

Development of the Effective Musculoskeletal Consumer Scale

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ABSTRACT. Programs and initiatives have been created to empower, educate, and provide information to consumers; these are sometimes generically known as self-management interventions. Evaluating and comparing such programs has been a challenge, as many skills that consumers believe are important to manage and participate in their individual healthcare are not currently captured by existing tools. The objective of the Effective Musculoskeletal Consumer Project is to develop a scale to measure an effective consumer. A review of the literature, interviews, workshops, and preliminary surveys at OMERACT 7 (May 2005) were conducted in the first phases of the Project. A questionnaire consisting of 64 items was developed to measure the skills and attributes of an effective musculoskeletal (MSK) consumer. Content experts on our team reduced this scale to 48 items, which was pilot-tested with consumers from Canada and Australia. Dimensionality assessment showed that the scale was unidimensional. Classical and item response theory analyses showed that the 48-item scale had quite high reliability, but that 2 items were very poor. Based on the item analysis, 35 items were retained. The revised scale was presented at OMERACT 8, where a panel reviewed the scale and provided input. This input and another expert review by our team was used to further refine the Effective Consumer Scale to 17 items. Plans are now under way to validate this 17-item scale in self-management interventions. (*J Rheumatol* 2007;34:1392–400)

Key Indexing Terms:

ARTHRITIS CONSUMER PARTICIPATION QUESTIONNAIRES PSYCHOMETRICS

Patients are being encouraged to participate in the healthcare system and in their own healthcare. With this shift has also come the movement to empower and equip patients to manage their healthcare and use healthcare resources effectively. Programs and initiatives have been created to empower, educate, and provide information to consumers; these are sometimes known generically as self-management interventions¹. Evaluating and comparing such programs has been a challenge; many skills that consumers believe are important are not currently captured by existing tools.

OMERACT has been very active in establishing outcomes for MSK diseases such as rheumatoid arthritis (RA) and osteoarthritis for pharmacologic, nonpharmacologic, and complementary interventions. Due to the shift to more patient-centered care, there has been greater emphasis on patient-reported outcomes in recent years. This emphasis is timely, as

there appears to be little agreement on outcomes in self-management interventions. For example, Newman and colleagues¹ found that there were over 16 different outcomes used in studies of self-management interventions for RA. Outcomes included standard core outcomes such as pain and joint counts, as well as psychoeducational outcomes such as self-efficacy, life satisfaction, coping, and social function. But none of these outcomes appears to capture skills that are important to managing and participating in healthcare.

The main objective of the Effective Musculoskeletal Consumer Project is to determine how to measure effective consumers who manage and participate in their care. A review of the literature, interviews, workshops, and preliminary surveys conducted in the first phases of the Project showed that empowered or effective consumers need a broad range of skills or attributes to manage their healthcare². Interviews conducted by this OMERACT Effective Consumer Project Group, with over 71 care providers and consumers, showed that there are many skills that are not currently captured by existing tools. These skills comprise abilities to find and evaluate information, to make and implement decisions, and to interact and function in society and in the healthcare system². The interviews also showed that some skills of an effective consumer can be learned, while others are part of personality, and thus are not amenable to change.

It became clear that a valid, comprehensive outcome scale

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to measure the skills and attributes of an effective consumer was needed. Such a scale may be used to differentiate between those who are already effective consumers and those who may need interventions to improve their skills, and may be used to evaluate the effectiveness of interventions. It is also plausible that individuals with different attributes may respond better to different interventions. The current objective of the 3-year Effective Musculoskeletal Consumer Project, funded by the Canadian Institutes of Health Research, is to create an outcome scale to measure an effective consumer using rigorous test construction methodology including item response theory analysis. We report on the present development of the Effective Consumer Scale.

MATERIALS AND METHODS

Questionnaire development. In the first stage of development, we reviewed the literature about health consumers and performed a thematic analysis. We identified 8 themes, which were refined by the project team to identify 4 main categories of skills and attributes of an effective consumer². To further develop these categories and generate a list of items for each category, key stakeholders including physicians and arthritis patients were interviewed. Then, before the OMERACT 7 meeting, a draft list of attributes and skills of an effective consumer was compiled. Two preliminary surveys (including a survey of members attending OMERACT 7) were conducted to obtain feedback about these items². Participants were asked to rate the importance of the items as skills of an effective consumer and they were also asked about the clarity of wording. Items identified as unclear, e.g., double-barreled, grammatically incorrect, were revised. Our process of reviewing the literature and obtaining expert opinions from physicians and patients helped to ensure content validity. This revised survey was pretested with 6 consumers and revised again.

