

ARTICLE

Comparable Real-World Patient-Reported Outcomes Data Across Health Conditions, Settings, and Countries: The PROMIS International Collaboration

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The patient voice is critical to achieving value-based care, improving health outcomes, and advancing medical research. However, a key challenge is how to translate this “voice” into scientifically valid data that can inform evidence-based clinical decisions. One of the biggest barriers is the sheer variety of available patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) and the associated challenges of translation, validation, implementation, and interpretation, making it difficult to obtain valid and comparable health outcomes. The authors present a harmonized global approach to international standardization of PROs and PROMs. This approach has the potential to accelerate patient-centered care by facilitating the collection of accurate and comparable real-world evidence on health outcomes that matter most to patients. This proposed approach consists of two elements: a data collection process based on a common set of PROs and a state-of-the-art measurement approach based on item response theory. First, there is growing evidence that outcomes such as pain, fatigue, anxiety, depression, sleep disturbance, physical function, and the ability to participate in social roles and activities are relevant for most people, irrespective of their health condition. Measuring these outcomes routinely in all patients could increase outcome comparability and utility for a range of stakeholders. Second,

a measurement strategy based on a state-of-the-art psychometric approach — using item response theory (IRT)-based item banks — offers short, flexible, sustainable, and universally applicable PROMs with robust measurement properties and a common measurement scale. The unique integration of these two elements offers the potential to collect comparable PROM data across patients and providers to support shared decision-making, which may lead to better outcomes. The Patient-Reported Outcomes Measurement Information System (PROMIS) is a globally used example of such an approach. The PROMIS Profile measures serve as a resource for measuring a harmonized core set of PROs across medical conditions, languages, and countries. To meet the United Nations Sustainable Development Goal of ensuring healthy lives and promoting well-being for all, at all ages, a collaborative effort is needed to achieve consensus on international standardization of PROs and PROMs to accelerate patient-centered care across health conditions, settings, and countries. The authors propose to routinely measure a core set of broadly relevant PROs in all patients, regardless of their health condition, with universally applicable IRT-based PROMs.

Health care systems globally face pressing challenges related to the high cost of care, shortage of providers, and increasing workload resulting from the rising number of patients with (multiple) chronic conditions. To address these challenges, the vision of value-based health care is increasingly adopted for its potential to improve health care efficiency. Value-based health care aims to deliver services aligned with what is important to patients.¹ One key prerequisite of value-based health care is the systematic measurement of clinical and patient-relevant outcomes.

The patient voice is a critical component of achieving value-based care, improving outcomes, and advancing health care research. A key challenge is to translate this “voice” into scientifically valid data that can be factored into evidence-based clinical decisions. Growing evidence suggests that routine measurement of patient-reported outcomes (PROs) — such as pain, fatigue, anxiety, and social, emotional, and physical function — contributes to a better relationship between health care provider and patient.^{2,3} It helps patients understand what to expect from treatment, facilitates shared decision-making,⁴ and helps to deliver the right care at the right time.^{2,5,6} This may reduce referrals, consultations, and hospital admissions, and improve patient and physician satisfaction, quality of care, quality of life, and even survival of patients.⁷⁻¹²

However, it is our view that these positive effects of patient-reported outcome measures (PROMs) can be fully leveraged only when PROs are collected from all patients in a standardized and comparable fashion using valid and reliable PROMs — optimally integrated into the clinical workflow — and results are routinely discussed with patients. One of the biggest barriers is the sheer variety of PROMs used. Thousands of (mostly disease-specific) PROMs are used across patient populations and countries. To illustrate, the [COSMIN database](#) currently includes over 1,600 systematic reviews of PROMs. More than 6,000 clinical outcomes assessments (of which most are PROMs) are described in detail within the [PROQOLID database](#). Churucca et al. identified 315 generic and condition-specific PROMs across common conditions and those

with a high burden of disease (e.g., cancers, cardiovascular disorders).¹³ Langendoen-Gort et al. identified 116 different PROMs used in patients with diabetes.¹⁴ The problems with these PROMs and their implementation are myriad: they differ in the questions asked (even among PROMs that aim to measure the same PROs) and use different scoring systems and measurement scales, making PROM scores difficult to interpret or compare. PROMs also often lack reference data and evidence on their quality (i.e., measurement properties).^{15,16} Each PROM needs to be rigorously translated, culturally adapted, translated into multiple languages, and validated for multiple countries in order to be used internationally. In addition, significant time and costs are associated with integrating PROMs directly into electronic health records and displaying results in real time in ways that can be easily interpreted by health care providers and patients. This situation slows down the adoption of value-based health care, limits the value of the outcomes collected for clinical decision-making and research, and hinders the generation of valuable real-world evidence needed to improve health care and comparative research.¹⁷ To truly enhance the opportunities for PROMs to improve quality of care and quality of life of patients on a global scale,⁵ PROs and PROMs should be standardized across patient populations and countries.¹⁸

