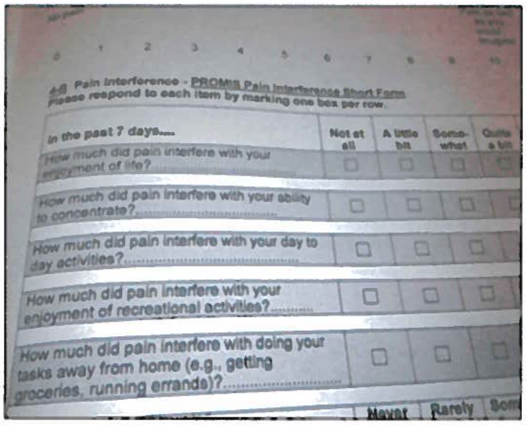
Aging Well with Post-Polio Syndrome: The *Promise* of PROMIS

Rehabilitation Research and Training Center (RRTC) on Aging with a Physical Disability,
agerrtc@uw.edu

Many aspects of a chronic condition cannot be measured with a tape measure, a blood test or an x-ray. Only the people living with the condition can tell, for example, how severe their fatigue is or how much pain interferes with their ability to do the things they value. It's these subjective measures that are often collected through someone's responses to a questionnaire or what we call a "Patient-Reported Outcome" (PRO).

In 2004, the National Institutes of Health (NIH) (www.nih.gov) funded a project to develop a set of PRO measures that doctors can use in their practices or researchers can use in clinical trials of new interventions. The project is called **PROMIS** – **P**atient **R**eported **O**utcomes **M**easurement **I**nformation **S**ystems (www.nihpromis.org) and seeks to develop questionnaires that measure what patients are able to do and how they feel about important issues.



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4-8 Pain Interference - PROMIS Pain Interference Short Form
Please respond to each item by marking one box per row.

In the past 7 days....	Not at all	A little bit	Some-what	Quite a bit
How much did pain interfere with your enjoyment of life?	☐	☐	☐	☐
How much did pain interfere with your ability to concentrate?	☐	☐	☐	☐
How much did pain interfere with your day to day activities?	☐	☐	☐	
How much did pain interfere with your enjoyment of recreational activities?	☐	☐	☐	
How much did pain interfere with doing your tasks away from home (e.g., getting groceries, running errands)?	☐	☐	☐	

Never Rarely

PROMIS covers three areas or domains: physical, mental and social health. Specific PROMIS measures include physical abilities, fatigue, pain, depression, sexual function and satisfaction with social participation or interactions.

PROs are important when studying conditions that have no cure, as the goal of treatment or therapy is to improve patients' abilities to function and to reduce symptoms associated with the condition.

PROMIS is being developed specifically for use in research on chronic health conditions.

Many readers of *Post-Polio Health* are participants in the RRTC's longitudinal survey that is also sent out to people with multiple sclerosis, muscular dystrophy and spinal cord injury. We use PROMIS measures in our survey, and our researchers were the first to have a larger group of people with post-polio answer these questions.

Whenever a new questionnaire is developed, it must be proven to work and also proven that it works in each population separately (e.g., post-polio, multiple sclerosis, etc.).

Dr. Karon Cook and our colleagues in the Department of Rehabilitation Medicine at University of Washington have just reported the results of a study addressing this issue in an upcoming edition of *The Archives of Physical Medicine and Rehabilitation*. They administered the short forms of six PROMIS measures to more than 2,000 people (part of this from our RRTC survey). Results support the use of PROMIS measures across different chronic conditions and across all ages.

The use of carefully designed and rigorously tested measures has several important advantages:

Short – The use of short forms – often just four questions – reduces the burden on patients because they need only answer a few questions.

Creates a Profile – When combined with traditional clinical measures, these questionnaires allow doctors to better understand the range of symptoms that their patients are experiencing. This understanding can be used to design treatment programs and to enhance management of chronic conditions. The questions can also be used to measure symptoms important to patients in research investigating the benefits of new treatments.

Flexible – PROMIS measures can be used face to face, in writing or by computer online. ▲