

PROMIS – A web-based interview instrument to assess health outcomes

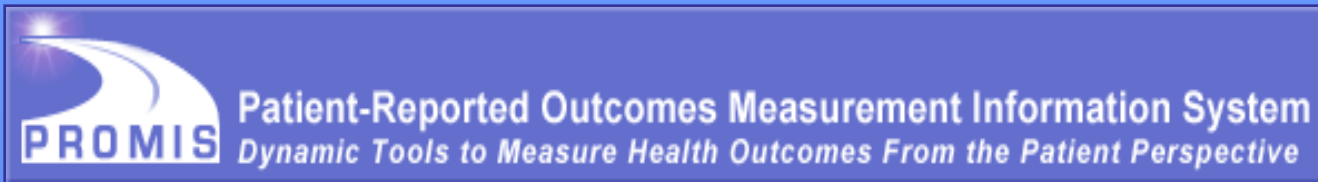


www.nihPROMIS.org

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What is PROMIS ?



- **Patient-Reported Outcomes Measurement Information System**
- Part of the NIH Roadmap for Medical Research
- Goal: improve + standardize patient-reported outcomes
- Managed through Assessment CenterSM:
A online research management tool that will allow researchers to centralize research activities.
- library of instruments / items, focus: health-related quality of life
- Assessment of disease outcomes reported by patients
- Assessment online/electronically (optionally paper version)

Instruments / Domains

- **Fatigue**
- Emotional **distress**: anger, anxiety, depression
- **Sleep** + wake disturbances
- **Physical function**
- **Pain** behavior + pain impact/interference
- Satisfaction with **Social Roles**, Social Function
- **Global health**

[Study Content \(Arctic health\)](#) >> Add an Instrument

Add an Instrument

Back

Select your instrument search criteria. Then, select the instruments to add to your study.

Study:
 Type:
 Domain:

Search Results

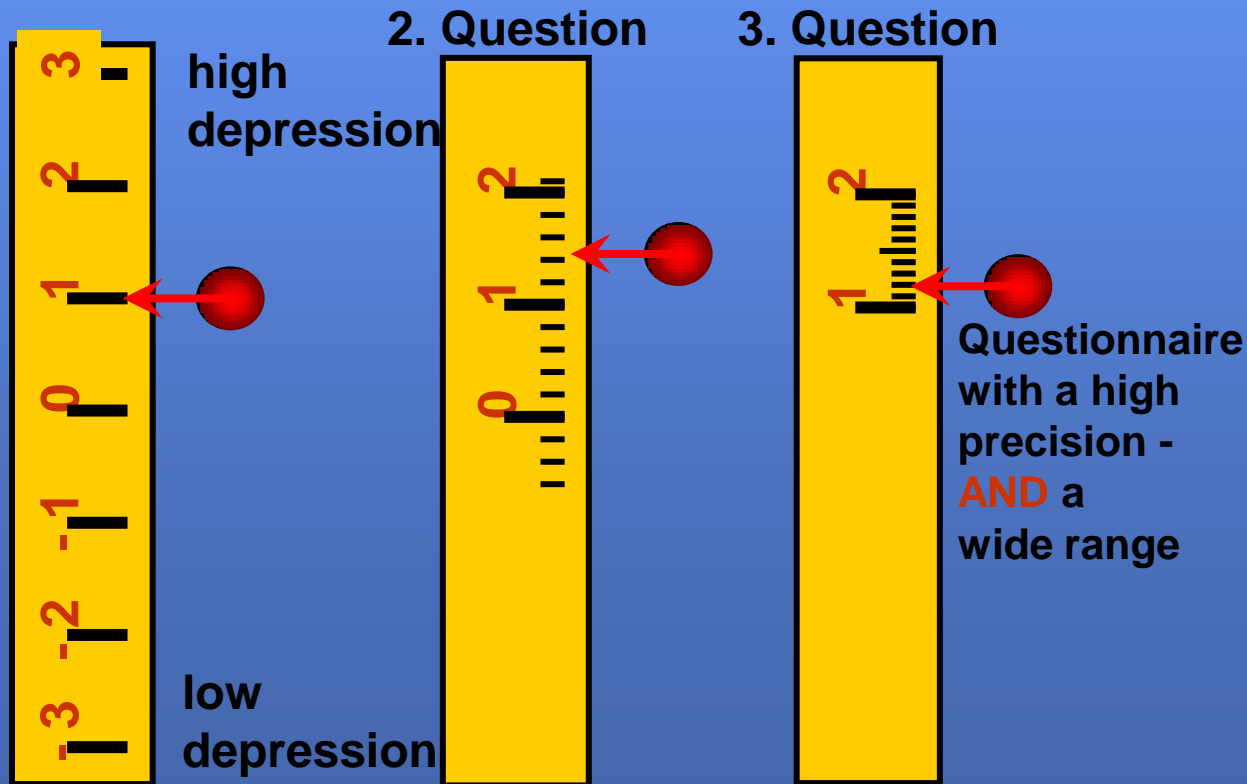
Select	Name	Study	Type	Domain	
<input type="checkbox"/>	<input type="checkbox"/> PROMIS Bank- Upper Ext	PROMIS- Pediatric	CAT (Computerized Adaptive Testing)	Physical Function	Statistics
<input type="checkbox"/>	<input type="checkbox"/> PROMIS Bank-Anger 1.0	PROMIS	CAT (Computerized Adaptive Testing)	Emotional Distress, Anger	Statistics
<input type="checkbox"/>	<input type="checkbox"/> PROMIS Bank-Anxiety 1.0	PROMIS	CAT (Computerized Adaptive Testing)	Emotional Distress, Anxiety	Statistics
<input type="checkbox"/>	<input type="checkbox"/> PROMIS Bank-Depression 1.0	PROMIS	CAT (Computerized Adaptive Testing)	Emotional Distress, Depression	Statistics
<input type="checkbox"/>	<input type="checkbox"/> PROMIS Bank-Fatigue 1.0	PROMIS	CAT (Computerized Adaptive Testing)	Fatigue	Statistics
FATIMP1	In the past 7 days To what degree did you have to push yourself to get things done because of your fatigue?			<input type="text" value="Not at all"/>	Statistics
FATIMP2	In the past 7 days To what degree did your fatigue make you feel slowed down in your thinking?			<input type="text" value="Not at all"/>	Statistics
FATIMP3	In the past 7 days How often did you have to push yourself to get things done because of your fatigue?			<input type="text" value="Never"/>	Statistics
FATIMP4	In the past 7 days How often did your fatigue interfere			<input type="text" value="Never"/>	Statistics

