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Whose Preferences Matter? A Patient-Centered Approach for Eliciting Treatment Goals

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Abstract

Background. Patients facing a high-stakes clinical decision are often confronted with an overwhelming array of options. High-quality decisions about treatment should reflect patients' preferences as well as their clinical characteristics. Preference-assessment instruments typically focus on pre-selected clinical outcomes and attributes chosen by the investigator. **Objective.** We sought to develop a patient-centered approach to elicit and compare the treatment goals of patients with multiple sclerosis (MS) and healthcare providers (HCPs). **Methods.** We conducted five nominal group technique (NGT) meetings to elicit and prioritize treatment goals from patients and HCPs. Five to nine participants in each group responded silently to one question about their treatment goals. Responses were shared, consolidated, and ranked to develop a prioritized list for each group. The ranked lists were combined. Goals were rated and sorted into categories. Multidimensional scaling and hierarchical cluster analysis were used to derive a visual representation, or cognitive map, of the data and to identify conceptual clusters, reflecting how frequently items were sorted into the same category. **Results.** Five NGT groups yielded 34 unique patient-generated treatment goals and 31 unique HCP-generated goals. There were differences between patients and HCPs in the goals generated and how they were clustered. Patients' goals tended to focus on the impact of specific symptoms on their day-to-day lives, whereas providers' goals focused on slowing down the course of disease progression. **Conclusions.** Differences between the treatment goals of patients and HCPs underscore the limitations of using HCP- or investigator-identified goals. This new adaptation of cognitive mapping is a patient-centered approach that can be used to generate and organize the outcomes and attributes for values clarification exercises while minimizing investigator bias and maximizing relevance to patients.

Keywords

clinical decision making, cognitive mapping, hierarchical cluster analysis, multidimensional scaling, multiple sclerosis, nominal group technique, preference assessment, preference sensitive care, shared decision making, values clarification

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Understanding what matters to patients is critical in high-stakes clinical decisions. Treatment decisions can influence many aspects of a patient's life beyond their clinical symptoms, including independence, emotional state, social interactions, and finances. While there is growing consensus that patients' values should be

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incorporated into clinical decisions,^{1,2} there is little consensus on how this should be done.³ Simply asking patients what they value is problematic, as people often do not have pre-formed ideas about what is important to them when confronted with complex or unfamiliar situations.⁴⁻⁶ Additionally, patients often have difficulty applying deeply held values to health decisions.⁷

Values clarification exercises (VCE) aim to help patients determine what matters most to them when making a health decision.^{3,8} They are recommended components of patient decision aids (DAs) and can help patients choose treatments that are consistent with their values.^{3,9} The most common approach to values clarification is listing the pros and cons of options.¹⁰ Other approaches include focused comparisons of the attributes of treatments and the outcomes affected, using mathematical models to assign weights to items (e.g., utility theory or stated preference approaches such as conjoint analysis,¹¹ best-worst-scaling, and discrete choice¹²).

While much attention has been given to the mathematical models for assigning weights to a set of attributes and outcomes, less attention has been given to how those attributes and outcomes are selected. It is established that an individual's values and preferences can be influenced, or even formed, by the way they are elicited; even small differences in rating procedures matter.^{13,14} Yet changing the attributes and outcomes discussed can shift the focus and trigger emotions, influencing how those outcomes are perceived and valued.¹⁵

The task of selecting and organizing the attributes and outcomes to include in a VCE is most often entrusted to

the developer or to expert physicians, often mirroring the outcomes reported in clinical trials or guidelines¹⁶ or the values deemed important by the developer. However, clinical outcomes are often valued differently by patients and physicians,¹⁷ and the inaccuracies of substituted judgment, when surrogate decision makers make decisions in lieu of the patient, have been well-documented.^{18,19} Thus, studies that ask patients to rate the wrong set of outcomes lack external validity.²⁰⁻²²

Focus groups and/or interviews are sometimes conducted to understand what matters to patients. However, extracting and prioritizing patient preferences from these discussions is difficult, subjective, and influenced by the investigator's own perspectives.²³ Furthermore, interacting groups can inhibit creative thinking by pursuing a single train of thought for a long period, promoting premature evaluation, and inhibiting the participation of more passive members. In contrast, the nominal group technique (NGT) minimizes investigator bias, avoids focusing on a single train of thought, prompts participants to generate their own issues, captures the specific language of participants, maintains the autonomy of individual viewpoints, allows equal input by each participant, and objectively prioritizes findings.²⁴⁻²⁶ Card sorting exercises can capture how participants themselves organize ideas generated in an NGT, further minimizing investigator bias. Analyzing card sorting results using multidimensional scaling (MDS)²⁷⁻²⁹ and hierarchical cluster analysis (HCA)³⁰ can produce a visual "cognitive map" that facilitates obtaining input from stakeholders who lack statistical expertise.³¹ This combination of NGT coupled with card sort exercises and MDS and HCA, referred to as "cognitive mapping," has been applied in many areas, but not yet to inform the attributes included in VCE or DAs.

Our clinical focus is multiple sclerosis (MS), an immune-mediated disease of the central nervous system.³² Choosing the best treatment for patients with MS has become more challenging because of the increasing number of disease-modifying treatments available (14 in 2017).³³ These treatments may differ in their effectiveness, side-effects, risks, costs, and method of administration. A search of the literature identified 5 studies and 1 DA that addressed MS treatment preferences,³⁴⁻³⁹ each using a different set of attributes and all but one³⁸ using investigator-selected attributes without specifying the selection process.

Our objective was to develop a patient-centered approach to identify the outcomes and attributes important to patients making a high-stakes medical decision regarding their MS. We sought to adapt cognitive

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mapping to compare the treatment goals of patients with MS to those of experienced MS healthcare providers (HCPs).

