

Appendix B. Survey Instrument for People With Osteoarthritis of the Knee

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Survey instrument overview

Instruments administered in field-testing with the cross-sectional and longitudinal samples included the following components:

1. Demographics
2. PROMIS Global Health Measure (10-item short form)
3. New and existing PROMIS items: Items were grouped and block-randomized by domain type (mental, physical, and social)
4. Global Rating of Change Scale (GRCS)
5. Condition-specific legacy instrument: Knee injury and Osteoarthritis Outcome Score (KOOS)

Only participants in the longitudinal study were asked to complete the GRCS. This scale was used to obtain patient's perceptions of the extent to which their health had changed since baseline in each of the domains being measured. The assessment ranged from very much worse (-4) to very much better (+4). Patients in the longitudinal sample were also asked to set a goal at baseline and then rate their achievement of that goal at 3-month follow-up.

Domain definitions for the existing PROMIS domains can be found on the HealthMeasures website: <http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures>. Definitions for the newly created PROMIS domains are:

- *Life satisfaction*: Appreciation for and enjoyment of life, including impact of illness on life satisfaction.
- *Symptoms*: Physical changes or sensations specific to the illness or condition.
- *Independence*: Loss of independence due to illness or condition. Includes reliance on others for assistance, fears of losing independence, and desire to regain independence.

The following tables contain the new and existing PROMIS items administered in field-testing, organized by the category (Mental, Physical, Social) and domain.

Appendix B, Table 1: New and Existing PROMIS items for Osteoarthritis of the Knee, Mental category*

Instrument	Item	Responses and Scores
Anger		
New PROMIS	In the past 7 days... I felt frustrated by limitations caused by my knee.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Anxiety		
New PROMIS	In the past 7 days... I worried about falling.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... I worried about my knee(s) giving out.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... I worried about losing my independence.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Depression		
Existing PROMIS	In the past 7 days, I withdrew from other people	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, I felt lonely	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, I felt depressed	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, I felt unhappy	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Life Satisfaction		
New PROMIS	In the past 7 days... I am able to enjoy life.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much

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Appendix B, Table 2: New and Existing PROMIS items for Osteoarthritis of the Knee, Physical category*

Instrument	Item	Responses and Scores
Fatigue		
Existing PROMIS	In the past 7 days, how often did you experience extreme exhaustion?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, how often did you feel tired even when you hadn't done anything?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, how often were you bothered by your fatigue?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, how often did you have to push yourself to get things done because of your fatigue?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, how often did your fatigue make you feel less alert?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	In the past 7 days, how often were you too tired to leave the house?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Existing PROMIS	During the past 7 days: I have to limit my social activity because I am tired	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	During the past 7 days: I feel fatigued	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Pain Intensity		
New PROMIS	In the past 7 days... how often did you have knee pain?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... how much pain did you feel when you tried to straighten your leg?	1=None, 2=Mild, 3=Moderate, 4=Severe, 5=Very Severe
New PROMIS	In the past 7 days... how much pain did you feel when you tried to bend your knee?	1=None, 2=Mild, 3=Moderate, 4=Severe, 5=Very Severe

Instrument	Item	Responses and Scores
Pain Interference		
Existing PROMIS	In the past 7 days, how much did pain interfere with your enjoyment of life?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how much did pain interfere with your close personal relationships?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how much did pain interfere with your day-to-day activities?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how much did pain interfere with your ability to work (include work at home)?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how much did pain interfere with your ability to participate in social activities?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how much did pain interfere with your ability to remember things?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how irritable did you feel because of pain?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, how often did pain prevent you from walking more than 1 mile?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
New PROMIS	In the past 7 days... how much did knee pain limit your daily activities?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... how much did knee pain interfere with your walking?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... how much did knee pain interfere with going up stairs?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... how much did knee pain interfere with going down stairs?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... how often did knee pain make you feel depressed?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always

Instrument	Item	Responses and Scores
Physical Function		
Existing PROMIS	Are you able to go for a walk of at least 15 minutes?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to stand unsupported for 10 minutes?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to walk a block (about 100 m) on flat ground?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to run 100 yards (100 m)?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to walk at a normal speed?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Are you able to sit on and get up from the toilet?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
Existing PROMIS	Does your health now limit you in walking more than a mile (1.6 km)?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
Existing PROMIS	Does your health now limit you in climbing one flight of stairs?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
New PROMIS	Are you able to straighten your knee?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
New PROMIS	Are you able to bend your knee?	5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do
New PROMIS	Does your knee condition limit you in walking on uneven ground?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do
New PROMIS	I use a cane, walker, or other support to prevent a fall.	5=Never, 4=Rarely, 3=Sometimes, 2=Often, 1=Always
New PROMIS	My concern about falling limits the things I can do.	5=Never, 4=Rarely, 3=Sometimes, 2=Often, 1=Always

Instrument	Item	Responses and Scores
Sleep Disturbance		
Existing PROMIS	In the past 7 days, my sleep was restful.	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
Existing PROMIS	In the past 7 days, my sleep was restless.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	In the past 7 days, my sleep quality was...	5=Very poor, 4=Poor, 3=Fair, 2=Good, 1=Very good
Existing PROMIS	In the past 7 days, I got enough sleep.	5=Never, 4=Rarely, 3=Sometimes, 2=Often, 1=Always
Existing PROMIS	In the past 7 days, it was easy for me to fall asleep.	5=Never, 4=Rarely, 3=Sometimes, 2=Often, 1=Always
Existing PROMIS	In the past 7 days, I had trouble sleeping.	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always
Symptoms		
New PROMIS	In the past 7 days... did you feel stiffness in your knee(s) when standing up after a period of rest?	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... did you have swelling in or around your knee?	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always

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Appendix B, Table 3: New and Existing PROMIS items for Osteoarthritis of the Knee, Social category*

Instrument	Item	Responses and Scores
Ability to Participate in Social Roles and Activities		
Existing PROMIS	I have to limit social activities at home	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have to limit social activities outside my home	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble participating in recreational activities with others	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble accomplishing my usual work (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble doing everything for work that I want to do (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble doing all the leisure activities with others that I want to do	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble doing all of the work that is really important to me (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Existing PROMIS	I have trouble doing all of the work that I feel I should do (include work at home)	5=Never, 4=Rarely, 3=Sometimes, 2=Usually, 1=Always
Independence		
New PROMIS	In the past 7 days... were you dependent on others to get things done?	5=Not at all, 4=A little bit, 3=Somewhat, 2=Quite a bit, 1=Very much
New PROMIS	In the past 7 days... I was satisfied with my ability to be independent.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	Does your knee condition limit you in doing things that make you feel independent?	5=Not at all, 4=Very little, 3=Somewhat, 2=Quite a lot, 1=Cannot do

Instrument	Item	Responses and Scores
Satisfaction with Social Roles and Activities		
Existing PROMIS	I am satisfied with my ability to socialize with friends	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to do things for my family	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with how much work I can do (include work at home)	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to do the work that is really important to me (include work at home)	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my current level of social activity	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to participate in family activities	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to do things for fun outside my home	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Existing PROMIS	I am satisfied with my ability to do household chores/tasks	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
New PROMIS	In the past 7 days... I am satisfied with my ability to do the activities that are important to me.	1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much
Social Isolation		
Existing PROMIS	I feel left out	1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always
Existing PROMIS	I feel isolated from others	1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

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