Hence, a harmonized global measurement approach is needed. We present an approach to international standardization of PROs and PROMs that has the potential to accelerate patient-centered care by facilitating the collection of accurate and comparable real-world evidence on health outcomes that matter most to patients. This approach consists of two elements. First, we propose to routinely measure a core set of broadly relevant PROs in all sectors of health care to generate comparable outcomes across different patient populations. Second, we highlight the benefits of modern psychometric methods, specifically item response theory (IRT) models, to standardize PRO measurement by creating short, flexible, sustainable, and universally applicable PROMs with robust measurement properties and a common measurement scale.¹⁹ The unique integration of these two elements is especially valuable for collecting comparable PROM data across patients and providers, supporting shared decision-making, and obtaining better outcomes. In this paper we describe how the international Patient-Reported Outcomes Measurement Information System (PROMIS) initiative has adopted this approach to develop a universal PRO measurement system to facilitate routine use of PROMs in clinical practice and research that can accelerate the adoption of value-based health care.²⁰⁻²²

“*By measuring a core set of generally relevant patient-reported outcomes in routine practice in all patients, regardless of their health condition(s), we believe that significant improvements in health care can be made by aligning health care provision with health outcomes from the patient perspective.*”

The Benefit of Measuring a Core Set of PROs Across Health Conditions

Growing evidence suggests that some symptoms — such as pain, fatigue, anxiety, depression, and sleep disturbance — are common across patient populations, cultures, and age groups.^{23,24} Furthermore,

the ability to perform daily activities and social roles (requiring at least some degree of physical, emotional, and cognitive functioning) is important for all people, regardless of their health condition. Aspects of these PROs are included in many generic and disease-specific PROMs and commonly recommended in core outcome sets for clinical trials and clinical applications, as demonstrated by the International Consortium for Health Outcomes Measurement (ICHOM) and others, but unfortunately not in a consistent way.^{25,26} By measuring a core set of generally relevant PROs in routine practice in all patients, regardless of their health condition(s), we believe that significant improvements in health care can be made by aligning health care provision with health outcomes from the patient perspective. Routine measurement of core symptoms and functions would ensure that consistent attention is given to the health-related issues that are most important to patients. This could potentially lead to better care and prevention of further health problems, for instance, through referral to allied health providers.^{8,10,27} Moreover, it would generate real-world evidence on the burden of health conditions and the effects of treatment that could help improve treatment strategies and prioritize development of therapeutic agents and preventive measures to improve public health.^{28,29} Such a core set of PROs can be supplemented with additional PROs to gather more information relevant to specific health conditions (e.g., itch, gastrointestinal symptoms, sexual function).

Next, these common PROs need to be measured in a consistent manner across all patients. A standardized set of reliable and valid PROMs is needed that is widely applicable and easy to implement and interpret and that provides comparable scores across different patient populations and countries.³⁰ We need measures that are short and precise and that can be tailored to the patient's level of symptoms/function, adapted for use in different populations and countries, and updated without scores becoming incomparable with previously collected PROM data. IRT-based PROMs can meet these requirements.^{19,31}

The Benefits of IRT-Based PROMs for Measurement Standardization

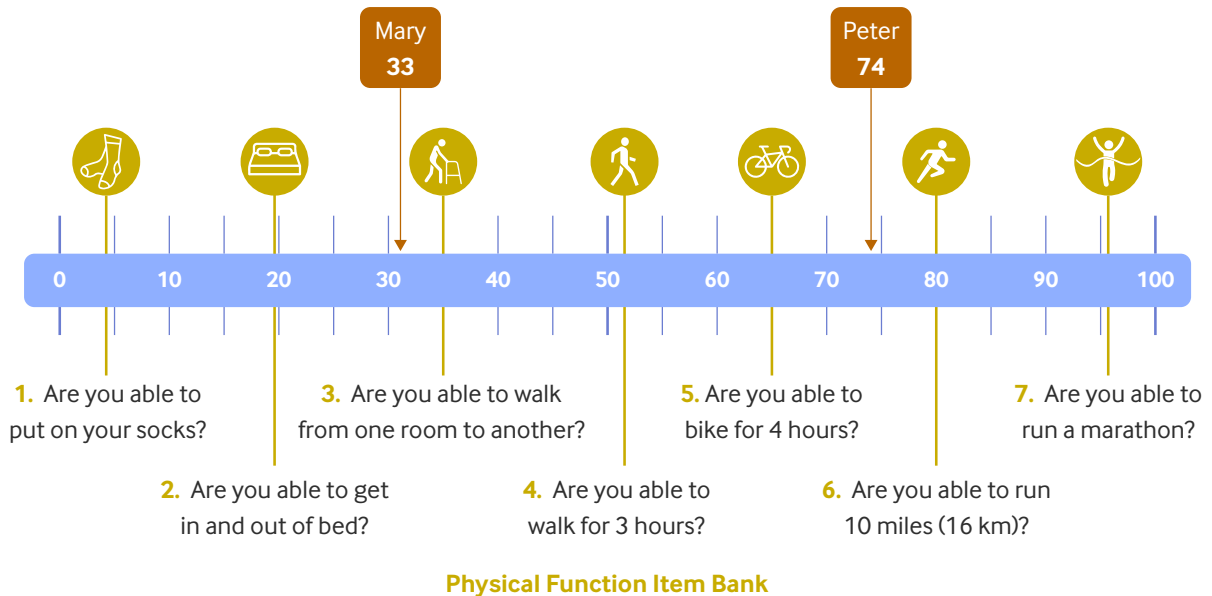
IRT-based PROMs are created from an item bank, which is a large set of questions (called *items*) that measure the same health outcome (also called *domain*, e.g., physical function). The items in the item bank are ordered (*calibrated*) on an underlying scale measuring the level of the health outcome using IRT. IRT is a set of statistical models from the psychological and educational field that describe and explain the behavior of people who respond to items in a questionnaire. IRT models the probability of a person giving a certain answer to an item. This probability depends on where the person is located on the measurement scale (the person's *ability level*) and the location or *difficulty* (and, in many models, also the discriminative ability) of the item on the same scale. For example, the higher someone's physical function level, the higher the probability that they will be able to walk for 3 hours, and if someone can run a marathon, they will likely have a high level of physical function. With IRT analyses, the location of the items and the location of the people are estimated simultaneously on the same scale ([Figure 1](#)).^{31,32}

PROMs based on IRT offer a number of advantages not available to traditional PROMs. IRT elevates the construct and its associated metric above any particular form or instrument used to measure it. This approach has the potential to unify and clarify PROM reporting.