Methods

Sample

We included non-pregnant, English-speaking patients with any type of MS between the ages of 21 and 75 years, reflecting the epidemiology of MS.⁴⁰

All patient participants were identified through patient and HCP advisers with access to MS networks, using a purposive sampling design. To enhance the inclusion of disabled persons and increase geographic and racial diversity, we offered both online and in-person activities. In-person activities were conducted in handicap-accessible facilities in Denver and Colorado Springs, CO, Atlanta, GA, and Worcester, MA. Patient recruitment targeted diversity in age, duration of MS, race/ethnicity, education, and gender.

Our HCPs included neurologists, nurse practitioners, physician assistants, or registered nurses who manage 10 or more MS patients a month, using a combination of convenience and purposive sampling designs. HCP recruitment targeted diversity in gender, years of training, and type of provider.

Recruitment used snowball sampling through strategically placed ads, flyers, and invitations. Recruitment channels included MS support groups, educational events, professional organizations, health blogs, and private Facebook groups. Participants were invited to participate between April 2015 and February 2016.

Informed consent was obtained online or in-person for each study activity. This study was approved by the New England Independent Review Board.

Study Procedures

We used a multi-step cognitive mapping approach in which NGT meetings were used to elicit and prioritize treatment goals from patients and HCPs. A subsequent card sorting exercise, involving a larger sample, rated and clustered the prioritized goals. MDS and HCA were used to analyze card sort responses. NGT participants could elect to participate in subsequent card sorting activities.

Five to nine participants were assigned to each NGT group. Groups were led by an experienced moderator (NFC) and co-led by a locally respected peer. To standardize meetings across sites, instructions were provided through a series of instructional videos. Participants were

asked to silently respond to one carefully worded question (pre-tested in cognitive interviews), writing down as many brief responses as they wished. Patients were asked “What do you specifically hope to achieve (or avoid), now and in the future, when you choose ways to manage your MS?” HCPs were asked: “What do you hope to achieve or avoid when you manage your patient’s MS?” Participants requiring assistance were paired with an assistant. Participants could submit sensitive topics anonymously. Next, in a round-robin, each subject read aloud one of their responses until all unique responses were recorded on a shared list. The moderator read any anonymous topics. Each item on the list was reviewed by the group for clarity and redundancy. Finally, participants were asked to silently identify and rank the 9 most important items (the maximum number that can be effectively ranked).⁴¹

We developed a 2-step online NGT protocol that mirrored the in-person protocol. Participants could respond when and where they chose (asynchronously), spend as much time as needed, and complete the activity over multiple sessions. Instructional videos (identical to those shown during the in-person meetings) explained procedures. In step one, participants viewed the videos, read the NGT question, and submitted their responses. After all participants’ responses were submitted, the responses were consolidated independently by 2 facilitators (NFC, VS), involving another advisor to resolve any differences. In step two, 1 to 3 weeks later, participants were shown the consolidated list, asked if they agreed with the way items were combined and how they would like to change it. They were then asked to rate each item for clarity (“Is this concept clear?”, “How would you suggest it be improved?”) and redundancy (Is the item unique? If not, “which other item(s) should it be combined with?”), and then asked to rank the top 9 items.

After completing all NGTs (in-person and online), 2 consolidated lists of treatment goals were generated (1 for patients, 1 for HCPs) by carrying forward all prioritized items (receiving at least 1 point), combining items that conveyed the same meaning, and removing or rewording confusing items. MS patient and HCP advisers (BT, AH, MM, LQ, CG, AS) guided this process. We attempted to combine patient and HCP prioritized responses onto a single list, but many of the HCP items were unclear to patients.

The consolidated list of patient treatment goals was used for rating and card sorting among both patients and HCPs. Participants rated the importance of each goal by indicating the strength of their agreement or disagreement with each one, using a 5- or 10-point Likert scale

(online v. in-person, respectively). Participants were then asked to use their own criteria (e.g., “how you see these items going together?”) to sort the 34 items into 3 to 10 groups containing any number of perceptually similar cards.⁴² This was done either in-person using a shuffled deck of cards, or online, using customized Qualtrics software. Online participants were asked to label each group.

Data Analyses

Within each NGT meeting, weights were assigned to each ranked item (i.e., 9 points for the 1st, 1 point for the 9th) and scores from each participant were summed to develop an aggregated, prioritized list. Ratings conducted during the card sorting exercises were calculated using the mean and SD, and rescaled to a 10-point scale. Results of all of the online and in-person activities appeared similar and were combined (the online Appendix compares online and in-person findings).

Using customized software, the card sort data were transformed into a 34 × 34 co-occurrence matrix that recorded how often 2 items were sorted into the same group. MDS (“PROXCAL” software algorithm) was applied to the group co-occurrence matrix using Euclidean (i.e., straight-line) distances. MDS creates a visual “cognitive map” of the spatial relationships between the attributes that approximates the perceived similarity of items. The more often items were sorted into the same group, the closer they appeared in the diagram. The space can be multi-dimensional, but only 2-dimension solutions are interpretable. Goodness-of-fit is determined by the stress statistic (below 0.15 corresponds to a good fit).^{43,44}

HCA (using Ward’s Linkage) was used to draw boundaries around groups of goals, demarcating conceptual clusters of related goals. A cluster tree (dendrogram) represents the distance between the clusters by the length of the branches. It illustrates potential clusters but not the actual number of clusters. Final clusters conformed to the dendrogram, using patient input to identify and label the most meaningful clusters (Appendix Figures 2A, 3A, and 4A). MDS and HCA are robust to violations of their assumptions. All analyses were performed using SPSS Statistics 23.