At this point, the survey questionnaire comprised 64 items. These items were separated into 5 categories from the original 4; the category of communication was separated from one of the original categories, and overall personality characteristics were combined in one unique category. The 5 categories were seek and use information, weigh values and priorities, communicate, make and implement decisions, and personality characteristics. After review, content experts in our working group eliminated the 16 personality items in the last category, as these were judged to be stable traits and thus not amenable to intervention. After this reduction, there were 48 items in the Effective Consumer Scale (Appendix 1), all using a 5-point scale from "always" to "never." Demographic questions were also added for age, sex, MSK disease and duration, and address by postal code. However, although our questionnaire was developed around themes and categories, the items were not divided into categories in the questionnaire survey; our aim was to create a unidimensional scale that would yield one overall score.

Pilot testing. Participants were randomly selected from membership lists of interested consumer organizations in Canada and Australia. They were stratified by age (under and over 50 years), sex, and form of MSK condition. Participants were also stratified by province or state. For example, in Canada, 440 surveys were sent to English-speaking Canadians in 9 provinces and in Australia, 40 persons from each participating state ($n = 6$) were sent surveys, a total of 240 surveys. Surveys were sent by post with return postage-paid envelopes in Australia and Canada. Reminders were sent within 2 months to those provinces/states with relatively low return rates.

Analyses. Data from the completed surveys were entered into SPSS 13³. A random check for accuracy of data input was performed on 10% of the surveys. Item analyses were performed using both classical and item response theory methods. The goal of item analyses was to substantially trim the scale by selecting items that most reliably measured the construct of "effective consumer."

We first assessed the number of missing responses for each item. Items that were missing responses for $\geq 5\%$ of the cases were reconsidered because this could signal a problem with question clarity or with actual question content.

Dimensionality. Most commonly-used item response theory models assume unidimensionality⁴. It is important to assess dimensionality to determine whether the scale can be analyzed as a unitary concept (items all measuring a single, overall trait) or whether it needs to be broken down into subscales. We tested dimensionality using principal-components analysis of the polychoric correlation matrices in Lisrel 8.72⁵. The ratio of the first to second eigenvalues was used to determine whether the scale was unidimensional or not. If the ratio of the first to second eigenvalues is > 3 to 1, then the scale can be considered unidimensional.

Classical item analyses. We assessed Chronbach's alpha for the overall scale and item-total correlation for each item. The alpha if item was removed for each item was also considered. In general, item total correlations near or < 0.20 are considered very poor.

Item response theory. Item response theory analyses were performed using Multilog 7.03⁶. Item response theory, or latent trait modeling, is a model-based tool that is increasingly being used to assess and refine tests and questionnaires⁷. Item response theory assumes that responses to all items on a scale are reflections of an underlying construct and that item performance can be related to the underlying trait or "ability" level⁷. Ability is measured on a standardized scale that is usually represented with numbers ranging from -3 to $+3$. A graph, or an item characteristic curve, is drawn showing probability of a given item response at each level of "ability" (in this case "effective consumerism")⁴. Item response theory overcomes some of the limitations of classical test theory in that the item parameters are not sample-dependent, nor are estimates of overall trait level item-dependent⁷. Item response theory provides "more comprehensive and more accurate evaluations of item statistics" (p. 1134)⁸. One important use of item response theory is to refine existing measures⁸ by identifying those items that most reliably measure the underlying construct that the test is designed to measure. In addition, item response theory allows items with different response scales to be used in the same analysis. It also yields item information curves and test information curves. Item information curves combine information from the discrimination and threshold parameters and show how well the item or test is measuring at particular levels of the underlying trait (i.e., does the item measure well for people with low levels of "effective consumerism")⁸. This allows the researcher to identify places where the test provides little information, which may suggest a need for new items. It also allows the developer to tailor the test to measure most reliably at certain trait levels or alternatively, to measure equally well across the "ability" spectrum.

A number of different item response theory models are available (e.g., Embretson and Reise⁴ and Hays, *et al*⁸). The choice between them depends on how well a particular measurement tool fits the model assumptions (e.g., does response scale match model?; guessing is likely). Samejima's graded response model⁹ was chosen as the model that best represents the ordinal nature of the data. This model is akin to a two-parameter logistic model for dichotomous items that assesses difficulty and discrimination⁴. In the graded response model, threshold parameters for each category represent the point on the ability scale at which there is $\geq 50\%$ probability of responding to the higher category (e.g., $\geq 50\%$ probability of responding "always" rather than "usually." In this study, 4 threshold parameters (5 response categories $- 1$) and one slope parameter were calculated. The slope parameter shows how well the item differentiates between people with a high trait level (e.g., effective consumerism) and people with low amounts of the trait. Item information (reliability of measurement) is higher for items with higher slope parameters⁹. Item discriminations < 0.5 are considered very poor. Our aim was to substantially reduce the number of items; therefore, our criteria for item retention were very high. Specifically, we initially retained items that had slope values ≥ 1.5 .