FIGURE 1

Item Response Theory-Based Item Bank

In item response theory (IRT), the questions (items) are ordered on an underlying scale (in this example, ranging from 0 to 100) measuring a health outcome (in this case, physical function), based on their difficulty. The item “Are you able to walk for 3 hours?” is more difficult than the item “Are you able to put on your socks?” People (in this instance, Peter and Mary) are placed (scored) on the same scale, based on their responses to the items. Peter is able to perform more strenuous activities than Mary and gets a higher physical function score.



Source: The authors

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Once the items are calibrated, any selection of items from an item bank can be administered as a short form and scored on the established scale. This reduces response burden. For example, broadly applicable short forms of a few key items from an item bank can be created, covering the whole range of the measurement scale, and more tailored short forms can be created to cover a specific range of the scale (e.g., a selection of *easy* items for an older population, addressing lower levels of physical function) or include a selection of items relevant for a specific population (e.g., upper extremity function for patients undergoing shoulder surgery). Scores of all short forms created from the same item bank are on the same scale and can be directly compared because the location of the items on the scale is taken into account when calculating scores. Thus, if a patient reports being able to run to catch a bus without any difficulty, this answer will place them on a higher level of function relative to a person who has trouble walking across the room. While this may seem like common sense, most traditional PROMs consider the responses to *hard* tasks (e.g., “Are you able to run 3 miles?”) and *easy* tasks (e.g., “Are you able to get in and out of bed?”) equally when calculating a score; that is, a low score of 1 for “Yes, limited a lot” counts the same for each of those activities, unlike the weighted scoring in an IRT-based PROM that considers the degree of difficulty.

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In a computerized adaptive test, after a fixed starting question, the computer selects follow-up questions from the item bank based on answers to the questions already administered.”

Even more efficient and more patient friendly is to administer an item bank as a computerized adaptive test (CAT). In a CAT, after a fixed starting question, the computer selects follow-up questions from the item bank based on answers to the questions already administered.³¹ The measurement is thereby tailored to the level of symptoms/function of the patient, which means that patients get appropriately relevant questions. For example, if one patient’s highest level of function is indicated as the ability to put on their own socks, and another patient’s level is the ability to run a marathon, each would receive different, relevant follow-up questions. Using a CAT, highly reliable scores across a broad range of the outcome can be obtained with only about five items. CAT scores are also directly comparable to scores from short forms created from the same item bank. Short forms and CATs can therefore be used interchangeably, depending on available technological resources.

IRT-based item banks also offer important advantages for measuring and comparing health outcomes across countries. For example, items that are not relevant in a specific country (e.g., the question “Are you able to use a knife and fork?” may not be relevant for some Asian countries) could be omitted in a translated version of the item bank, whereas other relevant items could be added (e.g., the question “Are you able to ride a bicycle?” for the Netherlands). If these items may have a different level of *difficulty*, this can be taken into account in the scoring, while the underlying established scale and comparability of scores across countries remains. This is possible as long as part of the items (and health concepts) are shared across countries. IRT also allows items to be removed from or added to an item bank when the bank needs updating while retaining score comparability with previously collected PROM data. IRT-based item banks can also address some of the challenges of PROM development and validation in patients with rare diseases by enabling the creation of suitable PROMs relatively quickly. In summary, IRT-based item banks offer a flexible and sustainable methodology for measuring a core set of PROs across medical conditions.

PROMIS — The Patient-Reported Outcomes Measurement Information System

PROMIS is a measurement system consisting of a large number of IRT-based PROMs to measure commonly relevant aspects of physical, mental, and social health in adults and children. As of May 2024, PROMIS contains 3,420 items covering 167 self-reported health domains in 190 item banks and more than 200 short forms. Based on a literature review, in which we could find no other PROMs system that both incorporates universal applicability across medical conditions and uses IRT-based item banks, we consider PROMIS the most comprehensive system available. PROMIS investigators used the most decisive content from existing generic and disease-specific PROMs to develop item banks, short forms, and CATs for adults, children, parents, and proxies across the

lifespan, starting from the age of 1 year.^{20,33,34} In addition, several PROMIS Profile measures (such as the PROMIS-29 for adults and PROMIS-25 for children) were developed as a “short list” of PROs that are relevant for most health contexts, including pain, fatigue, sleep disturbance, anxiety, depression, physical function, the ability to participate in social roles/peer relationships, and many other health outcomes. These domains were chosen based on an extensive literature review and consensus-building discussion within the original PROMIS Steering Committee.

