

Development of a Conceptual Framework of “Good Healthcare” from The Patient’s Perspective

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Objectives

- The primary objective of this study is to conceptualize “good healthcare” and aspects of healthcare that matter most to patients by utilizing concept mapping (CM), a mixed method (qualitative and quantitative). CM includes several stages, including statement generation, structuring (rating and sorting of statements into meaningful groupings), representation (analysis of results), and interpretation of findings (Trochim, 1989).
- Secondary objectives include an evaluation of the relative priorities of concept mapping domains among (1) various patient populations, including different demographic and clinical populations, and (2) patients and stakeholders (clinicians, researchers, purchasers, measure developers, health IT).

Methods

This study consists of two phases, presented below:

Phase 1: Statement Generation

- Statements about what constitutes “good healthcare” were generated from literature review, stakeholder interviews and survey of patients (n=157) and stakeholders (n=17) via the online Open Research Exchange platform of PatientsLikeMe (PLM; a network for patients to report their healthcare outcomes and help provide crowdsourced research).
- Active members of the PLM online community were sent an invitation to participate in the survey through the PLM platform.
- The majority of patients in Phase I self-identified as female (71%), White (85%), and Non-Hispanic (92%) with a mean age of 56 years. Patients reported 68 different primary diagnoses. Most commonly reported diagnoses included fibromyalgia (n=21), multiple sclerosis (n=15), systemic lupus erythematosus (n=13), diabetes type 2 (n=8), and Parkinson’s disease (n=7).
- The final statement pool of approximately 1300 patient statements, 350 stakeholder statements, and 150 statements generated from literature review was reduced to 79 statements for Phase II. To reduce the pool, two raters independently coded the statements based on theme to eliminate duplicates and reduce redundancy, resulting in approximately 250 unique keywords and statements. This list was then independently reviewed and rated regarding importance for inclusion by 3 experts. See Table 1 for a sample of the final statements.

Phase II: Structuring

- During Phase II, using ConceptSystems software (Concept Systems, 2007), patients (n=172) rated these statements on importance and sorted the statements into meaningful categories.
- The majority of patients in Phase II self-identified as female (64%), White (82%), Non-Hispanic (86%) with a mean age of 57 years. Patients reported 51 different primary diagnoses. More information about patient demographic and clinical information is presented in Table 2.
- Fifteen stakeholders have participated in Phase II, and an additional 10-20 are currently being recruited for participation.

Results

- Determining the optimal cluster solution requires both theoretical and empirical rational. Multiple cluster solutions were generated and reviewed by the research team, consisting of psychometricians, researchers, and content experts.
- An 8-cluster solution was identified as the optimal solution. These clusters include: (1) Doctor-Patient Communication, (2) Doctor Characteristics and Behavior, (3) Appropriate Care, (4) Outcomes, (5) Patient as an Active and Informed Participant in Their Care, (6) Office Attributes, (7) Team Communication, and (8) Insurance Limitations.
- The Cluster Rating map is presented in Figure 1, which provides a visual representation of results. As can be seen from this map, the items (represented by yellow dots) appear together in 8 clusters, representing different aspects of healthcare. Additionally, the layers of each cluster represent the average rating of importance for the items within that cluster, whereby more layers indicate higher ratings of importance. See Table 3 for cluster labels.

