

Appendix B: WATCH-PD qualitative study interview guide

PARTICIPANT INTERVIEW GUIDE INSTRUCTIONS AND QUESTIONS

Note: Below is a semi-structured interview guide. It is to be used as a guide only. The actual areas of conversation are fluid and may be discussed at moments different from the order appearing below. The interview will be approximately 60 minutes. The interviewer may adapt the guide in order to cover the topics in the amount of time allotted for the session or in order to best elicit concepts from the participants.

Prior to the start of the discussion, please check off:

Participant has been deemed eligible Yes No

Participant has consented prior to the discussion Yes No

Notes to Interviewer:

- This interview guide is meant to help guide the discussion, but not to be used as a verbatim script; probes and questions may change slightly depending on individual feedback.
- Additional unscripted probes to be used to gain further information or clarification may include:
 - **Clarification:** I don't quite understand that.
 - **Expressing understanding:** How did you cope with that?
 - **Justification:** Can you tell me a little bit more about why you chose that for your answer?
 - **Importance:** How important is this for you?
 - **Relationship:** I'm not sure how these 2 things are linked.
 - **Extending narrative:** Tell me a bit more about that.
 - **Accuracy:** Let's see if I've got that right.

Key for Interviewer:

- Questions/text to be asked of the participant
- *Notes to the interviewer (Do not read to participant)*

Introduction

Thank you for taking the time to speak with me today. Before we can start with the interview let's go over the information for the study.

We are talking to people such as yourself who have been participants in the WATCH-PD study. The purpose of our conversation today is to better understand how the data captured in the WATCH-PD study relates to your experience with Parkinson's disease symptoms and impacts. The interview data we collect will be used to support the use of wearable devices or digital health technologies that can record important features of Parkinson's disease progression in future clinical trials.

It is expected that approximately 40 participants will be enrolled in this interview study. There are no treatments being tested in this study.

You are being asked to take part in one interview, which will be audio/video recorded to ensure we capture everything you say accurately. The interview will take between 60-90 minutes to complete. The recording will be transcribed and no names will appear in the written transcript. All your responses will be anonymous; your name will not be linked with any of your responses. Recording the interview is a required part of the study. If you do not want to be recorded, you may not take part in the study.

Your participation is voluntary, which means that you do not have to take part in the interview. You can skip any question you do not want to answer, and you can choose to stop the interview at any time. You will be compensated \$X in the form of a gift card for your time after the interview.

Before we proceed, do you have any questions?

Address all questions the participant has before proceeding.

Before we get started, I would like to reiterate that this session will be audio recorded. However, your name will not be linked with the recording, transcription, or your responses during the interview.

Is it okay for me to record the conversation today?

If yes, continue to "Background for All Interviews."

If no: Unfortunately, since you do not agree to the recording of this session, you won't be able to participate in this study. Thank you for your willingness to consider participation in this study.

Background for All Interviews

- My role here is to ask questions and to listen. I will also be summarizing information at times. I will ask questions related to your experience and I will move the discussion from one question to the next to try to keep us on track so that we can finish on-time.
- I am not your medical doctor, so I am not qualified to give medical advice. I encourage you to follow-up with your regular doctor if you have any questions about your condition after this interview.
- Please feel free to let me know if you need a break. You can ask me questions at any time.

Any questions before we begin?

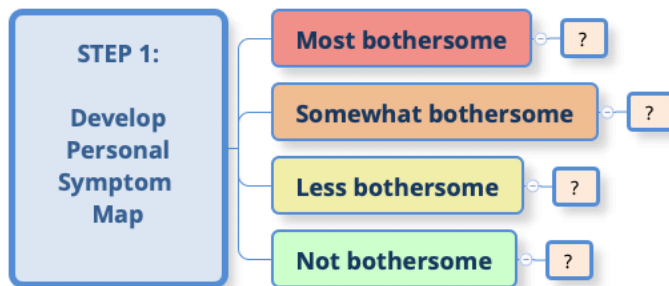
Begin Recorder: This is participant ID [insert ID number here] for the WATCH-PD Qualitative Sub Study on [Date]. Do I have your permission to record this interview? *Verbal response required.* And can you please confirm that you read and signed the Informed Consent Form? *Verbal response required.*