Most PROMIS scales are expressed on a T-score metric with a mean of 50 and standard deviation of 10 in a reference population, with higher scores representing more of the outcome being measured. This facilitates interpretability of scores. Local reference population data are available in several countries.³⁵⁻³⁸ Evidence increasingly demonstrates that PROMIS measures have similar or better measurement properties than traditional (also called *legacy*) PROMs.³⁹⁻⁴¹ In addition, relative to fixed short forms, CATs are more efficient and cover a wider range of the health outcome with lower patient burden.⁴²

Extensive use is made of the flexibility of IRT-based PROMIS item banks. For example, standard short forms of different lengths have been created,⁴³ as well as custom short forms for specific populations, such as people in geriatric rehabilitation settings.⁴⁴ Several item banks have been expanded to add new content and increase the range of measurement, while maintaining the underlying scale.^{45,46} A single preference-based score (also known as *health utility score*) for use in decision-making and cost-effectiveness analyses can be generated from PROMIS scores on the domains “Cognitive Function — Abilities, Depression, Fatigue, Pain Interference, Physical Function, Sleep Disturbance,” and “Ability to Participate in Social Roles and Activities.”⁴⁷ Crosswalk tables have been developed to transform legacy PROM scores to PROMIS scores and vice versa to facilitate scoring legacy PROMs on the PROMIS metric and to account for the preferences and existing requirements of health care systems for legacy PROMs.⁴⁸

“ *Item response theory also allows items to be removed from or added to an item bank when the bank needs updating while retaining score comparability with previously collected patient-reported outcome measure data.* ”

Global Adoption of PROMIS

PROMIS measures are maintained and distributed by the [HealthMeasures](#) group at Northwestern University in Chicago, Illinois, USA. In 2023, HealthMeasures registered more than 160,000 users, of which about 30% were from outside the United States (mainly Canada, the United Kingdom, Australia, China, the Netherlands, India, and Germany). PROMIS short forms can be downloaded in English or Spanish from the HealthMeasures website. Top downloads in the period 2017–2020 were the PROMIS Global Health (more than 33,000 downloads) and PROMIS-29 Profile (more than 10,000 downloads). PROMIS CATs and other measures are made available for implementation in clinical practice through the Assessment Center Application Programming Interface (API), which enables integration with other systems,

such as electronic health records and PROM platforms. The API includes more than 300 PROMIS measures in English and Spanish. In addition, since 2020, 192 translated PROMIS measures have been loaded into the API in Danish, Dutch, Finnish, French, German, Italian, Korean, Portuguese, Spanish, and Swedish. As of June 2024, there are more than 150 API licensees, of which 88 are Epic licensees. PROMIS measures are also made available through a PROMIS iPad app and other data collection tools, such as REDCap. The [PROMIS Health Organization](#), a collaborative and supportive nonprofit professional membership organization, offers training, education, and resources to advance the science of health outcomes by promoting widespread use and adoption of PROMIS in research and clinical care.

The PROMIS Profile measures, covering the most commonly relevant domains of pain, fatigue, anxiety, depression, sleep disturbance, physical function, and the ability to participate in social roles and activities/peer relationships, have been translated into more than 70 languages for adults and 30 languages for children. Additional translations are available for other domains.⁴⁹ [Figure 2](#) shows the unique PROMIS measures available in each country.

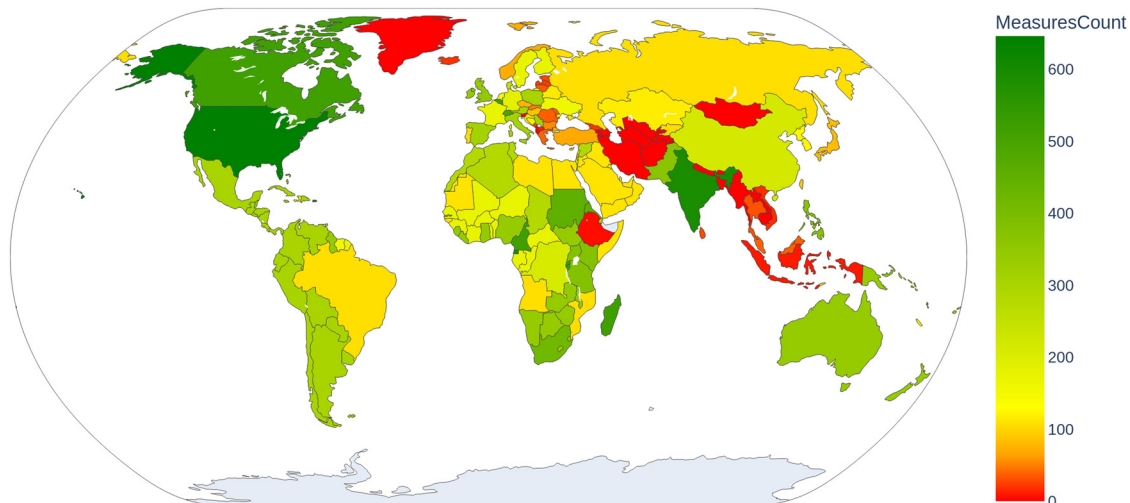
The availability of many translations not only facilitates the comparability of PROM data across countries, but also aids patient equity, diversity, and inclusion in clinical practice within countries.

FIGURE 2

Count of Available Patient-Reported Outcomes Measurement Information System (PROMIS) Measures for All Official Languages by Country, 2024

This illustration uses a color key to show the number of unique PROMIS measures available per country. The measures are available in the official, official regional, or official de facto language of that country (including English).

