# Original Research

# **Patients First: Toward a Patient-Centered Instrument to Measure Impact of Chronic Pain**

Michiel F. Reneman, Kees P.D. Brandsema, Ernst Schrier, Pieter U. Dijkstra, Paul F.M. Krabbe

M.F. Reneman, PT, PhD, Department of Rehabilitation Medicine, University of Groningen, University Medical Center Groningen, PO Box 30002, 9750 RA Haren, the Netherlands. Address all correspondence to Dr Reneman at: m.f.reneman@umcg.nl.

K.P.D. Brandsema, MS, Faculty of Behavioral, Management, and Social Sciences, University of Twente, Enschede, the Netherlands.

E. Schrier, PT, MS, Department of Rehabilitation Medicine, University of Groningen, University Medical Center Groningen.

P.U. Dijkstra, PT, PhD, Department of Rehabilitation Medicine and Department of Oral and Maxillofacial Surgery, University of Groningen, University Medical Center Groningen.

P.F.M. Krabbe, PhD, Department of Epidemiology, University of Groningen, University Medical Center Groningen.

[Reneman MF, Brandsema KPD, Schrier E, et al. Patients first: toward a patientcentered instrument to measure impact of chronic pain. Phys Ther. 2018;98:616-625.]

© American Physical Therapy Association 2018. Published by Oxford University Press [on behalf of the American Physical Therapy Association]. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http://creativecommons.org/ licenses/by-nc/4.0/), which permits noncommercial reuse, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial reuse, please contact journals.permissions@oup.com

Published Ahead of Print: March 21, 2018 Accepted: May 22, 2018 Submitted: March 19, 2018 **Background.** Numerous instruments are available to measure the impact of chronic pain, yet most have been developed with little or no patient involvement. This study seeks to start bridging that gap by determining which health aspects or attributes (to be included in a future instrument) are considered most important by people with chronic pain.

**Objective.** The goal of this study was to reveal which attributes reflecting impact of chronic pain are considered most important by people with chronic pain and to analyze differences in importance according to gender, age categories, diagnostic subgroups, and pain intensity categories.

**Design.** This study used a sequential explanatory mixed-methods design: literature search, focus group meetings, and online survey.

**Methods.** First, a literature search was performed to identify the attributes in existing instruments. In 68 instruments meeting inclusion criteria, 155 unique attributes were identified, 85 of which remained after applying the exclusion criteria. Second, 2 focus group meetings, with 6 and 4 patients, respectively, were held to verify that no attributes had been missed. Three attributes were subsequently added. Third, individuals with chronic pain were then sent an online survey through several patient organizations.

**Results.** A total of 939 patients were asked to select the 8 attributes they deemed most important, which resulted in the following list: fatigue, social life, cramped muscles, sleeping, housekeeping, concentration, not being understood, and control over pain. The importance assigned to these 8 attributes varied slightly according to age, gender, and diagnostic subgroup.

**Limitations.** Participation rate could not be established because of the online survey.

**Conclusions.** Attributes reflecting impact of chronic pain deemed most important by patients are revealed. Importance of impact differs according to subgroups. The "patients-first" methodology used here revealed attributes that were not comprehensively covered in currently available instruments for measuring the impact of chronic pain.

ealth-related quality of life (HRQoL)—embracing functionality, social interaction, and physical, emotional, and psychological well-being—is reduced in people who suffer from chronic pain.1,2 There are numerous instruments to measure distinct domains of chronic pain related to HRQoL, such as pain sensation, psychological impact, functional disability, related symptoms, activities of daily living (ADL), and social functioning.3 Many of these instruments also contain domains that are less clearly part of HROoL, such as coping strategies, environmental factors, and financial burden. There are 2 main types of instruments: profile instruments (questionnaires) and nonweighted index instruments.4 Profile instruments assess 1 or more HRQoL domains and comprise several items (questions), and are based on analytical procedures (correlations). Index instruments, in contrast, are generally based on clinical practice and expertise instead of statistical procedures, so the items are rated and given a total score.5,6

Although many of these instruments aim to measure the intensity or frequency of complaints or limitations, they do not measure the impact of chronic pain that is deemed relevant by the patient himself. It is of increasing importance to embed patients' values and preferences into instruments, now that health care is becoming increasingly patient-centered.1,7-10 By applying preference-based measurement approaches, the personalized impact of chronic pain on patients can be measured.11 Consequently, an appropriate selection of the attributes based on patient input is important. It is not clear to what extent patient input has been used in the development of the current range of instruments. An attribute refers to a distinct aspect of health. Attributes often are operationally defined in items; for example, in the domain of mobility, an attribute could be "walking," and its corresponding item might be "able to walk 1 mile" or "able to walk on uneven surface."