Results

Seventy-one participants took part in the study (47 patients, 24 HCPs; Figure 1). Our patient sample (Table 1) appears representative, as it resembles another representative study’s sample.⁴⁵ Our HCPs had an average of 10.5 years in practice (range, 1 to 32), 71% were female, and 42% were physicians (neurologists), 33% physician

Table 1 Patient Characteristics (*n* = 47)

	<i>n</i> (%)
Age in years, average (SD)	52 (12)
Gender	
Male	9 (19.2%)
Female	38 (80.8%)
Race	
White/Caucasian	87.2%
Black/African American	12.8%
Type of MS	
Relapsing Remitting MS	40 (85.1%)
Primary Progressive MS	4 (8.5%)
Secondary Progressive MS	2 (4.3%)
Not reported	1 (2.1%)
Time since diagnosis in years, mean (SD)	12.41 (9.4)
Patient Determined Disease Steps score, ⁴⁶ mean (SD)	3.54 (2.1) ^a
Past or current DMT ^b use	92.31%
Educational level	
High school graduate/GED	2 (4.3%)
Some college	11 (23.4%)
2-year college/technical school	5 (10.6%)
College graduate	17 (36.2%)
Graduate school or professional degree	12 (25.5%)

^aExcludes participants in the in-person card sort group

^bDMT, disease modifying treatment

assistants, and 25% nurses or nurse practitioners. Forty-six percent of the HCPs who participated in the NGT meetings were affiliated with a MS Center, 31% reported seeing over 50 patients with MS each month, 62% between 11 and 50 patients, the remainder seeing approximately 10 patients/month.

Treatment Goals Generated by Patients and HCPs

All subjects who consented completed the NGT activities. Three patient NGT meetings (2 in-person, 1 online) generated 34 unique goals; 2 in-person HCP NGT meetings generated 31 unique goals. Many of the patient goals were not mentioned by HCPs and vice versa; in addition, differences in terminology were observed (Table 2). Among patients, maintaining bladder and bowel function was the most important symptom management goal, much more than managing pain. In contrast, HCPs endorsed pain more strongly than bladder and bowel function.

Ratings of Patient Treatment Goals

All subjects who consented to the card sorting exercise completed all ratings. Both HCPs and patients strongly

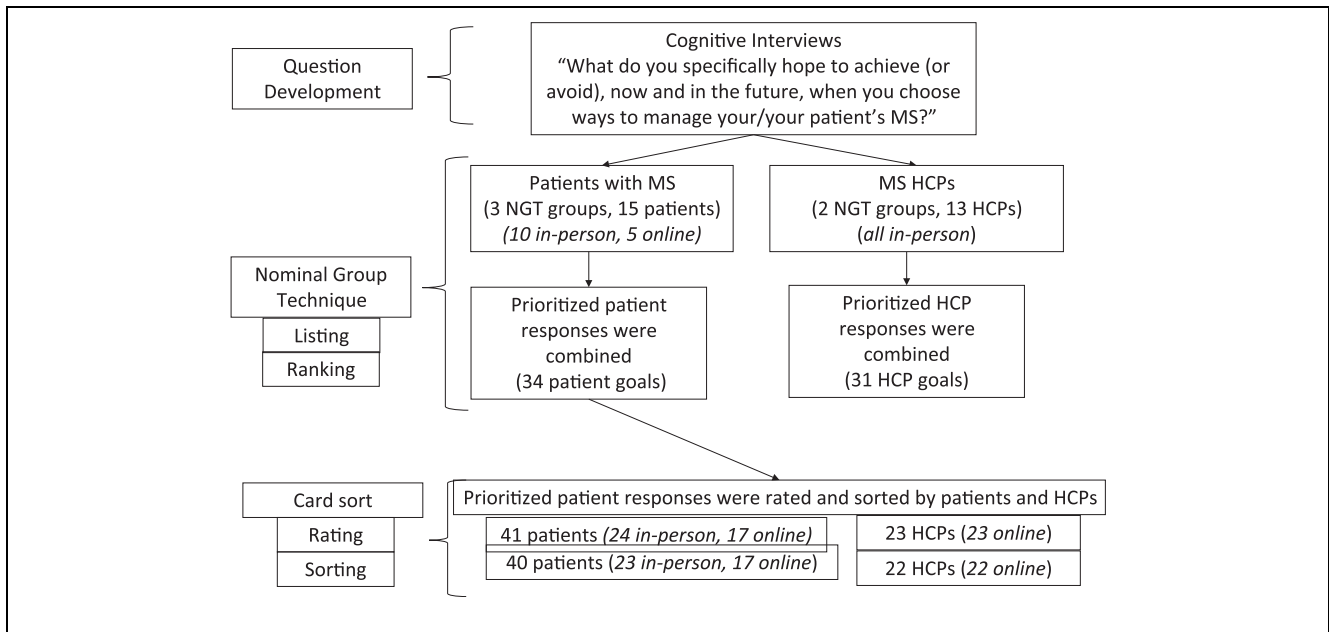


Figure 1 Study design and sample.

endorsed most of the goals, HCPs more so than patients (mean ratings of 9.49 (0.58) and 8.83 (1.32), respectively; $P < 0.05$). “Avoiding medicines with fatal side effects” was the most endorsed goal for patients but one of the least endorsed goals for HCPs (Figure 2). The goals most similarly rated by patients and HCPs were “Maintain or improve memory,” “Prevent brain atrophy,” and “Stay relatively healthy.” Those with the greatest differences were “Avoid assistive devices,” “Stay working,” “Decrease pain,” and “Help with symptoms of depression,” which were more strongly endorsed by HCPs than patients.

Cognitive Mapping

All but one person who consented to the card sorting activity completed the sorting (100% for the online sample, 95.8% for the in-person sample). The 2-dimensional solutions for the MDS analyses indicated robust goodness-of-fit measures for the patient, HCP, and combined models (stress = 0.0426, 0.0133, and 0.0319, respectively). Nine patient clusters and 8 HCP clusters were derived from the 34 patient treatment goals (Figures 3, 4; Tables 3, 4; Appendix Figure 4A). Our cluster analyses revealed areas of overlap between clusters; yet, none of the clusters were identical across the 2 cohorts. Among patients, the most important cluster was “Brain health,” followed by “Disability concerns.”

We interpreted one dimension of the patients’ cognitive map as ranging from factors internal to the patient to external to the patient; the other dimension, ranging from physical to psychosocial impact. We interpreted one dimension of the HCPs’ cognitive map as factors internal v. external to the patient; the other dimension, ranging from biological to social impact.