After the item parameters were estimated, item characteristic curves, item information curves, and the test information curve were plotted. Results of the psychometric analyses were used to reduce the number of items. Then, the scale was reformatted and presented during the OMERACT 8 Special Interest Group session. The working group then incorporated the feedback from the OMERACT 8 session and reevaluated the discrimination parameters to further reduce the items and revise the scale.

RESULTS

Of the 640 people who were mailed a questionnaire, 335 responded; 213 of these were Canadian and 122 Australian. Of these respondents, 49% were over age 60 years and 79% were female. In terms of type of arthritis, 57% had diagnosed osteoarthritis, 36% had diagnosed RA, and 10% had fibromyalgia (note that some people had multiple diagnoses).

Psychometric analyses.

Dimensionality: Results of the principal-components analysis showed that the ratio of the first eigenvalue to the second was 17.8 to 2.48, or > 7 to 1. Thus, the 48-item effective consumer scale was unidimensional. This meant that we could run item response analyses on the scale as a whole. It also means that we can calculate a score based on all items, rather than using subscales.

Classical item analyses: The overall alpha for the scale of 48 items was 0.96. Item-total correlations ranged from 0.11 to 0.74 (Table 1). Two items (Items 1 and 2) had very low item-total correlations of 0.11 and 0.22, respectively. Although no item had more than 5% of missing values, Item 15 ("I can deal with the deformities caused by the disease") stands out as having many more missing (3.7%) than the others (see Appendix 1 for detailed results of the classical item and item response theory analyses).

Item response theory analyses: The marginal reliability for the 48-item scale was high, at 0.978. As shown in Table 1, most items differentiated well between those who were high on the scale and those low on the scale. However, some items performed much better than others. Item slope values ranged from 0.55 (Item 1) to 2.91 (Item 38). Echoing the classical analyses, Items 1 and 2 had very low slope values, 0.55 and 0.6 each. Examination of the threshold parameters for these items reveals that the threshold values were all very low. Indeed, threshold 4 was -0.38 ; this means that respondents needed a lower than average amount of the trait to have a 50% probability of responding "always" rather than "usually." Thus, Items 1 and 2 showed ceiling effects. Thirteen items (Table 1) had slope values < 1.5 and were recommended for elimination in the first round of revisions before OMERACT 8.

Figure 1 shows item information curves for a very poor item (Item 1) and a very good item (Item 38). Figure 1 shows that Item 1 (slope parameter = 0.55) does not measure "effective consumerism" reliably at any point on the ability scale. In contrast, Item 38 measures very reliably at levels ranging from -2 to 1.5 , or over most of the ability range, measurement for this item is poorest at very high levels of effective consumerism (e.g., 2.5 to 3).

The test information curve is shown in Figure 2 (solid line represents test information and broken line represents standard error). Figure 2 shows that the 48 item scale measures very reliably at most levels of effective consumerism; particularly well at lower levels of effective consumerism, but less well at very high levels of effective consumerism.

Overall, after considering the slope parameters, 13 items with values < 1.5 were excluded from the scale, leaving 35 items. Although the scale was identified as unidimensional, the 35 scale items were classified into categories to make it easier for patients to complete it. These sections were (1) uses health information, (2) clarifies and weighs values and priorities, (3) communicates with others, (4) negotiates roles and takes control, and (5) decides and acts. As noted, the Effective Consumer Scale will be scored as one unitary scale. For simplicity, ease of use, and transparency, we chose to add up item scores to reach one overall score, rather than to use more sophisticated methods such as item response theory scoring.

OMERACT 8

The reduced and reformatted 35-item scale was presented at the OMERACT 8 Special Interest Group of the Effective Consumer. There were 40 participants at the session including many from the OMERACT Patient Group. The session started with a background presentation from Peter Tugwell and Annette O'Connor, who described the Effective Consumer Project, the progress to date, and possible use of the scale in self-management programs. Participants reviewed the reduced scale and then were asked

- (1) Have you had experiences with these programs?
- (2) Did you see changes as a result of these programs?
- (3) Would the Effective Consumer Scale be useful to evaluate the effects of these programs?

