

**Introduction by Interviewer:** *The purpose of this interview is to gain information to assess the use and value of the Patient Reported Outcomes Measurement Information System (PROMIS®) in the clinical research and care communities. This interview will take approximately xx minutes to complete. We will first ask questions about your awareness of the PROMIS® measures and use of other Patient-Reported Outcome (PRO) measures. If you have experience with the PROMIS® measures, Assessment Center, or the PROMIS® Web site, we will ask you to answer some additional questions about using them.*

Public reporting burden for this collection of information is estimated to average 40 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: OMB Control number: 0925-0648, Expiration date: 01/2015. Do not return the completed form to this address.

1. **We would like to verify that you currently work for [insert organization], is this correct?** Yes  No
  
2. **We would like to verify that your current title within your organization is [insert job title], is this correct?** Yes  No
  
3. **Choose which best describes your role (If the individual is support staff, please skip to the “Early Close A”):**
  - Investigator or Co-Investigator; someone who is responsible for study design, study decisions and measurement endpoints
  - Clinical or Research Operations/Support; someone who is responsible for or participating in the execution of a protocol once designed and funded; may have input but not primarily responsible for study design or measure selection.
  
4. **Which of the following best describes your setting? (Check all that apply)**
  - Clinical
  - Academic
  - Public Health researcher/Private Industry researcher: \_\_\_\_\_
  - Other – specify: \_\_\_\_\_
  
5. **We are interested in learning about the use of PRO measures (for example, SF-36, SF-12, EQ-5D) in the clinical research and care communities. Have you used PROs?**
  - Yes, currently using PROs
  - Yes, used PROs in the past
  - No, never used PROs please skip to the “Early Close A”.
  - Yes, if yes, which measures have you used and how did you use them?
    - Measures (e.g. SF-36):** \_\_\_\_\_
    - Use (e.g., research, clinical care):** \_\_\_\_\_
  
6. **How familiar are you with NIH PROMIS® measures?**
  - Not at all familiar

- Not very familiar
- Somewhat familiar
- Very familiar

For those respondents who are not at all familiar, please go to question 8.

7. To be asked of those respondents who are not very familiar, somewhat or very familiar with NIH PROMIS® measures. **Please select the most relevant context that makes you familiar with PROMIS®.**

- Using the tool in your research or care community: \_\_\_\_\_
- Familiarizing yourself with the tool using the NIH PROMIS® Web site: \_\_\_\_\_
- Reading about the tool in the literature: \_\_\_\_\_
- Hearing about the tool when attending a meeting or conference: \_\_\_\_\_
- Hearing about the tool from colleagues/others who may have used it: \_\_\_\_\_
- Other – specify: \_\_\_\_\_

For those who responded they have used the tool in their research/care community, please go to question 10. All others, please go to question 9.

8. To be asked of those respondents who are not at all familiar with NIH PROMIS® measures. **The NIH developed PROMIS® a system to provide precise measures of patient-reported health status for physical, mental, and social well-being in an efficient manner. PROMIS® tools measure what patients are able to do and how they feel by asking questions. The PROMIS® Computer Adaptive Test (CAT) provides an immediate personal health status report on up to nine different areas (or domains) of health. The CAT works by choosing the questions in each area that are best for you based on your answers to earlier questions. PROMIS® measures can be used as primary or secondary endpoints in clinical studies of the effectiveness of treatment. Hearing about PROMIS®, how likely are you to look for more information about this tool?**

- Not at all likely
- Somewhat likely
- Very likely

If not at all likely, please describe why you wouldn't seek information about using this tool?

\_\_\_\_\_

**8a. What information would you need in order to use the PROMIS® measures?**

\_\_\_\_\_  
\_\_\_\_\_

**8b. Would you consider using the tool if you had more information?**

\_\_\_\_\_  
\_\_\_\_\_

**8c. If you have heard about the tool or read about it, why didn't you use it?**

\_\_\_\_\_  
\_\_\_\_\_

Please skip to the "Early Close B".

9. To be asked of those respondents who are familiar with PROMIS® measures. It sounds like you are familiar with the PROMIS® measures, but have not used them in your research or care community. The next few questions will help us understand researchers' decisions to use PROMIS® versus other PROs.

9a. Have you ever considered using PROMIS® measures in your current work?

Yes, if yes, please describe in as much detail as possible, the type of research or clinical setting and in what context you considered using PROMIS®.

\_\_\_\_\_  
\_\_\_\_\_

No, if no, please describe in as much detail as possible why you have not considered using PROMIS®.

\_\_\_\_\_  
\_\_\_\_\_

9b. What are some of the perceived benefits, if any, you saw when considering the PROMIS® measures in your research or clinical care?

\_\_\_\_\_  
\_\_\_\_\_

9c. What are some of the perceived barriers, if any, you saw when considering the PROMIS® measures in your research or clinical care?

\_\_\_\_\_  
\_\_\_\_\_

9d. Is there anything that would have made it more likely for you to have used the PROMIS® measures in your work?

\_\_\_\_\_  
\_\_\_\_\_

Please go to question 29.

