

# Supplementary Material

## Hispanic Perspectives on Parkinson's Disease Care and Research Participation

### Supplementary Material 1. Survey

*You are being asked to complete this survey because you have Parkinson's disease. We are requesting about 5-10 minutes of your time to respond to the statements and questions below. Your participation in completing this survey is voluntary. Please understand that by completing the survey, you are agreeing to have your responses reviewed and analyzed as part of our ongoing research project to improve clinical trial recruitment.*

*As a thank you for completing this survey, you will receive a \$15.00 gift card to a local store. To receive your gift card, please bring your completed survey to the front desk. The attendant will take your survey and give you a gift card. Your survey will then be placed with all the other completed surveys. Your survey responses will be confidential and anonymous, meaning your responses will not have your name on them.*

***For the statements listed below, please circle the number/response that best indicates how strongly you agree.***

#### **Q1. I am aware where research is being conducted for my condition**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q2. In general, I am aware of what types of studies are being conducted for my condition**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q3. I have participated in medical research in the past**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q4. My doctor has discussed my participating in clinical trials**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q5. My doctor has recommended I participate in a clinical trial**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q6. If my doctor recommended I participate in a study, I would strongly consider it**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q7. I am interested in participating in research for therapies that might help my condition**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q8. I am interested in studies where I might not benefit directly but may lead to a better understanding of my condition**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

#### **Q9. I am interested in studies where I might not benefit directly but may lead to new treatments for my condition**

1                      2                      3                      4                      5                      6                      7  
Strongly disagree                      Neutral                      Strongly agree

<b>Q10. I am interested in learning more about studies I might participate in</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q11. I would like to participate in studies but have concerns that keep me from becoming involved</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q12. I worry that the time commitment for studies would be too much</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q13. I worry that the potential risks associated with studies are much greater than my current treatment</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q14. Getting to and from research study visits would be difficult for me</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q15. Participating in research would be a strain on my family</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q16. I worry that participating in research would represent a financial burden to me</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q17. I worry that participating in research would expose my condition to people outside the clinic</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q18. Medical researchers are generally honest about telling patients about the different treatment options available to them</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q19. Medical researchers are generally honest about the risks associated with studies</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q20. If I were to participate in research, it is important to me that the medical research team be from the same background as me, including speaking my native language</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q21. If I were to participate in research, it is important to me that my family be comfortable with the medical research team</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	
<b>Q22. Getting payment, in the form of a gift card, for completing this survey is the reason I am doing it</b>	1	2	3	4	5	6	7
	Strongly disagree		Neutral			Strongly agree	

## Supplementary Material 2. Interview Guides

### An Educational Toolkit for Hispanic PD Community Engagement HISPANIC PD PATIENTS & CAREGIVERS

**Introduction:** Thank you for taking the time to speak with me today. Your input is very important and will contribute to the development of education and outreach materials that can be used to better engage with individuals in the Hispanic community around Parkinson's disease. I would like to start our conversation today by learning a bit about you, your Parkinson's diagnosis, and your views on participation in clinical research.

**Recording:** I would like to record this discussion for note taking purposes. I will destroy the tape as soon as the notes have been completed. You do not have to agree to be taped; you can still participate in this conversation if you do not want to be taped. Please let me know if you agree to be recorded. If you agree to be recorded, I will ask that you please state your name, today's date and that you consent to being recorded.

#### Consent:

- 1) Please state your name, the date and that you consent to this interview being recorded

#### Tell Me about You:

- 2) When were you diagnosed with Parkinson's disease?
- 3) Can you describe for me what the experience was like when you were first diagnosed? (Probes: *how did you feel, what did you think, did you have a loved one with you?*)
- 4) What sort of actions did you take after receiving your diagnosis? (Probes: *did you go see a neurologist? Did you call a family member or friend? Did you seek treatment? Did you seek out additional information?*)

#### Learning Process:

- 5) After receiving your diagnosis, did you seek out additional information on Parkinson's disease? If so, what were some of the sources that you used to learn more about Parkinson's disease? (Probe: *did you ask your doctor? did you look online? Did you find a support group? Did you rely on family members and friends to find the information?*)
- 6) Out of the sources you mentioned, which ones did you find to be most helpful? Why were they helpful? (Probe: *What did you like about those sources? Was there information that was particularly helpful? If so, what was that information?*)
- 7) Was there information that you were looking for about Parkinson's disease that you couldn't find?