Initial discussions focused on the details of the scale. Suggestions were made around the concept, format, length and wording of the scale, the target audience, the timing of delivery, and other aspects of validity. There was an understanding that the concept of "effective consumer" refers to consumers who participate or are leaders in their healthcare management. But there was some question whether the scale needed to distinguish between how often or to what extent consumers are effective. Presently, the scale uses a Likert scale from "always" to "never" to indicate "how often." Participants also indicated the risk of a ceiling effect for most items, i.e., there is a potential that responders may choose the extreme ends in a pretest situation, but may realize after completing a program that they were actually not at the extreme end and would therefore have little room to move beyond the extreme.

Suggestions to improve wording were made for specific items. Participants recommended the use of a plain language specialist to ensure that items were clear and easy to understand. Wording was also an issue in discussions about the concept of the scale. Participants pointed out the present wording of the scale makes it unclear whether items ask if responders think they have the ability to perform the skill, or have already performed or will perform it. There was no consensus on whether the overall length of the scale was appropriate or too long.

Overall, the scale was well received. Most participants thought it could be used in self-management programs but

Table 1. Item-response and classical item analyses for 48 items in the Effective Consumer survey (continued next page); for detailed analyses see Appendix 1.

Item	Item-total correlation	Alpha if item removed	Discrimination (** Eliminated in first cut)
1. I want information about my disease. [I]	.100	.965	0.55**
2. I look for information about the causes of my disease, treatments, side effects of treatments, and so forth. [I]	.223	.964	0.60**
3. I know how to find information about my disease from different sources (such as the Internet, health care providers, friends, support groups, etc...) [I]	.580	.963	1.59
4. I know how to judge the quality of the information I find or receive about my disease. [I]	.588	.963	1.67
5. I know who can help me judge the quality of the information I receive about my disease. [I]	.588	.963	1.74
6. I understand the information I receive about my disease. [I]	.520	.963	1.50
7. I know how to adapt general health information to my own situation. [I]	.639	.963	1.93
8. I know how my disease affects my body. [I]	.512	.963	1.39**
9. I know how my disease affects how I feel inside (my emotions). [I]	.400	.964	1.11**
10. I know how my disease affects my lifestyle (for example, what I can do). [I]	.427	.963	1.21**
11. I see myself as a whole person, not just someone with a disease. [V]	.527	.963	1.23**
12. I know that what is 'normal' or a 'normal life' changes with the effects of my disease. [V]	.382	.964	1.19**
13. I can have a good relationship with my family and friends. [V]	.432	.963	1.03**
14. I can have a good relationship with other people who have my disease. [V]	.422	.964	1.14**
15. I can deal with any deformities caused by my disease. [V]	.553	.963	1.62
16. I can deal with the problems about not looking sick to other people. [V]	.554	.963	1.44
17. I can be clear about what is important in my life when I make decisions about my disease. [V]	.580	.963	1.83
18. I also know what is important to those around me (e.g., my family) about my disease. [V]	.561	.963	1.52
19. I understand the role my family and friends can play when I make decisions about my disease. [V]	.652	.963	1.96
20. I understand the role health care providers can play when I make decisions about my disease. [V]	.691	.962	2.14
21. I don't let my disease stop me from playing the role I want to in society. [V]	.475	.963	1.20**
22. I can weigh the pros and cons of a decision about my disease. [V]	.671	.963	2.25
23. I know that decisions I make about my disease may have bad as well as good consequences. [V]	.457	.963	1.24**
24. I know how to ask good questions about my health and my disease. [C]	.669	.963	2.20
25. I can express my concerns well to my family and friends. [C]	.659	.963	1.81
26. I can express my concerns well to health care providers. [C]	.682	.963	2.36
27. I am able to listen to the views of my family and friends. [C]	.507	.963	1.20**
28. I am able to listen to the views of health care providers. [C]	.553	.963	1.62
29. I have built an open and trusting relationship, based on mutual respect, with my health care providers. [C]	.694	.962	2.20
30. I know what information and how much information to share with my friends and family about my disease. [C]	.678	.963	2.08
31. I know what information and how much information to give to my health care providers. [C]	.678	.963	2.14
32. I can manage my time with my health care providers for a productive appointment (for example, preparing beforehand, making a list of questions, prioritizing my concerns, etc.). [C]	.602	.963	1.68
33. I can be assertive to get what I need to meet my health needs (for example, information and treatments). [C]	.715	.962	2.34
34. I know who to work with to meet my health needs. [C]	.701	.962	2.47