2 Types of Questionnaires

- CAT: Computerized adaptive testing
- Static short forms

Computer Adaptive Test

- selects questions on the basis of a person's response to previous questions
- determines a person's score with minimum of questions and high precision



Short Forms

- Static forms = no adaptive testing
- Versions with differing length

2 Options:

- Online administration
 - algorithm to calculate total score
- Paper administration
 - summed score

Problem:

- No simple mix of online and paper assessment possible
- No score if some item is unanswered

Extensions of PROMIS item banks

Create your own...

- Items:

Socio-demography: Age, sex, residence, education, occupation

Current diseases, symptoms

Disease history

- Item banks / validated questionnaires

SF36

... and add them to PROMIS items to complete your study!

Pro and Con's of PROMIS in "Arctic Research" (1)

Online assessment

- + Ready for export
- + avoid manual conversion into PC
- + Reach people in remote areas
- Dependence on PC skills of participants / internet access
 - > risk of introducing selection bias into our data

Possible solution

- Option of posted questionnaire
- Assistance through study nurse or the like

Pro and Con's of PROMIS in "Arctic Research" (2)

Available Instruments

- + Thoroughly tested instrument, published psychometrics
- + CAT: long questionnaire can be filled in quickly,
no bottom/ceiling effects
- New instruments derived from others (SF36 etc.)
 - > New translations necessary
 - > No direct comparison to existing data

Possible solution:

- Translation via FACIT.org or assisted by Promis team
- Create own prevalence data of general populations

PROMIS Workshops

- Regular introduction into Assessment Center and PROMIS in Chicago
- 1 full day
- Costs: \$ 300
- Next: January, May 2011

PROMIS Plans of Umeå University

Puumula virus Follow up-Study

- Examination of ca. 1000 patients with NE in 2007
- Intention: follow up of patients – Interview about chronic outcomes of the disease
- Frequency of fatigue, pain, sleeping disorders and other health outcomes
- Investigate determinants of fatigue (severity of disease in 2007, age, ...)
- Promis: Use web-based questionnaires (fatigue?), added by own items in assessment center platform
- To be resolved: choice of questionnaires, cost / duration of translation into Swedish; posted and/or web-based forms
- Possibly extend to other regions in Northern Europe

Thank you for your attention!