2024 Count of Available PROMIS Measures for All Official Languages by Country



Source: HealthMeasures
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A universal translation methodology is used to harmonize translations between and within languages.⁵⁰ Translations are anchored to item definitions that explain the intention and context of each item, helping the target language translation to be true to the intended meaning while culturally appropriate. Furthermore, translations are adapted to common linguistic and cross-cultural differences, such as terms used to describe domains and intensity levels (e.g., fatigue), units of measurement (e.g., distances, weights), and lifestyle and living environment (e.g., cooking and eating habits, social activities, and types of stairs, toilets, and doors). IRT allows examination of whether items function substantially differently after translation or across different groups (e.g., men vs. women; young vs. old). This is called *differential item functioning* (DIF). If DIF is found, as was the case for the Spanish translation of PROMIS Physical Function, an adapted IRT-based scoring algorithm could be created for the translated version (by giving items a different location on the scale), while keeping scores comparable on the same scale. For most item banks and languages such adaptations were deemed not necessary and the default PROMIS scoring algorithms are used.

“ *As of May 2024, PROMIS contains 3,420 items covering 167 self-reported health domains in 190 item banks and more than 200 short forms.*”

A growing number of PROMIS measures have been validated (to at least some extent) in many countries and in a range of health conditions; they are used in registries and clinical practice settings across a variety of patient populations, settings, and countries. HealthMeasures publishes a [list of primary citations](#) for PROMIS measures. PROMIS allows comparable measurement of a wide range of PROs across the world.

As of June 2024, 20 countries have a PROMIS national center, which acts as the information resource and contact point for PROMIS in the country, and more are likely to follow ([Figure 3](#)).

Using PROMIS in Practice

The University of Rochester Medical Center (URMC) in Rochester, New York, USA, was one of the early adopters and is an example of the implementation and use of PROMIS in routine medical care. Clinicians started using PROMIS CATs at the orthopedic surgery department in 2015. PROMIS CATs were completed by patients on an iPad in the waiting room during every outpatient clinic visit. This practice was later expanded throughout more than 30 departments and divisions. A university-wide initiative was started in 2023 to collect and use PROs as standard of care in all departments. PROMIS CATs measuring pain, physical function, and depression were chosen for their ease of use and accuracy. By June 2024, more than 495,000 patients have completed PROMIS CATs under the URMC program. PROMIS scores are available to providers during patient interaction and are discussed with the patient to enhance the understanding of the patient’s health situation ([Figure 4](#)).⁵¹⁻⁵³

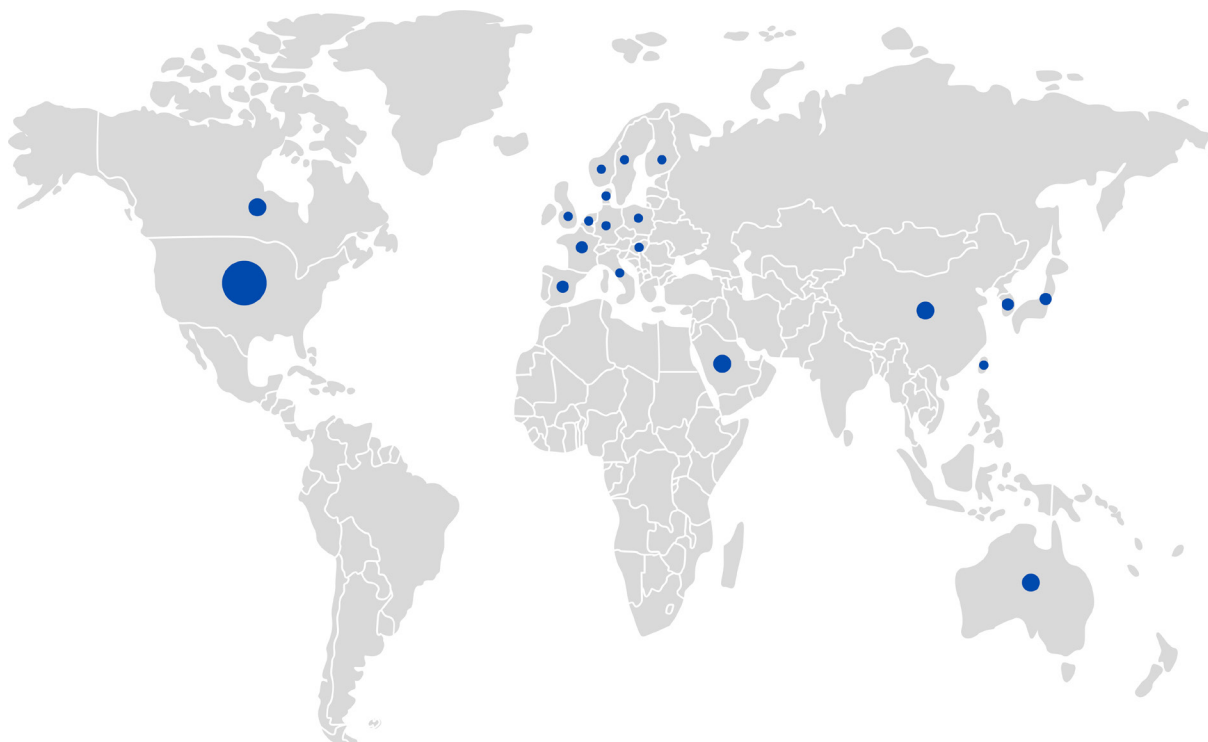
A [video](#) of the PROM process in the hospital is available online.

