Supplement A. Aortic Stenosis Patient Interview Guide for TAVI, SAVR, and MM

Introductions and Explanation of Interview Process:

Hello, thank you for taking the time to speak with me today. My name is [provide name]and I am from the American Heart Association. Our team is interested in talking with you today to better understand your personal experiences and perspectives as you've navigated your Aortic Stenosis diagnosis and treatment journey. Aortic Stenosis is a heart valve disease where your heart valve is tight or narrowed. You may have been told that you have a “leaky valve”.

To help capture the information you share with me, we will use an interview format. I will ask you a series of open-ended questions that are designed to encourage you to talk freely and openly about your experiences. There are no right or wrong answers to my questions. The interview will last approximately an hour. I would like to audio record our conversation today to help with our note taking process. All information collected on the recording will be kept confidential and anything you say today will not be shared in any way that identifies you personally.

Do I have your permission to proceed with the audio recording?

Before we begin, do you have any questions?

1. **Aortic Stenosis Initial Symptomology and Pre-Diagnosis Experience**

Now let’s talk about how you first came to realize you have aortic stenosis.

1. First, before you knew you had aortic stenosis, did you experience any symptoms related to the condition?
   * [If yes:] tell me about any symptoms you initially felt or experienced that you think were the first signs of having aortic stenosis?
2. Tell me about what initially caused you to see a doctor or other healthcare provider for your aortic stenosis?
3. **Aortic Stenosis Diagnosis Experience**

Next, let’s talk about your experiences with your doctors or other healthcare providers when you were diagnosed with aortic stenosis.

1. What type(s) of healthcare provider(s) did you see when you were going through the process of being diagnosed with aortic stenosis?
2. How much time passed between when you first saw a healthcare provider for your symptoms and when you got a diagnosis aortic stenosis?
3. When you were told that you have aortic stenosis, what did your doctors or other healthcare providers explain to you about the disease?
4. **Aortic Stenosis Symptoms and Management**

MM: Next, let’s talk about your current symptoms.

TAVI or SAVR: Next, let’s talk about the symptoms you experienced prior to your treatment.

1. MM: Tell me about the symptoms related to aortic stenosis that you experienced in the past month.

TAVI or SAVR: Tell me about the symptoms related to aortic stenosis that you experienced *prior* to having your valve replacement.

* 1. How frequently do (did) you experience this?
  2. Describe for me what that symptom feels (felt) like.

1. MM: tell me about any changes you make or have made to your day-to-day life because of your aortic stenosis symptoms?

TAVI or SAVR: Tell me about any changes you made to your day-to-day life because of your aortic stenosis symptoms prior to your valve replacement?

1. TAVI or SAVR: Now let’s talk about the symptoms related to your aortic stenosis that you may have experienced after your valve replacement. Tell me about the symptoms related to aortic stenosis that you experiencedafter you *recovered* from the surgery to have your valve replaced.
   1. How frequently do you experience this?
   2. Describe for me what that symptom feels like.
   3. Describe for me how this symptom has changed over time.
2. TAVI or SAVR: Tell me about any changes you make or have made to your day-to-day life because of your aortic stenosis symptoms after your valve replacement?
3. **Aortic Stenosis Treatment and Shared Decision Making**
4. Think back to when you were making the decisions about what treatment options you had for your aortic stenosis. Talk to me about your experience learning about the types of treatment options related to your aortic stenosis.
5. After learning about your potential treatment options, how did you and your doctor decide on what treatment for aortic stenosis was best for you?
   1. What sort of factors influenced your decision for your treatment option? Tell me about what you considered when making the decision?
   2. Tell me about any concerns you had when deciding which treatment options for aortic stenosis was right for you.
   3. Tell me about how comfortable you felt discussing those concerns to your doctor or other healthcare providers.
6. How do you currently feel about the treatment option that you made for your aortic stenosis?
7. TAVI or SAVR: If someone is considering having TAVI or SAVR, what do you think they should know?

MM: If someone is managing their aortic stenosis with medications only, what do you think they should know?

1. TAVI or SAVR: Now, think back to when you had your valve replacement. Talk to me about your experience immediately after your procedure.
2. MM, TAVI or SAVR: Talk to me about anyone that helps you manage your aortic stenosis.
3. **Experiences Living with Aortic Stenosis**

Next, I would like to talk about how aortic stenosis impacts your life day-to-day.

1. Imagine you are talking to someone who knows nothing about aortic stenosis.

MM: How would you describe what it is like for you to live with aortic stenosis?

TAVI or SAVR: How would you describe what it was like for you to live with aortic stenosis prior to your valve replacement?

1. TAVI or SAVR: How would you describe what it is like for you to live with aortic stenosis after your valve replacement?
2. In general, tell me how you feel about having aortic stenosis.
3. **Tools and Resources for Patients with Aortic Stenosis**

We are almost finished. The last thing we want to talk to you about is how the American Heart Association can best develop resources and tools that would be most helpful to people living with aortic stenosis.

1. *[only for patients that had symptoms leading to diagnosis – mentioned in section a]:* Think back to when you first noticed your aortic stenosis symptoms.
   1. What advice would you have for a patient newly diagnosed with aortic stenosis, based on your experience that would have made a positive difference in your journey?
   2. What do you think would be most helpful to tell people about aortic stenosis that might help them recognize their symptoms earlier?
2. Think back to when you first learned that you had aortic stenosis. What types of resources or tools did you use to help understand the diagnosis of aortic stenosis?
3. What do you think would have been helpful for a person newly diagnosed with aortic stenosis to help them understand what aortic stenosis is?
4. What types of resources or tools did you use initially to understand what the treatment options were for aortic stenosis?
5. What types of resources or tools do you think would be helpful for a newly diagnosed person to understand what the treatment options are?
6. Were there any tools or resources that helped you to communicate with your doctor or other healthcare provider about your treatment options?
7. MM: Think about your life today living with aortic stenosis. What types of resources or tools do you think would be helpful for a newly diagnosed person to help them manage their aortic stenosis?

We sincerely appreciate your time today. Your input has been so valuable for the American Heart Association!