Section 1. Personally Important Parkinson's Disease Symptoms

The purpose of our conversation today is to better understand how the data captured in the WATCH-PD study relates to your experience with Parkinson's disease symptoms and impacts. As part of this I'm going to ask you to describe your symptoms of Parkinson's and then I will create a map or a "picture" of symptoms that are important to you, based upon what you tell me. As I create the map, please point out anything you see that needs adjusting, as this will help me to best represent your experience.

1. First, would you tell me what Parkinson's disease-related symptoms you experience? From your responses on the survey, I see that you listed....

[Step 1 of the symptom mapping activity begins here. As the participant directs, the interviewer will map the participants symptoms by order of personal importance.]



- Probe: Are there other symptoms that you experience that you have not told me about and that I don't have in your map?
 - Probe [yes/no] on any they do not spontaneously state (tremor, slow movements, gait disturbances, fine motor coordination, speech articulation, cognitive impairment, daytime sleepiness, mood symptoms).
2. Of those symptoms you mentioned, explain to me which are the most bothersome to you. What specifically makes those symptoms bothersome, and in what situations?

[The interviewer will add concise details to the symptom map delineating what makes specific symptoms important/bothersome. Example: if gait, is it foot lift or gait speed? Does it occur at home during regular daily activities or mostly when out exercising?]

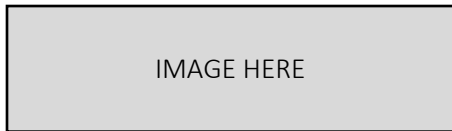
3. Are the symptoms that are most bothersome also the most important to you, or is that different in some way?
 - Probe: Have we captured all the symptoms that you experience correctly? Is there anything we missed?

Section 2. Patient Perspectives on WATCH-PD Battery – Task Debriefing

In the WATCH-PD study you completed a range of tasks at home through use of the iPhone and Apple Watch and in the clinic. Now we will discuss those tasks.

The goal of the following questions is to determine if the tasks (and specifically what tasks) assessed via the WATCH-PD technologies are important/relevant/meaningful to patients. How do the tasks relate to how they feel and function?

1. You completed a **shapes task**. The screen looked like this:



- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

2. You completed a **trails task**. The screen looked like this:



- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

3. You completed a **finger tapping task**. The screen looked like this:



- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

4. You completed a **visual-spatial task**. The screen looked like this:

IMAGE HERE

- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

5. You completed **symbols swap task**. The screen looked like this:

IMAGE HERE

- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

6. You completed a **reading task**. The screen looked like this:

IMAGE HERE

- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

7. You completed a **phonation task**. The screen looked like this:

IMAGE HERE

- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?

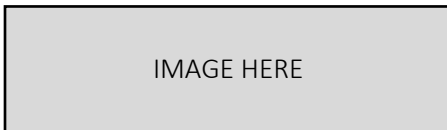
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

8. You completed an **articulation task**. The screen looked like this:



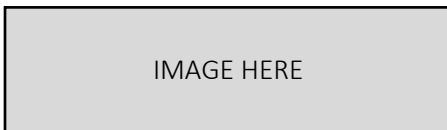
- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

9. You completed a **walking and balance task**. The screen looked like this:



- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

10. You completed a **tremor task**. The screen looked like this:






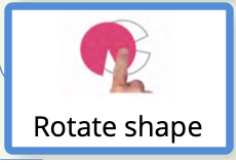



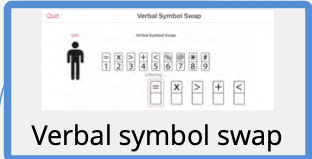
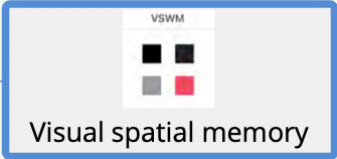

- a. In your own words, what was this task asking you to do?
- b. What Parkinson's symptoms do you experience that are related to completion of this task?
- c. How is this task similar [*or relevant*] to tasks you do in your daily life?
- d. Do you believe completion of this task is important to measuring the progression of your Parkinson's? If not, why?