Conclusion

- Research is lacking on what is most relevant and meaningful to patients in the evaluation of healthcare performance. By relying on patients to (1) generate statements describing good healthcare, (2) to identify the statements that are most important to them when it comes to their care, and (3) to group the statements in a way that is meaningful from their perspective, we were able to generate a model of good healthcare defined by the priorities of patients. This model is likely more content valid and relevant for patients than other models developed by researchers or clinicians.
- Although data collection is not complete, preliminary results suggest that patients value a relationship with clinicians based on mutual respect where they are fully informed and active participants in decisions that lead to appropriate care. This finding is relatively consistent across various demographic and clinical groups.
- The conceptual model generated from this study provides an important foundation to incorporate patient priorities in performance measurement.
- Results from this research may support efforts to more appropriately measure performance with patient-reported data that connects patient-centric concepts to value.
- This research relied on PatientsLikeMe, an online research network of patients who donate their own healthcare data and experiences. Therefore, certain patients (e.g., patients with limited Internet access, patients with health functioning that prevents them from engaging in online surveys, patients with limited reading skills or computer literacy, patients whose primary language is not English, etc.) may not be represented in our study. Future research should replicate these results across more diverse patient populations and other media (e.g., paper and pencil based surveys).

References

- Concept Systems, Inc. (2007). Concept Systems® Global Max®. Ithaca, NY.
- Trochim, W. (1989). An introduction to concept mapping for planning and evaluation. Evaluation and Program Planning, 12(1), 1-16. doi:10.1016/0149-7189(89)90016-5

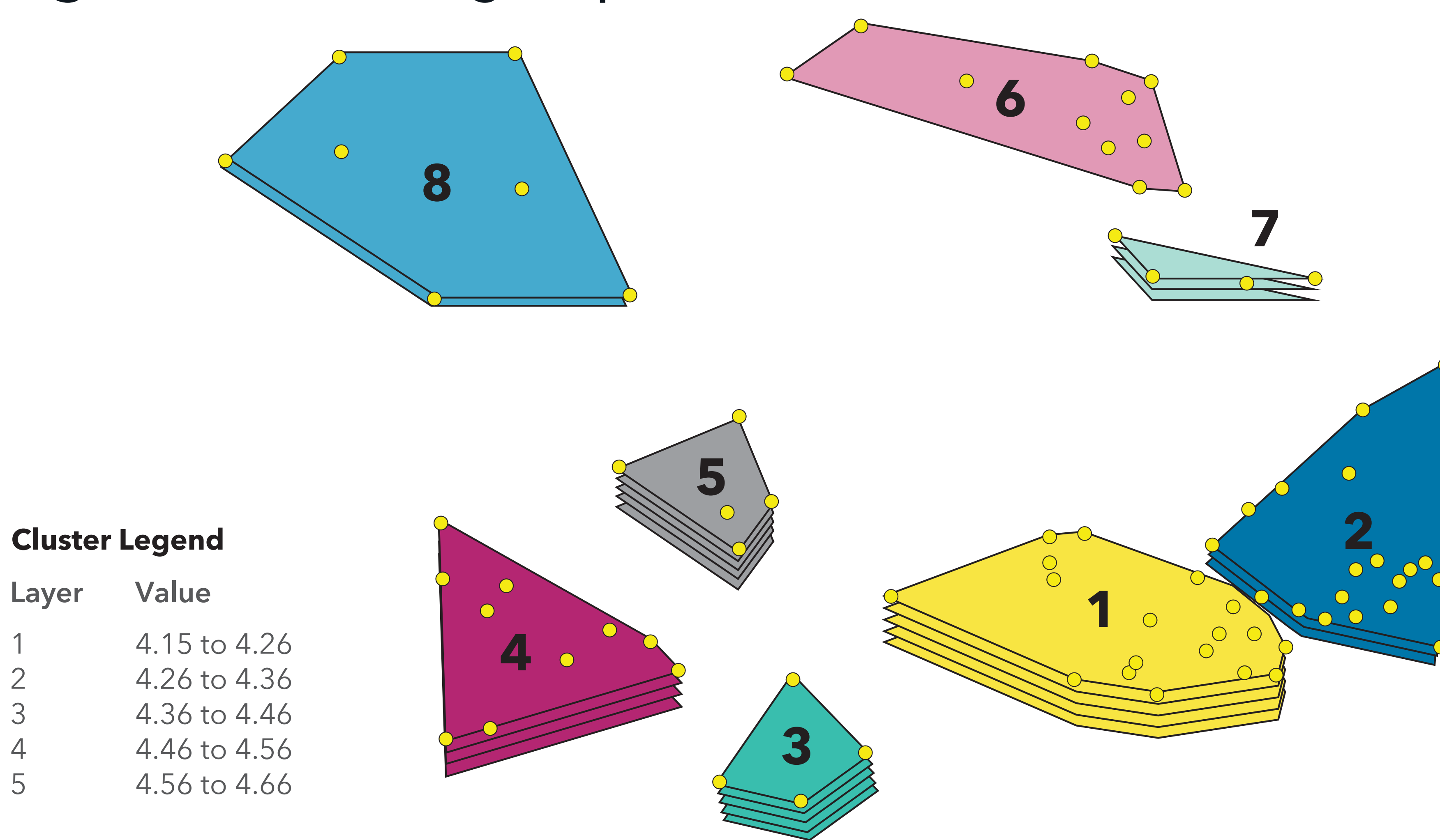
Table 1: Example statements generated from Phase 1