Table 1. Continued

Item	Item-total correlation	Alpha if item removed	Discrimination (** Eliminated in first cut)
35. I know how much I should participate in decision making with my health care providers. [D]	.678	.963	2.28
36. I want to participate in decision making with my health care providers. [D]	.476	.963	1.31**
37. I feel confident in making decisions about my health. [D]	.695	.962	2.36
38. I am able to play the role I want to in my health care team. [D]	.744	.962	2.91
39. I make decisions about my health (for example, about choosing a health care provider or treatments, when to find information, about changing my lifestyle, etc.). [D]	.666	.963	2.27
40. I feel a sense of control over my disease. [D]	.708	.962	2.17
41. I can take charge of day to day aspects of living with my disease. [D]	.629	.963	2.08
42. I am aware of what I have a right to get in the health care system where I live (for example, my right to information, treatment options, time with health care providers, safety, healthy environment, etc.). [D]	.719	.962	2.30
43. I can set realistic goals about the management of my disease. [D]	.656	.963	2.27
44. I can negotiate with others about what we need to do to manage my disease. [D]	.778	.962	2.58
45. I can negotiate with the health care system about what to do to manage my disease. [D]	.740	.963	2.46
46. I can organize my life to act on decisions about how to manage my disease. [D]	.673	.963	2.32
47. I can change my lifestyle based on decisions (for example, changing diet, exercise, daily routines, chores, etc.). [D]	.571	.963	1.76
48. I know what to do when I get conflicting advice about my disease (for example, about treatments, peer pressure to go beyond my limitations, etc.) after I make a decision. [D]	.735	.962	2.25

[I]: seeks and uses health Information; [V]: weighs Values and priorities; [C]: Communicates; [D]: makes and implements Decisions

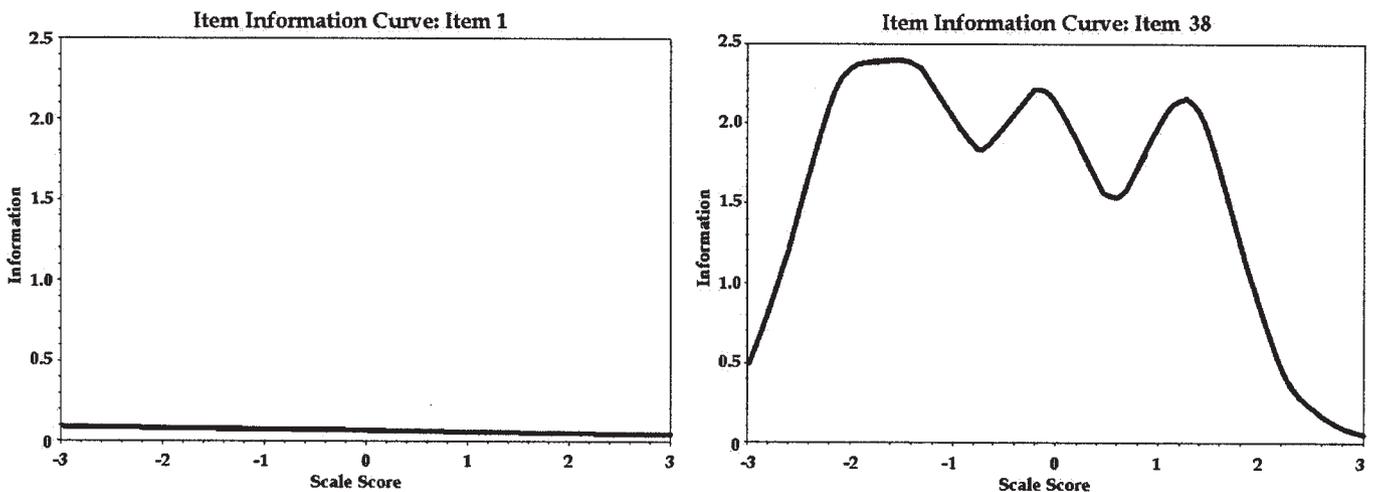


Figure 1. Item 1 (slope parameter = 0.55) did not measure “effective consumerism” reliably at any point on the ability scale. In contrast, Item 38 measured very reliably at levels ranging from -2 to 1.5, or over most of the ability range; measurement for this item was poorest at very high levels of effective consumerism (2.5 to 3).

wondered whether such programs would include education in all of the categories presently in the scale. The scale was also seen as an evaluation tool that could be used before and after self-management programs. Some participants suggested that an “effective consumer score” would be very useful, especially in cost/benefit analyses in health services utilization.

Participants agreed that the scale was ready to be validated. As a result of the session, 3 participants contacted the investigators with the possibility of using the Effective Consumer Scale to evaluate their education programs in the near future.