The overarching aim of our project is to develop and validate a new, short, patient-centered, preference-based in-

strument to measure the impact of chronic pain on HRQoL. Main features of this instrument will be: explicitly patient-driven from the start and applicable to all subgroups of patients with chronic pain (because chronic pain is often not confined to 1 bodily region, which makes the use of instruments that focus on a region-based subgroup restrictive), preference-based with a focus on impact of pain (instead of pain characteristics), and short (maximally 8 attributes). We are aware of other initiatives and instruments with similar ambitions. These may suit 1 or some of these features, but to our knowledge, none of them have combined all features. This paper reports on the initial phase of development. The aims of this study were to reveal which attributes are considered important to adult people suffering from chronic pain; and to analyze differences in importance according to gender, age categories, diagnostic subgroups, and pain intensity categories. A mixed-method design was applied in 3 stages: a literature search, focus group meetings, and an online survey. Mixed-methods research combines elements from both qualitative and quantitative paradigms to produce converging findings.

#### Methods

sequential explanatory methods design12 was applied, consisting of a literature review (step 1), focus groups (step 2), and an online survey (step 3). This design is characterized by an initial phase of qualitative data collection and analysis (steps 1 and 2), followed by a phase of quantitative data collection and analysis (step 3). All study participants signed informed consent forms stating that their data may be used anonymously for research purposes. The Medical Ethics Review Committee at the University Medical Center of Groningen issued a waiver for this study, indicating that the pertinent Dutch legislation (the Medical Research Involving Human Subjects Act) did not apply (METc 2015/496).

#### **Literature Review**

The aim of the first step in our mixed-methods approach was to construct a list of all attributes used in existing pain instruments. A database search was performed to identify instruments that assess chronic pain and its impact on people. Pubmed, PsycINFO, and Google Scholar were searched using 7 terms: chronic pain, assessment, instrument, index, questionnaire, measurement, and disability. The search turned up 1 paper that summarized 116 instruments.3 We subsequently applied our inclusion and exclusion criteria to these 116 instruments. Instruments measuring the impact of chronic pain were included. Instruments excluded were more diverse: instruments assessing pain with a defined cause, or only presenting in a particular region (eg, rheumatoid arthritis or neck pain); instruments assessing chronic pain caused by malignancy (eg, Palliative Care Outcome Scale); diagnostic instruments; instruments measuring pain but not its consequences (eg, only measuring the type or severity of pain); and observer-based instruments. After reviewing the initial 116 instruments, additional instruments were retrieved from databases, sorted by date of publication in PubMed and PsychINFO and by relevance in Google Scholar. We subsequently applied the same inclusion and exclusion criteria to these additional instruments. The final step was to search the Patient Reported Outcomes Measurement Information System (PROMIS) item bank to measure pain interference.<sup>13</sup> All of the retrieved instruments were examined to discern which attributes they contained. Since instruments were sorted based on date of publication, data saturation was assumed when adding 7 instruments did not yield any new attributes. For each instrument, supporting information on its development was collected to analyze whether and to what extent patient input had been used.

Because this study was geared to measure the consequences of pain, attributes of pain itself, such as severity, cause, and duration, were excluded. Additionally, treatment-related attributes and attributes that were either unclear or unrelated to chronic pain were also excluded (eg, "afraid to say something embarrassing" and "use of recreational drugs"). Multicomponent instruments could be included, but only attributes from these instruments that suited the criteria

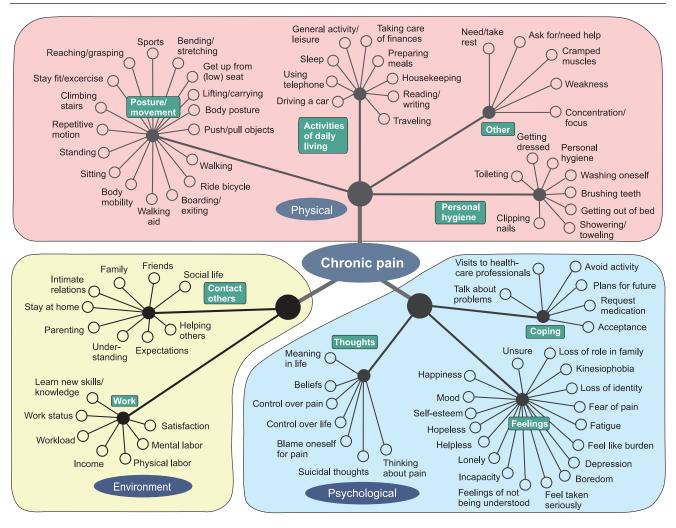


Figure 1. Eighty-four attributes from the literature search classified under higher-order domains.

were included. All included attributes were arranged in a diagram to create an attractive and clear overview, using HealthFan® software (Château Santé, Groningen, the Netherlands) (Fig. 1). They were classified under higher-order domains as physical, psychological, and environmental attributes and grouped in accordance with the ICF core set for chronic widespread pain and the ICF core set for low back pain.14,15 The class of physical attributes was subdivided into posture/movement, activities of daily living, personal hygiene, and "other." The class of psychological attributes was subdivided into thoughts, feelings, and coping. The class of environmental

attributes was subdivided into contact with others and work.

