Common patient-reported outcomes across ICHOM Standard Sets – the potential contribution of PROMIS®

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Abstract

Background: The International Consortium for Health Outcomes Measurement (ICHOM) develops condition-specific Standard Sets of outcomes to be measured in clinical practice for value-based healthcare evaluation. Standard Sets are developed by different working groups, which is inefficient and may lead to inconsistencies in selected PROs and PROMs. This study aimed to identify common PROs across ICHOM Standard Sets and examined to what extent these PROs can be measured with a generic set of PROMs: the Patient-Reported Outcomes Measurement Information System (PROMIS®).

Methods: All PROs and recommended PROMs were extracted from all available ICHOM Standard Sets. Similar PROs were categorized into unique PRO concepts. Subsequently, it was examined which of these PRO concepts can be measured with PROMIS.

Results: A total of 216 PROs were identified in 28 ICHOM Standard Sets and 96 PROMs are recommended for measuring these PROs. Inconsistencies were found in selected PROs, terminology used, and recommended PROMs. The 216 PROs could be categorized into 21 unique PRO concepts. More than half (16/21) of these PRO concepts (covering 75% of the PROs and 79% of the PROMs) can be measured with a PROMIS measure.

Conclusion: Considerable overlap was found in PROs across ICHOM Standard Sets, and large differences in terminology used and PROMs recommended, even for the same PROs. Inconsistencies in selected PROs and PROMs across Standard Sets questions the validity of the Standard Sets. We recommend a more universal and standardized approach to the selection of PRO and PROM, using PROMIS.

Introduction

In 2006 Michael Porter and Elisabeth Teisberg published their book “Redefining Health Care”, in which they introduced the concept of value-based healthcare.(1) The authors argue that the fundamental goal of healthcare is to create value for patients, where value is defined as health outcomes divided by the cost of delivering these outcomes. Value-based healthcare is a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes achieved rather than services delivered. Measuring outcomes that matter to patients -- including Patient-Reported Outcomes (PROs, Table 1) -- can help healthcare providers to benchmark treatment effects against their peers and, by identifying and learning from best practices, provide opportunities to improve quality of care. If healthcare providers measure and publish health outcomes, patients can be better informed about their own health, expected effects of treatment, their own treatment effects, and thus make better informed treatment decisions.(1-3)

To realize the potential of value-based healthcare, outcomes and costs must be measured in every patient. This requires an acceleration of the measurement of health outcomes in daily clinical practice. In 2012, the International Consortium for Health Outcomes Measurement (ICHOM) was founded with the aim to define Standard Sets of outcomes for every major medical condition.(4) Standard Sets are minimum sets of outcomes that matter most to patients. These sets should be measured and reported in all patients with a specific condition (or disease). Standard Sets have been developed using a standardized consensus methodology among a team of experts and patient representatives in the field.(5) Up to January 2020, 28 Standard Sets were published and another eight were being developed.(4, 6-31)

Although important to do, the implementation of Patient-Reported Outcome Measures (PROMs, Table 1) in clinical practice is challenging. PROMs are increasingly being administered to patients but they are not yet routinely used in the consultation room for

monitoring treatment effects and shared decision making. Commonly mentioned barriers for using PROMs in clinical practice are the time investment for healthcare providers to administer PROMs and for patients to complete them, the high number of different PROMs recommended for different patient groups, an overwhelming amount of PROMs for patients with multi- or comorbidity, a lack of recommended PROMs for patients without a diagnosed condition, long questionnaires for patients, difficult or irrelevant questions to patients, lack of knowledge on how to interpret (change) scores, and lack of training and support on using and communicating about PROMs in the consultation room.(32-34)

A specific barrier for implementing ICHOM Standard Sets is that they are independently developed by different working groups, which is inefficient and leads to large differences and inconsistencies in selected PROs, terminology used, and recommended PROMs, even for the same PROs.(4, 6-17)

A system of common data elements across conditions could improve the situation. Generally speaking all people want to feel and function ‘normally’, i.e., live without symptoms, such as pain, fatigue or depression, and be able to carry out daily activities and social roles. These feelings and functions can be affected by different health conditions. For example, climbing stairs can be affected by knee osteoarthritis, COPD or heart failure. So different conditions can result in the same non-condition specific patient-reported problem: difficulty in climbing stairs. This is one of the reasons why there is considerable overlap in relevant PROs across conditions.(35) Ideally, these non-condition specific (or common) outcomes could be measured with just one set of universal (or generic) PROMs across conditions.