Discussion

We were able to adapt cognitive mapping techniques to identify and prioritize patient treatment goals and compare them to HCP goals. Our approach elicited a broad spectrum of goals directly from patient and HCP stakeholders and organized them into meaningful clusters with minimal investigator input. Many of the domains identified have not been previously reported, including “Brain health,” “Daily living and lifestyle expectations,” “Disability concerns,” “Preventative measures,” and “Medical team.” We also identified many specific preference attributes for MS that have not been previously identified, including prevent brain atrophy; avoid loss of strength; have a doctor who is very aware, knowledgeable, and compassionate; better balance; overcome fatigue; lessen heat sensitivity; be independent; maintain a normal sex life; stay working; avoid hospital admissions; avoid assistive devices; and age in place. Our identification of new domains could reflect the success of our

Table 2 Top Ten Ranked Treatment Goals, Patient-Reported V. HCP-Reported (from 3 NGTs)^a

Rank	Patient-Reported Goals	HCP-Reported Goals
1	Avoid medicines with fatal side-effects	Avoid or prevent disability (physical, cognitive, function)
2	Maintain or improve memory	Prescribe effective medications (to control the disease process)
3	Prevent brain atrophy	Improve patient's quality of life
4	Have a doctor who's aware, knowledgeable, and compassionate	Effectively manage symptoms associated with MS
5	Avoid losing ability to walk	Make sure there is unbiased patient education about MS (pathophysiology), importance of treatments, risks and benefits of each option
6	Maintain good cognitive ability	Minimize risks to the patient (do no harm)
7	To stay relatively healthy	Build a good patient-physician relationship—communication/ Build trust in patient-provider relationship
8	Avoid losing vision	Support the emotion distress of the disease burden/Address the mental health aspects of their disease
9	Avoid loss of full or partial body strength	Create a sense of mental control of the patient against their disease
10	Stay as active as possible (e.g., exercise)	Keeping updated on new treatments and side-effects

^aResponses include the original wording of items.

methods or that few previous studies have asked patients themselves.

We found some differences between the treatment goals generated by patients and HCPs. Goals generated by patients more often involved improving specific day-to-day symptoms, whereas those generated by HCPs involved slowing disease progression. HCP goals appeared to reflect, in part, outcomes that they perceived they could influence with the medical interventions at their disposal. Improving conditions that were beyond their sphere of influence (e.g., heat sensitivity) were not offered by HCPs and also received lower endorsement ratings. HCPs' stronger endorsement of pain may reflect the influence of the 'Pain as the Fifth Vital Sign' initiative.⁴⁷ However, because of the limited variation in HCP and patient ratings, we have less confidence in those findings.

Differences between how patients and HCP cohorts clustered treatment goals may reflect differing understandings of underlying disease processes. For example, HCPs grouped cognition and memory as symptoms along with bladder and bowel function, whereas patients grouped cognition and memory in a separate category along with brain atrophy.

HCPs used global constructs (e.g., quality of life) more frequently than did patients. Some of those global constructs could be loosely interpreted as encompassing many of the specific items that patients listed as distinct goals. However, relating the HCPs' broad goals to the patient's specific goals was impeded by differences in terminology and differences in the semantic meaning

attached to the terms. Confusion about terms used to describe the clinical course of MS has been a recurring theme in the scientific literature on MS,^{48,49} with the meaning of terms such as "disability" and "progression" changing as the definitions of MS have evolved. Clinically, progression implies "progression of clinical disability," reflected in HCPs' grouping of "Avoiding further disability" with "Avoid or slow progression of MS," "Avoid flare-ups," and "Preventing brain atrophy". In contrast, patients grouped "Avoiding further disability" with "Losing ability to walk," "Loss of full or partial body strength," and "Losing vision," consistent with the lay definition of disability (conditions that limit a person's movements). These differences underscore the potential problems with using HCP-identified instead of patient-identified goals. Moreover, because many of the terms used by patients convey a different meaning to HCPs, simply asking patients to share their goals with their HCP may not suffice to bridge communication gaps. To support shared decision making, patient goals may need to be explained to HCPs in different terms.

As the number of treatment choices for chronic diseases increases and the spectrum of clinical, functional, and economic outcomes affected by treatments increase, so do the challenges of selecting the best outcomes and attributes for inclusion in VCE and DAs. Guidance for developing DAs concluded that there is no consensus on how to select material for inclusion in DAs, recommending "needs assessment via focus groups and literature review, and direct observations of clinical interactions during office visits."⁵⁰ Yet those traditional approaches

