Supplement 2 to the article: Development and Validation of the Patient Experience with Treatment and Self-Management (PETS): A Patient-Reported Measure of Treatment Burden

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Authors: David T. Eton,[*] Kathleen J. Yost, Jin-shei Lai, Jennifer L. Ridgeway, Jason S. Egginton, Jordan K. Rosedahl, Mark Linzer, Deborah H. Boehm, Azra Thakur, Sara Poplau, Laura Odell, Victor M. Montori, Carl R. May, Roger T. Anderson

*Corresponding author: Division of Health Care Policy & Research, Department of Health Sciences Research, Mayo Clinic, 200 First Street SW, Rochester, MN USA 55905.
Tel.: +507-293-1353; Fax: +507-284-1516. Email address: eton.david@mayo.edu (D.T. Eton).

Supplement 2. Item diagnostic results

DOMAIN / ITEM	RETAIN, REMOVE, or SET ASIDE?[1]
Learning about health conditions & care	
How easy/difficult has it been to …	
1 learn about your health problem(s)?	Retain
2 learn what foods you should eat to stay healthy?	Retain
3 find information on the medications that you have to take?	Retain
Response scale: very easy, easy, neither easy nor difficult, difficult, very difficult, does not apply to me	
Medications	
How much of a problem has it been for you to...	
4 organize your medicines?	Retain
5 take more than one medicine every day?	Retain
6 take your medicines several times each day?	Retain
7 refill your medicines?	Retain
8 adjust your medicines (including the amount, type, or time when you take it)?	Retain
Response scale: not at all, a little, somewhat, quite a bit, very much	
Difficulty with taking medications	
How easy/difficult has it been to …	
9 take your medicines as directed?	Retain
10 plan your meals around your medicine schedule?	Remove (high correlation [rho=0.85] and content overlap with item 11)
11 plan your daily activities around your medicine schedule?	Retain
12 prepare your medicines, such as cutting pills or mixing solutions?	Remove (33% missing)

Response scale: very easy, easy, neither easy nor difficult, difficult, very difficult, does not apply to me	
How bothered have you been by...	
13 how much you have to rely on your medicine(s)?	Retain
14 side effects of your medicine(s)?	Retain
Response scale: not at all, a little, somewhat, quite a bit, very much	

Medical appointments

How much of a problem has it been for you to...	
15 make or keep your medical appointments?	Retain
16 schedule and keep track of your medical appointments?	Retain
17 make or keep appointments with different healthcare providers?	Retain
Response scale: not at all, a little, somewhat, quite a bit, very much	
How much do you agree/disagree w/ following?	
18 Difficult for me to get to my appointments because I am too busy with other things	Set aside (inter-correlations with items 15-17 are low, rhos=0.27 – 0.33)
19 Difficult for me to get to my appointments because I am too tired	Set aside (inter-correlations with items 15-17 are low, rhos=0.36 – 0.44)
20 Difficult for me to get to my appointments because of trouble with transportation	Set aside (inter-correlations with items 15-17 are low, rhos=0.29 – 0.33)
Response scale: strongly agree, agree, disagree, strongly disagree	

Monitoring health

How much of a problem has it been for you to...	
21 monitor your health behaviors, e.g., tracking exercise, foods you eat, or medicines you take?	Retain
22 monitor your health condition, e.g., weighing yourself, checking blood pressure, or checking blood sugar?	Retain
Response scale: not at all, a little, somewhat, quite a bit, very much	

Exercise or Physical Therapy[2]

How much do you agree/disagree w/ following?	
24 Spend too much time following my exercise or physical therapy plan	Set aside (57% missing, mostly due to screening out of question)
25 Difficult for me to follow my exercise or physical therapy plan because of physical pain or discomfort	Set aside (58% missing, mostly due to screening out of question)
26 Difficult for me to get motivated to exercise or do physical therapy	Set aside (58% missing, mostly due to screening out of question)
27 Difficult for me to follow my exercise or physical therapy plan because I do not have	Set aside (58% missing, mostly due to screening out of question)

someone to do it with	

Response scale: strongly agree, agree, disagree, strongly disagree

Diet[3]

How much do you agree/disagree w/ following?

29 Diet plan requires me to give up too many foods that I like.	Set aside (60% missing, mostly due to screening out of question)
30 Difficult for me to follow my diet plan because it is hard to find healthy foods	Set aside (61% missing, mostly due to screening out of question)
31 Difficult for me to follow my diet plan because I crave less healthy foods	Set aside (61% missing, mostly due to screening out of question)

Response scale: strongly agree, agree, disagree, strongly disagree

Medical equipment[4]

How easy/difficult has it been to …

33 use your medical equipment or device?	Set aside (46% missing, mostly due to screening out of question)
34 keep your medical equipment or device working correctly?	Set aside (46% missing, mostly due to screening out of question)

Response scale: very easy, easy, neither easy nor difficult, difficult, very difficult

Interpersonal challenges

How bothered have you been by...