#### **Focus Groups**

The focus groups used in the present study had all 5 of the features described in the original definition by Krueger.<sup>16</sup> The qualitative data (characteristic 3) consisted of identification of additional attributes. Two 1.5-hour focus group meetings were held to verify that no attributes of importance had been missed in the literature search. To recruit participants, people with chronic pain were contacted through 2 patient associations. Purposeful sampling was applied to set up a focus group that

included adults with different pain conditions, a substantial age range, and both males and females. People living >100 km from Groningen and people with chronic pain due to malignancy were not included. Focus group meetings were chaired by a senior rehabilitation psychologist (E.S.). First, the participants were introduced to the aim of the study. They were then asked which aspects or consequences of chronic pain were most important to them, though without revealing the attributes gleaned from the literature to ensure an unbiased response. Saturation was defined as "no additional attributes" that were brought up by the

Table 1. Characteristics of Participants in the Focus Groups

Group No.	Sex	Age (y)	Diagnosis	Treatment	Pain Severity
Focus group 1					
#1	Female	39	Ehlers-Danlos syndrome	Yes	Moderate/severe
#2	Female	74	Fibromyalgia	No	Severe
#3	Male	51	Hereditary multiple	Yes	Moderate/severe
#4	Female	54	Exostoses	No	Moderate
#5	Female	31	Irritable bowel syndrome	Yes	Severe
#6	Male	66	Headaches/fibromyalgia Addison disease/fibromyalgia/apnea	Yes	Severe
Focus group 2					
#1	Female	52	Low Back Pain	No	Moderate
#2	Female	78	Low Back Pain	No	Moderate
#3	Male	61	Low Back Pain	No	Severe
#4	Male	63	Low Back Pain	Yes	Moderate

participants. Thereafter, participants were shown the diagram with attributes from the literature search, which were classified under several higherorder domains (Fig. 1). All attributes that were mentioned by the participants were recorded. The exact wording of the attribute was codeveloped by the participants and the moderator. The final decision was made by the participants. After the meeting, the results were compared with the attributes from step 1. Attributes that were not identified by the literature search were added to the figure. This new figure was presented to the participants of the online survey.

#### **Online Survey**

People with chronic pain were invited to take part through an advertisement on the website or by email of participating patient organizations. These were an umbrella organization representing 14 separate entities and an organization representing patients with back pain. The survey introduced the topic at hand and familiarized the respondents with the type of questions to expect. First, they were asked to provide their gender, age, pain intensity (on a numeric rating scale, NRS), duration of pain, and location of pain. Second, participants were asked to fill in the Pain Disability Index (PDI) to assess the degree of disability in 7 domains: family/ home responsibilities, recreation, social activity, occupation, sexual behavior,

self-care, and life-support activities.<sup>17</sup> Third, they were asked to select the 8 attributes on the diagram (Fig. 1) that were most important to them. Additionally, the respondents were asked if they missed any attributes.

The survey ended with 4 feasibility statements regarding its clarity and difficulty. The respondents were asked how much they agreed with the following statements: "the instructions made clear what was expected of me"; "it was easy to distinguish the attributes in the overview"; "it was easy to choose the eight attributes that I find most important"; and "the questions were easy to understand." Feasibility was assumed when the statements were answered with "neutral," "agree," and "strongly agree." The respondents had the opportunity to comment on the survey. Data were checked to ensure that there were no double entries. If there were any, the entries that were least complete were excluded. If both were complete, the first one was excluded because it was assumed that the respondents had wanted to alter their answers.

### **Data Analysis**

The importance of the attributes was determined by constructing frequency distributions. Four subgroups were created on the basis of gender, age, diagnostic subgroup, and pain intensity. A chi-square test was used to calculate differences in pain intensity based on the NRS ("mild" [1-4], "moderate" [5-7], and "severe" [8-10]) between genders, age categories ( $<40, 40-59, and \ge 60 years$ ), and diagnostic groups (fibromyalgia, back pain, and other pain diagnoses).18 A conservative significance level of  $\alpha$  = 0.01 was chosen to account for multiple testing. Associations between the importance assigned to attributes were estimated with phi-coefficients (\$\phi\$).19 Data were analyzed using SPSS (IBM SPSS Statistics for Windows, Version 22.0, Armonk, NY; IBM Corp).