My doctor/provider is knowledgeable about my condition(s) and appropriate treatments for my condition(s)
My doctor/provider takes time to explain (diagnosis, treatment options, prognosis, side effects) in sufficient detail
My doctor/provider appreciates my input and asks my opinion
My doctor/provider makes eye contact with me
The doctor/provider does not seem rushed
I am treated with respect
My care is thorough
Treatments are effective
I understand my diagnosis and my options for treatment
The office is well organized
I am able to contact my doctor’s office with any needs, even between visits
The doctor/provider is on time for appointments
I am able to choose which provider(s) I want to see
The costs for office visits and treatments/medicine are reasonable

Table 2: Demographic and clinical characteristics of patients who participated in structuring (rating & sorting)

Race	Frequency	Percent
White	158	81.8%
Black or African American	7	3.6%
Mixed Race	8	4.2%
I prefer to skip/ Did not respond	20	10.4%
Ethnicity	Frequency	Percent
Hispanic or Latino	6	3.1%
Not Hispanic or Latino	166	86.0%
I prefer to skip/ Did not respond	21	10.9%
Satisfaction with Healthcare (M, SD)		7.64 (2.3)
Health Status	Frequency	Percent
Poor	16	8.3%
Fair	64	33.2%
Good	65	33.7%
Very Good	28	14.5%
Excellent	4	2.1%
Did not respond	16	8.3%
Primary Diagnosis	Frequency	Percent
Cancer	29	15.0%
Fibromyalgia	22	11.4%
Diabetes	21	10.9%
Hypertension	10	5.2%
Heart Disease	5	2.6%
Arthritis	3	1.6%
Stroke	2	1.0%
Other	84	43.5%
Did not respond	17	8.8%

Fig 1. Cluster rating map



Cluster Legend

Layer	Value
1	4.15 to 4.26
2	4.26 to 4.36
3	4.36 to 4.46
4	4.46 to 4.56
5	4.56 to 4.66

Table 3: Cluster labels and rating of importance

Cluster Number	Cluster Label	Sample Statement	Rating of Importance (1 = not important, 5 = extremely important)
1	Doctor-Patient Communication	My doctor/provider takes time to explain (diagnosis, treatment options, prognosis, side effects) in sufficient detail	4.59
2	Doctor Characteristics and Behavior	I am treated with respect	4.44
3	Appropriate Care	My care is thorough	4.61
4	Outcomes	Treatments are effective	4.51
5	Patient as an Active and Informed Participant in Their Care	I understand my diagnosis and my options for treatment	4.67
6	Office Attributes	The office is well organized	4.15
7	Team Communication	I am able to contact my doctor’s office with any needs, even between visits	4.43
8	Insurance Limitations	The costs for office visits and treatments/ medicine are reasonable	4.27

Fig 2. Pattern matching - gender