At URMC, during the first 15 weeks of implementation, PROMIS CATs were administered to 17,892 unique patients. The median number of questions completed was 13 and the median time

FIGURE 3

Countries with Patient-Reported Outcomes Measurement Information System (PROMIS) National Centers, June 2024

The 20 dots on the map indicate the presence of a PROMIS national center (PNC) in that country. The United States serves as the home for the PROMIS Health Organization (PHO). Each PROMIS national center is part of the PHO and works with the PHO Board of Directors to help PHO achieve its mission. The PNC acts as the information point for PROMIS in that country, has an educational and promotional role, and is responsive to questions about translation issues.



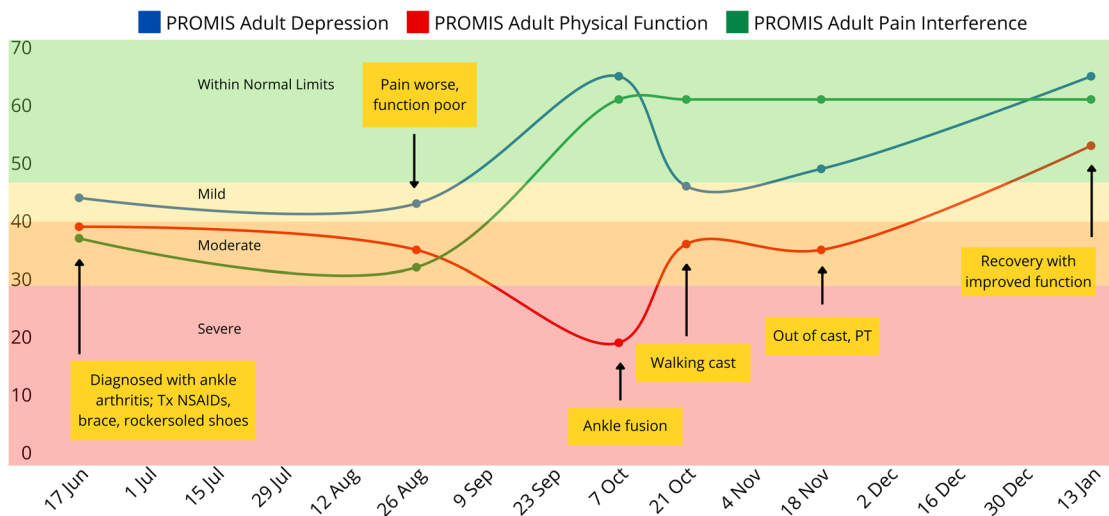
Source: PROMIS Health Organization
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taken to complete all assessments was 2.6 minutes. By week 10, the entire orthopedic outpatient clinic (excluding children) was collecting PROMIS data (and still is).⁵² The data obtained are also analyzed to learn from them and improve health care delivery. For example, clinical staff learned that preoperative PROMIS scores predict postoperative success of foot and ankle surgery. Patients with higher pain levels have more potential for improvement. This information is used in setting patient expectations prior to surgery, and physicians may caution patients with low preoperative pain levels against surgery.⁵³ In addition, the researchers found that after patients had already achieved substantial recovery — defined as having two consecutive postoperative minimal clinically important differences above preoperative PROMIS scores — patients continued to attend an average of four additional follow-up visits, at a cost of \$266–\$322 per patient. These results call into question the value of visits after substantial improvement has been achieved. When patients are making significant improvements, remote follow-up may be just as effective and more cost efficient.²⁹

FIGURE 4

Dashboard Example Showing Patient-Reported Outcomes Measurement Information System (PROMIS) Depression, Pain Interference, and Physical Function Scores in an Individual Patient Over Time

This figure illustrates the capacity for the clinician to monitor the patient-reported outcomes (PROs) related to pain, depression, and function over the course of care for an adult patient undergoing ankle surgery. Key events and milestones are noted over time on this dashboard, along with the related impact on the PROs, which can range from severe limitations to functioning within normal limits. The patient and clinician can review and discuss the care plan during their clinical encounter. The vertical axis represents the severity T-score (mean = 50, standard deviation = 10).



NSAIDs = nonsteroidal anti-inflammatory drugs, PT = physical therapy, Tx = treatment/therapy.

Source: Obtained from and used with permission from J. Baumhauer, University of Rochester Medical Center, Rochester, New York, USA.