#### Results

In total, 140 potentially suitable instruments were identified, of which 116 came from 1 review paper.3 After application of inclusion and exclusion criteria, n = 68 instruments were included. Some form of patient input was evident in 13 instruments (19%). In these instruments, a total of 155 attributes were identified, of which 84 remained after excluding attributes relating to pain itself, to treatment, or to unclear attributes.

Ten people with chronic pain took part in 2 focus group meetings (Tab. 1). In the first one, 3 attributes came up that had not been identified in the literature search: showering/toweling, feelings of uncertainty, and meaningfulness in life. No new attributes were mentioned in the second focus group meeting.

In total, 1182 people with chronic pain filled in the survey, although 243

**Table 2.**Characteristics of People With Chronic Pain (n = 939)

Characteristics	N	%
Male/female	113/826	12/88
	Mean	SD
Age	49.6	12.5
Pain intensity (scale = 0–10)	6.5	1.7
Pain duration (years)	17.9	12.6
Pain location <sup>a</sup>	N	%
Head	466	
Face/throat	172	
Neck	632	
Shoulder/upper back	719	
Arm	515	
Hand/fingers	617	
Chest/belly	287	
Lower back	693	
Hip	524	
Leg/knee	606	
Ankle/foot	505	
Other	78	
Most severe pain location		
Head	68	7.2
Face/throat	10	1.1
Neck	51	5.4
Shoulder/upper back	199	21.2
Arm	30	3.2
Hand/fingers	60	6.4
Chest/belly	31	3.3
Lower back	222	23.6
Hip	64	6.8
Leg/knee	82	8.7
Ankle/foot	48	5.1
Other	74	7.9
PDI scores (scale 0–10)		
Family	6.3	2.0
Recreation	6.8	1.9
Social life	6.3	2.3
Occupation	6.8	2.4
Sexual activity	6.1	2.6
Self-care	4.2	2.6
Life support activities	4.0	2.7
Total (scale 0–70)	41.0	12.3
Diagnostic group		
Fibromyalgia	307	32.7
Back pain	88	9.4
Other <sup>b</sup>	544	57.9

of them were subsequently excluded because they did not select any attributes. Consequently, data on 939 respondents were included in the analysis. Whereas 186 respondents chose more than 8 attributes (9-60 attributes, all were analyzed), 26 respondents chose fewer than 8. Sixty respondents said that 8 attributes were not enough. Due to technical errors, the first 100 respondents could not indicate which patient association they belonged to, and the first 212 respondents were unable to choose the attribute "walking ability." The relative importance of the attributes was determined by the percentage of people who selected each one, and the end result was corrected for the reduced number of people who were able to choose "walking ability."

Sample characteristics are presented in Table 2. The 8 most frequently chosen attributes were fatigue, social life, cramped muscles, sleeping, housekeeping, concentration/focus, feelings of not being understood, and control over pain (Fig. 2).

The frequency at which attributes were chosen was also calculated for both genders separately (Fig. 3a), for age categories (Fig. 3b), diagnostic subgroups (Fig. 3c), and pain intensity categories (Fig. 3d). The list of attributes chosen most frequently differed among the subgroups. One example is "housekeeping," which is the fifth most frequently chosen attribute for women, but 29th for men. There were also differences between diagnostic subgroups. An example is "sitting"; for people suffering from back pain; it is the third most frequently chosen attribute, while in the total sample "sitting" is the 36th most frequently chosen attribute. Three attributes featured among the 8 attributes chosen most frequently by all subcategories: fatigue, social life, and cramped muscles.

Associations ( $\phi$ ) among the 20 most frequently chosen attributes ranged from 0.000 to 0.194. The strongest association was observed between "lifting/carrying" and "standing." The instructions were clear (94% agreed), as was the ability to distinguish attributes in the overview (88%), and the questions

(Continued)

Table 2. Continued

Characteristics	N	%
Pancreas	2	0.2
Adrenal	1	0.1
Osteochondromes	2	0.2
Spinal cord injury	10	1.1
Chronic fatigue syndrome	87	9.3
Headache	41	4.4
Osteoporosis	2	0.2
Neurostimulation	4	0.4
Complex regional pain syndrome	8	0.9
Irritable bowel syndrome	22	2.3
Repetitive strain injury	1	0.1
Syringomyelitis	1	0.1
Ehlers-Danlos syndrome	35	3.7
Whiplash associated disorder	2	0.2
Unknown	326	34.7

<sup>a</sup>Some participants reported pain in several regions, so no percentages were calculated. PDI = Pain Disability Index.

were understood well by most (95%) respondents. The ease with which 8 attributes could be chosen as important was more challenging (55% agreement). According to the respondents, the following attributes were missing (each named once): stress, (lack of) appetite, forgetfulness, confusion, and endurance.

