

## ATTACHMENT 5: MODERATOR'S GUIDE

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### **A 60-Minute Online/By Phone Focus Group With Persons Diagnosed With Temporomandibular Disorders (TMD)**

## **MODERATOR'S GUIDE** Spring 2020

### **BACKGROUND** [5 minutes]

#### Moderator:

- Welcome / thank you for your participation
- My name / not an employee of the National Institute of Dental and Craniofacial Research (NIDCR) or the federal government / independent researcher
- My role (facilitate discussion and end on time at x:xx a.m./p.m.)
- *The purpose of today's discussion is to:*
  - Get your feedback on the Temporomandibular Disorders brochure we mailed you.

**THE MODERATOR WILL CONFIRM THAT PARTICIPANTS RECEIVED THE BROCHURE, READ IT AHEAD OF TIME, AND HAVE THE BROCHURE IN FRONT OF THEM FOR REFERENCE. FOR THOSE USING A COMPUTER, THE MODERATOR WILL CONFIRM THEY CAN SEE THE BROCHURE ON THE SHARED COMPUTER SCREEN.**

- *Some guidance for our conversation:*
  - Please talk one at a time.
  - Please talk in a voice at least as loud as mine.
  - Please mute your line when you are not speaking to reduce background noise.
  - I need to hear all of your opinions—i.e., everyone should have more or less equal “airtime.”
  - There are no right or wrong answers—that said, if someone disagrees with what someone else says, please speak up (we are respectful of all opinions).
  - This discussion is private—first names only (no last names) / no names will be used in the summary report.
  - Your participation is voluntary (you are free to decline to answer a question / you are free to leave this discussion at any time).

- o I did not have anything to do with the development of the material we are going to review—if you have constructive criticism, I will not be offended or penalized.
  - Please be honest.
- o This discussion is NOT intended to test your knowledge of what you read in the brochure, but rather, to test how well the brochure communicates what it is intending to say.
- o Our time together is limited—please don’t be offended if I have to interrupt you to turn to the next question; there is simply a lot to cover, and we have to finish on time.
- o We would like to audio-record this discussion so that when we write the summary report, we will have the “raw” data to turn to, as needed. Does anyone object to our audio-recording this focus group discussion? *[Dismiss any participant(s) that object to being audio-recorded.]*
- o Project staff, including a notetaker, are on the line listening to today’s discussion.

### **PARTICIPANT INTRODUCTIONS [5 minutes]**

- One thing everyone here has in common is that you are all [men] [women] who were diagnosed with a temporomandibular disorder, also known as “TMD” or “TMJ,” within the past 5 or fewer years.
- When I call your first name, please let us know:
  - o Your city and state.
  - o If you had heard the full term “temporomandibular disorder” before being contacted for this focus group?
  - o What term do you and your healthcare provider(s) use when talking about your condition (e.g., temporomandibular disorder; TMD; TMJ; other)?

USING THE REMAINING TIME AVAILABLE, THE MODERATOR WILL ASK THE BELOW QUESTIONS. IF SOMETHING IS NOT COVERED IN ONE TRIAD DISCUSSION, IT CAN BE ADDRESSED IN ANOTHER TRIAD DISCUSSION. THIS GUIDE IS NOT INTENDED AS ONE WHERE EVERY SINGLE QUESTION MUST BE POSED. QUESTIONS MARKED WITH AN “\*” ARE PRIORITY QUESTIONS.

### **DESIGN [5 minutes]**

Let’s start with the design of the front cover.

1. \*What are your first impressions of the cover of the brochure?
2. How clear is the title, “Temporomandibular Disorders”?
  - a. What would you change to make this brochure title even clearer?
  - b. How would you make this brochure title more attention-grabbing?
  - c. If you saw a brochure with this title, how likely would you be to pick it up?
3. Tell me your thoughts on:
  - a. The colors, font size, and font type used on the cover.
4. \*What else, if anything, would you change about this cover? Why?

Let’s now look at the interior cover where the title reads, “Contents.”

5. Tell me your thoughts on:

- a. The colors, font size, and type used in the interior cover.
6. What, if anything, would you change about the interior cover?
7. \*Overall, what suggestions do you have on how the designers could improve the cover?

## OVERALL CONTENT [5 minutes]

Now let's talk about the content or text within this brochure, in *general* terms.

8. \*Who do you think this brochure is for (who is the ideal "target audience" for this brochure)?
9. \*Was the brochure too long, too short, or "just right"?
  - a. Please explain your response.
10. \*In big picture/very broad terms, what did you especially like about the brochure *overall*?
11. \*In big picture/very broad terms, what did you especially dislike about the brochure *overall*?
12. \*On a scale of 1 to 10 (where 1 is "very hard to understand" and 10 is "very easy to understand"), how easy to read was the brochure?