To prepare the scale for validation, the team incorporated the feedback from OMERACT 8 and revised the scale. The

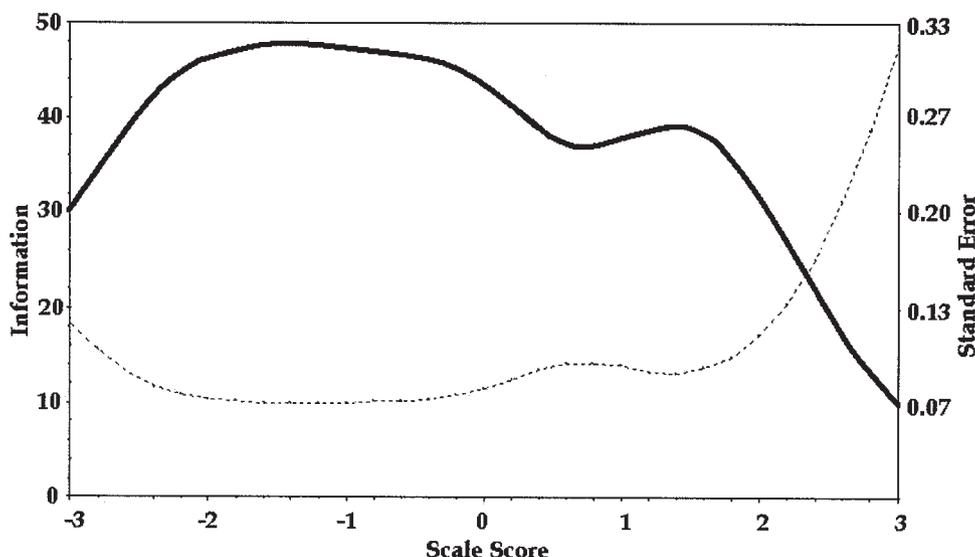


Figure 2. The test information curve shows that the 48-item scale measures very reliably at most levels of effective consumerism (solid line: test information; broken line: standard error).

team also decided that a shorter version was needed in order to avoid respondent burden in validation studies with multiple scales. Therefore, the team reexamined slope values from the original analysis; the aim was to retain those items with the highest slopes (usually values > 2.0) while ensuring that at least 3 to 4 items in each category were maintained. From this reassessment, a 17-item scale was developed (Appendix 2). To address the question about whether the scale should measure effectiveness “how often” versus “to what extent,” this 17-item scale will be validated in self-management interventions in 2 formats: one will ask how often the respondent acts effectively, while the other will ask how effectively the respondent acts or how effective the respondent is.

Conclusion

Few outcome measures exist to adequately evaluate self-management interventions that empower and educate people with rheumatologic conditions. Most scales do not appear to measure the unique skills and attributes of a consumer who is effective at managing his/her healthcare. For this reason, the effective MSK scale is being developed. Over the past 3 years, we have used rigorous methods to define the concept of an effective consumer, to develop items around important themes, to ensure content validity, to pretest and pilot-test items, and to test item performance. In the months leading up to and during OMERACT 8, psychometric analysis of our questionnaire survey of Canadian and Australian consumers identified a subset of the best-performing items. Feedback from the participants at OMERACT 8 provided additional feedback into the acceptability of such a scale.

Overall, the scale was well received and acceptable to participants. Participants highlighted areas for improvement, such as wording, response format, and length. The Effective

Musculoskeletal Consumer Project team used these suggestions to reassess the scale and further reduce the items. A 17-item Effective Consumer Scale was developed from the team discussions. Exciting opportunities to pilot-test and validate this new scale lie ahead, with offers for use of the scale in programs planned in Ireland, Canada, Australia, and New Zealand.

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APPENDIX 1. Classical item analyses and item-total correlations (continued next page).

