

Appendix 1: Structured Interview Questions

1. Diagnosis of SUI (incontinence – urinary leakage)

- We first want to understand your experience with incontinence, or urinary leakage. Walk me through the process of getting to the surgeon who talked with you about treatment for urinary leakage.
 - o Who did you first talk with about incontinence?
 - o Who or what motivated you to talk to your doctor about treatment options?
 - o What was your goal in discussing treatment?

□ Severity/burden of SUI

- How much did the leakage bother you?
- How did SUI change your lifestyle, relationships, or affect your quality of life?

□ Motivations for seeking counsel/treatment

- Overall what were your biggest concerns about your SUI?
- Before your consultation with Dr. xxx at UCSF/VA, did you learn about any treatment options (conservative or surgical) from anyone else? Who was that (PCP, local urologist, friends, support group, etc)?
- What went into your decision to seek treatment for your incontinence?
 - o What was motivating you?
 - o Was there anything that dissuaded you or made you nervous? (minimal leakage, concerns about treatment, concerns about urologists, etc)
- Did you have anyone to talk with about incontinence besides your doctor? (family, friends, support groups)

□ Initial interactions with provider about incontinence

- How long after you began to experience symptoms did you seek treatment?
- How was your incontinence diagnosed?
- What were you told was the cause of your incontinence?
- What did your physician tell you at the time regarding your prognosis for incontinence? Did s/he expect things to improve, stay stable, or get worse?
- Did you try any interventions or treatments on your own before seeking treatment?
 - o Did these treatments improve your SUI symptoms?

2. Treatment Options

- When you met with (Dr. xxxx), tell me about that conversation.
 - o Do you recall what treatment options they gave you?
 - o How did you think about those options?
 - o What were the benefits and downsides of these options?

□ Choice?

- Do you recall what options the surgeon gave you?
- Did you feel like choosing to do nothing was an option?
- Do you remember hearing about conservative management options (penile clamp, kegels, condom catheter)?

☐ Risks and benefits

- Do you recall any of the risks or benefits the surgeon discussed about the sling or sphincter?
- In your mind, what were the benefits of sling surgery? What were the downsides?
- In your mind, what were the benefits of sphincter surgery? What were the downsides?

3. Treatment Decision

- **When you were deciding whether or not to have surgery (and what type of surgery if you had options), what was important to you?**
- **Why did you decide on (treatment decision)?**

☐ Decision-making

- How did you and your physician come to a treatment decision?
 - ☐ Who was most influential in deciding which treatment to pursue – you, your surgeon, or someone else?
- Did you feel that you had enough information to make a decision? If not, what other information would you have liked to have?
 - ☐ What made you decide on that treatment?

☐ Risks and benefits

- ☐ Ultimately, what were the main factors that influenced your decision to undergo/not undergo implantation of the sling?
- ☐ Ultimately, what were the main factors that influenced your decision to undergo/not undergo implantation of the sphincter?
- ☐ Ultimately, what were the main factors that influenced your decision not to have surgery?

☐ Influence of incontinence impact

- How did the severity of your incontinence influence your decision?
- How did the impact on your day to day life influence your decision?
- Were there any aspects of your life that were particularly impacted by the incontinence that influenced your decision?

☐ Influence of others

- How did your physician's recommendation influence your treatment decision?
- Did you discuss your options with your partner, family or friends?
- Why did you feel this was the right choice for you?
- Did you seek multiple opinions about surgery?
- What did you use to inform your decision about surgery?

☐ Influence of sexual health

- How much did the incontinence impact your sexual function? Was this a motivating factor for you in pursuing treatment?

☐ Medical/surgical history

- How did your medical history or other urologic conditions affect your treatment options?
- How did your overall health status play a role in this decision? Did you have other medical conditions that influenced your decision?
- How did your prior surgical history affect your treatment options?

☐ Mental/emotional health

- A lot of men dealing with incontinence have a lot of depression or anxiety associated with it. Did that happen to you?
Did that impact your decision to pursue treatment?

☐ Thoughts and feelings about:

☐ Surgery in general

- Why did or did you not choose surgery?
- Did you have any concerns about undergoing surgery in general?

4. Surgical expectations

- **Going into surgery, you probably had some expectations about the outcome. What were your treatment goals and expectations? (Pause for narrative response)**

☐ Pre-surgery goals and expectations

☐ Did you want to be completely dry?

☐ Did you expect to be completely dry after surgery?

- What were your expectations about how your symptoms might improve following your surgery? How likely did you feel it was that your expectations would be met?
- Did you have any expectation of how things might change over time after surgery?

☐ Experience with pre-surgical counsel

- Do you remember the surgeon telling you about the likelihood of you being completely dry after surgery?
- Is there anything the surgeon told you ahead of time that you found important or valuable?
- What didn't the surgeon tell you that you wish you had known?

5. Surgical outcomes

- **How did your surgery measure up to your expectations?**

☐ Experience with pre-surgical counsel

- What didn't the surgeon tell you that you wish you had known?

☐ Surgical outcome

- How did the outcome of your surgery compare to your expectations?
- Did you experience any post-surgical complications? Did that play a role?

☐ Reflection on personal decision making process

☐ **Looking back, what was important for you to know ahead of time about the surgery?**

What do you wish you would have considered prior to surgery that you did not?

☐ What do you feel are the most important factors to consider for older men with incontinence facing a treatment decision?

☐ If you were to go back in time, would you make the same choice again? Why or why not?

☐ How the decision-making could have been aided/improved

☐ **What do you wish you would have known prior to surgery that you did not?**

- Is there anything that you wish the surgeon would have told you ahead of time that you know now or found out after the surgery?