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“ In 2023, HealthMeasures registered more than 160,000 users, of which about 30% were from outside the United States (mainly Canada, the United Kingdom, Australia, China, the Netherlands, India, and Germany). ”

Other hospitals have had similar learning experiences. For example, in 2019, the Henry Ford Cancer center in Detroit, Michigan, USA, integrated PROMIS CATs in a variety of clinical settings capturing many cancer disease sites (23–38 clinical units) within a diverse patient population. All cancer patients with an oncologic visit complete PROMIS CATs prior to their visit using a patient portal or tablet. PROMs are integrated into the clinical workflow and discussed with

the patients during their visit. In addition, a cancer symptom management clinic or ambulatory case management team is alerted and patients with severe pain, fatigue, physical function, or depression scores are contacted.⁵⁴ The center also found that pain interference and physical function scores were associated with unplanned health care utilization. Thresholds of 60–65 for PROMIS Pain Interference and 35–40 for PROMIS Physical Function were defined to inform clinicians' actions with the goal of preventing ED or urgent care visits.⁵⁵ (The [PROMIS T-score cut points](#) vary based on the specific measure.) The Henry Ford Health system expanded the use of PROMIS to other departments, such as orthopedic surgery. For example, it uses the PROMIS Upper Extremity CAT to monitor patients undergoing rotator cuff repair. PROMIS CATs are completed at each postoperative orthopedic clinic appointment scheduled by the patient. It used the five most frequently asked questions in the PROMIS CAT to determine functional milestone achievements after surgery. The clinical team found that after 3 months, 50% of the patients were able to put on or take off a jacket. At 11 months, 70% of the patients were able to do so. However, the majority of patients were not able to put on a shirt or blouse 1 year after surgery.⁵⁶ Understanding these milestone achievements is key to the shared decision-making process regarding whether surgery is appropriate for certain patients; for example, some patients may have occupational or other essential requirements that necessitate a specific return to functional activity. Based on the observed results, better information can be provided to patients during their consultation, and patients are more able to evaluate treatment options considering the requirements of their livelihood.⁵⁶

In Europe, several hospitals in the Netherlands have implemented PROMIS short forms or CATs in daily clinical practice. At Amsterdam University Medical Center, a large tertiary hospital in the Netherlands, PROMIS CATs measuring core PROs — including physical function, pain, fatigue, anxiety, depression, and the ability to participate in social roles and activities — are routinely used by 15 health care teams, and another 30 teams are in the process of implementation. As part of the implementation process, a hospital-wide PROM policy was developed. Key components include the use of generic PROMs (PROMIS CATs) by default, supplemented with disease-specific PROMs where needed. The primary aim for PROM collection should be clinical care, and it is considered essential to discuss the PROMs with patients during consultations.⁵⁷ The effects of introducing PROMIS on the quality of routine clinical care will be evaluated, for example in HIV care. It is expected that the experience of quality of care among people living with HIV will be improved by introducing PROMIS to routine HIV care through the early signaling of physical and psychosocial health problems, followed up with actions if needed.⁵⁸ In the St. Elisabeth Hospital, a nonacademic level I trauma center in the Netherlands, PROMIS CATs are routinely collected through the personal electronic health records of patients prior to all clinical appointments with an orthopedic or trauma surgeon. When analyzing the real-world data, surgeons found that both upper and lower extremity fracture patients did not reach a physical health status comparable to that of the general population after 1 year.⁵⁹ These results emphasize the burden of trauma and provide important data for managing patient expectations.

In North America, the Princess Margaret Cancer Centre at the University Health Network in Toronto, Canada, has pioneered the routine implementation of PROMs in outpatient oncology care. Subsequently, several divisions (rheumatology, nephrology, multi-organ transplant) started

working with PROMIS. In a clinical pilot study, patients on maintenance hemodialysis completed PROMIS CATs once a month for 6 months on a third-party electronic data capture platform. The PROMs were scored in real time and the results were shared with participants and with the clinical team. Moderate to severe symptoms were flagged using established cutoff scores. Referral options to manage those symptoms were shared with the clinical team, and additional symptom management resources were also provided for both participants and clinicians. This study confirmed the feasibility and acceptability of PROMIS-guided symptom management among prevalent patients on maintenance hemodialysis.⁶⁰ Integration into the electronic health record (Epic) is now almost complete, and several additional clinical pilot studies are under way now to prepare for program-wide implementation. A quality improvement project is ongoing to guide symptom management for incident solid organ transplant recipients and kidney transplant recipients to facilitate discharge and to prevent readmission to hospital. These examples demonstrate the clinical utility of PROMIS tools among patients with kidney disease.⁶¹

PROMIS measures also increasingly play a key role in population-based studies, multinational clinical trials, registries, and patient support initiatives. A leading example of this is the Scleroderma Patient-Centered Intervention Network, known as [SPIN](#). SPIN was launched in 2011 at McGill University in Montreal, Canada, and now includes more than 1,800 people living with scleroderma from 45 clinical sites in seven countries. Patients at least 18 years old who speak English, French, or Spanish are recruited into SPIN by their rheumatologist and complete the PROMIS-29 and other outcomes in an online assessment every 3 months. PROMIS-29 data have contributed important new information that has increased understanding about how people with scleroderma feel and function, identified unmet needs, and contributed to the development of new tools and online support programs for patients. For example, an online international mental health support program was developed to reduce anxiety and social isolation during the Covid-19 pandemic.⁶²

“*The application programming interface (API) includes more than 300 Patient-Reported Outcomes Measurement Information System (PROMIS) measures in English and Spanish. In addition, since 2020, 192 translated PROMIS measures have been loaded into the API in Danish, Dutch, Finnish, French, German, Italian, Korean, Portuguese, Spanish, and Swedish.*”

The Care4BrittleBones organization, a charity based in the Netherlands, is dedicated to enabling a better quality of life for people with osteogenesis imperfecta (OI) through international research. They funded the development of a standard set of outcomes and measurement instruments to support longitudinal and cross-sectional comparison of outcomes between centers that serve OI populations. PROMIS measures were selected as the preferred instruments for most domains.⁶³