Item	Missing (%)	Classical Item Analysis (Overall = .96)		Item Response Theory Analyses				
		Item-total correlation	Alpha if item removed	DT 1	DT 2	DT 3	DT 4	Discrimination (** Eliminated in first cut)
1. I want information about my disease. [I]	0	.100	.965	-9.30	-6.18	-2.68	-0.38	0.55**
2. I look for information about the causes of my disease, treatments, side effects of treatments, and so forth. [I]	0	.223	.964	-7.66	-5.36	-2.08	0.46	0.60**
3. I know how to find information about my disease from different sources (such as the Internet, health care providers, friends, support groups, etc...) [I]	0	.580	.963	-2.85	-1.80	-0.59	0.99	1.59
4. I know how to judge the quality of the information I find or receive about my disease. [I]	0.3	.588	.963	-3.46	-2.07	-0.25	1.92	1.67
5. I know who can help me judge the quality of the information I receive about my disease. [I]	0	.588	.963	-2.23	-1.32	-0.29	1.28	1.74
6. I understand the information I receive about my disease. [I]	0	.520	.963	-5.67	-3.77	-0.85	1.81	1.50
7. I know how to adapt general health information to my own situation. [I]	0.6	.639	.963	-3.20	-2.55	-0.68	1.71	1.93
8. I know how my disease affects my body. [I]	1.2	.512	.963	-5.84	-3.18	-1.11	1.15	1.39**
9. I know how my disease affects how I feel inside (my emotions). [I]	0	.400	.964	-6.40	-3.25	-1.04	1.25	1.11**
10. I know how my disease affects my lifestyle (for example, what I can do). [I]	0	.427	.963	-1.39	-15.63	-1.95	0.75	1.21**
11. I see myself as a whole person, not just someone with a disease. [V]	0	.527	.963	-4.49	-3.89	-1.68	0.35	1.23**
12. I know that what is 'normal' or a 'normal life' changes with the effects of my disease. [V]	0.6	.382	.964	-4.04	-3.46	-1.32	1.34	1.19**
13. I can have a good relationship with my family and friends. [V]	0	.432	.963	-7.23	-4.61	-2.15	0.71	1.03**
14. I can have a good relationship with other people who have my disease. [V]	3.4	.422	.964	-3.06	-2.08	-0.89	1.29	1.14**
15. I can deal with any deformities caused by my disease. [V]	3.7	.553	.963	-2.16	-1.33	-0.06	1.93	1.62
16. I can deal with the problems about not looking sick to other people. [V]	0.9	.554	.963	-3.39	-1.89	-0.31	1.91	1.44
17. I can be clear about what is important in my life when I make decisions about my disease. [V]	0.3	.580	.963	-4.79	-2.73	-0.64	1.49	1.83
18. I also know what is important to those around me (e.g., my family) about my disease. [V]	0.6	.561	.963	-3.22	-1.85	-0.40	1.89	1.52
19. I understand the role my family and friends can play when I make decisions about my disease. [V]	0.3	.652	.963	-2.24	-1.39	-0.21	1.68	1.96
20. I understand the role health care providers can play when I make decisions about my disease. [V]	0.9	.691	.962	-2.26	-1.29	-0.32	1.36	2.14
21. I don't let my disease stop me from playing the role I want to in society. [V]	0.3	.475	.963	-3.24	-2.08	-0.58	1.60	1.20**
22. I can weigh the pros and cons of a decision about my disease. [V]	0.9	.671	.963	-2.47	-2.09	-0.45	1.14	2.25
23. I know that decisions I make about my disease may have bad as well as good consequences. [V]	0	.457	.963	-4.46	-3.15	-0.65	1.68	1.24**
24. I know how to ask good questions about my health and my disease. [C]	0	.669	.963	-2.80	-1.60	-0.22	1.76	2.20