One such universal measurement system is the Patient-Reported Outcomes Measurement Information System (PROMIS®, Table 1). PROMIS developed a conceptual framework of commonly relevant PROs across the broad domains of physical, mental, and

social functioning and developed PROMs within each of these domains, that are universally applicable across patients populations.(36, 37) PROMIS used modern psychometric techniques (i.e. Item Response Theory), to create item banks (i.e. large sets of questions), enabling the possibility of applying short forms where needed and computerized adaptive tests (CAT) where possible, that yield highly reliable and comparable scores with a few relevant items only.(38-40)

The aim of this study was to identify common PROs across ICHOM Standard Sets and examine to what extent these PROs can be measured with PROMIS.

Methods

One author (MZ) downloaded the reference guides of all 28 available ICHOM Standard Sets from the ICHOM website on January 2020 and extracted all individuals PROs and recommended PROMs.(4) Another author (CT) checked the data extraction, identified unique PRO concepts, and classified all PROs within the domains of global health, physical health, mental health, and social health, in accordance with the PROMIS conceptual framework. Finally, one author (CT) searched the HealthMeasures website(41) to examine which of these PROs can be measured with a PROMIS measure.

Results

A total of 216 PROs were extracted from the 28 Standard Sets (Table 2). The number of PROs included in these Standard Sets varies from 1 (cataract) to 27 (Parkinson's disease). The 216 PROs refer to 21 unique PRO concepts, three in the domain of global health (general health status, health-related quality of life, quality of life), fourteen in the domain of physical

health (six included in the PROMIS profile (i.e. core) domains: fatigue, pain intensity, physical function, mobility, upper extremity function, sleep disturbances; three included in the PROMIS additional Domains: dyspnea, gastrointestinal symptoms, sexual function; and five that are not included in the PROMIS conceptual framework: hearing, speech/communication, urinary symptoms, vision, other), three in the domain of mental health (anxiety, depression, cognitive function), and one in the domain of social health (ability to participate in social roles/peer relationships) (Table 2). The most commonly included PROs are physical function (included in 22 out of 28 Standard Sets, of which 7 used the same term, i.e. ‘physical function(ing)’), ability to participate in social roles/peer relationships (included in 20 Standard Sets, of which 5 used the same term, i.e. ‘social function(ing)’), anxiety and depression (including emotional functioning, included in 16 Standard Sets), pain intensity (included in 13 Standard Sets, of which 8 used the same term, i.e. ‘pain’), gastrointestinal symptoms (included in 12 Standard Sets), sexual function (included in 11 Standards Sets), and health-related quality of life (included in 11 Standard Sets).

In total 96 different PROMs are being recommended for measuring the 216 PROs. The number of PROMs recommended for the 21 unique PRO concepts varies from two (sleep disturbances) to 19 (physical function) per concept. Only a few PROMs are included in more than one Standard Set: PROMIS Global Health is included in seven Standard Sets, EORTC QLQ-C30 is included in four Standard Sets, the EQ-5D is included in four Standard Sets, and another 16 PROMs are included in two Standard Sets.

More than half (16/21) of the PRO concepts (covering 161 of the 216 extracted PROs (75%) and 76 of the 96 PROMs (79%)) can be measured with PROMIS. Table 3 shows which PROMIS item banks are available to measure these PRO concepts. Figure 1 shows the most commonly included PROs in ICHOM Standard Sets that can be measured with PROMIS.