# Discussion

The 8 attributes chosen most frequently by patients as having the most impact on them were: fatigue, social life, cramped muscles, sleeping, housekeeping, concentration/focus, feelings of not being understood, and control over pain. These attributes in itself are in fact not new, but discovering which attributes are most important to people with chronic pain leads to new insights, which should be used to guide further developments of a truly patient-centered preference-based instrument.

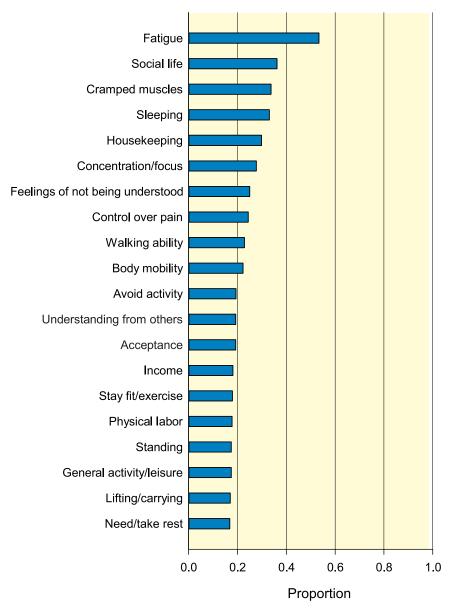
Fatigue was consistently identified as an important health aspect. This observation is supported by comments in the open questions of the survey, in which the importance of fatigue is

(re)emphasized by many respondents. Many instruments for chronic pain do not include fatigue in their item list. There are, however, separate instruments that assess fatigue, such as the Multidimensional Fatigue Inventory.20 Some attributes may seem alike, such as "feelings of not being understood" and "understanding from others." However, they differ slightly: the one denotes an actual situation, whereas the other refers to how a situation is perceived (or felt). Some other attributes seem similar, and the differences might not have been clear to the respondents, so associations between items were calculated. All of those associations were very weak ( $\phi$  < 0.2) or nonsignificant. Therefore, we assumed that the differences between attributes were clear to the respondents. That assumption is supported by a feasibility of 88% regarding the ease with which the attributes could be distinguished.

The present study reports on the first phase of the development of a new instrument. Although we are aware that many (high-profile) instruments are already available, there are several reasons to develop a new one. In our analysis of currently available instruments, patient input in the development stage was evident in only 13 instruments (19%). To assess if a patient's first approach would lead to different attributes compared to existing instruments, we compared the 20 most frequently chosen attributes of our study to those used in some key instruments: the Pain Disability Index (PDI);17 the comprehensive International Classification of Functioning, Disability and Health (ICF) core sets for Low Back Pain;<sup>15</sup> the comprehensive ICF core sets for Chronic Widespread Pain:14 the EuroOol-5D;21 and PROMIS-PI13 (Tab. 3). For each of these instruments or item banks, some attributes were regarded as important by patients, but there were also attributes that they considered less important. Also, some of the attributes that were found to be important in this study were missing in the ICF core sets, the PDI, the EuroQol-5D, and PROMIS-PI (eg, acceptance, feelings of not being understood). This result provides preliminary evidence that this systematic "patients first" approach does lead to different attributes that are deemed important by patients. Consequently, application of 1 of these comparator instruments will lead to measurement of (relatively) irrelevant attributes as well as missing of relevant attributes.

To measure the impact of chronic pain, it is useful to consider the potential of preference-based methods. Of particular interest are the methods based on item response theory (IRT).22 IRT is the most renowned measurement framework for subjective phenomena. One of the promising features of PROMIS is its reliance on IRT methods and computerized adaptive testing (CAT), whereby the latter generates subsequent questions in light of previous responses.<sup>13</sup> With CAT, instruments can be customized to accommodate individual conditions (to a certain degree). While the attributes of PROMIS may not fit the patients' preferences revealed here, the principles of IRT and CAT are planned at a next stage of development of our novel preference-based IRT measurement instrument for chronic pain. In this extended instrument (applicable

<sup>&</sup>lt;sup>b</sup>Diagnostic groups are derived from membership of patient organization.



Top 20 attributes representing the impact of chronic pain (n = 939).