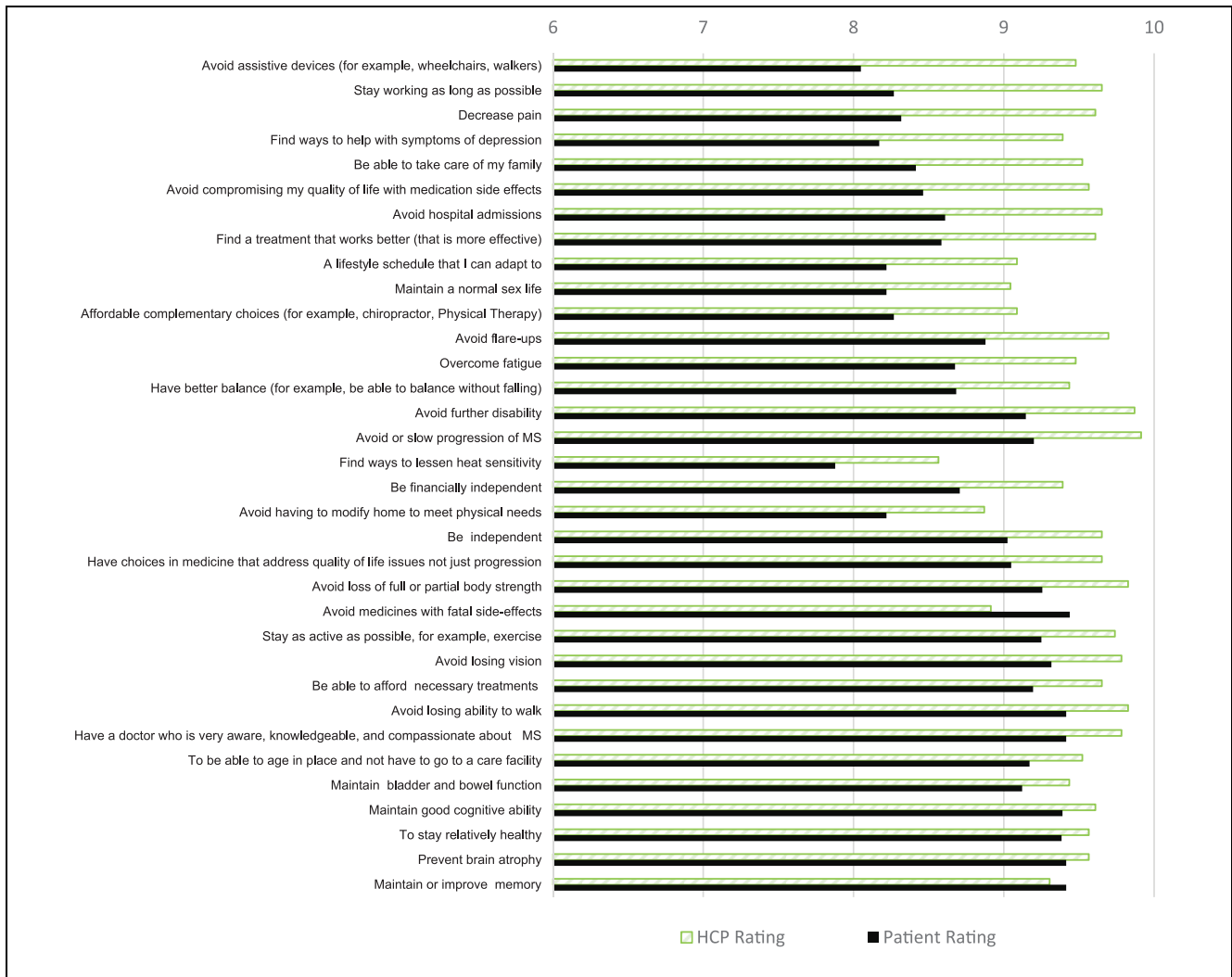


Figure 2 Ratings of patients' treatment goals. Patients v. HCPs (ranked according to differences in rating).

are themselves prone to investigator bias.²⁴ Further, relying on a literature review can propagate errors if those published studies did not involve patients. A systematic review of patient priorities for practice care reported that 25% of the published studies included items that were “invented by the researchers,” 44% were “unclear,” and 23% were sourced from other literature.⁵¹ VCE that do not include the attributes that matter to the decision maker will produce unreliable results. No amount of finesse or mathematical sophistication in comparing items can compensate for choosing the wrong set of outcomes. There is a pressing need to both standardize and increase the transparency of the process used to select the outcomes and attributes included in DAs and VCE.

This approach addresses the issue of how to select attributes, by minimizing the influence of the researcher and allowing selections to be made by the patients.

Our study had several limitations. Comparisons of patients with HCPs was hindered by a small HCP sample. However, because MDS and HCA are not based on parametric statistics, their validity is not dependent on the size of the sample but rather on the representativeness of the participants.⁴⁷ Differences in treatment goals might be expected because HCPs were asked about their treatment goals, not patients'. However, because expert physician opinion is commonly used to identify attributes, this seemed the most meaningful approach. HCPs highly endorsed all goals, rendering differences in

Table 3 Patient Treatment Goals, Clustered with Patient Ratings

	Treatment Goals	Mean Rating	SD
Cluster 1	Brain health (<i>memory, thinking, brain</i>)	9.41	0.01
	Maintain or improve memory	9.41	0.97
	Prevent brain atrophy	9.41	0.97
	Maintain good cognitive ability	9.39	1.00
Cluster 2	Disability concerns (<i>walking, strength, vision</i>)	9.28	0.06
	Avoid losing ability to walk	9.41	1.18
	Avoid losing vision	9.32	1.27
	Avoid loss of full or partial body strength	9.26	1.14
Cluster 3	Avoid flare-ups or progression	9.04	0.19
	Avoid or slow progression of MS	9.20	1.57
	Avoid flare-ups	8.88	1.19
Cluster 4	Caring and knowledgeable medical team	9.02	0.25
	Have a doctor who is very aware, knowledgeable, and compassionate about MS	9.41	1.07
	Have choices in medicine that address quality of life issues not just progression	9.05	1.20
Cluster 5	Safe treatments	8.95	0.24
	Avoid medicines with fatal side-effects	9.44	1.14
	Avoid compromising my quality of life with medication side effects	8.46	1.63
Cluster 6	Symptom management (<i>including fatigue, bladder issues, heat sensitivity, pain, balance</i>)	8.83	0.15
	Maintain bladder and bowel function	9.12	1.05
	Have better balance (for example, be able to balance without falling)	8.68	1.40
	Overcome fatigue	8.68	1.33
	Decrease pain	8.32	1.49
	Find ways to help with symptoms of depression	8.17	1.32
Cluster 7	Daily living and lifestyle expectations	8.74	0.30
	To stay relatively healthy	9.38	0.85
	Stay as active as possible, for example, exercise	9.25	0.93
	To be able to age in place and not have to go to a care facility	9.17	1.38
	Be independent	9.02	1.23
	Be able to take care of my family	8.41	1.61
	Stay working as long as possible	8.27	1.76
	A lifestyle schedule that I can adapt to	8.22	1.31
Cluster 8	Financial Concerns (<i>affordable treatments, financial independence</i>)	8.72	0.09
	Be able to afford necessary treatments	9.20	1.19
	Be financially independent	8.71	1.40
Cluster 9	Preventative measures (<i>avoiding hospitalizations assistive devices</i>)	8.29	0.12
	Affordable complementary choices (for example, chiropractor, Physical Therapy)	8.27	1.36
	Avoid hospital admissions	8.61	1.55
	Avoid having to modify home to meet physical needs	8.22	1.46
	Avoid assistive devices (for example, wheelchairs, walkers)	8.05	1.75

importance ratings less meaningful. We combined findings from online and in-person activities, recognizing that the method of collecting responses likely had some influence on those responses. The labels assigned to the dimensions identified by MDS are speculative, as are our interpretations of differences between groups.⁵² This method minimizes researcher bias but does not eliminate it. Judgment and investigator input were needed to combine lists across NGTs, select the number of clusters, and

interpret findings. Our protocol minimized these influences by involving non-HCP and patient advisers in all steps.

