

# USER MANUAL AND SCORING INSTRUCTIONS

## PROMIS Medication Adherence



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## INTRODUCTION

This **User Manual and Scoring Instructions** includes information on measure development, administration, scoring, and interpretation for the measures listed below.

## PROMIS MEDICATION ADHERENCE MEASURE

ADULT
PROMIS Scale v1.0 – Medication Adherence

## DESCRIPTION OF MEDICATION ADHERENCE

The PROMIS Medication Adherence Scale assesses behaviors related to taking oral medication as prescribed by a doctor. It includes information about the medication (what it is and how often it is meant to be taken), overarching beliefs about the medication (4 items), and behaviors related to medication adherence in the past 7 days (5 items). It is generic rather than disease-specific.

## OBTAINING MEASURES

All English and some Spanish PROMIS measures are available to download in respondent-ready PDF format at [Search & View Measures](#) on [HealthMeasures.net](#). These measures may be used in **paper administration** without permission or fees as long as the text is not changed.

Non-commercial users<sup>1</sup> can program a PROMIS measure into a digital administration platform for research<sup>2</sup> without permission or fees as long as the text is not changed. Programming PROMIS measures into digital administration platforms for other purposes (e.g., registries, routine outcome assessment, quality measurement) and any use by commercial users<sup>3</sup> requires a permission letter and screenshot review (HealthMeasures Electronic Administration Permission or HEAP). The screenshot review ensures the digital implementation retains validity. Contact [Help@HealthMeasures.net](mailto:Help@HealthMeasures.net) for permission and to learn more about HEAP.

PROMIS measures are also available in **additional languages**. Information on currently available translations can be found at [HealthMeasures.net](#) under [Available Translations](#). Contact [translations@HealthMeasures.net](mailto:translations@HealthMeasures.net) to request a translated measure or to learn more.

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<sup>1</sup> A non-commercial user is any institution, organization, or other incorporated entity which is defined as a Tax-exempt Organization under the regulations of the United States' Internal Revenue Service; for users outside the United States, all not-for-profit entities including national health services and their affiliate providers and academic institutions.

<sup>2</sup> Research includes randomized controlled trials, cohort studies, case control studies, and cross-sectional studies.

<sup>3</sup> A commercial user is any company, organization, or other incorporated limited liability entity which does not fit the definition of a Tax-exempt Organization under the regulations of the United States' Internal Revenue Service or which otherwise operates under the rubric of financial profit.

## MEASURE DEVELOPMENT

PROMIS utilizes rigorous methodology for developing its measures and testing their validity.

- Comprehensive literature searches (e.g., Klem et al., 2009) of existing measures, yielding hundreds of potential items, are performed to ensure content validity (i.e., the assurance that each measure represents all facets of a domain).
- To ensure comprehensive coverage of the conceptual area, focus groups are conducted with relevant participants and thematic analyses are performed of the topics discussed. Following the focus groups, an initial item-review process is completed involving elimination of items that are redundant, confusing, or poorly written (DeWalt et al., 2007).
- Cognitive interviews are also performed so that each candidate item is reviewed by multiple individuals with diverse characteristics (i.e., both genders, members of minority groups, participants with modest reading levels) for feedback on the language and clarity of items and the relevance of the content (DeWalt et al., 2007, Irwin et al., 2009).
- Responses to candidate items are collected from relevant participants, usually via computer administration to both community and clinical samples, during the psychometric testing stage of item bank development (Cella et al., 2010). Data from large samples confirm the factor structure of the domains and allow for analyses at the item level. This approach is described by Reeve et al. (2007) with an update from Hansen et al (2014).
- Validity studies are conducted to determine the degree to which an instrument measures what it is intended to measure. This includes:
  - Cross-sectional validity (e.g., Cella et al., 2010)
  - Responsiveness to change (e.g., Forrest et al., 2019, Pilkonis et al., 2014, Wohlfahrt et al., 2019)
  - Clinical validity (see 2016 Journal of Clinical Epidemiology series with a summary by Cook et al.)
- Translations result from a process of forward and back-translation, multiple expert reviews, harmonization across languages, and cognitive debriefing with a sample of native speakers of the target language (linguistic validation). A universal approach to translation ensures that, whenever possible, one language version is created for multiple countries instead of country-specific versions of the same language (Eremenco et al., 2005, Eremenco et al., 2017).
- Details on measure development for the PROMIS Medication Adherence Scale are published and available (Peipert et al., 2020).
- Conduct a literature review for up-to-date information on measure validation.

## Primary Citations

Adult	PROMIS Scale v1.0 – Medication Adherence	Peipert, J.D., Badawy, S. M., Baik, S. H., Oswald, L. B., Efficace, F., Garcia, S. F., Mroczek, D. K., Wolf, M., Kaiser, K., Yanez, B., & Cella, D. (2020). Development of the NIH Patient-Reported Outcomes Measurement Information System (PROMIS) Medication Adherence Scale (PMAS). <i>Patient Preference and Adherence</i> , 14. <a href="https://doi.org/10.2147/PPA.S249079">https://doi.org/10.2147/PPA.S249079</a>
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## BEST PRACTICES IN ADMINISTRATION