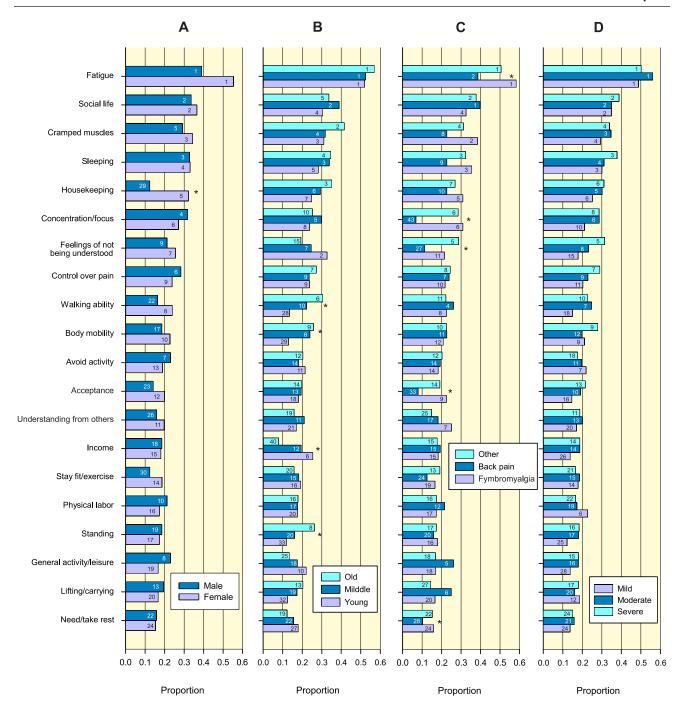
on mobile or tablet), up to 40 of the attributes indicated by the patients in this study will be included, out of which patients can select up to 8 that are most relevant.

Patient input is expected to facilitate the selection of attributes that are relevant to them. While most of the available instruments consist of items that are imposed on people,23 the prototype instrument that is under development

(using the results of the present study) will only contain attributes that are relevant to people with chronic pain. A key characteristic of a preference-based IRT measurement approach is that all of the attributes under study have to be assessed in combination. This constrains the measurement procedure: it has to present a restricted set of attributes because respondents can process only a certain amount of information simultaneously. Nonetheless, a limited

set of key attributes may be sufficient to describe HROoL and impact of chronic pain, provided attributes are the most important and relevant ones.24,25 Including non-key attributes might marginally increase the amount of information gained, but will substantially increase the difficulty of the assessment. A preference-based measuring method allows attributes to be weighted so that HROoL can be calculated. It was determined that 8 attributes would be adequate for a prototype instrument. A substantial amount of information regarding the patient's health status can be ascertained with these top 8 attributes. Also, the number of information elements (attributes) would be manageable for respondents. Keeping the instrument short allows them to stay focused and keep completion time low to enable routine measurements, and would make a "battery" of instruments each measuring separate constructs less appealing.

This study has some limitations. Because we did not perform a systematic review, we may have missed instruments/attributes. To compensate for this limitation, we applied a data saturation approach, and we also actively solicited for missing attributes during steps 2 and 3 of our study. Because the attributes were extracted from the literature, decisions had to be made on what the items in the instruments represented. For instance, items about one's level of energy were allocated to "fatigue." The allocation process is subjective and perhaps debatable. Regarding attribute selection, we assumed data saturation if 7 consecutively published measurement instruments did not vield new attributes. It is possible that new attributes would have come up if this criterion was set at 20, for instance, but to ensure that no important attributes were missed, 2 focus group meetings were held. The attributes added in the first focus group (showering/toweling, feelings of uncertainty, and meaningfulness in life) were never chosen in the survey. Because the sample size of the focus groups was small, the respondents of the survey were also asked to identify missing attributes. Some of the missing



**Figure 3.**Top 20 attributes representing the impact of chronic pain by (A) sex, (B) age group, (C) diagnostic subgroup, and (D) pain intensity (n = 939).

attributes mentioned by the respondents of the survey (stress, forgetfulness, confusion) are related to the attribute anxiety and depression, and endurance has an overlap with workload. On the other hand, workload may induce stress. At this point, the

importance of the missing attributes remains unclear. It is deemed unlikely that technical errors during the online survey have introduced bias; we calculated proportions based on answering possibilities to compensate for partial unavailability of "walking ability." The survey was sent to people suffering from chronic pain in the Netherlands, which means that all attributes obtained from the literature had to be translated into Dutch. Translation of attributes could affect the validity of these constructs, but unlike items

**Table 3.**Comparison of the Top 20 Most Frequently Chosen Attributes in the Present Study With Attributes in Other Instruments<sup>a</sup>