11. Overall, how well do you feel your Parkinson's symptoms were captured through the WATCH-PD iPhone and Apple Watch tasks you completed?

- **Probe: What symptoms were NOT captured and why is that important to you?**

Section 2A: Mapping Activity (Relating Tasks to Personal Symptoms)

Now let's incorporate each of the WATCH-PD tasks we just talked about into your personal symptom map where you feel they fit best. There is one task per card.

Movement			
Fine coordination			
Speaking			
Thinking			

BrainBaseline application screenshots reprinted with permission from Clinical ink.

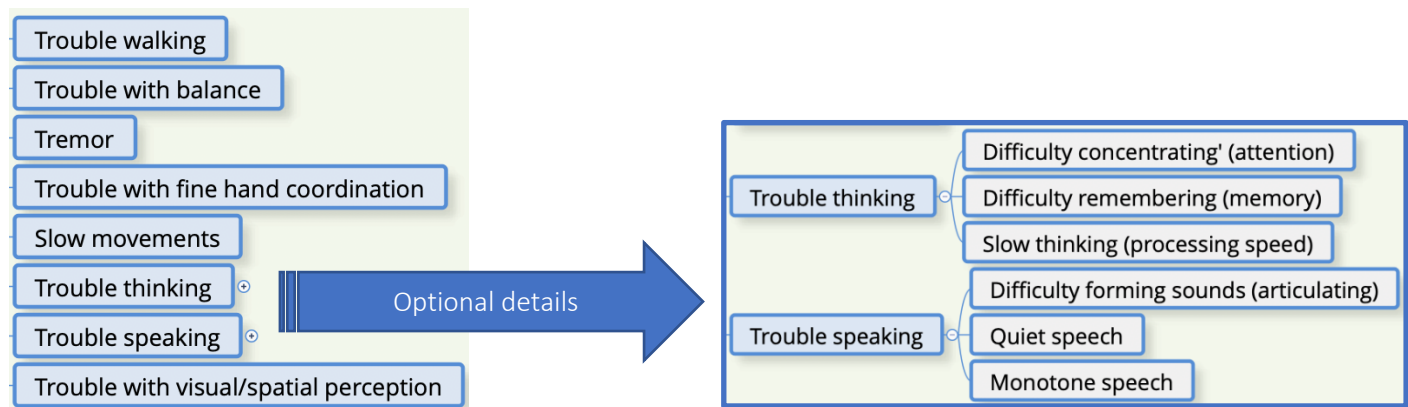
1. Where would you place each task card in relationship to the symptoms in your personal symptom map?

[As the participant directs, the interviewer will integrate the WATCH-PD tasks into the personal symptom map, relating each task to meaningful symptoms, or indicating if the task is not relevant to the participant, along with details as to what makes those tasks relevant or not relevant.]

Section 2B: Mapping Activity (Relating Concepts of Interest to Personal Symptoms)

Now that we have sorted each of the tasks, let's consider the various symptoms of Parkinson's Disease that the tasks were intended to measure. Again, there is one concept per card.

Main concepts of interest



2. Where would you place each of the [main concept] cards in relationship to the symptoms in your personal symptom map?

[As the participant directs, the interviewer will integrate the WATCH-PD concepts of interest into the personal symptom map, relating each concept to meaningful symptoms, or indicating if the concept is not relevant to the participant, along with details as to what makes the concepts relevant or not relevant. If able, participants will also be asked to consider the more granular concepts show in the call out box for trouble thinking and speaking.]

Closing

3. Are there any other things that come to mind when you think about your participation in WATCH-PD and the assessment of the Parkinson's disease symptoms and impacts that you have experienced?

Thank you for your time and for all the insightful information and experiences you have shared with me today. Now, let's discuss the next steps before we end the interview.

[Stop recording and go through any closing logistical items with the participant.]