PROMIS measures are also used by international initiatives such as ICHOM⁶⁴ (which now includes them as part of a large number of population- and condition-specific outcome

sets) and the Organisation for Economic Co-operation and Development (OECD), which is developing — through the Patient-Reported Indicator Surveys initiative — a set of key health system performance patient-reported indicators of capabilities, experiences, and outcomes.⁶⁵ The availability of high-quality generic PROMIS measures for the most relevant symptoms and functions and available reference scores has also proven its worth during the pandemic, when studies on the effects of Covid-19 on the health and quality of life of patients and health care providers had to be designed extremely quickly without prior information on relevant outcomes.⁶⁶

Moving Forward

International harmonization of PROs and PROMs has the potential to accelerate patient-centered care by facilitating the collection of accurate and comparable real-world evidence on health outcomes that matter most to patients. It allows the consistent collection and comparison of patient data across different countries and health care systems. This enhances the ability to conduct international research, benchmarking, and cross-country comparisons. International standards facilitate the pooling of data from diverse populations, increasing the robustness and generalizability of research findings. This can lead to more comprehensive and inclusive evidence for clinical guidelines and health care interventions. Policy makers can use standardized PROM data to make informed decisions about health care priorities, resource allocation, and policy development. This can help address global health challenges more effectively and equitably. Using a common set of measures also reduces the need for developing and validating new tools in different regions, saving time and resources.

We urge health care providers, directors of health care systems, and other stakeholders to accelerate efforts to routinely measure a core set of PROs in all sectors of health care that are most patient-valued and actionable, including pain, fatigue, anxiety, depression, sleep disturbance, physical function, and the ability to participate in social roles and activities. We believe that the PROMIS Profile measures are most suitable for this purpose and should be supplemented with disease-specific PROMs where needed. For example, a symptom checklist, such as the Dialysis Symptom Index or patients with kidney disease,⁶⁷ could be added to measure the presence or absence of relevant disease-specific symptoms. A core set of commonly relevant PROs and PROMs across health conditions could also speed up the development and uptake of core outcome sets and standard sets considerably.

The use of one system of IRT-based PROMs for measuring a core set of PROs would facilitate harmonized measurement across conditions, settings, cultures, and countries. We specifically recommend PROMIS (particularly the PROMIS Global Health and PROMIS Profile measures), which is increasingly recognized as the international gold standard because of its general applicability, extensive validation in multiple populations and languages, use of comparable scales, and ease of interpretation.^{21,68,69} In some countries, including the Netherlands, Canada, Australia, and Sweden, as well as in a European Union-funded project to build a European Health Outcomes Observatory ([H₂O](#)), PROMIS is already considered a key resource for measuring a harmonized core set of PROs for national registries and population monitoring.⁷⁰⁻⁷² For example, in the Netherlands, a working group of mandated representatives of umbrella organizations

involved in Dutch medical specialist care, together with PROM experts and patient organizations, developed a consensus-based standard set of generic PROs and PROMs to be implemented across Dutch medical specialist care. PROMIS short forms were selected as the preferred instruments for all selected PROs.⁷¹ The Dutch Ministry of Health, Welfare, and Sport financially supports the Dutch-Flemish PROMIS National Center to facilitate the implementation and use of PROMIS across hospitals, for example, by advising on relevant domains and PROMIS measures — and providing graphs for displaying PROMIS scores compared with Dutch general population reference scores and severity cutoff values for mild, moderate, and severe scores — to facilitate shared decision-making. In Saudi Arabia, there also has been activity in exploring the development and integration of PROMIS resources.^{73,74}

“ *The use of one system of item response theory-based PROMs for measuring a core set of patient-reported outcomes would facilitate harmonized measurement across conditions, settings, cultures, and countries.* ”

PROMIS can also be an important resource for improving research by facilitating synthesis of research findings, multinational population monitoring, and policy development.

However, several challenges remain. First, implementing and using (whatever) PROMs in a busy clinical setting is a complex, context-specific process that requires a change in the organization and in the behavior of patients and health care professionals. The implementation process comes with many interrelated barriers and challenges.^{17,75} Practical implementation guidelines have been developed to address these barriers, for instance, by the International Society for Quality of Life Research ([ISOQOL](#)) and the Patient-Reported Outcomes Tools: Engaging Users and Stakeholders ([PROTEUS](#)) Consortium. Second, a standardized approach for routine PRO measurement requires a shared understanding and acceptance of the benefits of IRT-based PROMs and how to use them effectively by patients, clinicians, registries, health technology assessment agencies, regulatory bodies, and other stakeholders. A large-scale international training and implementation strategy needs to be developed. Third, while the PROs covered by the PROMIS Global Health and Profile measures (the most often downloaded PROMIS measures) were chosen based on an extensive literature review and consensus-building discussion, international consensus on the most relevant core PROs and PROMs across conditions and countries is still recommended. Fourth, there are significant costs and sometimes technical challenges associated with integrating PROMs — especially PROMIS CATs — directly into electronic health records and in displaying results in real time in ways that can be easily interpreted by health care providers and patients.

IRT-based item banks innovate PRO assessment and bring flexibility and sustainability to PRO measurement that is needed to put patients at the center of care. The PROMIS Health Organization and national centers can be a valuable resource to facilitate the global uptake of a standardized set of PROs and PROMs that can ultimately be used to improve the health care and quality of life of individuals everywhere.

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