Top 20 Present Study	ICF LBP	ICF WSP	PROMIS-PI	PDI	EQ-5D
Fatigue	+	+	-	-	-
Social life	+	+	+	+	-
Cramped muscles	+	+	_	-	-
Sleeping	+	+	+	+	_
Housekeeping	+	+	+	+	+
Concentration/focus	-	+	+	-	_
Feelings of not being understood	-	_	_	-	-
Control over pain	-	_	+	-	-
Walking ability	+	+	+	-	+
Body mobility	+	+	-	-	_
Avoid activity	-	_	+	-	_
Understanding from others	+	+	_	-	-
Acceptance	-	_	_	-	-
Income	-	_	_	-	-
Stay fit/exercise	-	-	_	-	_
Physical labor	+	+	+	+	+
Standing	-		+	-	_
General activity/leisure	+	+	+	+	+
Lifting/carrying	+	+	_	-	_
Headache	_	_	_	_	-

<sup>&</sup>lt;sup>e</sup>EQ-5D = EuroQol-5D; ICF LBP = International Classification of Functioning, Disability, and Health core sets for low back pain; ICF WSP = International Classification of Functioning, Disability, and Health core sets for chronic widespread pain; PDI = Pain Disability Index; PROMIS-PI = Patient-Reported Outcomes Measurement Information System-Pain Interference.

or full questions, attributes are single words or short phrases. Conversely, 2 Dutch-language questionnaires (Brief Pain Inventory-2 and Pain Vigilance and Awareness Questionnaire) were obtained from the literature, so the items had to be translated into English for this paper. Generalizability to patients outside the Netherlands should be performed with care and should not be assumed without further research. For the survey, patients were recruited from patient organizations. The extent to which this has introduced bias toward generalizability of all patients, including nonmembers, is unknown. Another limitation is the external validity of the sample of people with chronic pain. The pain intensity and PDI scores were higher and the pain duration was longer than found in epidemiological data<sup>26</sup> and reference values.23 It is expected

that these characteristics will make a respondent more of an expert than someone who has had less pain, for a shorter period of time, and experiencing less disability. While mean age was similar to that in the epidemiological data, the proportion of women was much higher.26 The difference with epidemiologic data and reference values is most likely due to the large number (≥307) of people suffering from fibromyalgia in our sample, and fibromyalgia is more prevalent among women.27 Differences between genders regarding their chosen attributes were only statistically significant for "fatigue" and "housekeeping." The gender difference in the frequency of selecting "fatigue" seems irrelevant, as it is still the attribute most frequently chosen by both genders. This argument does not apply to "housekeeping," and probably its importance is overestimated. Regarding future efforts to develop patient-centered instruments, a logical step would be to use CAT methods to ensure that each of the subgroups is presented with the attributes that are most relevant to them.

Some respondents chose more than 8 attributes (n = 186), and 60 respondents mentioned that they had trouble selecting only 8 attributes or that they had selected more than 8. Their deviations are evidenced by the 55% feasibility found for the ease with which 8 attributes were chosen. These respondents were still included. When more than 8 attributes were selected, it was assumed that the respondents had included the 8 that were most important to them.

A new instrument containing the attributes that are most relevant to patients

suffering from chronic pain would provide valuable information on the impact of chronic pain and HRQoL. Those attributes, according to the present study, are fatigue, social life, cramped muscles, sleeping, housekeeping, concentration/ focus, feelings of not being understood, and control over pain. At least these 8 attributes will be included in the prototype instrument that is now being developed.

# **Author Contributions and Acknowledgments**

Concept/idea/research design: M.F. Reneman, K.P.D. Brandsema, E. Schrier, P.U. Dijkstra, P.F.M. Krabbe

Writing: M.F. Reneman, K.P.D. Brandsema, E. Schrier, P.U. Dijkstra, P.F.M. Krabbe

Data collection: K.P.D. Brandsema, E. Schrier, Data analysis: M.F. Reneman, K.P.D. Brandsema, E. Schrier, P.U. Dijkstra, P.F.M. Krabbe

Project management: M.F. Reneman, P.U. Dijkstra, P.F.M. Krabbe

Providing participants: M.F. Reneman Providing facilities/equipment: M.F. Reneman, P.F.M. Krabbe

Providing institutional liaisons: M.F. Reneman, P.F.M. Krabbe

Consultation (including review of manuscript before submitting): M.F. Reneman, K.P.D. Brandsema, E. Schrier, P.U. Dijkstra, P.F.M. Krabbe

The authors thank 2 patient organizations in the Netherlands, "Samenwerkende Pijn-patiënten naar één stem (SWP)" and "Nederlandse Vereniging Voor Rugpatiënten NVVR)," for their help in recruiting participants for the focus group meetings and for disseminating the survey among their members.

#### Funding

The authors reported no funders for this study.

## Disclosures

The authors completed the ICMJE Form for Disclosure of Potential Conflicts of Interest. No conflicts of interest were reported.