10. To be asked of those who responded they have used the tool in their research/care community. We are interested in learning about the experiences of PROMIS® users. Which PROMIS measures have you used? \_\_\_\_\_

\_\_\_\_\_

11. Please select the most relevant context(s) in which you have used PROMIS®. (check all that apply)

- Clinical trial: \_\_\_\_\_
- Epidemiological study: \_\_\_\_\_
- Clinical care: \_\_\_\_\_
- Other – specify: \_\_\_\_\_

**12. In what type of research or clinical setting have you used PROMIS? (check and describe all that apply)**

- Patient population (e.g., adult, pediatric): \_\_\_\_\_
- Disease or practice: \_\_\_\_\_
- Study Design (e.g., clinical trial, observational study, cross-sectional): \_\_\_\_\_
- Other – specify: \_\_\_\_\_

**13. What format(s) of PROMIS measures did you use for your research or clinical setting? (check and describe all that apply)**

- Computer Adaptive Testing (CAT): \_\_\_\_\_
- Short Forms: \_\_\_\_\_
- Domains of Health/Item Banks: \_\_\_\_\_
- Other – specify: \_\_\_\_\_

**14. Have any of the PROMIS measures helped your research or clinical care in any of the following ways:**

- Shortened the length of time it takes to administer questionnaires
- Reduced sample size needed
- Provided better precision
- Reduced patient or participant burden
- Other – specify: \_\_\_\_\_

**15. What are some of the weaknesses, if any, that you saw when using the PROMIS® measures in your research or clinical care?**

*(We are not as concerned with barriers related to convincing colleagues, a grant review study section, or your organization to use the measures. Rather, we would like to know about any or the following potential weaknesses you may have experienced with data validity, standardization and interpretation.)*

\_\_\_\_\_  
\_\_\_\_\_

**16. In your role, what topics/items/additional modes of administration are you most interested in seeing in the development of future PROMIS® measures?**

\_\_\_\_\_  
\_\_\_\_\_

**17. Do you or someone you know have plans to use the PROMIS® measures in your future research or clinical care?**

- Yes, if yes, please describe which measures will most likely be used and how they will be used:  
\_\_\_\_\_  
\_\_\_\_\_
- No, if no, please describe the reasons why not:  
\_\_\_\_\_  
\_\_\_\_\_

**Interviewer Script:** Next we would like to ask you some questions about using the PROMIS® Web site and the Assessment Center (AC). The PROMIS® website can be found at [www.nih.PROMIS.org](http://www.nih.PROMIS.org) and includes background information, what's new, and the science related to the measures. AC is a free, online research management tool that enables researchers to create study-specific Web sites for capturing participant data securely. However a user must register to access the AC.

**18. Have you visited the PROMIS® Web site?** Yes  No

For those respondents who say NO, please go to question 29.

**19. What information were you looking for when visiting the PROMIS® Web site? (check all that apply)**

- Background/Overview on PROMIS®
- Instrument Overview/Development
- PROMIS® Methodology/Science
- Publications and Presentations
- Access to the Assessment Center:
- Other – specify: \_\_\_\_\_

**20. Did you find the information you were looking for when visiting the PROMIS® Web site?** Yes  No

Please explain: \_\_\_\_\_  
\_\_\_\_\_

**21. Did you find the PROMIS® Web site was easy to navigate?**

- Not very easy to navigate
- Somewhat easy to navigate
- Very easy to navigate

**22. Approximately, how many times have you visited the PROMIS® Web site?**

1 to 3 times  4 to 6 times  7 to 9 times  10 or more times

**23. Have you used the CAT demonstration on the PROMIS® Web site?** Yes  No

For those respondents who say NO, please go to question 24.

**24. Was the CAT demonstration informative?**

- Not at all informative
- Somewhat informative
- Very informative

**25. Have you used the Assessment Center?** Yes  No

For those respondents who say NO, please go to question 29.

**26. Did you use the Assessment Center to conduct a study/collect data for a study?** Yes  No

27. Did you find the Assessment Center easy to navigate?

- Not very easy to navigate
- Somewhat easy to navigate
- Very easy to navigate

28. Approximately, how many times have you visited the Assessment Center?

- 1 to 3 times       4 to 6 times       7 to 9 times       10 or more times

29. Have you worked with other researchers/colleagues to use the PROMIS® measures?

- Yes       No

30. Are you aware of partnerships that exist among individuals using or seeking to use the PROMIS® measures?

- Yes       No

Please specify: \_\_\_\_\_

\_\_\_\_\_

31. Can you suggest any ways that we should consider using to effectively distribute information on the PROMIS® measures to organizations like yours?

- Meetings       Website

Other: \_\_\_\_\_

\_\_\_\_\_

**Thank you so much for your time today. Your answers were very helpful. Do you have any comments or questions? We are trying to get as much information from individuals who use patient-reported outcome measures as possible. We would like to know if there is anyone you know that has experience using these measures we may speak with? If so, would you be willing to provide their contact information?**

**Early Close A**

**Thank you so much for your time. Unfortunately, we are looking for clinical investigators, academic investigators, public health, and private industry researchers who have experience using patient-reported outcome measures. However, we would like to know if there is anyone you know that has experience using these measures we may speak with? If so, would you be willing to provide their contact information?**

**Early Close B**

**Thank you so much for your time today. Your answers were very helpful in gaining a better understanding of researchers' awareness regarding PROMIS® measures. The remaining items are geared toward researchers who have experience using the PROMIS® measures. However, we would like to know if there is anyone you know that has experience using these measures we may speak with? If so, would you be willing to provide their contact information?**

Name:

Organization:

Telephone Number:

Email Address:

**Thank you again for your time.**