The disadvantages of traditional NGT meetings include constrained time for responding, variations in the protocol across groups, and the suppression of sensitive topics (due to round-robin reporting). The adaptations developed for this study minimize those challenges by including a protocol for the anonymous submission

Table 4 HCP Clusters and HCP ratings of Patient Treatment Goals

	Treatment Goals	HCP rating	SD
Cluster 1	Disease process	9.76	0.41
	Avoid or slow progression of MS	9.91	0.28
	Avoid further disability	9.87	0.34
	Avoid flare-ups	9.70	0.46
Cluster 2	Prevent brain atrophy	9.57	0.58
	Mobility issues	9.72	0.42
	Avoid loss of full or partial body strength	9.83	0.38
	Avoid losing ability to walk	9.83	0.38
Cluster 3	Avoid losing vision	9.78	0.41
	Have better balance (for example, be able to balance without falling)	9.43	0.50
	Activity	9.61	0.55
	Stay as active as possible, for example, exercise	9.74	0.44
	Avoid hospital admissions	9.65	0.48
	To stay relatively healthy	9.57	0.58
Cluster 4	Avoid assistive devices (for example, wheelchairs, walkers)	9.48	0.71
	Disease modifying treatment (DMT) issues	9.50	0.68
	Have a doctor who is very aware, knowledgeable, and compassionate about MS	9.78	0.41
	Have choices in medicine that address quality of life issues not just progression	9.65	0.48
	Find a treatment that works better (that is more effective)	9.61	0.64
	Avoid compromising my quality of life with medication side effects	9.57	0.58
	Avoid medicines with fatal side-effects	8.91	1.28
	Independence/ Quality of life	9.39	0.64
Cluster 5	Be independent	9.65	0.70
	Stay working as long as possible	9.65	0.56
	To be able to age in place and not have to go to a care facility	9.52	0.58
	Be able to take care of my family	9.52	0.50
	Be financially independent	9.39	0.64
	A lifestyle schedule that I can adapt to	9.09	0.78
	Avoid having to modify home to meet physical needs	8.87	0.74
Cluster 6	Financial issues	9.37	0.56
	Be able to afford necessary treatments	9.65	0.48
	Affordable complementary choices (for example, chiropractor, Physical Therapy)	9.09	0.65
Cluster 7	Symptom management	9.35	0.63
	Maintain good cognitive ability	9.61	0.64
	Maintain bladder and bowel function	9.43	0.58
	Maintain or improve memory	9.30	0.69
	Maintain a normal sex life	9.04	0.62
Cluster 8	Complex outcomes affected by MS	9.26	0.67
	Decrease pain	9.61	0.49
	Overcome fatigue	9.48	0.58
	Find ways to help with symptoms of depression	9.39	0.64
	Find ways to lessen heat sensitivity	8.57	0.97

of topics, videos that standardize the protocol across groups, and asynchronous online activities that support more inclusive sampling and thoughtful responses by removing time limits.

Tailoring discussions about treatments to reflect outcomes of importance to the decision maker is essential to shared decision making.^{53,54} But the critical and often missing first step is identifying those outcomes. The patient-centered cognitive mapping approach described in this manuscript could be used to improve the validity

of VCE and stated preference methods by improving the process for selecting the attributes that they include, increasing the transparency of the attribute development process and resulting in a more appropriate set of attributes. This approach could also be used to guide the content of DAs, tailor behavioral change interventions, and improve patient-provider communication. Knowing what matters to a patient could assist HCPs in understanding their patients, help build more trusting relationships, identify treatments that are a better fit for that

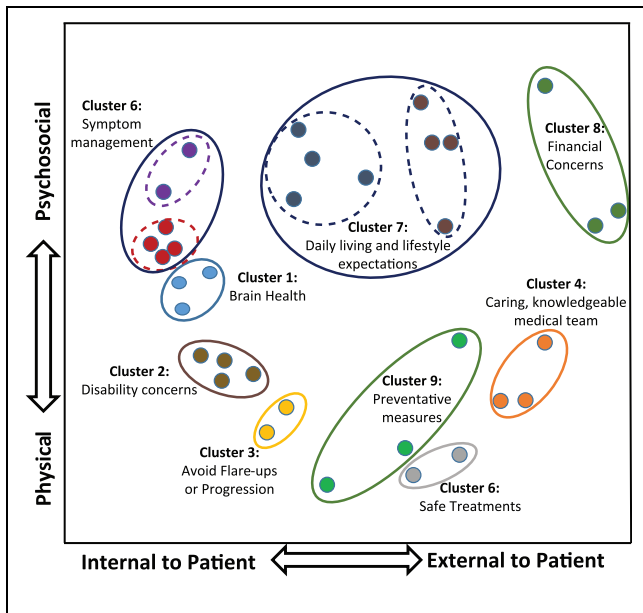


Figure 3 Patients' cognitive map.

