Standardizing patient-reported outcome measurement in pediatrics

Validation & implementation of PROMIS

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Publication date
2022

CHAPTER I

Introduction

The impact of chronic conditions

In the Netherlands about half a million children grow up with a chronic condition [1]. The prevalence of children growing up with such conditions is on the rise as a result of earlier diagnosis and improved treatment [1, 2]. The term chronic condition can refer to many different conditions ranging from congenital conditions to acute conditions acquired in later life and can affect aspects of physical, social and cognitive functioning [3, 1]. Growing up as a child with a chronic condition can have a substantial impact on one's life, ranging from medication use or regular hospital visits to severe limitations in performing daily activities. Several studies and meta-analyses have shown the impact of a chronic condition on the physical [4-7], mental [8-10, 4, 6, 7] and social health of children [4, 8, 6, 7].

Due to the wide variety of possible problems a child with a chronic condition may face, it is important to routinely measure in clinical practice how the children are doing, physically, mentally and socially [11] and to include these outcomes in research, such as clinical trials [12, 13] but also in exploratory studies on the impact of chronic conditions on health.

PROs & PROMs

To be able to measure outcomes of conditions and treatments from the patient's perspective, also known as patient-reported outcomes (PROs), questionnaires are required. These questionnaires are called patient-reported outcome measures (PROMs). PROMs are developed to assess domains of health and quality of life in a standardized way [14]. The domain assessed by a PROM can either be a specific domain (such as anxiety) or an overall perspective on perceived health. In addition, PROMs can be divided into disease-specific and generic PROMs. Disease-specific PROMs contain items (or questions) in relation to a specific condition (such as specific symptoms), while generic (or universal) instruments contain items on health which are not related to a specific condition but are relevant to multiple conditions, such as instruments that assess pain. Generic (or universal) PROMs are applicable to all patient populations and can thus be used to reduce administrative burden for patients with comorbidities as well as provide comparisons with reference data from the general population. In pediatrics, PROMs are recommended as self-reported instruments for children above 8 years [15] or as parent-proxy report for younger children or children affected with conditions which makes them unable to complete self-report instruments.

PROMs can serve a multitude of goals in both research and clinical practice. Traditionally PROMs were developed to compare the burden of having a chronic condition to reference data from the general population [14] and for use in clinical trials to assess the effects of interventions [16-18] on an aggregate level. PROM data can be collected through quality registries or health systems to facilitate comparisons between treatments, health care teams or hospitals, which can subsequently be used to evaluate and improve performance [19-21]. Finally, PROMs can be used for individual patients in psychological diagnostics or to routinely assess patient outcomes in clinical practice.

Effects of PROMs in clinical practice

Previous studies have shown that the implementation of PROMs in daily clinical practice results in improved patient-clinician communication as well as improved health outcomes, such as quality of life, and even survival [22-26]. The use of PROMs can also increase patient participation as patients are asked to elaborate on their responses [27] and may serve as a foundation to support communication between patients and clinicians and to facilitate shared decision making [21, 28, 29, 20, 30]. Discussing outcomes during consultation improves patients sense of well-being and satisfaction with care [30, 31, 23, 32]. Additionally, PROMs can help with timely recognizing and identifying problems of individual patients [33], which may improve health outcomes. Two recent systematic reviews of the effects of PROMs in pediatrics concluded that the use of PROMs improves detection of problems, communication and health outcomes (specifically quality of life, mental and social health) [34, 35]. These studies provide evidence for the importance of PROMs in clinical practice, which has previously also been established in clinical studies and trials [17, 36].

Pediatric PROMs in daily clinical practice; the KLIK PROM portal

The KLIK PROM portal is an evidence-based online portal developed in the Emma Children's Hospital and has been implementing PROMs into pediatric clinical practice for over a decade [37, 38]. Children or their parents complete the PROMs at home prior to consultation and the health care professional discusses the outcomes during consultation. Previous studies on the effectiveness of KLIK PROM implementation have shown improved discussion of psychosocial functioning and better identification of health problems [39, 30]. A training was developed to support health care professionals on how to work with the KLIK PROM portal and how to discuss outcomes during consultation [40]. During recent yearly evaluations of the KLIK PROM portal with health care professionals, the portal was described as useful and efficient in improving patient-clinician communication [41]. In a recent qualitative study, pediatric patients and their parents have indicated they were satisfied with the KLIK PROM portal and that it

improved the detection and discussion of problems [42].

During the years of implementation some barriers were identified regarding the choice and selection of PROMs. Currently the KLIK PROM portal contains over 300 different PROMs, which has become increasingly complex to manage and to keep up-to-date. Recently several barriers were identified for the implementation of the KLIK PROM portal using the Consolidated Framework for Implementation Research (CFIR) [43]. These barriers included the adaptability, costs and complexity of the KLIK PROM portal. These barriers are not only a problem for the KLIK PROM portal, but they also hinder the implementation of PROMs in general. The choice of a suitable PROM is a vital part of improving multiple aspects of PROM implementation. Patients have previously mentioned that selected PROMs were too burdensome, confrontational and repetitive [42]. Health care professionals have confirmed that there are simply too many different PROMs out there which are incomparable, difficult to interpret or that lack (relevant) reference data [41]. The choice of PROMs is thus a common problem in clinical practice and the available PROMs to choose from may not be sufficient.

Problems with PROMs

Depending on the intended goal and target population, PROM selection may be complex and researchers may be inclined to develop new (disease-specific) instruments [19, 14, 44]. This has resulted in a staggering growth of PROMs over the past two decades. In the comprehensive PROM database Patient-Reported Outcomes Quality of Life Instrument Database (PROQOLID™) [45], there are over 4500 PROMs available of which the majority are disease-specific PROMs. A considerable amount of these PROMs assess the same PRO domain (or construct; e.g. anxiety) with different items [46, 47] or even contain overlapping items which are included in multiple PROMs [14, 46]. In addition PROMs may differ in content, length, and scoring methods [48], their psychometric qualities [49, 50], contain outdated reference values [7] and may suffer from floor/ceiling effects when applied to different populations [44]. For research this means study results that assess the same domains are incomparable, which means resources are wasted. For clinical practice it means that PROM data is difficult to interpret across PROMs and reference data may be outdated or not present at all [41]. In addition, (pediatric) patients report that existing PROMs are too long, confrontational, repetitive or irrelevant [42, 51, 52, 32].

Harmonization of PROs and PROMs has thus become increasingly important [44]. Several initiatives have been founded to develop more manageable sets of PROMs. One of the largest initiatives is the International Consortium of Health Outcomes Measures (ICHOM), which develops standard sets of outcomes [53-55] for implementation in clinical practice. These standard sets are a selection of outcomes, including PROs, that

are deemed most relevant for specific conditions or target population. However, a recent study performed on the standard sets developed by ICHOM has shown that disease-specific PROMs are often recommended. This has resulted in over 114 unique PROMs being recommended. The majority of the PROs measured by these PROMs could be covered by 22 unique PRO concepts [47], such as physical functioning. For clinical trials similar Core Outcome Sets (COS) have been developed and are available within the Core Outcome Measures in Effectiveness Trials (COMET) database [56]. A core outcome set (COS) is an agreed standardized set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care. Similarly to the standard sets of ICHOM a recent study has shown that the 323 unique PROMs included in COS target overlapping domains (e.g. 22% assessed physical functioning), but with different instruments (of which 77% were disease-specific)[46].

Solution - A common metric

A more harmonized approach to measuring PROs is required for successful implementation of PROMs in clinical practice and research. Instead of a focus on the PROM, measurement should focus on the PRO we are attempting to measure. The use of generic, rather than disease-specific instruments may be a step in the right direction [47, 46]. However, it has been argued that generic instruments do not provide the same accuracy or responsiveness as disease-specific instruments because the items of a generic instrument must be broad to be able to cover the entire spectrum of functioning [14, 19, 57, 58, 44]. Furthermore, traditional PROMs (also known as legacy instruments) that assess generic domains of health are often scored using classical test theory (CTT), where all items carry the same weight when calculating domain scores. For example, an item on suicidal ideation would carry the same weight as an item about feeling sad in CTT. The item on suicidal ideation should, based on the content, have a heavier influence on the final depression score for a patient. As CTT is unable to differentiate these items from each other, it limits the accuracy and responsiveness of the instrument [59, 60].

These limitations of generic CTT instruments can be reduced by the use of item banks and item response theory (IRT) modeling [59-61]. Item banks are large selections of items that measure the same domain (e.g., depression) across a wide range of a domain [61]. IRT is a psychometric method where differences in item content are taken into account when calculating scores. In essence, it is a collection of probabilistic functions that models the relationship between a person's level of a domain (e.g. level of depression) and the probability of a certain response to an item. This function results in a model with item parameters for items (representing the 'difficulty' or 'location' of the items on the scale) and person parameters for patients (representing the patients' scores on the scale). Both are

expressed on the same theta (θ) scale (also called metric), which improves interpretability of scores. A type of IRT model often applied to ordinal data is the graded response model (GRM)[62]. The GRM allows us to order the item responses in a questionnaire based on their difficulty, defining threshold parameters for each response category of an item (b)[62]. The threshold parameter represents the amount of functioning (or symptoms) required to be more likely to select an adjacent (higher) response category on a questionnaire (for example from "Never" to "Almost Never"); see Figure 1. The IRT model also includes an item parameter that tells us how well the item discriminates patients from each other, the discrimination parameter (α)[62].
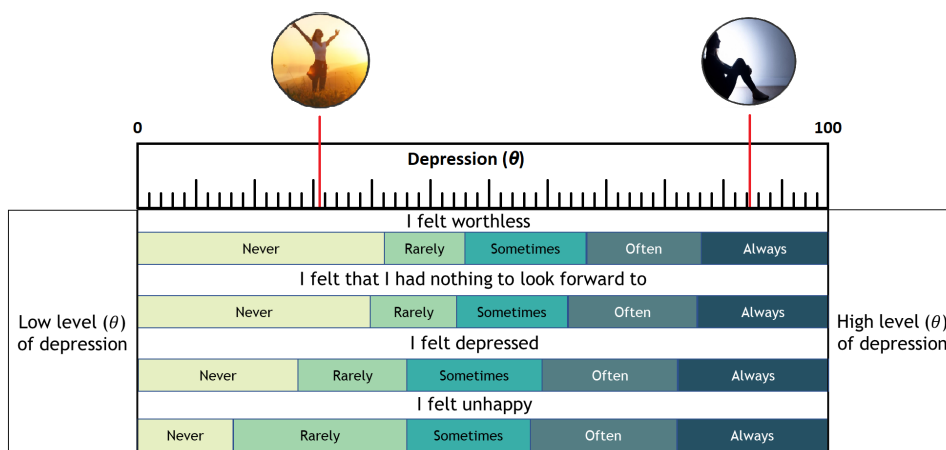

Figure 1. Example of an item bank (PROMIS Depression) with item response categories divided along the θ continuum. Each response category (for example "Rarely") covers a different range of symptoms (θ) for each item. The level of depressive symptoms where the response categories change are the item thresholds (b).

Using this information we can select items from an item bank that best match our patients' level of functioning/symptom severity while providing accurate measurements, for example by developing tailored short-forms. A more advanced method of administration can be used to adaptively select items from an item bank rather than developing static short-forms, this is known as computerized adaptive testing (CAT)[61, 63]. CATs tailor the items administered to the previous responses given by the patient. For example we would not ask a patient that has responded that he/she never feels unhappy if he/she is depressed. At each step of the CAT the person's score (θ) is estimated based on all responses given thus far and the next item is selected based on the item information at the estimated θ value. A CAT uses predefined stopping rules to determine when to stop administering items. In most cases the stopping rules include a minimum and maximum number of items administered and a certain accuracy of θ. The accuracy is θ is determined by the standard error of θ. A common stopping rule is to have a standard error of 0.32 or lower (which corresponds to a reliability of 0.90 or higher). The use

of CATs has previously demonstrated to provide reduced administrative burden and increased accuracy and efficiency than static instruments [61, 64, 63]. Patients have reported to prefer CATs over static instruments [52]. While CATs have to be administered and scored through IRT using a computer, short-forms can be administered on paper and scored using traditional sum scores. Sum scores can subsequently be transformed to a score on the IRT metric by using a transformation table. However, this results in a loss of measurement accuracy compared to applying IRT scoring directly [65, 66].

In addition to these benefits, the theta scale generated under an IRT model allows us to add additional items, as long as these items measure the same PRO [61]. Using overlap between items included in the scale and new items, we can determine parameters for additional, new items on the same metric or we can retire certain items, without losing comparability to previously collected data. This makes item banks developed under IRT sustainable for the future [61] and allows us to even add items from other PROMs to express the scores of different PROMs on the same scale (also known as crosswalks), as long as they assess the same PRO, resulting in a common metric for each specific PRO [67-71].

PROMIS

One of the largest systems in the medical field that applies these benefits of IRT is the Patient-Reported Outcomes Measurement Information System (PROMIS®). The PROMIS initiative developed item banks for children and adults for generic domains of physical, social and mental health [72, 61, 73], which were deemed relevant for most patients. For children it covers domains of anxiety, depression, relationships with peers, physical functioning, fatigue and more (see the Figure 2 below). The PROMIS pediatric item banks have been developed by combining the best items of all available pediatric PROMs after an extensive literature review [66]. The PROMIS pediatric item banks have subsequently been rigorously validated during its' development phase [74-80, 66]. In the U.S., the pediatric PROMIS item banks have been validated and used to assess and monitor disease burden in disease-specific populations, such as oncology [81], diabetes [82], brain tumor [83] and juvenile idiopathic arthritis [84]. Over the past decade researchers in the U.S. have gathered evidence for many aspects of validity for the pediatric item banks and scales; structural validity [74-80, 66, 85], convergent validity [86, 87], criterion validity [86], discriminant validity [88, 87], and responsiveness [85]. Internationally, PROMIS is active in 19 different countries, which each has their own PROMIS National Center. PROMIS is increasingly recognized as the international gold standard [89].
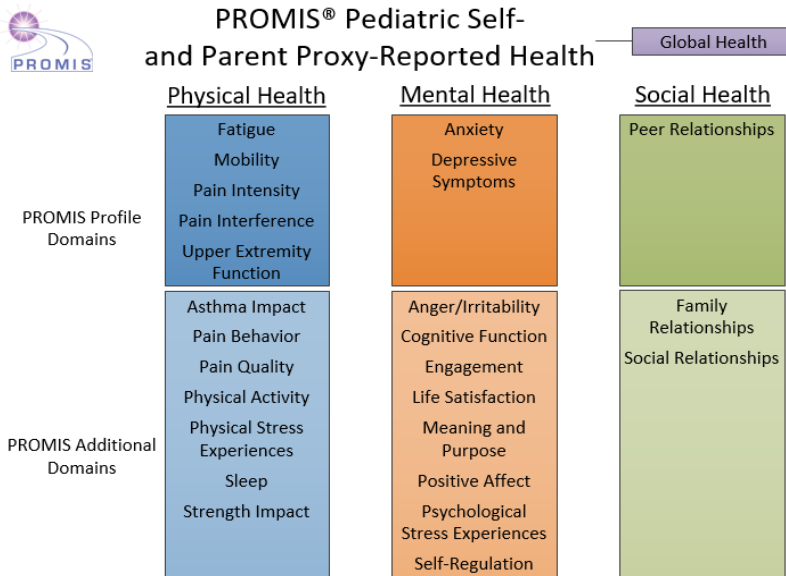
Figure 2. All available pediatric PROMIS item divided across their corresponding generic domains of physical, mental and social health.

PROMIS has developed standard short-forms which can be used to assess these domains as a static form. The short-forms have been specifically developed to measure accurately over a broad level of functioning/symptoms while minimizing administrative burden [63, 66]. To reduce patient burden further the PROMIS item banks can also be administered adaptively by CAT. The default minimum number of items administered for a PROMIS CAT is 4 and the maximum is 12. In addition the PROMIS CAT uses a stopping rule for the standard error of θ of 0.32. For CAT administration PROMIS provides an API. It can be linked to existing systems (such as electronic health records) to administer CATs within a healthcare system.

PROMIS transforms θ scores into T-scores through a linear transformation ($\theta * 10 + 50$). T-scores are used to interpret the results and cut-off values are determined based on the distribution of T-scores to display severity of T-scores (e.g. mild, moderate or severe symptoms). Carle. et al [90] provided reference data and defined cut-off values for the pediatric item banks based on a representative sample of the U.S. population for the 75th (mild) and 95th (severe) percentile. These reference values and cut-offs can be useful to interpret data in research and can be used to visualize outcomes in clinical practice to make scores easier to interpret by clinicians and thus easier to discuss during consultation [41, 91-93]. Currently, there is no standardized method of visualizing PROMIS CAT outcomes and reference values in dashboards, which is recommended to improve interpretability in clinical practice [94].

PROMIS in the Netherlands

A set of nine pediatric item banks v1.0 were previously translated into Dutch-Flemish [95]. However most pediatric item banks were recently revised (v2.0) and new item banks became available which were not previously translated. The Dutch-Flemish pediatric item banks have not yet been validated and Dutch reference values are not yet available, which are important for the interpretation and visualization of outcomes. To ensure that the pediatric PROMIS instruments can be used in the Netherlands the following three steps are required.

Step	Goal
1. Translation	Obtain accurate translations, including cognitive debriefing with pediatric patients, of the pediatric instruments.
2. Validation	
A. General Population	Assess the psychometric properties of the instruments in the Dutch population and provide reference values and comparisons to legacy instruments.
B. Clinical Population	Assess the psychometric properties of the instruments in clinical populations and examine the benefits of CAT compared to static forms.
3. Implementation	Investigate whether the implementation of PROMIS in research and clinical practice is feasible and examine how hurdles of implementation can be overcome.

Outline of this thesis

To facilitate successful implementation of PROMIS in pediatrics in the Netherlands the previous described steps need to be completed. Therefore, the aims of this thesis are: 1) Investigate the psychometric properties of the PROMIS pediatric instruments; 2) Compare the psychometric properties of PROMIS pediatric instruments with traditional instruments; 3) Assess the efficiency of PROMIS CAT in pediatrics; 4) Provide reference values for the PROMIS pediatric instruments; and 5) Assess and improve feasibility of implementing pediatric PROMIS in clinical practice, including visual feedback options in electronic dashboards and practical feasibility by reducing patient burden of CAT administration.

Aim	Chapter(s)
1. Investigate the psychometric properties of the PROMIS pediatric instruments.	Chapter 2, 3, 4, 5.
2. Compare the efficiency and reliability of PROMIS instruments to common legacy instruments.	Chapter 2, 3, 4, 5.
3. Assess whether computerized adaptive tests (CAT) can improve efficiency of administration.	Chapter 2, 3, 4, 5.
4. Provide reference data for PROMIS pediatric instruments.	Chapter 2, 3, 4.
5. Assess feasibility for of PROMIS CATs in research and improve the feasibility for clinical practice, by developing a feedback option for scores and reducing burden of CATs.	Chapter 6, 7, 8.

The first part of this thesis focuses on translating and ***assessing the psychometric properties of the PROMIS pediatric instruments***. Three validation studies were performed in the Dutch general population as PROMIS is intended to measure across a broad range of health and the general population includes both healthy participants as well as participants with chronic conditions. In addition, general population studies can provide reference values for future studies. **Chapter 2** describes the translational procedure of the revised and new pediatric item banks (V2.0) and the data collection procedure to obtain a representative sample of the Dutch population. Subsequently, this chapter describes the validation of the Peer Relationships item bank in the Dutch population and presents Dutch reference values. We investigated the fit of a GRM to the data, as the scoring method would have to be adjusted if certain items did not function well in the Dutch population. The parameters resulting from the graded response model were compared to the U.S. parameters to see if the item parameters of the original U.S. model were internationally applicable, as when administering PROMIS (CATs) the U.S. model parameters will be used. In addition we looked at convergent validity of the Peer Relationships item bank by correlating it to the social functioning subscale of the Pediatric Quality of Life Inventory (PedsQL™, 4.0)[96]. Finally, we assessed the efficiency of applying CAT. In **Chapter 3** we assessed the psychometric properties of the Anxiety and Depressive Symptoms item banks and compared them to the Revised-Child Anxiety and Depression Symptom (RCADS) scale. The RCADS is a commonly used legacy instrument to assess anxiety and depression in children.

In **Chapter 4** we compared the psychometric properties of the PROMIS Pediatric Global Health-7 (PGH-7) scale to the PedsQL, which is commonly used to assess overall health(-related quality of life) in pediatrics. We report on the efficiency on both measures and provide a balanced discussion on the use of both instruments in clinical practice. **Chapter 5** focusses on the validation of PROMIS in assessing physical, mental and social health in a clinical population of children with juvenile idiopathic arthritis. In addition to assessing the validity and reliability in this sample, we also look at the efficiency of CATs and the number of items administered in a clinical population and assess the test-retest reliability of several PROMIS pediatric item banks.

Regarding ***the feasibility of the implementation of PROMIS in research and clinical practice*** we provided a proof-of-concept study in **Chapter 6** for the feasibility of PROMIS CATs in research and provide partial evidence for its' responsiveness to change. The COVID-19 pandemic has had a substantial impact on the psychological/psychiatric health of children. In this chapter, we show how PROMIS can be used to measure health change in a population. We were able to use PROMIS CATs to quickly assess multiple relevant domains of physical, mental and social health. Due to the use of CAT we were able to assess multiple domains of health, while administering only few items per domain. To measure the impact of COVID-19 we compared the results during the COVID-19 pandemic to the pre-COVID data described in Chapter 1- 3. In **Chapter 7** we investigate and attempt to improve the applicability of PROMIS CATs in clinical practice by investigating how to feedback PROMIS scores to clinicians to improve interpretability. We performed focus groups with clinicians to determine the optimal feedback options of scores and item responses in the KLIK PROM portal dashboard, thus facilitating practical implementation. During this thesis we started implementing PROMIS CATs in clinical practice. However, a common complaint of clinicians (and patients) was the administrative burden of certain item banks, especially when assessing mental health domains in children who do not report any problems. These children need to complete the maximum amount of 12 items per CAT. To take full advantage of CAT, we investigate advanced stopping rules in **Chapter 8** to improve the efficiency of CATs and reduce patient burden by lowering the number of items to complete without losing accuracy.

In **Chapter 9** I provide a general discussion on all the previous chapters. I provide the main findings in accordance to the aforementioned aims and reflect on the key findings. I look at the current implementation of PROMIS in the Netherlands and discuss methodological considerations regarding the studies included in this thesis as well as considerations on harmonizing outcomes. Finally, I recommend future directions on harmonizing PROMs in research and clinical practice.

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