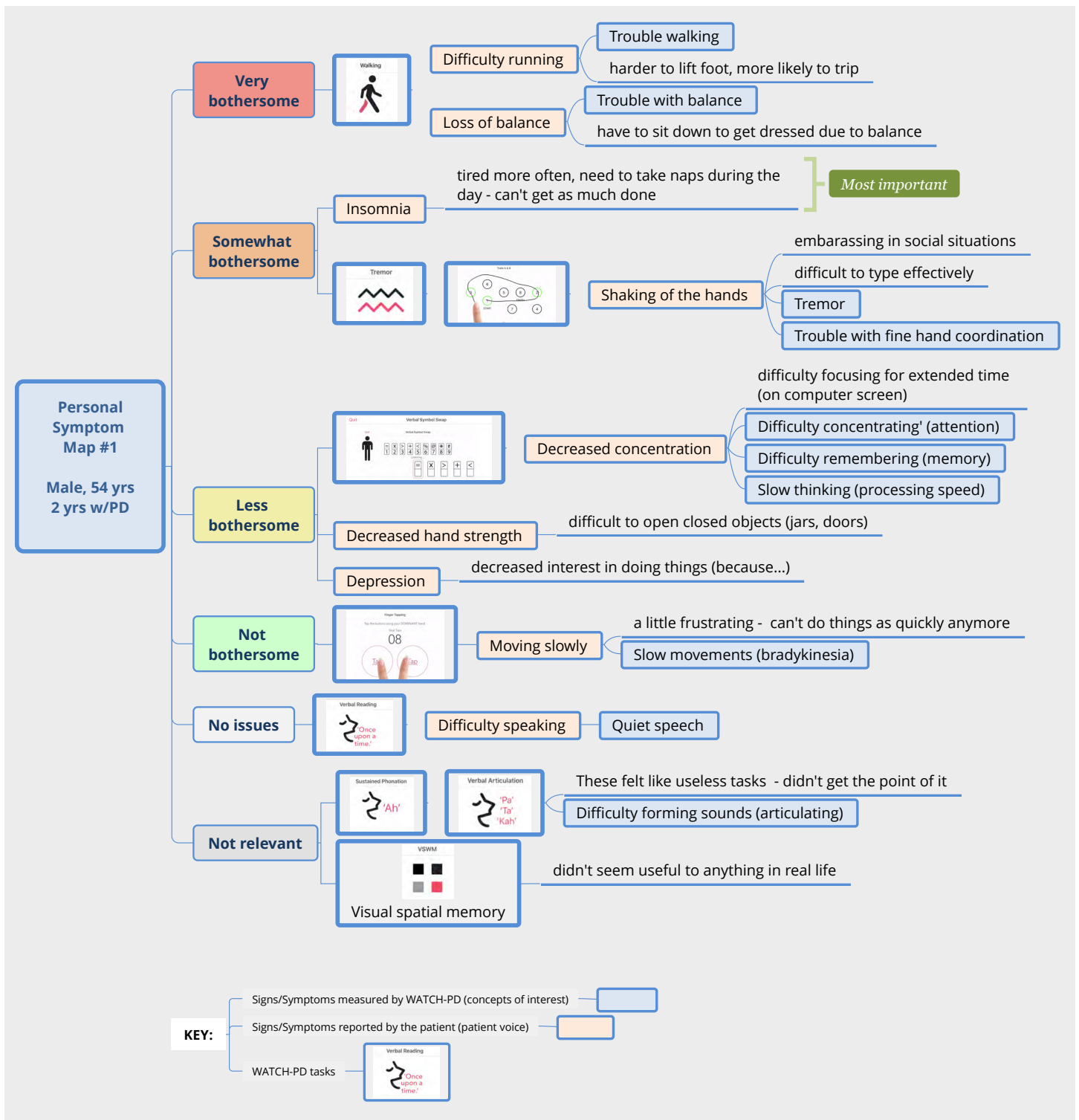


Figure 1. Sample personal symptom map showing perceived relevance of WATCH-PD tasks and concepts of interest