#### Awareness of Clinical Research:

- 8) While seeking out information on Parkinson's disease, did you learn about clinical trials and studies? (Probes: *Did you hear about potential treatments being tested? Did anyone contact you about participation in a trial or study?*)
- 9) Had you ever heard of clinical trials or studies?
- 10) What comes to mind when you think about clinical trials or studies? (Probe: *Why does this come to mind? Have you heard of people who have had good experiences? Have you heard of people who have had bad experiences?*)

- 11) Do you think clinical trials are needed? Why or why not? (Probe: *What sort of value, if any, do clinical trials or studies provide?*)
- 12) Is there any research that you have heard about specifically? (Probe: *are there any experimental treatments you have heard about for Parkinson's disease? How did you hear about this research?*)
- 13) Have you been asked to participate in clinical research? (Probe: *If so, what was that experience like? How did you feel about being asked to participate? Did you participate?*)
- 14) Would you be willing to participate in clinical research for Parkinson's disease? Why or why not?
- 15) If you are not willing to participate in clinical trials or studies, what are the main reasons why you would not participate?
- 16) If you are willing to participate in clinical trials or studies, what are the main reasons why you would participate?

## **An Educational Toolkit for Hispanic PD Community Engagement**

### **HEALTH CARE PROVIDERS**

**Introduction:** Thank you for taking the time to speak with me today. Your input is very important and will contribute to the development of education and outreach materials that can be used to better engage with individuals in the Hispanic community around Parkinson's disease. I would like to start our conversation today by learning more about your interactions with Hispanic PD patients, views on how Hispanic PD patients obtain information on clinical research, and your perceptions of clinical research.

**Recording:** I would like to record this discussion for note taking purposes. I will destroy the tape as soon as the notes have been completed. You do not have to agree to be taped; you can still participate in this conversation if you do not want to be taped. Please let me know if you agree to be recorded. If you agree to be recorded, I will ask that you please state your name, today's date and that you consent to being recorded.

#### Consent:

Please state your name, the date, and that you consent to this interview being recorded

#### In the Clinic:

How often do you see Hispanic patients with Parkinson's disease? From your experience, do you think Parkinson's disease is under-diagnosed, over-diagnosed, or accurately diagnosed within the Hispanic community? (Probe: *Why do you think that? What have you experienced in your practice that may have led you to that conclusion?*)

- 1) Can you describe for me a few situations in which you might refer a patient to a movement disorder specialist?

- 2) For those Hispanic patients that you see with a Parkinson's disease diagnosis, how would you characterize their level of knowledge of Parkinson's disease? (Probe: *Does it seem like they know a lot about the progression, the symptoms, the medications etc...? Does it seem like they need you to help explain a lot to them? Do they ever tell you about resources where they've gotten information? Do you feel like you are frequently providing resources for how to learn more information about PD?*)
- 3) What are the symptoms that lead you to think a patient may have Parkinson's disease?
- 4) What do you do with patients that show these symptoms?

Clinical therapies/support for Parkinson's disease:

- 5) Are you aware of any organizations or services that specifically provide support to Hispanic PD patients? (Probe: *If you are aware of organizations or services, how frequently do you recommend your patients to them?*)
- 6) Do Hispanic PD patients or their caregivers ask you about clinical research, support services or additional information on Parkinson's disease? (Probes: *How frequently do they ask you for this information? What type of information are they looking for most? Do you feel that you have adequate resources to address their questions/meet their needs?*)
- 7) Do you have preferences around the types of studies or trials that you recommend to a patient? (Probes: *do you prefer that your patients participate in interventional trials, observational studies, web-based studies, etc... Do you feel you know what research is happening in the field? Would you like more information on research happening in the field?*)
- 8) If you learn about a trial, what type of trial you suggest patients to participate?

Clinical research on Parkinson's disease:

- 9) Have you ever referred patients to clinical research?
- 10) Is clinical research performed in your facility? If yes, is information on clinical research advertised in your facility?
- 11) How do you feel that your Hispanic patients view clinical research? (Probes: *do you think they are interested in participating but don't know about opportunities? Do you think that they are uninterested in participating?*)
- 12) Why do you think Hispanic individuals are less frequently involved in clinical research?
- 13) Do you think there are any barriers that prevent Hispanic individuals from participating in clinical research?
- 14) As a physician, what would help you to participate more in clinical research and/or refer more of your patients to clinical research? (Probes: *do you have any hesitations about referring patients to participate in clinical research?*)