Discussion

We identified 216 different PROs in 28 ICHOM Standard Sets. The 216 PROs refer to 21 unique PRO concepts. A total of 96 different PROMs are being recommended for measuring these 216 PROs. Sixteen of the 21 unique PRO concepts, covering 161 of the 216 (75%) PROs and 76 of the 96 (79%) PROMs, can be measured with PROMIS.

The selection of PROs in ICHOM Standard Sets seem to be inconsistent. It is unclear why some PROs are included in some Standard Sets, but not in others. For example, fatigue is included in the Standard Sets for inflammatory arthritis and heart failure, but not in the Standard Set for hip and knee osteoarthritis or coronary artery disease. Sleep disturbances is only included in the Standard Sets for Parkinson's disease and heart failure, although it is a common symptom in many other diseases.(42) These inconsistencies question the validity of the ICHOM Standard Sets.

We also found large differences in PRO terminology used. For example, the PRO concept physical function is included in 28 Standard Sets, but only seven Standard Sets use a similar term, i.e. 'physical function(ing)'. Other terms used are 'activities of daily living', 'activity limitations', 'disability', 'functional status', 'mobility', and 'motor function'. It is unclear whether these terms really refer to different concepts or whether they actually refer to the same concept. Definitions of the PROs are mostly lacking in the ICHOM reference guides. Eleven Standard Sets included the PRO 'health-related quality of life'. This is a very broad concept and can cover different PRO concepts. It is unclear whether this term refers to the same concept or to different concepts across Standard Sets.

More attention need to be paid to the terms and definitions of PROs to be measured.

There are also inconsistencies in the recommended PROMs. For some patient groups a disease-specific PROM is recommended, while for another patients group, a domain-specific or generic PROM is recommended to measure the same PRO. For example, to measure

depression, a disease-specific instrument (MDS-UPDRS for Parkinson), a cancer-specific instrument (EORTC QLQ-C30), four domain-specific instruments (HADS, PHQ-2, PHQ-9, WHO-5) and three generic instruments (PROMIS-29 Profile, PROMIS Global Health and SF-36) are being recommended. A rationale for any of these choices is lacking. Furthermore, eight different PROMs are being recommended to measure fatigue. Recommending different PROMs for the same PROs hampers outcome measurement in daily clinical practice and comparisons across patient groups with different conditions. One can argue whether it is really necessary to measure common symptoms like fatigue or depression with a different instrument for each different patient group. Research in patients with rheumatoid arthritis , for example, found that up to 90% of patients with arthritis would rate their level of fatigue similarly when asked in a general sense about fatigue or when asked about the fatigue they attributed to their rheumatoid arthritis, which suggest that a generic PROM can be used instead of a disease-specific PROM.(43)

We argue that the current ICHOM strategy of independent PROs and PROMs selection by different disease-specific working groups, even though this strategy may facilitate adoption by individuals in specialty fields, is inefficient, inconsistent and threatens the validity and successful implementation of ICHOM Standard Sets across a health delivery system. Our study showed that many PROs that matter to patients are common across patient groups. It may not be necessary to use a different PROM to measure common PROs, like pain, fatigue, depression, in different patient populations. It is hard to identify the best PROM for a specific patient population because the number of validation studies of PROMs in specific patient populations is limited and evidence on important measurement properties (e.g. responsiveness) is often lacking. (See for example (44-46)) It is too expensive and time-consuming to develop, validate, translate, and maintain different high quality PROMs for every patient group. It is also too expensive, complex and time-consuming to implement all

these different PROMs in electronic health records, give the right PROM to the right patient, interpret the scores for every PROM in the correct way, and discuss them appropriately with patients in the consultation room. It is burdensome and confusing for patients with multi- or comorbidity to complete multiple, partly overlapping, PROMs for every health care professional they consult. It also hampers value-based healthcare for patients without a definite diagnosis or patients with rare diseases, for which validated disease-specific PROMs are quite often not available. And finally, the current approach hampers benchmarking, learning and improve quality of care across patient groups. While value-based healthcare is trying to eliminate the silos between medical specialties, it has created new silos between conditions.