We are now going to review each section of the brochure, one-by-one. As I ask questions, please feel free to refer to your hard copy brochure, as well as the notes you took while you reviewed the brochure on your own.

## CONTENT PART 1: TEMPOROMANDIBULAR DISORDERS [~3-4 minutes]

Let's start on the page that reads, "Temporomandibular Disorders."

13. How many of you noticed that, "Over 10 million Americans are affected by TMDs"? Who, here, was/is surprised by this number? Did you think this seemed like a high number or a low number when you first saw it?
14. How many of you noticed that, "TMDs appear to be more common *in women* than men"? How many of you already knew that TMDs are more common *among women* than men? Where did you learn that?
15. How many of you noticed that, "Discomfort from TMD conditions is *temporary*"? How many of you were surprised by this and why?
16. \*How many of you noticed that, "It's important to avoid, when possible, procedures that can cause permanent changes in your bite or jaw"? How many of you were surprised by this and why?
17. \*What word do you usually use to refer to a *medical* doctor? [Note to moderator: Listen for *doctor vs. physician.*]

18. \*What word do you usually use to refer to your dentist? [Note to moderator: Listen for *doctor* vs. *dentist*.]
19. \*What words or concepts did you circle in your review that you found confusing or difficult to understand?
  - a. What suggestions do you have for how to make these words or concepts easier to understand?

## **CONTENT PART 2: WHAT IS THE TEMPOROMANDIBULAR JOINT? AND ILLUSTRATION** [~3-4 minutes]

Now let's look at the section titled, "What is the Temporomandibular Joint?"

20. \*What did you think of the description for the way the temporomandibular joint works? How easy is this first paragraph to understand and visualize?
21. How many of you noticed that, "The temporomandibular joint is the *most complicated* joint in the body"? How many of you were surprised by this and why?
22. For how many of you were "mandible," "condyles," and "load-bearing" new words/terms? How well were these words/terms defined/described?

Please turn the page to the illustration.

23. What are your first impressions of this illustration?
24. \*Describe, in your own words, what you think the illustration is trying to show you.
25. \*What might be missing from this illustration (what could be added)? What could be removed from this illustration?
26. How helpful is it to have both an open mouth version and a closed mouth version in the illustration?
27. \*Do you have any suggestions for how this illustration could be improved?

## **CONTENT PART 3: WHAT ARE TEMPOROMANDIBULAR DISORDERS?** [~3-4 minutes]

Onto the next section titled, "What are Temporomandibular Disorders?"

28. \*What does "co-exist" mean in this sentence: "TMDs can co-exist with other health problems"?
  - a. Did the following statement stand out to you in any way, "TMDs can co-exist with other health problems such as chronic fatigue syndrome, sleep disturbances, anxiety, depression, or chronic pain"? For those of you who did not already know this, were you surprised to learn this? Does anyone here have co-existing health conditions as described in this section of the brochure? If so, were you aware that TMD can co-exist with other health conditions? How did you first learn this about this association?

29. \*For how many of you were “myalgia,” “myofascial pain,” “intra-articular,” “disc-condyle complex,” “displaced disc,” “degenerative joint disease,” “arthralgia,” and “chronic fatigue syndrome” new words/terms? How well were these words/terms defined/described?
  - a. For terms that are explained well, what specifically helped you understand them (e.g., certain words)?
  - b. For terms that are not explained well, how would you suggest modifying the explanations so that they are easier to understand?
30. Did this section of the brochure generate additional questions which you would like addressed in the brochure?

**CONTENT PART 4: WHAT CAUSES TEMPOROMANDIBULAR DISORDERS? [~3-4 minutes]**

Please turn to, “What Causes Temporomandibular Disorders?”

31. Would someone please define, in your own words, “trauma,” in the context of the first sentence in this section (“Trauma to the jaw or temporomandibular joint plays a role in some TMDs”)?
32. \*Would someone explain how they interpret the last sentence in the first paragraph of this section, “...the potential role of female hormones and genetic and environmental factors in the development of TMDs”? What were the writers of the brochure trying to communicate in that sentence?
30. Would someone please define, in your own words, “bad bite”? “Orthodontic braces”?
31. \*Could anyone relate to the “clicking” sounds described in the last paragraph of this section? How well is this aspect of TMD explained in this paragraph?
  - a. If this is not explained well, how would you suggest modifying the explanation so that it is easier to understand?

**CONTENT PART 5: WHAT ARE THE SIGNS AND SYMPTOMS? [~3-4 minutes]**

Moving on, we will now look at, “What are the Signs and Symptoms?”