- PROMIS self-report measures are intended to be completed by the respondent without help from anyone else.
- If respondents are unable to answer on their own, have someone else (“proxy”) report on their behalf. Respondents requiring a proxy may include: young children, people in the early stages of dementia who may not recognize the extent of their impairment, people with cognitive or communication deficits, and people with severe disease burden.
- Use the same proxy across multiple assessments. Different proxies may have different perspectives.
- Keep respondents’ privacy in mind, but have staff readily available to help with any technology issues that may arise.
- It is acceptable for staff to define a term (e.g., “nausea”), but not to define a concept where the respondent’s subjective interpretation is the goal of the question (e.g., “quality of life”).
- Respondents should be instructed to answer all items to the best of their ability. For a respondent who indicates the item asks about an activity they don’t do, instruct them to consider what that activity would be like, and imagine or predict how it would be for them. For example, for the item “Are you able to use a hammer to pound a nail?” imagine the upper body strength, coordination, and dexterity needed to pound a nail with a hammer and evaluate to what degree they have that level of function. Respondents should always have the opportunity to skip an item if needed as well.
- Utilize the same method (e.g., computer, telephone, or paper) and mode (e.g., self vs. interviewer) of administration. However, this is not always possible, and PROMIS measures have produced similar scores when the method of administration varied.
- In clinical settings, give respondents the optimal time needed to capture the most relevant perspective and complete data (e.g., before/after clinician visit or in between visits). This may depend on the study aims and/or clinic workflow.

## GUIDANCE ON THE APPEARANCE OF ITEMS

PROMIS measures have requirements for how they appear to the respondent. This helps support administration that is consistent with how the measures were developed, tested, and validated. The PDF versions of PROMIS measures from HealthMeasures.net's [Search & View Measures](#) meet these requirements. If you are integrating PROMIS measures into a digital administration platform, please contact [Help@HealthMeasures.net](mailto:Help@HealthMeasures.net) to learn about how to have your implementation approved.

## HANDLING MULTIPLE RESPONSES ON A PAPER FORM

Guidelines on how to deal with multiple responses have been established. Resolution depends on the responses noted by the respondent.

- If two or more responses are marked by the respondent and they are next to one another, then a data entry specialist will be responsible for randomly selecting one of them to be entered and will write down on the form which answer was selected. Note: To randomly select one of two responses, the data entry specialist will flip a coin (heads - higher number will be entered; tails – lower number will be entered). To randomly select one of three (or more) responses, a table of random numbers should be used with a statistician's assistance.
- If two or more responses are marked and they are NOT all next to one another, the response will be considered missing.

## MEASURE NAMES IN ADMINISTRATION PLATFORMS

Measure names may be abbreviated or use altered terms in some administration platforms.

- Scale = a set of items that are administered in their entirety. They are not a subset of items from an item bank.
- PMAS = abbreviated title for the PROMIS Medication Adherence Scale.

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## SCORING INSTRUCTIONS

Scoring the PROMIS Medication Adherence Scale requires two steps:

### 1.) Score each subscale.

- For the Medication Beliefs & Knowledge subscale (MBK; items 1 through 4), sum the individual items. Then, multiply the sum of the item scores by 4. Next, divide by the number of items answered. This produces the MBK subscale score, which ranges between 4 and 20.
- For the Medication Taking Behaviors subscale (MTB; items 5 through 9), sum the individual items. Then, multiply the sum of the item scores by 5. Next, divide by the number of items answered. This produces the subscale MTB score, which ranges between 5 and 25.
- If cost of medication is determined not to be relevant to the clinical setting, **MedAd9** can be omitted from assessment. In these cases, enter a missing value for **MedAd9**, so that the MTB and PMAS scores will be comparable to other applications where this item has been administered.

### 2.) Sum the two subscales to derive the total PMAS scale score.

For an overall measure of medication adherence, **MedAd5** may be administered as a single item.

A scoring sheet is provided on the next page.

## PROMIS Scale v1.0 – Medication Adherence Scoring Instructions

- Instructions:
1. Record answers in "item response" column. If missing, mark with an X
  2. Sum individual items, as indicated below.
  3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.
  4. Sum the two subscales to derive the total PMAS scale score.

### Subscale: Medication Beliefs & Knowledge (MBK)

Item Name	Item Response
MedAd1	= _____
MedAd2	= _____
MedAd3	= _____
MedAd4	= _____

Score range: 4-20

*Sum individual item scores:* \_\_\_\_\_  
*Multiply by 4:* \_\_\_\_\_  
*Divide by number of items answered:* \_\_\_\_\_ = **MBK subscale score**

### Subscale: Medication Taking Behaviors (MTB)

Item Name	Item Score
MedAd5	= _____
MedAd6	= _____
MedAd7	= _____
MedAd8	= _____
MedAd9	= _____

Score range: 5-25

*Sum individual item scores:* \_\_\_\_\_  
*Multiply by 5:* \_\_\_\_\_  
*Divide by number of items answered:* \_\_\_\_\_ = **MTB subscale score**

**Total Score:** \_\_\_\_\_ + \_\_\_\_\_ = \_\_\_\_\_ = **PMAS Total score**  
(MBK score) (MTB score)

Score range: 9-45

### **Additional Notes on the PMAS**

1. For an overall measure of medication adherence, **MedAd5** may be administered as a single item.
2. If cost of medications is determined not to be relevant to the clinical setting, **MedAd9** can be omitted from the assessment. In these cases, enter a missing value for **MedAd9**, so that the MTB and PMAS scores will be comparable to other applications where this item has been administered.



## DIRECTION OF SCORES

A higher score on the PMAS indicates greater medication adherence.

## REPORTING SCORES

Scores should be reported as integers. Additional decimal places may be retained in interim computations, but the reported value should be rounded to an integer to maintain the appropriate level of significant figures.

A Publication Checklist should be used when writing about PROMIS measures in publications and presentations. Checklist categories include measure details, administration, scoring, and reporting. The checklist is available on HealthMeasures.net at [Publication Checklist](#) as well as in Hanmer et al., 2020.

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