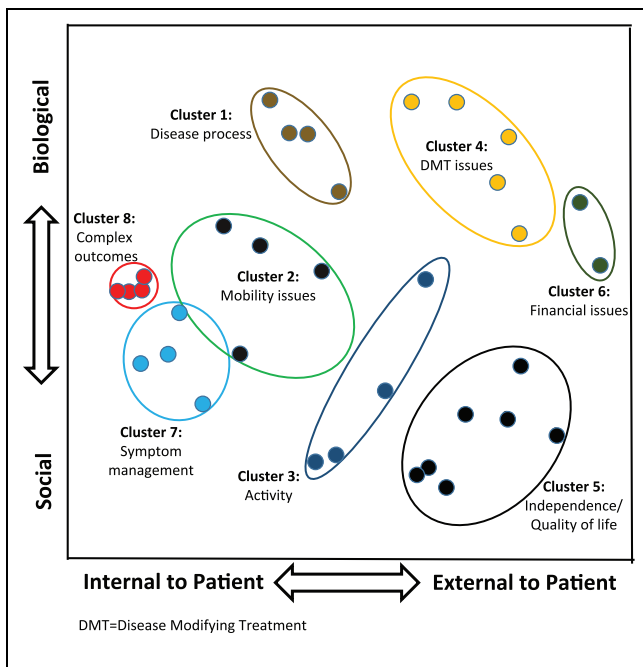


Figure 4 Health care providers' cognitive map.

patient, and focus on the pros and cons of treatments that are most important to the patient, thereby reducing information overload and promoting patient engagement.

The NGT is beginning to be used to understand patient preferences for MS treatments. The first study using NGTs (combined with best-worst scaling) among patients with MS was published in late 2016,⁵⁵ focusing on attributes of disease-modifying drugs.

The findings from this study have been used to develop and validate a preference assessment tool to help patients with MS explore and share their goals with their HCP. (This is available at Available at <https://tinyurl.com/WhatMattersMS>.) This tool is currently being expanded into a shared decision making tool for MS and will be evaluated in real-world settings. While we have focused on MS treatment goals in this study, the approach is applicable to other preference-sensitive clinical decisions. Helping patients better understand their treatment goals and making HCPs aware of their goals should improve patient-provider communication and promote shared decision making.

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References

1. Barry M and Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *N Engl J Med.* 2012;366:780–1.
2. Palace J. Partnership and consent in MS treatment choice. *J Neurol Sci.* 2013;335:5–8.
3. Wittman HO, Scherer LD, Gavaruzzi T, et al. Design Features of Explicit Values Clarification Methods: A Systematic Review. *Med Decis Making.* 2016; 36:453–71.
4. Peters E, Dieckmann N, Dixon A, Hibbard JH and Mertz CK. Less is more in presenting quality information to consumers. *Med Care Res Rev.* 2007;64:169–90.
5. Hibbard JH and Jewett JJ. What type of quality information do consumers want in a health care report card? *Med Care Res Rev.* 1996;53:28–47.
6. Slovic P. The construction of preference. *Am Psychol.* 1995;50:64–371.
7. Nabozny JA, Kruser JM, Steffens NM, et al. Constructing high stakes decisions: It's better to die trying. *Ann Surg.* 2016;263:64–70.
8. Fagerlin A, Pignone M, Abhyankar P, et al. Clarifying values: an updated review. *BMC Med Inform Decision Mak.* 2013;13(Suppl 2):S8.
9. Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2014 (1). Art. No.: CD001431.
10. Wittman H, Gavaruzzi T, Scherer L, et al. Effects of design features of explicit values clarification methods: A systematic review. *Med Decis Making.* 2016;36:760–76.

