB_N10]	I felt fully involved in all decision making.	1	2	3	4	7
N-20. [QB_N20]	I would probably have made different decisions if I had had more information.	1	2	3	4	7
N-30. [QB_N30]	All measures were taken to keep [RESIDENT] comfortable.	1	2	3	4	7
N-40. [QB_N40]	The health care team was sensitive to my needs and feelings.	1	2	3	4	7
N-50. [QB_N50]	I did not really understand [RESIDENT'S] condition.	1	2	3	4	7
N-60. [QB_N60]	I always knew which doctor or nurse was in charge of [RESIDENT'S] care.	1	2	3	4	7
N-70 [QB_N70].	I felt that [RESIDENT] got all necessary nursing assistance.	1	2	3	4	7
N-80. [QB_N80]	I felt that all medication issues were clearly explained to me.	1	2	3	4	7
N-90. [QB_N90]	[RESIDENT] received all treatments or interventions that [HE/SHE] could have benefited from.	1	2	3	4	7
N-100. [QB_N100]	I feel that [RESIDENT] needed better medical care during the last month.	1	2	3	4	7

Surrogate ID#

**O. Symptom Management at the End of Life (SM-EOLD)**

Now if you would think about [RESIDENT'S] physical and emotional state during the **last month**. How often do you think [RESIDENT] experienced the following?

	Never	Once A Month	2 or 3 Days A Month	Once A Week	Several Days A Week	Every Day	Don't Know
O-10. [QB_O10] Pain	0	1	2	3	4	5	7
O-20. [QB_O20] Shortness of breath	0	1	2	3	4	5	7
O-30. [QB_O30] Skin breakdown	0	1	2	3	4	5	7
O-40. [QB_O40] Calm	0	1	2	3	4	5	7
O-50. [QB_O50] Depression	0	1	2	3	4	5	7
O-60. [QB_O60] Fear	0	1	2	3	4	5	7
O-70. [QB_O70] Anxiety	0	1	2	3	4	5	7
O-80. [QB_O80] Agitation	0	1	2	3	4	5	7
O-90. [QB_O90] Resistance to care	0	1	2	3	4	5	7

[Note: Skin breakdown refers to pressure sores only. 1= one day, 2 = 2 or 3 days, 3 = one week, 4 = more than one week but less than one month, and 5 = every day]

Anxiety: a state of uneasiness of mind, fearful concern or interest, displeasing feeling of fear and concern (internal and emotional)

Agitation: Restlessness, uneasy, distressed, unsettled (external and shown by outward behavior)



Surrogate ID#

## P. Spiritual Well-being scale (FACIT-Sp)

We're getting near the end of the interview – thanks for being so patient! My next questions are about how you have been feeling, and where you turn for strength as a caregiver. The questions are answered not at all, a little bit, somewhat, quite a bit, or very much. The questions are based on *how you felt in the past 7 days*.

	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much	Refused
P-10. [QB_P10] I feel peaceful.	0	1	2	3	4	8
P-20. [QB_P20] I have a reason for living.	0	1	2	3	4	8
P-30. [QB_P30] My life has been productive.	0	1	2	3	4	8
P-40. [QB_P40] I have trouble feeling peace of mind.	0	1	2	3	4	8
P-50. [QB_P50] I feel a sense of purpose in my life.	0	1	2	3	4	8
P-60. [QB_P60] I am able to reach down deep inside myself for comfort.	0	1	2	3	4	8
P-70. [QB_P70] I feel a sense of harmony within myself.	0	1	2	3	4	8
P-80. [QB_P80] My life lacks meaning and purpose.	0	1	2	3	4	8
P-90. [QB_P90] I find comfort in my faith or spiritual beliefs.	0	1	2	3	4	8
P-100. [QB_P100] I find strength in my faith or spiritual beliefs.	0	1	2	3	4	8
P-110. [QB_P110] [RESIDENT'S] illness has strengthened my faith or spiritual beliefs.	0	1	2	3	4	8
P-120. [QB_P120] I know that whatever happens with [RESIDENT'S] illness, things will be okay.	0	1	2	3	4	8

If Decision Maker answered 0 at least one of the following questions: P-20, P-50 or P-80=2,3, or 4, please use this script:

"Your answers to the last set of questions indicate you may need some extra support to help you deal with how you are feeling as other people do in situations similar to yours. I can give you the name of the on-site social worker at the nursing home for support or refer you to Hospice for grief support"