To go forward, we recommend a more standard, universal approach to PRO and PROM selection. Much can be gained by selecting common PROs and PROMs across conditions wherever possible, for example using the conceptual framework and measures of PROMIS. There are several initiatives ongoing in this direction. One is the development of the ICHOM adult overall health and pediatric overall health Standard Sets, which were published after the data extraction of this study was done.(47, 48) These Standard Set contain 15 and 10 PROs respectively, to be measured in all adult or pediatric patients. Eleven of the 15 PROs for adults and eight of the 10 PROs for children the can be measured with PROMIS. The relevance and feasibility of measuring a common set of PROs in all patients needs to be evaluated. In the Netherlands, an alternative approach is being proposed. A national PROM working group developed a ‘menu’ of commonly relevant PROs and recommended PROMs, that can be used to select relevant PROs for a specific patient group(s).(49) Both the ICHOM overall health Standard Sets and the Dutch ‘menu’ recommend measuring generic PROs where possible, supplemented with disease-specific PROs where needed. An approach which may be referred to as 'generic unless'. Both initiatives include PROMIS measures in their

recommendations to standardize and reduce the number of PROMs being used. PROMIS measures are also included in 7 out of the 28 ICHOM Standard Sets. There is, however, much room left for improving the efficiency and validity of ICHOM Standard Sets.

An additional advantage of PROMIS is the possibility of computerized adaptive testing (CAT).(50) With CAT the computer selects items from an item bank, based on answers to previous items. This yield highly reliable scores with a few relevant items only, which is an important benefit for using PROMs in clinical practice. Technical solutions for CAT application are currently available in a limited number of countries, but this is expected to increase in the near future.

A limitation of our study is that our conclusion that 75-79% of the PROs and PROMs can be measured with PROMIS was based on information in the ICHOM reference guides only. We did not map the recommended PROMs on item level to the PROMIS measures. Our classification may therefore be not completely correct. However, the exact numbers are not important for our call for a more standard, universal approach to PRO and PROM selection.

In conclusion, we found considerable overlap in selected PROs across ICHOM Standard Sets, and large differences in terminology and recommended PROMs for the same PROs. For measuring 216 different PROs, covering 21 unique PRO concepts, a total of 96 different PROMs are currently being recommended. We also found inconsistencies in the selected PROs and PROMs across Standard Sets, which questions the validity of the ICHOM Standard Sets. We recommend a more universal, standardized approach to the selection of PROs and PROMs. PROMIS offers an evidence-based conceptual framework of commonly relevant PROs and provides validated PROMs, that are applicable across patient populations and medical specialties.

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Table 1. Glossary of terms

Abbreviation	Full text	Definition	Example
PRO	Patient-Reported Outcome	Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.(51)	Depression
PROM	Patient-Reported Outcome Measure	A questionnaire used to measure the PRO	Patient Health Questionnaire (PHQ-9)
PROMIS	Patient-Reported Outcomes Measurement Information System	A set of generic PROMs that can be used as short forms or CAT to measure aspects of physical, mental, and social health in adults and children across medical conditions	www.healthmeasures.net/promis
PROMIS measure	Patient-Reported Outcomes Measurement Information System measure	A PROM (short form or CAT) from the PROMIS system	PROMIS ® Item Bank V1.0 Depression - Short Form 8a

CAT = Computerized Adaptive Test, where a computer algorithm consecutively selects questions from a large set of questions (item bank), based on responses to previous questions.

