Comparative Analysis of Stakeholder Experiences with an Online Approach to Prioritizing Patient-Centered Research Topics

Dmitry Khodyakov,[1] Sean Grant,[1] Daniella Meeker,[1,2] Marika Booth,[1] and Katherine K Kim[3]

[1] RAND Corporation, [2] University of Southern California, [3] University of California, Davis

Introduction

Engaging stakeholders in prioritization and resource allocation exercises is a critical component of research. However, little is known about best methods of stakeholder engagement.

Many engagement methods require face-to-face interaction and are considered to be **"high-touch."** Such approaches involve direct contact with stakeholders and therefore are time-consuming, logistically challenging, prone to cognitive bias, expensive to implement, and difficult to scale up.

As an alternative, **"high-tech"** engagement approaches conducted online are becoming more popular. Online approaches are scalable, can engage large numbers of stakeholders at lower cost, and allow participants to contribute remotely at their convenience. Nonetheless, there is little research on what different stakeholders think about high-tech engagement approaches.

Research Objectives

1. To explore patient/caregiver experiences with a high-tech online engagement approach for patient-centered research prioritization;
2. To compare patient/caregiver experiences with those of professional stakeholders;
3. To identify factors associated with favorable participant experiences.

Research Methods

8 online modified-Delphi (OMD) engagement panels on 3 conditions. Participants explored consensus on research priorities for pSCANNER - one of PCORI's Patient-Centered Clinical Research Networks.

For weight management and heart failure, we conducted a patient-only panel, a clinician-only panel, and a mixed panel that included patients, clinicians, and researchers. For Kawasaki, we conducted a patient/caregiver-only panel and a mixed panel.

Each panel consisted of 2 rating rounds with a statistical feedback/online discussion round in between administered using the ExpertLens OMD platform. At the end of the last round, panelists used a 7-point agreement scale to rate different aspects of the online engagement process and the ExpertLens platform.

Study sample includes 292 participants (84% of the 349 OMD panelists) across all 8 panels who completed the participant experience surveys at the end of the last round.

Measures

Willingness to use OMD again, main outcome measured by responses to the following statement: "I would like to use ExpertLens in the future."

OMD system's ease of use, measured by responses to the following statement: "The ExpertLens system was easy to use."

Study participation experience index, measured by responses to 4 statements in Table 2 ($\alpha = 0.67$).

Online discussion experience index, measured by responses to 8 statements in Table 2 ($\alpha = 0.60$).

Active participant engagement, a dichotomous measure that defined participants as actively engaged if they answered at least 90% of the ratings questions in both rating rounds, explained at least 90% of their ratings in either of the rating rounds, and commented at least twice during the discussion round.

Data Analysis

Multivariate regression, controlling for gender, participant type, panel composition, perceived OMD system's ease of use.

Results

Of 292 participants, 46% were patients, 36% were clinicians, and 19% were researchers (Table 1).

In multivariate models, patients were not significantly more actively engaged ((OR)=1.69, 95% CI: .94–3.05) but had more favorable study participation (β=.49; P<.05) and online discussion (β=.18; P<.05) experiences and were more willing to use OMD again (β=.36; P<.05), compared to professional stakeholders (Table 3).

Positive perceptions of the OMD system's ease of use (β=.16; P<.05) and favorable study participation (β=.26; P<.05) and online discussion (β=.57; P<.05) experiences were also associated with increased willingness to use OMD in the future (Tables 4 and 5).

Active engagement was not associated with online experience indices or willingness to use OMD again (Tables 4 and 5).

Table 1. Characteristics of study participants by stakeholder type

Participant characteristics	Total (N = 292)* N (%)	Patients/caregivers (N = 133) N (%)	Professionals (N = 159) N (%)	P-value
Gender				
Female	160 (60)	83 (68)	77 (54)	.02
Race				
White	164 (66)	88 (78)	76 (57)	.02
Black	13 (5)	8 (7)	5 (4)	
Asian	56 (23)	11 (10)	45 (34)	
Other	14 (5)	6 (6)	8 (6)	
Hispanic origin				
Yes	30 (10)	18 (14)	12 (8)	.09
Highest level of education				<.001
Up to high school	5 (2)	4 (3)	1 (1)	
High school/technical school graduate	4 (2)	4 (3)	0	
Some college or 2-year degree	33 (12)	33 (26)	0	
4-year college degree	42 (16)	35 (28)	7 (5)	
Graduate or professional degree	182 (68)	48 (38)	134 (94)	
Prefer not to answer	2 (1)	2 (2)	0	
Panel type				
Mixed	141 (48)	41 (31)	100 (63)	<.001
Condition				
Weight management/obesity	101 (35)	37 (28)	64 (40)	<.001
Heart failure	86 (29)	30 (23)	56 (35)	
Kawasaki disease	105 (36)	66 (50)	39 (25)	
Participated in prior expert panel				
Yes	93 (35)	22 (17)	71 (50)	<.001
Participated in prior online survey				
Yes	226 (84)	87 (70)	139 (97)	<.001

Note: *Some variables contain missing values, so the total across categories may not add up to 292.