11. Green P, Krieger A and Wind Y. Thirty years of conjoint analysis: reflections and prospects. *Interfaces*. 2001;31: S56–S73.
12. Ryan M and Gerard K. Using discrete choice experiments to value health care programmes: current practice and future research reflections. *Appl Health Econ Health Policy*. 2003;2:55–64.
13. Lenert LA, Sherbourne CD and Reyna VF. Utility elicitation using single item questions compared with a computerized interview. *Med Decis Making*. 2001;21: 97–104.
14. Tversky A and Kahneman D. The framing of decisions and the psychology of choice. *Science*. 1981;211:453–8.
15. Peters E. Affect and Emotion (Chapter 10). In: Baruch Fischhoff, Noel T. Brewer, Julie S. Downs, eds. *Communicating Risks and Benefits: An Evidence-Based User's Guide*. US Department of Health and Human Services, Food and Drug Administration, Risk Communication Advisory Committee and Consultants; 2011. Available from: <http://www.fda.gov/downloads/AboutFDA/ReportsManualsForms/Reports/UCM268069.pdf>
16. Dolan JG. Patient priorities in colorectal cancer screening decisions. *Health Expect*. 2005;8:334–44.
17. Lee CN, Dominik R, Levin CA, et al. Development of instruments to measure the quality of breast cancer treatment decisions. *Health Expect*. 2010;13:258–72.
18. Shalowitz DI, Garrett-Mayer E and Wendler D. The accuracy of surrogate decision makers: A systematic review. *Arch Intern Med*. 2006;166:493–7.
19. Seckler AB, Meier DE, Mulvihill M and Cammer Paris BE. Substituted judgment: How accurate are proxy predictions? *Ann Intern Med*. 1991;115:92–8.
20. Coast J, Al-Janabi H, Sutton EJ, et al. Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations. *Health Econ*. 2012;21:730–41.
21. Marshall D, Bridges JF and Hauber B. Conjoint analysis application in health—how are studies being designed and reported? An update on current practice in the published literature between 2005 and 2008. *Patient*. 2010;3:249–56.
22. Hollin IL, Young C, Hanson C, Bridges JF and Peay H. Developing a patient-centered benefit-risk survey: A community-engaged process. *Value Health*. 2016;19:751–7.
23. Delbecq AL, Van de Ven AH and Gustafson DH. *Group Techniques for Program Planning: A Guide to Nominal Group and Delphi Processes*. Middleton: Green Briar Press; 1975.
24. Potter M, Gordon S and Hamer P. The Nominal Group Technique: A useful consensus methodology in physiotherapy research. *N Z J Physiother*. 2004;32:126–30.
25. Gallagher M, Hares T, Spencer J, Bradshaw C and Webb I. The nominal group technique: a research tool for general practice? *Fam Pract*. 1993;10:76–81.
26. Scott D and Deadneck D. The nominal group technique applications for training needs. *Train Dev*. 1982:26–33.
27. Schiffman SS, Reynolds ML and Young FW. *Introduction to multidimensional scaling: theory, methods, and applications*. New York: Academic Press; 1981.
28. Fitzgerald LF and Hubert LJ. Multidimensional scaling: Some possibilities for counseling psychology. *J Counsel Psychol*. 1987;34:469–80.
29. Kruskal JB and Wish M. *Multidimensional Scaling*. Beverly Hills: Sage Publications; 1978.
30. Aldenderfer MS and Blashfield RK. *Cluster analysis*. Beverly Hills: Sage Publications; 1984.
31. Delbecq AL and Van de Ven AH. A group process model for problem identification and program planning. *J Appl Behav Sci*. 1971;7:466–92.
32. Ramagopalan SV and Sadovnick AD. Epidemiology of multiple sclerosis. *Neurol Clin*. 2011; 29:207.
33. Heesen C, Solari A, Giordano A, Kasper J and Kopke S. Decisions on multiple sclerosis immunotherapy: new treatment complexities urge patient engagement. *J Neurol Sci*. 2011;306:192–7.
34. Utz KS, Hoog J, Wentrup A, et al. Patient preferences for disease-modifying drugs in multiple sclerosis therapy: a choice-based conjoint analysis. *Ther Adv Neurol Disord*. 2014;7:263–75.
35. Johnson FR, Van Houtven G, Özdemir S, et al. Multiple sclerosis patients—benefit-risk preferences: serious adverse event risks versus treatment efficacy. *J Neurol*. 2009;256: 554–62.
36. Wilson LS, Loucks A, Gipson G, et al. Patient preferences for attributes of multiple sclerosis disease-modifying therapies: development and results of a ratings-based conjoint analysis. *Int J MS Care*. 2015;17:74–82.
37. Wilson L, Loucks A, Bui C, et al. Patient centered decision making: Use of conjoint analysis to determine risk–benefit trade-offs for preference sensitive treatment choices. *J Neurol Sci*. 2014;344:80–7.
38. Arroyo R, Sempere AP, Ruiz-Beato E, et al. Conjoint analysis to understand preferences of patients with multiple sclerosis for disease-modifying therapy attributes in Spain: a cross-sectional observational study. *BMJ Open* 2017;7:e014433.
39. Healthwise. Healthwise Helps You Make Better Health Decisions. <https://www.healthwise.net/cochranedecisionaid/Content/StdDocument.aspx?DOCHWID=tf2571>. [Accessed 10 September, 16].
40. Alonso A and Hernán MA. Temporal trends in the incidence of multiple sclerosis: a systematic review. *Neurology*. 2008;71:129.
41. Delp P, Thesen A, Motiwalla J and Seshardi N. *Systems tools for project planning*. Bloomington: International Development Institute; 1977.
42. Crenshaw K, Shewchuk RM, Qu H, et al. What should we include in a cultural competence curriculum? *Acad Med*. 2011;86:333–41.
43. Dugard P, Todman J and Staines H. *Approaching multivariate analysis. A practical introduction. Second Edition*. New York: Routledge; 2010.

44. Hair Jr, JF, Anderson RE, Tatham, RL and Black WC. Multivariate data analysis. Fifth Edition. *New Jersey: Prentice-Hall*; 1998.
45. Lublin FD, Cofield SS, Cutter GR, et al. Randomized study combining interferon and glatiramer acetate in multiple sclerosis. *Ann Neurol*. 2013;73:327–40.
46. Learmonth YC, Motl RW, Sandroff BM, Pula JH and Cadavid D. Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis. *BMC Neurol*. 2013;25:13:37.
47. Department of Veterans Affairs. Pain management. VHA Directive 2003–021. Available from: [http://webcache.googleusercontent.com/search?q=cache:k6zWTKQtWCQJ:www.va.gov/painmanagement/docs/vha09paindirective.pdf + &cd=1&hl=en &ct=clnk&gl=us](http://webcache.googleusercontent.com/search?q=cache:k6zWTKQtWCQJ:www.va.gov/painmanagement/docs/vha09paindirective.pdf+%&cd=1&hl=en&ct=clnk&gl=us). [Accessed 27 September, 2016].
48. Lublin FD and Reingold SC. Defining the clinical course of multiple sclerosis: results of an international survey. National Multiple Sclerosis Society (USA) Advisory Committee on Clinical Trials of New Agents in Multiple Sclerosis. *Neurology*. 1996;46:907–11.
49. Lublin FD, Reingold SC, Cohen JA, et al. Defining the clinical course of multiple sclerosis: the 2013 revisions. *Neurology*. 2014;83:278–86.
50. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ and van der Weijden T. A systematic development process for patient decision aids. *BMC medical informatics and decision making*. 2013;13(Suppl 2):S2.
51. Wensing M, Jung H, Mainz J, Olesen F and Grol R. A systematic review of the literature on patient priorities for general practice care. Part 1: description of the research domain. *Soc Sci Med*. 1998;47:1573–88.
52. Speece D. *Methodological Issues in Cluster Analysis: How Clusters Become Real*. Hillsdale: Erlbaum; 1990.
53. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *BMJ*. 2006;333:417.
54. Reuben DB and Tinetti ME. Goal-oriented patient care—an alternative health outcomes paradigm. *N Engl J Med*. 2012;366:777–9.
55. Kremer IE, Evers SM, Jongen PJ, van der Weijden T, van de Kolk I, Hiligsmann M. Identification and prioritization of important attributes of disease-modifying drugs in decision making among patients with multiple sclerosis: A nominal group technique and best-worst scaling. *PLoS One*. 2016 Nov 3;11(11):e0164862. doi: 10.1371/journal.pone.0164862.