Surrogate ID#

## Q. DEMOGRAPHICS

<p>Q-10. [QB_Q10] What is [RESIDENT'S] marital status? Is (HE/SHE) never married, married, widowed, separated, or divorced?</p>	<p>1 = NEVER MARRIED  2 = MARRIED  3 = WIDOWED  4 = SEPARATED  5 = DIVORCED  7 = DON'T KNOW  8 = REFUSED</p>
<p>Q-20. [QB_Q20] Is (HE/SHE) READ CHOICES.</p>	<p>1 = HISPANIC OR LATINO  2 = NOT HISPANIC OR LATINO  7 = DON'T KNOW  8 = REFUSED</p>
<p>Q-30. [QB_Q30] What is (HIS/HER) race?</p>	<p>1 = American Indian or Alaska Native  2 = Asian  3 = Black or African American  4 = Native Hawaiian or Other Pacific Islander  5 = White  6 = Other—Specify: _____ [QB_Q30_SP] _____  7 =Don't Know  8 =Refused</p>
<p>Q-40. [QB_Q40] And what is (HIS/HER) religious affiliation?  READ CHOICES IF UNABLE TO ELICIT:</p>	<p>01 = Jewish  02 = Catholic  03 = Jehovah's Witness  04 = Christian Scientist  05 = Seventh Day Adventist  06 = Protestant (includes Methodist, Episcopal, Presbyterian, Christian, and Lutheran)  07 = Native American  08 = Muslim  09 = Buddhist  10 = Baptist  11 = No religion  12 = Other—Specify: _____ [QB_Q40_SP] _____  88 = REFUSED  99 = NA</p>

Surrogate ID#

## R. SURROGATE DEMOGRAPHICS

R-10. [QB_R10] Surrogate Gender (DO NOT ASK)	1 = MALE 2 = FEMALE 7 = DON'T KNOW 8 = REFUSED
R-20. [QB_R20] What is your age?	(USE DROPDOWN BOX, INCLUDING AGE IN YEARS AND THE OTHER TWO ANSWERS _____ <b>YEARS</b> 7 = DON'T KNOW 8 = REFUSED
R-30. [QB_R30] Are you: READ CHOICES.	1 = Hispanic or Latino 2 = Not Hispanic or Latino 7 = DON'T KNOW 8 = REFUSED
R-40. [QB_R40] What is your race?	1 = American Indian or Alaska Native 2 = Asian 3 = Black or African American 4 = Native Hawaiian or Other Pacific Islander 5 = White 6 = Other—Specify: _____ [QB_R40_SP] _____ 7 = Don't Know 8 = Refused
R-50. [QB_R50] What is your highest educational level?	1 = Less than high school 2 = High school graduate 3 = Some college/vocational school 4 = College graduate 5 = Advanced degree 7 = Don't Know 8 = Refused
R-60. [QB_R60] And what is your religious affiliation? READ CHOICES IF UNABLE TO ELICIT.	01 = Jewish 02 = Catholic 03 = Jehovah's Witness 04 = Christian Scientist 05 = Seventh Day Adventist 06 = Protestant (includes Methodist, Episcopal, Presbyterian, Christian, and Lutheran) 07 = Native American 08 = Muslim 09 = Buddhist 10 = Baptist 11 = No religion 12 = Other—Specify: _____ [QB_R60_SP] _____ 88 = REFUSED 99 = NA
R-70. [QB_R70] To what extent do you consider yourself a religious or spiritual person? READ CHOICES	01 = Very religious / spiritual 02 = Moderately religious / spiritual 03 = Slightly religious / spiritual 04 = Not religious / spiritual at all 7 = DON'T KNOW 8 = REFUSED 9 = NA

Surrogate ID#

S-80. [QB\_S80] What is your relationship to [RESIDENT]? **CIRCLE RESPONSE.**

<b>RESPONDENT RELATIONSHIP TO RESIDENT</b>	01 = SPOUSE 02 = BROTHER 03 = BROTHER- IN-LAW 04 = SON 05 = SON-IN- LAW 06 = GRANDSON 07 = NEPHEW 08 = FATHER	09 = SISTER 10 = SISTER-IN- LAW 11 = DAUGHTER 12 = DAUGHTER-IN- LAW 13 = GRANDDAUGHTER 14 = NIECE 15 = MOTHER	16 = OTHER RELATIVE 17 = FRIEND, NEIGHBOR 18 = NON-RELATED PAID HELPER  19 = OTHER  SPECIFY: ____[QB_S80_SP]____  77 = DON'T KNOW 88 = REFUSED
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S-81. [QB\_S81] Number of Additional Respondents: \_\_\_\_\_  
Specify relationship of respondents to resident [QB\_S81\_SP]: \_\_\_\_\_

Thank you for completing the first interview.

**For "A group" only:** You will attend a care plan meeting in the next few weeks at the nursing home. The nursing home will contact you to set up a day and time for the care plan meeting. We have a copy of the decision aid for you to review and a care plan guide. Please share the decision aid with only your family members. Once the decision aid trial is complete we will distribute to the nursing homes.

I will call you in 3 months for the follow-up telephone interview.

Thank you for participating in the study and helping us learn more about decision making related to Goals of Care for people with dementia. You will receive a \$35 gift card in the mail in the next 1-2 weeks.

**For "B group":** I will call you in 3 months for the follow-up telephone interview.

Thank you for participating in the study and helping us learn more about decision making related to Goals of Care for people with dementia. You will receive a \$35 gift card in the mail in the next 1-2 weeks.