32. \*How many of you could relate to the symptoms listed in this section? What symptoms might be missing, from your personal experiences?
33. Are the words, “clicking,” “popping,” “grating,” and “locking,” clear as currently written in this context? Are there any other words you might use for these sounds/experiences/feelings?

**CONTENT PART 6: HOW ARE TEMPOROMANDIBULAR DISORDERS DIAGNOSED? [~3-4 minutes]**

Next, please turn to, “How are Temporomandibular Disorders Diagnosed?”

34. \*How many of you noticed that, “There is no widely accepted, standard test now available to correctly diagnose TMJ disorders”? How many of you were surprised by this and why?

35. Would someone please define, in your own words, “psychological stressors” / “oral habits” / “imaging studies” in this context?

36. For how many of you was “facial neuralgia” a new term? How well was this term defined?

## **CONTENT PART 7: HOW ARE TEMPOROMANDIBULAR DISORDERS TREATED?**

[~3-4 minutes]

Let’s now look at, “How are Temporomandibular Disorders Treated?”

37. \*In your own words, what is the main message of this section of the brochure? [Listen for: **Treatments that cause permanent changes should be avoided.**]

38. How many of you noticed that, “Most patients still do *not need* aggressive types of treatment” (last sentence, first paragraph)? Were you surprised by this information?

39. \*Which, if any, of the self-care practices listed, such as “eating soft foods, applying ice packs, avoiding extreme jaw movements, etc.,” have you used? To what extent have they helped?

40. Would someone please define, “safety and effectiveness,” in the context of this section? “Conservative, reversible treatments”? “Aggressive treatments”? “Nonsteroidal anti-inflammatory drugs (NSAIDs)”? “Bite splint,” bite guard,” and/or “oral appliance”?

41. Would someone please define, “Botox,” in the context of this section? Is Botox currently approved by the FDA for use in TMDs?

42. What are “clinical studies” / “clinical trials”? What does “inconclusive” mean? \*Would you consider participating in a clinical trial for TMD?

43. Would someone please define, in your own words, “occlusal adjustment”? “Crown and bridge work”? “Orthotics”?

44. How helpful was it to learn that, “A bite splint should not cause permanent changes in the bite”?

45. \*How are treatments listed similar to your own experiences? How do the treatment methods listed in this section differ from those offered by your healthcare provider?

46. How likely would you be to contact the FDA through MedWatch (via the email and/or phone number provided in the brochure) if you wanted to report a serious problem with an implant?

## **CONTENT PART 8: IF YOU THINK YOU HAVE A TEMPOROMANDIBULAR DISORDER...** [~3-4 minutes]

A few more sections to go. Let’s now turn to, “If you Think you Have a Temporomandibular Disorder...”

47. \*How helpful is the advice to seek a second opinion in this section? How realistic is this—would you seek a second opinion?

48. How surprised were you to learn that, “There is no certified specialty for TMDs”?
49. \*Have any of you been to specialists in the fields mentioned in this section (neurology, rheumatology, pain management [or any other not mentioned here])? To a pain clinic in a hospital or university?
50. Is there any other information that you would like to see in this section?

### **CONTENT PART 9: RESEARCH** [~3-4 minutes]

Next, the section titled, “Research.”

51. \*How helpful are the studies listed in this section?
52. \*What additional information about these studies would you like to have?
53. \*What terms did you find confusing or difficult to understand in this section? For example, would someone define, in your own words, “stem cells”?

### **CONTENT PART 10: HOPE FOR THE FUTURE** [~3-4 minutes]

Last, but not least, let’s look at the section titled, “Hope for the Future.”

54. \*In your own words, what is the main message of this section?
55. [As needed] Would someone please define, in your own words, “acute to chronic disease”? “Mechanisms of the disorder”? “Personalized treatment”? “Quality of life”?

### **WRAP UP/CLOSE** [5 minutes]

We are now going to wrap up this discussion with a few final questions.

56. \*What questions do you still have about TMD/TMJ that the brochure did not discuss?
57. What, if anything, do you think is still missing from this brochure?
58. Is there anything that you would remove from this brochure?
59. \*What, if anything, are you likely to do now that you’ve read this brochure?
60. On a scale of 1 to 10 (with 1 being “not at all likely” and 10 being “very likely”), how likely are you to recommend this brochure to someone who has TMD/TMJ?
61. \*Where should the National Institute of Dental and Craniofacial Research (NIDCR, the sponsor of this project) consider promoting this brochure? In other words, what do you think is the best way to raise awareness of this brochure?

62. \*Do you have any final comments to share before we close?

Thank you for your time. The National Institute of Dental and Craniofacial Research greatly appreciates your feedback.