35 feeling dependent on others for your healthcare needs?	Retain
36 others reminding you to do things for your health like take your medicine, watch what you eat, or schedule medical appointments?	Retain
37 your healthcare needs creating tension in your relationships with others	Retain
38 others not understanding your health situation	Retain

Response scale: not at all, a little, somewhat, quite a bit, very much

Medical & healthcare expenses

How easy/difficult has it been for you to …

39 fill out forms related to your medical expenses or insurance coverage?	Remove (item correlated about equally with items in two domains: *medical/ healthcare expenses* [rhos = 0.55 to 0.68] and *confusion/concern about medical information* [rhos = 0.57 to 0.62]) – does not clearly fall into a single domain.
40 plan for the future because of your medical expenses?	Retain
41 pay for healthy foods?	Retain
42 pay for all of your medical expenses?	Retain
43 pay for expenses related to exercise, like gym	Remove (34% missing)

memberships or exercise equipment?	
44 pay for your health insurance?	Remove (high correlation and content overlap with item 42 [rho=0.80] and item 45 [rho=0.84])
45 pay for your medicines?	Retain
46 understand what is and what is not covered by your health insurance?	Retain
Response scale: very easy, easy, neither easy nor difficult, difficult, very difficult, does not apply to me	

Confusion/concern about medical information	
How easy/difficult has it been for you to …	
47 keep up on changes in medical information related to your health problem(s) or illness(es)?	Remove (high correlation [rho=0.86] and content overlap with item 48)
48 understand changes to your treatment plan?	Retain
49 understand the reasons why you are taking some medicines?	Retain
50 find sources of medical information that you trust?	Retain
51 understand advice from different healthcare providers?	Retain
52 understand how to monitor your health problem(s) or illness(es)?	Remove (25% missing)
Response scale: very easy, easy, neither easy nor difficult, difficult, very difficult, does not apply to me	

Healthcare providers	
How much do you agree/disagree w/ following?	
53 My healthcare provider(s) listens carefully to me	Remove (domain items do not conceptually fit with the treatment burden construct)
54 It is easy for me to communicate with my healthcare provider(s)	Remove (domain items do not conceptually fit with the treatment burden construct)
55 My healthcare provider(s) treats me with dignity and respect	Remove (domain items do not conceptually fit with the treatment burden construct)
56 My healthcare provider(s) is up to date on my medical history	Remove (domain items do not conceptually fit with the treatment burden construct)
57 My healthcare provider(s) spends enough time with me	Remove (domain items do not conceptually fit with the treatment burden construct)
58 My healthcare provider(s) treats me as a whole person	Remove (domain items do not conceptually fit with the treatment burden construct)
59 I have trust in my healthcare provider(s)	Remove (domain items do not conceptually fit with the treatment burden construct)
Response scale: strongly agree, agree, disagree, strongly disagree	

Difficulty with healthcare services	
How much do you agree/disagree w/ following?	
60 Have problems with different healthcare providers not communicating with each other	Retain

about my medical care	
61 Have to see too many different specialists for my health problem(s) or illness(es)	Retain
62 Have problems filling out forms related to my healthcare	Retain
63 Have problems getting appointments at times that are convenient for me	Retain
64 Have problems getting appointments with a specialist	Retain
65 Have to wait too long at my medical appointments	Retain
66 Have to wait too long at the pharmacy for my medicine	Retain
Response scale: strongly agree, agree, disagree, strongly disagree, does not apply to me	

Role and social activity limitations	
How much has your <u>self-care</u> interfered with…	
67 work (include work at home)?	Retain
68 family responsibilities?	Retain
69 daily activities?	Retain
70 hobbies and leisure activities?	Retain
71 ability to spend time with family and friends?	Retain
72 ability to travel for work or vacation?	Retain
Response scale: not at all, a little, somewhat, quite a bit, very much	

Physical and mental exhaustion	
How often did your <u>self-care</u> make you feel…	
73 angry?	Retain
74 preoccupied?	Retain
75 depressed?	Retain
76 worn out?	Retain
77 frustrated?	Retain
78 overwhelmed?	Remove (high correlation [rho=0.83] and content overlap with item 77)
Response scale: never, rarely, sometimes, often, always	

<u>Note.</u> [1]Removed items are permanently deleted from the measure. Set aside items (i.e., provisionally excluded items) require further analyses. [2]Screening question present for these items: "Has a doctor, nurse, physical therapist or other healthcare provider given you an <u>exercise or physical therapy plan</u> to follow?" (Y/N) If <u>no</u> then exercise/physical therapy questions are skipped. [3]Screening question present for these items: "Has a doctor, nurse, dietician or other healthcare provider given you a <u>diet plan</u> to follow?" (Y/N) If <u>no</u> then diet questions are skipped. [4]Screening question present for these items: "Do you currently use any <u>medical equipment or devices</u> (e.g., blood pressure cuffs, insulin pens, blood sugar monitors, breathing machines for sleep apnea, or asthma inhalers, among others?" (Y/N) If <u>no</u> then questions are skipped.