

1 **APPENDIX**

2

3 *Demographics Form*

4

5 *Instructions:* Please complete the following form to the best of your abilities.

6

7

8 1. Have you ever had oral cavity (tongue, cheek, etc) cancer before?

9 Yes10 No

11

12 2. Have you ever had this type of surgery or operation before?

13 Yes14 No

15

16 3. Do you feel you have difficulty talking and being understood on the phone?

17 Yes18 No

19

20 4. Do you feel you have difficulty talking and being understood in person?

21 Yes22 No

23

24 5. Do you feel you have difficulty hearing?

25 Yes26 No

27

28 6. Have you ever been there when someone else signed approval for surgery (for example,
29 family, friends, etc)?30 Yes31 No

32

33 7. If yes to question 6, please describe the setting as best as you remember:

34

35

36

37

38

39

40

41

42

43

44 *Semi-Structured Interview Questions (Patients):*

- 45 1. [open] Tell me about how your cancer was diagnosed and what has happened since
46 then
- 47 2. [open] What did you think about the information your surgeon gave you?
- 48 3. [open] Which parts of the information were the most important for you and why?
49 Example given: The advantages, disadvantages of treatment, the duration of the
50 treatment, the side effects etcetera.
- 51 4. [open] What parts of the information your surgeon gave you were confusing?
- 52 5. [open] What would you have liked to know more about?
- 53 6. [closed] Would you have liked more emotional support?
- 54 7. [open] What did you do to prepare for your meeting with the surgeon?
- 55 8. [open] Which information did you look up and why?
- 56 9. [open] How would you prefer to get extra information?
- 57 10. [open] What was the hardest part of being involved in making a treatment decision?
- 58 11. [open] What was the role of people other than yourself when making a decision?
59 Example: family, friends, coworkers, etc
- 60 12. [open] What did you think about the decision-making process?
- 61 13. [open] What did you consider when making a decision to proceed with surgery
- 62 14. [open] How did you feel about making your decision?
- 63 15. [closed] Did you feel involved in the decision-making process?
- 64 16. [open] What do you think about an aid or tool to help make decisions like this one?
- 65 17. [open] What should be included in the decision aid?
- 66 18. [open] Do you have anything else to add about the decision-making process that we
67 haven't talked about?

68

69

70

71 *Semi-Structured Interview Questions (Surgeons):*

- 72 1. [open] Tell me about your thoughts on shared decision-making in major head and neck
73 surgery
- 74 2. [open] What are your thoughts on patient involvement in the shared decision-making
75 process for oral cavity cancer requiring major resection and reconstruction?
- 76 3. [open] What decisions do you think should be made by healthcare professionals and not
77 patients?
- 78 4. [open] What do you think would be important to include in the decision aid for oral
79 cavity cancer requiring major resection and reconstruction?
- 80 5. [open] What are some barriers for patient involvement in the shared decision-making
81 process in this setting?
- 82 6. [open] What are some facilitators for patient involvement in the shared decision-making
83 process in this setting?
- 84 7. [open] What are your thoughts on using a decision support tool to help with the
85 decision-making process?

86

87