DOI: 10.1093/ptj/pzy040

#### References

- 1 Doth AH, Hansson PT, Jensen MP, Taylor RS. The burden of neuropathic pain: a systematic review and meta-analysis of health utilities. Pain. 2010;149:338-344.
- 2 Goossens MEJB, Vlaeyen JWS, Rutten-van Mölken MPMH, van der Linden SMJP. Patient utilities in chronic musculoskeletal pain: how useful is the standard gamble method? Pain. 1999;80:365-375.
- 3 Grimmer-Somers K, Vipond N, Kumar S, Hall G. A review and critique of assessment instruments for patients with persistent pain. J Pain Res. 2009;2:21-47.
- 4 Cappelleri, JC, Zou KH, Bushmakin AG, Alvir JM, Alemayehu D, Symonds T. Patient-Reported Outcomes: Measurement, Implementation and Interpretation. Boca Raton, FL: CRC Press; 2014.
- 5 Feinstein AR. Multi-item "instruments" vs Virginia Apgar's principles of clinimetrics. Arch Intern Med. 1999;159(2):125-128.
- 6 de Vet HC, Terwee CB, Mokkink LB, Knol DL. Measurement in Medicine. A Practical Guide. Cambridge, United Kingdom: Cambridge University Press;
- 7 Sullivan M. The new subjective medicine: taking the patient's point of view on health care and health. Soc Sci Med. 2003;56:1595-1604.
- 8 Carr AJ, Higginson IJ. Measuring quality of life: are quality of life measures patient centred? *BMJ*. 2001;322:1357–1360.
- 9 Hamming JF, De Vries J. Measuring quality of life. Br J Surg. 2007;94:923-924.
- 10 Stenner PHD, Cooper D, Skevington SM. Putting the Q into quality of life: the identification of subjective constructions of health-related quality of life using Q methodology. Soc Sci Med. 2003;57:2161-2172.
- 11 Krabbe PFM. Thurstone scaling as a measurement method to quantify subjective health outcomes. Medical Care. 2008:46:357-365.
- 12 Creswell JW, Klassen AC, Plano Clark VL, Smith KC for the Office of Behavioral and Social Sciences Research. Best Practices for Mixed Methods Research in the Health Sciences. Bethesda, MD: National Institutes of Health; 2011.
- 13 Amtmann D. Cook KF. Jensen MP. et al. Development of a PROMIS item bank to measure pain interference. Pain. 2010;150:173-182.
- 14 Cieza A, Stucki G, Weigl M, et al. ICF core sets for chronic widespread pain. J Rehabil Med 2004;36:63-68.

- 15 Cieza A, Weigl M, Disler P, et al. ICF core sets for low back pain. J Rehabil Med 2004;36:69-74.
- 16 Krueger RA, Casey MA. Focus Groups: A Practical Guide for Applied Research. 5th ed. Thousand Oaks, CA: SAGE Publications; 2014.
- 17 Tait RC, Pollard CA, Margolis RB, Duckro PN, Krause SJ. The Pain Disability Index: psychometric and validity data. Arch Phys Med Rehabil. 1987;68: 438-441.
- 18 Woo A, Lechner B, Fu T, et al. Cut points for mild, moderate, and severe pain among cancer and non-cancer patients: a literature review. Ann Palliat Med. 2015;4:176–183.
- 19 Siegel S, Castellan JN. Nonparametric Statistics for the Behavioral Sciences. 2nd ed. New York, NY: McGraw-Hill Inc; 1988.
- 20 Smets EM, Garssen B, Bonke B, De Haes JCJ. The Multidimensional Fatigue Inventory (MFI) psychometric qualities of an instrument to assess fatigue. J Psychosom Res. 1995;39:315-325.
- 21 EuroQol Group. EuroQol—a new facility for the measurement of health-related quality of life. Health Policy. 1990;16:199-208.
- 22 Krabbe PF. A generalized measurement model to quantify health: the multi-attribute preference response model. PLoS ONE. 2013;8:e79494.
- 23 Soer R, Köke AJ, Speijer BL, et al. Reference values of the Pain Disability Index in patients with painful musculoskeletal and spinal disorders. Spine (Phila Pa 1976). 2015;40:E545–E551.
- 24 Arons AM, Schölzel-Dorenbos CJ, Olde Rikkert MG, Krabbe PF. A simple and practical index to measure dementia-related quality of life. *Value Health*. 2016;19:60-65.
- 25 Brazier J. Measuring and Valuing Health Benefits for Economic Evalua-tion. New York, NY: Oxford University Press; 2007.
- 26 Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. Eur J Pain. 2006;10:287-287.
- Wolfe F, Ross K, Anderson J, Russell IJ, Hebert L. The prevalence and characteristics of fibromyalgia in the general population. Arthritis Rheum. 1995;38: