

HRS 2018 -- MODULE 9: END OF LIFE DECISIONS

FINAL VERSION -- 06/01/2018

NOTE ABOUT BRANCHPOINTS:

Where there is more than one jump within a branchpoint box, the jumps are to be applied in order from the top.

NOTE ABOUT COLORS AND MODE:

All question text in black is for the core interview (except if CAPI and CAWI text is the same).

Question text and codes in teal denotes CAWI (Web). The CAWI text will always be directly after the CAPI text. If wording is the same in both CAPI (Iwer Administered) and CAWI (Web), the text is black.

Otherwise, black text for codeframes, interviewer instructions, jumps and branchpoints, etc., which can apply to both the CAPI and the CAWI interview unless specified otherwise or there is a CAWI alternative.

On a black-and-white hard copy of the document, the TEAL text will appear somewhat lighter than the original black.

NOTE ABOUT NON-RESPONSE FLOW:

ANY QUESTION THAT IS ASKED BUT LEFT WITHOUT A RESPONSE IN CAWI INTERVIEWS WILL FOLLOW THE SAME PATH AS A REFUSAL FOR THAT QUESTION, UNLESS OTHERWISE SPECIFIED.

MAJOR FLOW CONTROL, CONDITION AND FILL VARIABLES

IF RANDOM X009 (1-10) = 9

IF THIS IS A PROXY INTERVIEW (A009={2 or 3}), GO TO END OF MODULE 8 [SELF-INTERVIEWS ONLY]

V551 BRANCHPOINT: ASK IF X009 = 9 AND THIS IS A SELF INTERVIEW (A009 = 1), ELSE GO TO END OF MODULE

V551_PREFER

Now we have some questions about health care treatments that you might want in certain situations and about how you would like health care decisions to be made.

How do you prefer to make medical decisions with your doctor? Do you prefer to make these decisions on your own, make decisions together with your doctor, or to have your doctor make all medical decisions for you?

1. YOU MAKE THESE DECISIONS ON YOUR OWN
2. YOU AND YOUR DOCTOR MAKE DECISIONS ABOUT YOUR CARE TOGETHER
3. YOUR DOCTOR MAKES ALL MEDICAL DECISIONS FOR YOU
1. I MAKE THESE DECISIONS ON MY OWN
2. MY DOCTOR AND I MAKE DECISIONS ABOUT MY CARE TOGETHER
3. MY DOCTOR MAKES ALL MEDICAL DECISIONS FOR ME

V552_

Imagine that you are ill and cannot make decisions. A loved one is making decisions for you. How would you like them to decide what to do? Would you like your loved one to decide what they think is best, your loved one to make decisions together with your doctor, or to have your doctor make medical decisions alone?

1. YOUR LOVED ONE DECIDES WHAT THEY THINK IS BEST
2. YOUR LOVED ONE AND DOCTOR MAKE MEDICAL DECISIONS TOGETHER
3. YOUR DOCTOR MAKES MEDICAL DECISIONS ALONE
1. MY LOVED ONE DECIDES WHAT THEY THINK IS BEST
2. MY LOVED ONE AND DOCTOR MAKE MEDICAL DECISIONS TOGETHER
3. MY DOCTOR MAKES MEDICAL DECISIONS ALONE

V553_

Would you like your loved ones to donate your organs to help a patient recover their vision, restore kidney function, or treat other chronic diseases after your death?

1. YES
5. NO

V554_

Imagine that you have brain damage or some brain disease like dementia which cannot be cured. This condition makes you unable to recognize people and speak understandably. You are physically healthy and could live in this condition for a long time. For each of the following treatments, let us know if you would want the treatment, would not want the treatment, or are unsure if you would want the treatment.

1. CONTINUE

V555_

First, treatments that extend length of life but may be invasive or painful such as placing a feeding tube into your stomach for liquid food if you cannot eat on your own, or chest compressions to restart your heart if your heart stops beating, or major surgery like open heart surgery. Would you want this treatment, not want this treatment, or are you unsure if you would want the treatment?

1. WANT THIS TREATMENT
2. NOT WANT THIS TREATMENT
3. UNSURE ABOUT THIS TREATMENT
1. I WOULD WANT THIS TREATMENT
2. I WOULD NOT WANT THIS TREATMENT
3. I'M UNSURE ABOUT THIS TREATMENT

V556_

Next, treatments with few side effects, like providing fluids through your veins to give you water if you cannot drink enough on your own or antibiotics if you develop an infection. Would you want this treatment, not want this treatment, or are you unsure if you would want the treatment?

1. WANT THIS TREATMENT
2. NOT WANT THIS TREATMENT
3. UNSURE ABOUT THIS TREATMENT
1. I WOULD WANT THIS TREATMENT
2. I WOULD NOT WANT THIS TREATMENT
3. I'M UNSURE ABOUT THIS TREATMENT

V557_

How about efforts to keep you as comfortable as possible, including pain medications -- would you want this treatment, not want this treatment, or are you unsure if you would want the treatment?

1. WANT THIS TREATMENT
2. NOT WANT THIS TREATMENT
3. UNSURE ABOUT THIS TREATMENT
1. I WOULD WANT THIS TREATMENT
2. I WOULD NOT WANT THIS TREATMENT
3. I'M UNSURE ABOUT THIS TREATMENT

V558_

Now imagine that you are unconscious due to a sudden, severe disease such as a heart attack. Your doctors believe that treatments can extend your life, but would leave you unable to get out of bed or move around without assistance for the rest of your life. You would not have memory or speech problems. For each of the following treatments, let us know if you would want the treatment, would not want the treatment, or are unsure if you would want the treatment as part of your care.

1. CONTINUE

V559_

Would you want treatments that extend length of life but may be invasive or painful such as placing a feeding tube into your stomach for liquid food if you cannot eat on your own, or chest compressions to restart your heart if your heart stops beating, or major surgery like open heart surgery? Would you want this treatment, not want this treatment, or are you unsure if you would want the treatment?

1. WANT THIS TREATMENT
2. NOT WANT THIS TREATMENT
3. UNSURE ABOUT THIS TREATMENT
1. I WOULD WANT THIS TREATMENT
2. I WOULD NOT WANT THIS TREATMENT
3. I'M UNSURE ABOUT THIS TREATMENT

V560_

Next, treatments with few side effects, like providing fluids through your veins to give you water if you cannot drink enough on your own or antibiotics if you develop an infection. Would you want this treatment, not want this treatment, or are you unsure if you would want the treatment?

1. WANT THIS TREATMENT
2. NOT WANT THIS TREATMENT
3. UNSURE ABOUT THIS TREATMENT
1. I WOULD WANT THIS TREATMENT
2. I WOULD NOT WANT THIS TREATMENT
3. I'M UNSURE ABOUT THIS TREATMENT

V561_

How about efforts to keep you as comfortable as possible, including pain medications -- would you want this treatment, not want this treatment, or are you unsure if you would want the treatment?

1. WANT THIS TREATMENT
2. NOT WANT THIS TREATMENT
3. UNSURE ABOUT THIS TREATMENT

1. I WOULD WANT THIS TREATMENT
2. I WOULD NOT WANT THIS TREATMENT
3. I'M UNSURE ABOUT THIS TREATMENT

V562_

Thank you very much for answering these questions. We know these issues are difficult to think about. Your opinions on these matters are very important.

1. CONTINUE

[END MODULE]

