

Dominic Voehler, MPH¹; Peter J. Neumann, PhD¹; Daniel A. Ollendorf, PhD¹

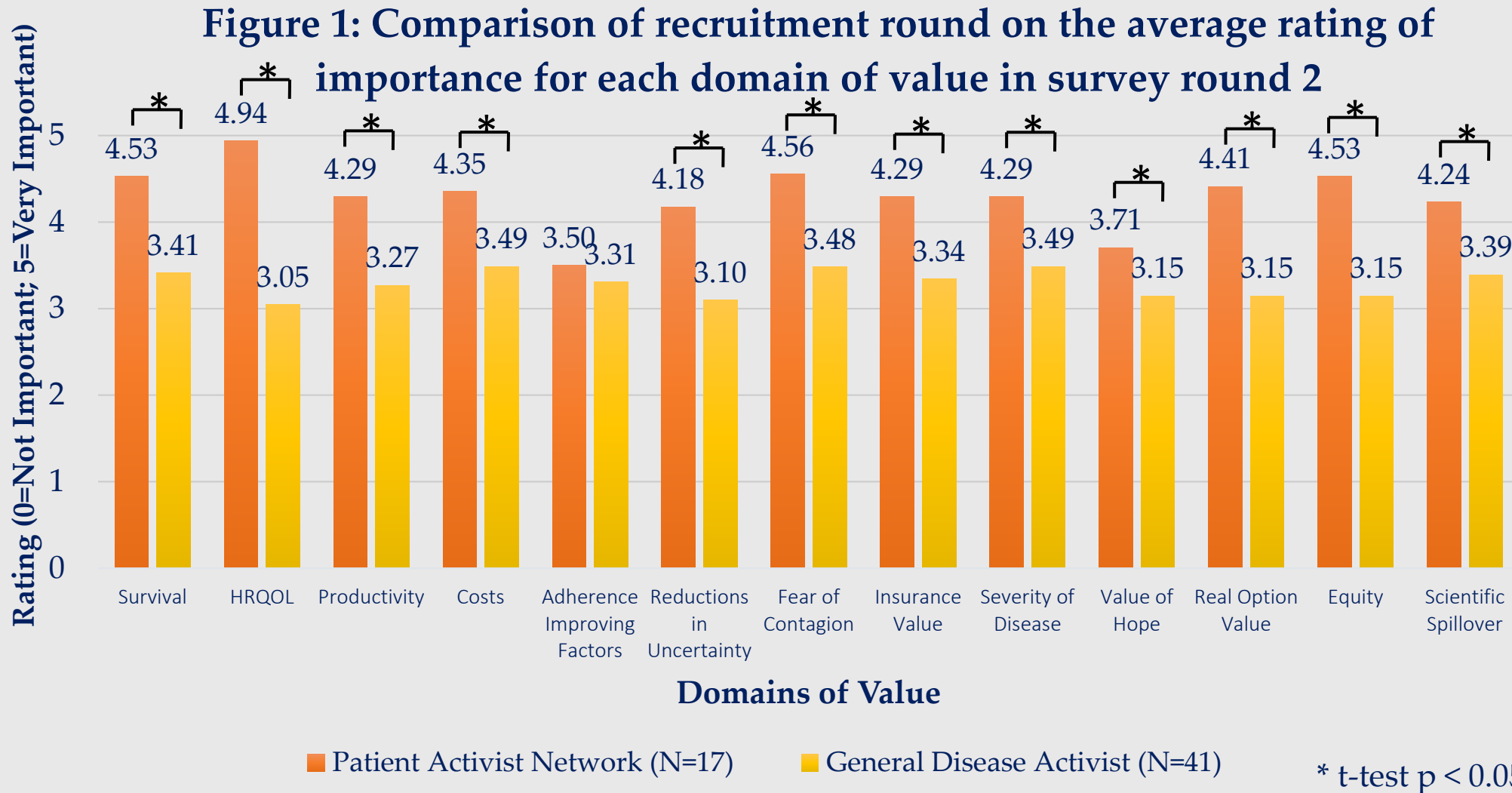
¹ Center for the Evaluation of Value and Risk in Health, Institute for Clinical Research and Health Policy Studies, Tufts Medical Center, Boston, MA, USA

Background & Objectives

- Despite the usefulness of the QALY, researchers, policy makers, and advocates note limitations in incorporating all domains of health¹
- Inclusion of “novel” domains of value of potential interest in generating more comprehensive cost-effectiveness analyses, through an adjustment of the QALY or alternative measures²
- Objective:** investigate patient and caregiver views on the importance of traditional and novel domains of value

Table 1. Demographic characteristics of survey participants

Variable	Frequency (n=58)	Percent
Sex		
Female	35	60.3%
Age		
18-34	12	20.7%
35-54	34	58.6%
55-64	9	15.5%
65+	3	5.2%
Type of Participant		
Patient	39	67.2%
Caregiver	19	32.8%
Recruitment Source		
Patient Activist Network	17	29.3%
General Disease Advocacy	41	
Number of Conditions		
1	38	65.5%
2+	20	



Methods

- Eligibility & Survey Population:**
- Adult patients managing a chronic medical condition or adult caregivers of a patient with chronic illness
 - Recruited from patient activist network (Patients Rising Now) and disease-specific patient advocacy groups (subscribers to The Aging Experience)
- Two-round modified Delphi survey**
- Questions about demographics, rating domains of value, and ranking domains rated as “important” or “very important”
- Statistical Analysis:**
- Paired t-test for rating and ranking between survey rounds
 - Multiple logistic regression analysis to identify factors associated with rating a value domains as “important” or “very important”

Table 2. Likelihood of rating and domains important or very important in round 1 and 2

Variable	Odds Ratio	95% Confidence Interval	p-value
Age			
18-34	Ref		
35-54	1.40	(1.04, 1.89)	0.027
55-64	2.10	(1.31, 3.37)	0.002
65+	1.15	(0.59, 2.24)	0.68
Sex			
Female	Ref		
Male	0.76	(0.59, 0.995)	0.046
Type of Participant			
Patient	0.57	(0.43, 0.76)	<0.001
Caregiver	Ref		
Recruitment Source			
Patient Activist Network	5.68	(3.99, 8.07)	<0.001
General Disease Advocacy	Ref		
Survey Round			
Round 1	Ref		
Round 2	1.27	(1.00, 1.62)	0.05

Results

- Survey Response:**
- 63 (41 patients, 22 caregivers) completed round 1
 - 58 (39 patients, 19 caregivers) completed round 2
- Survey Round Comparison:**
- Traditional measures of value consistently ranked highest: survival, health-related quality of life, costs, and productivity
- Factors Associated with Increased Odds of Assigning Importance**
- Participants from patient activist network (OR 5.68, p<0.001)
 - Age 35-54 (OR 1.40, p=0.027) and 55-64 (OR 2.10, p=0.002)
- Factors Associated with Decreased Odds of Assigning Importance**
- Patients (OR 0.57, p<0.001)
 - Male sex (OR 0.76, p=0.046)

Discussion

- Conclusion**
- Traditional domains (e.g., survival, health-related quality of life, and costs) consistently rated higher than novel domains (e.g., real option value & value of hope)
 - Respondents from patient activist network considered nearly all domains important, while general disease advocates were more discriminate in their views
- Relevance & Policy Implication**
- Patients and caregivers emphasize well-accepted measures of value
 - Further research recommended to integrate individual tradeoffs & implications of expanded value assessments in context of constrained budgets

References

- Neumann PJ, Cohen JT. QALYs in 2018-Advantages and Concerns. JAMA. 2018;319(24):2473-2474.
- Lakdawalla DN, Doshi JA, Garrison LP, Jr., Phelps CE, Basu A, Danzon PM. Defining Elements of Value in Health Care-A Health Economics Approach: An ISPOR Special Task Force Report [3]. Value Health. 2018;21(2):131-139.

Acknowledgements