Table 2. Descriptive results by stakeholder type

Study variables	Total (N = 292) M (SD)	Patients/caregivers (N = 133) M (SD)	Professionals (N = 159) M (SD)	P-value
Willingness to use OMD again	5.31 (1.31)	5.73 (1.13)	4.95 (1.34)	<.001
Active participant engagement (yes)				
Answered at least 90% of rating questions in Rounds One and Three	0.51 (0.50)	0.58 (0.50)	0.46 (0.50)	.04
Explained at least 90% of ratings in Round One or Three	0.77 (0.42)	0.76 (0.43)	0.77 (0.42)	.78
Posted at least 2 comments in Round Two discussions	0.60 (0.49)	0.66 (0.58)	0.55 (0.48)	.06
OMD system's ease of use	0.90 (0.30)	0.90 (0.30)	0.89 (0.31)	.80
Experience with the online process (1 = strongly disagree to 7 = strongly agree)	5.39 (1.44)	5.58 (1.39)	5.21 (1.47)	.04
Study Participation Experience Index	4.33 (1.13)	4.67 (1.08)	4.03 (1.10)	<.001
This study was too long*	3.88 (1.60)	3.41 (1.44)	4.28 (1.63)	<.001
Participation in this study was frustrating*	3.04 (1.58)	2.65 (1.49)	3.39 (1.58)	<.001
Participation in this study took a lot of effort*	4.23 (1.72)	4.06 (1.80)	4.37 (1.63)	.16
The right set of questions was asked in this study	4.46 (1.49)	4.83 (1.46)	4.14 (1.43)	<.001
Online Discussion Experience Index	4.92 (0.67)	5.06 (0.63)	4.79 (0.68)	<.001
The discussions gave me a better understanding of the issues	5.37 (1.26)	5.63 (1.17)	5.14 (1.30)	.002
I had trouble following the discussion*	3.76 (1.74)	3.24 (1.60)	4.21 (1.72)	<.001
Participants debated each other's viewpoints during the discussions	4.94 (1.15)	5.07 (1.11)	4.83 (1.17)	.11
The discussions brought out views I had not considered	5.25 (1.12)	5.46 (1.36)	5.06 (1.27)	.02
The discussions brought out divergent views	5.31 (1.08)	5.27 (1.15)	5.34 (1.03)	.62
Participants sometimes misinterpreted each other's comments during the discussion	4.40 (1.35)	4.34 (1.33)	4.46 (1.37)	.47
The discussion round caused me to revise my original answers	4.80 (0.88)	4.83 (1.40)	4.77 (1.38)	.73
I was comfortable expressing my views in the discussion round	5.91 (0.88)	5.94 (0.94)	5.89 (0.82)	.63

Note: *These items were reverse-coded before being included in an index so that 7 corresponded to the most favorable rating and 1 to the least favorable.

Table 3. Results from logistic multivariate model of active participant engagement

Model variables	β Coefficient	Odds ratio (95% CI)	P-value
Intercept	0.02		
Gender: female	-0.46	0.63 (0.36, 1.11)	.11
Patient/caregiver: yes	0.53	1.69 (0.94, 3.05)	.08
Panel type: mixed	0.08	1.08 (0.61, 1.92)	.80
OMD system's ease of use	0.06	1.06 (0.88, 1.29)	.52

Table 4. Results from linear multivariate models predicting 2 indices measuring experiences with the online process

Model variables	Study participation		Online discussion	
	β coefficient	P-value	β coefficient	P-value
Intercept	2.31	<.001	3.90	<.001
Active engagement	-0.04	0.79	0.04	.65
Gender: female	0.15	0.29	0.11	.17
Patient/caregiver: yes	0.49	<.001	0.18	.04
Panel type: mixed	0.11	0.43	0.07	.42
OMD system's ease of use	0.31	<.001	0.15	<.001

Table 5. Results from linear multivariate model predicting willingness to use online modified-Delphi again

Model variables	β coefficient	P-value
Intercept	0.18	
Active engagement	0.11	.43
Study participation	0.26	<.001
Online discussion	0.57	<.001
Gender: female	0.15	.29
Patient/caregiver: yes	0.36	.02
Panel type: mixed	-0.10	.49
OMD system's ease of use	0.16	.002

Methodological Limitations

- Non-representative, purposeful sample of participants.
- Results may not be generalizable to other conditions, tasks, or online platforms.
- Measures of participant experiences and engagement were not validated before,

Conclusions

- Participants were willing to use OMD in the future, felt that the OMD system was easy to use, had a positive online discussion experiences, and had a neutral opinion about their study participation.
- Half of participants were actively engaged in the OMD process.
- Although patients/caregivers were not more actively engaged than professional stakeholders, they had better experiences and were more willing to use OMD again.
- Positive perceptions of the OMD system's ease of use, as well as favorable study participation and online discussion experiences, were associated with participants' willingness to use OMD in the future. The effect sizes, however, were modest.
- High-tech approaches to engaging large numbers of stakeholders are a promising and efficient adjunct to in-person meetings. They can allow a large number of diverse stakeholders located in different parts of the country to engage at a time convenient to them, and patients appear to have more positive experiences with this approach than professionals.