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Item	Missing (%)	Classical Item Analysis (Overall = .96)		Item Response Theory Analyses				
		Item-total correlation	Alpha if item removed	DT 1	DT 2	DT 3	DT 4	Discrimination (** Eliminated in first cut)
25. I can express my concerns well to my family and friends. [C]	0.3	.659	.963	-2.61	-1.09	0.32	2.04	1.81
26. I can express my concerns well to health care providers. [C]	0	.682	.963	-2.65	-1.26	-0.11	1.63	2.36
27. I am able to listen to the views of my family and friends. [C]	0.6	.507	.963	-4.02	-2.39	-0.67	1.96	1.20**
28. I am able to listen to the views of health care providers. [C]	0	.553	.963	-3.60	-2.71	-1.40	0.98	1.62
29. I have built an open and trusting relationship, based on mutual respect, with my health care providers. [C]	0.6	.694	.962	-2.05	-1.23	-0.52	0.99	2.20
30. I know what information and how much information to share with my friends and family about my disease. [C]	0.6	.678	.963	-2.24	-1.27	-0.14	1.73	2.08
31. I know what information and how much information to give to my health care providers. [C]	0.9	.678	.963	-2.36	-1.52	-0.67	1.12	2.14
32. I can manage my time with my health care providers for a productive appointment (for example, preparing beforehand, making a list of questions, prioritizing my concerns, etc.). [C]	0.3	.602	.963	-2.60	-1.54	-0.52	0.99	1.68
33. I can be assertive to get what I need to meet my health needs (for example, information and treatments). [C]	0.6	.715	.962	-2.12	-1.12	-0.03	1.48	2.34
34. I know who to work with to meet my health needs. [C]	0.6	.701	.962	-2.27	-1.05	-0.14	1.71	2.47
35. I know how much I should participate in decision making with my health care providers. [D]	0.3	.678	.963	-2.38	-1.38	-0.47	1.17	2.28
36. I want to participate in decision making with my health care providers. [D]	0	.476	.963	-3.72	-3.17	-2.09	-0.06	1.31**
37. I feel confident in making decisions about my health. [D]	0	.695	.962	-2.65	-1.44	-0.37	1.16	2.36
38. I am able to play the role I want to in my health care team. [D]	1.2	.744	.962	-2.06	-1.32	-0.13	1.26	2.91
39. I make decisions about my health (for example, about choosing a health care provider or treatments, when to find information, about changing my lifestyle, etc.). [D]	0	.666	.963	-2.52	-1.14	-0.36	1.11	2.27
40. I feel a sense of control over my disease. [D]	0.6	.708	.962	-1.55	-0.66	0.39	1.98	2.17
41. I can take charge of day to day aspects of living with my disease. [D]	0	.629	.963	-2.98	-1.84	-0.60	1.49	2.08
42. I am aware of what I have a right to get in the health care system where I live (for example, my right to information, treatment options, time with health care providers, safety, healthy environment, etc.). [D]	0	.719	.962	-1.84	-0.86	0.17	1.47	2.30
43. I can set realistic goals about the management of my disease. [D]	0.6	.656	.963	-2.23	-1.30	-0.18	1.94	2.27
44. I can negotiate with others about what we need to do to manage my disease. [D]	0.3	.778	.962	-2.02	-1.01	0.16	5.46	2.58
45. I can negotiate with the health care system about what to do to manage my disease. [D]	1.5	.740	.963	-1.59	-0.61	0.37	2.14	2.46
46. I can organize my life to act on decisions about how to manage my disease. [D]	0.9	.673	.963	-2.08	-1.46	-0.23	1.83	2.32
47. I can change my lifestyle based on decisions (for example, changing diet, exercise, daily routines, chores, etc.). [D]	0.3	.571	.963	-2.91	-1.73	-0.19	1.76	1.76
48. I know what to do when I get conflicting advice about my disease (for example, about treatments, peer pressure to go beyond my limitations, etc.) after I make a decision. [D]	0.3	.735	.962	-2.15	-0.91	0.22	1.66	2.25

DT: Difficulty Threshold; [I]: seeks and uses health Information; [V]: weighs Values and priorities; [C]: Communicates; [D]: makes and implements Decisions

APPENDIX 2. The Effective Consumer Survey (17 items).

This survey asks you about yourself and how you manage your disease. It asks questions about the skills, attitudes and knowledge you may or may not have.

Please check how much of the time each statement is true of you.

	Never	Rarely	Some- times	Usually	Always
How I use health information					
1. I know who can help me judge the quality of the information I receive about my disease	<input type="checkbox"/>				
2. I understand the information I receive about my disease	<input type="checkbox"/>				
3. I know how to adapt general health information to my own situation	<input type="checkbox"/>				
How I clarify my priorities					
4. I can be clear about what is important in my life when I make decisions about my disease	<input type="checkbox"/>				
5. I can weigh the pros and cons of a decision about my disease	<input type="checkbox"/>				
6. I can set realistic goals about the management of my disease	<input type="checkbox"/>				
How I communicate with others					
7. I can express my concerns well to health care providers	<input type="checkbox"/>				
8. I know how to ask good questions about my health and my disease	<input type="checkbox"/>				
9. I have built an open and trusting relationship, based on mutual respect, with my health care providers	<input type="checkbox"/>				
How I negotiate my role and take control					
10. I am able to play the role I want to in my health care team	<input type="checkbox"/>				
11. I know who to work with to meet my health needs	<input type="checkbox"/>				
12. I can be assertive to get what I need to meet my health needs (for example, information and treatments)	<input type="checkbox"/>				
13. I feel a sense of control over my disease	<input type="checkbox"/>				
How I decide and take action					
14. I feel confident in making decisions about my health	<input type="checkbox"/>				
15. I can negotiate with others about what we need to do to manage my disease	<input type="checkbox"/>				
16. I can negotiate with the health care system about what to do to manage my disease	<input type="checkbox"/>				
17. I can organize my life to act on decisions about how to manage my disease	<input type="checkbox"/>				