Table 2. Outcomes included in ICHOM Standard Sets, classified according to the PROMIS domain framework(52)

	PROMIS Global Health domain			PROMIS Profile domains									PROMIS Additional Domains				Non-PROMIS Domains					Total
				Physical Health						Mental Health		Social Health	Physical Health			Mental Health	Physical Health					
						Physical Function																
	General Health Status	Health-Related Quality of Life	Quality of Life	Fatigue	Pain	General	Mobility	Upper Extremity	Sleep Disturbance	Anxiety	Depression	Ability to participate in social roles / peer relationships	Dyspnea	Gastro-intestinal Symptoms	Sexual Function	Cognitive Function	Hearing	Speech Communication	Urinary Symptoms	Vision	Other	
Advanced prostate cancer				1	1	1				1	1			1	1				1		1	9
Atrial fibrillation		1				1				1	1	1				1					1	7
Breast cancer			1	1	1	1		1		1	1	2			2	1					5	17
Cataract																				1		1
Colorectal cancer			1	1	1	1	1			1	1	1		6	3						1	18
Congenital upper limb anomalies		1						1		1	1										1	5
Coronary artery disease		1				1					1		1								1	5
Chronic kidney disease		1		1	1	2					1											6
Craniofacial microsomia		1				1				1	1	1	1				1	1		1	4	13
Depression and Anxiety						1				4	1	2									3	11
Diabetes			1								1										1	3
Dementia			1		1																1	3
Heart failure		1		1		2			1	1	1	1									2	10
Hip and knee osteoarthritis			1		1	1						1										4
Hypertension in low and middle income			1												1							2

countries																						
Inflammatory arthritis	1			1	1	1						1										5
Inflammatory bowel disease				1	1					1				2							3	8
Localized prostate cancer														1	1				2		1	5
Low back pain		1			2	1						1										5
Lung cancer	1		1	1	1	1				1	1	1	2			1						11
Macula degeneration							1			1	1									1		4
Older person					1	1				1	1	2					1					7
Overactive bladder		1													1						1	3
Parkinson's disease		1	1	1	1	5	1		2			2		2	1	1		1	1		7	27
Pediatric facial palsy		1										1									2	4
Pregnancy and childbirth		1									1				1				1			4
Cleft lip and Palate										1	1	2	1					1			5	11
Stroke	2					1	1					1				1		1			1	8
Total	4	11	8	9	13	22	4	2	3	16	16	20	5	12	11	5	2	4	5	3	41	

Number represent the number of outcomes included in the ICHOM Standard Set Reference Guide

Table 3. Common PROs that can be measured with PROMIS

PRO	PROMIS adult item bank	PROMIS pediatric item bank
General health status / health-related quality of life	PROMIS v1.2 Global Health	PROMIS v1.0 Global Health
Quality of life	PROMIS Global02	
Fatigue	PROMIS v1.0 Fatigue	PROMIS v2.0 Fatigue
Pain	PROMIS v1.1 Pain Interference PROMIS v2.0 Pain Behavior PROMIS v1.0 Pain Intensity PROMIS v2.0 Pain Quality	PROMIS v2.0 Pain Interference PROMIS v1.0 Pain Behavior PROMIS v1.0 Pain Intensity PROMIS v2.0 Pain Quality
Physical Function	PROMIS v2.0 Physical Function PROMIS v2.0 Mobility PROMIS v2.0 Upper Extremity	PROMIS v2.0 Physical Function – Mobility PROMIS v2.0 Physical Function – Upper Extremity
Sexual Function	PROMIS v2.0 Sexual Function and Satisfaction	
Sleep Disturbance	PROMIS v1.0 Sleep Disturbances	PROMIS v1.0 Sleep Disturbances
Gastrointestinal symptoms	PROMIS v1.0 Gastrointestinal Symptoms	
Anxiety	PROMIS v1.0 Anxiety	PROMIS v2.0 Anxiety
Depression	PROMIS v1.0 Depression	PROMIS v2.0 Depressive symptoms
Cognitive function	PROMIS v2.0 Cognitive Function PROMIS v2.0 Cognitive Function Abilities subset	PROMIS v2.0 Cognitive Function
Ability to participate in social roles / peer relationships	PROMIS v2.0 Abilities to Participate in Social Roles and Activities PROMIS v2.0 Satisfaction with Social Roles and Activities	PROMIS v2.0 Peer Relationships

PROMIS = Patient-Reported Outcomes Measurement Information System

Figure 1. Most commonly included PROs in ICHOM Standard Sets that can be measured with PROMIS (relative number of ICHOM sets that include this PRO)