

Choosing Appropriate Stakeholder Engagement Methods: The Stakeholder Engagement Navigator Webtool

- Matt DeCamp, MD, PhD; Brad Morse, PhD; Kate Ytell, MPH



COPRH Con

Colorado Pragmatic
Research in Health
Conference



ACCORDS

UNIVERSITY OF COLORADO
CHILDREN'S HOSPITAL COLORADO



Colorado Clinical and Translational
Sciences Institute (CCTSII)

UNIVERSITY OF COLORADO DENVER | ANSCHUTZ MEDICAL CAMPUS

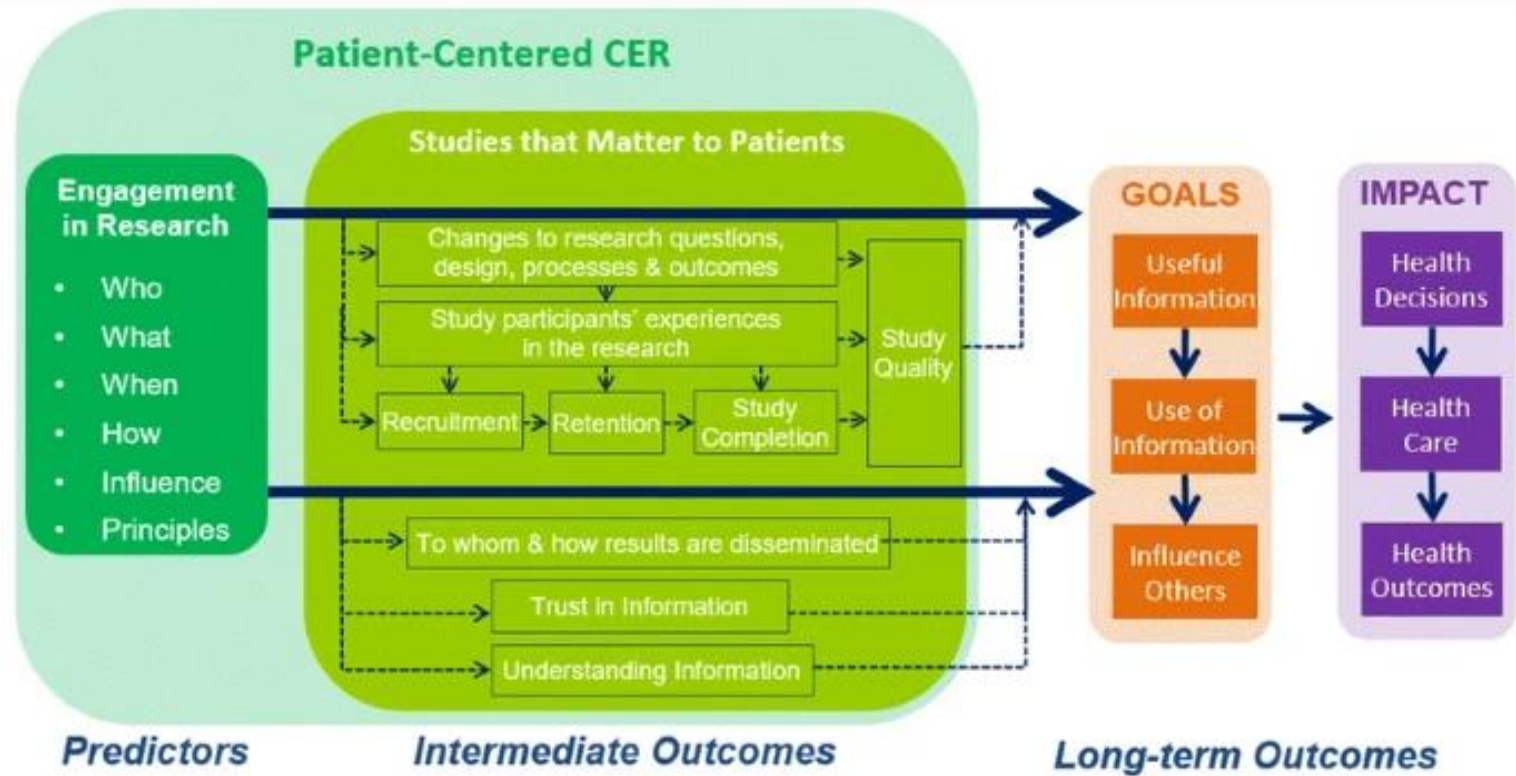
OBJECTIVES

By the end of this session, participants will be able to:

1. Describe the untapped potential of stakeholder engagement for enhancing your research.
2. Explain two unmet research needs for improving stakeholder engagement.
3. Feel comfortable using the Stakeholder Engagement Navigator webtool as described in the demonstration.

ENGAGEMENT IN RESEARCH

Engagement of stakeholders plays a foundational upstream role in shaping how research gets done.



Forsythe L, Heckert A, Margolis MK, Schrandt S, Frank L. Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute. *Qual Life Res.* 2018 Jan;27(1):17-31

EVIDENCE THAT ENGAGEMENT WORKS

A growing body of literature is documenting that engagement works:

Summary of contributions of engagement and effects of contributions described in included articles, by project phase

Project phase	Themes for contributions of engagement	Themes for effects of contributions
DESIGN		
Research focus (41)	Identification or expansion of topic (5) or aims or research questions (5) Determination of outcomes (35) Choice of comparator(s) (6)	Research focus that is meaningful for patients (36) Comparators that are acceptable, feasible, or most relevant (4)
Research design (19)	Practical aspects (for example, setting or timeline) (7) Broader inclusion/less restrictive exclusion criteria (7) Choice of designs, including numbers/types of arms (9) and participant allocation/randomization (3)	Address real-world barriers to implementation (6) Alignment with patients' preferences or practical realities (4) Maximize participation of real-world patients (8)
Interventions (54)	Adaptation of intervention elements, including delivery (20), materials or tools (14), and topics or content (18) Training for intervention providers (4)	Less burden for patients or providers (12) Alignment with participants' culture (6) and preferences (21) Enhanced intervention usability (14) Greater adherence to or retention in interventions (6)
CONDUCT		
Recruitment/enrollment (24)	Optimal strategies to find or recruit for specific populations or settings (11) Appropriate recruitment and consent materials (7)	Effective communication to the target population (4) Strong/enhanced enrollment (7) More generalizable findings (3)
Retention (7)	Frequency or timing (3) and modes of follow-up (4) Incentives for study participants (3)	Alignment with patients' preferences or practical realities (5)
Data collection/measures (25)	When or how to collect data (7) Selection (6) or assessment (4) of measures Reorder, shorten, or add items (10)	Quality of the data (3) Enhanced participant experience (for example, less burden, greater comfort) (6) Findings based on relevant, important measures (5) Measures aligned with participants' culture (4)
Data analysis/results review (9)	Specific aspects of analytic approach (for example, suggest covariates) (4) Interpretation of results (6)	Inform real-world use of the results (3)
DISSEMINATION		
Dissemination (8)	Plans (4), products (5), and activities (3)	Wider reach (4) More effective communication for target audiences, especially consumers and policy makers (5)

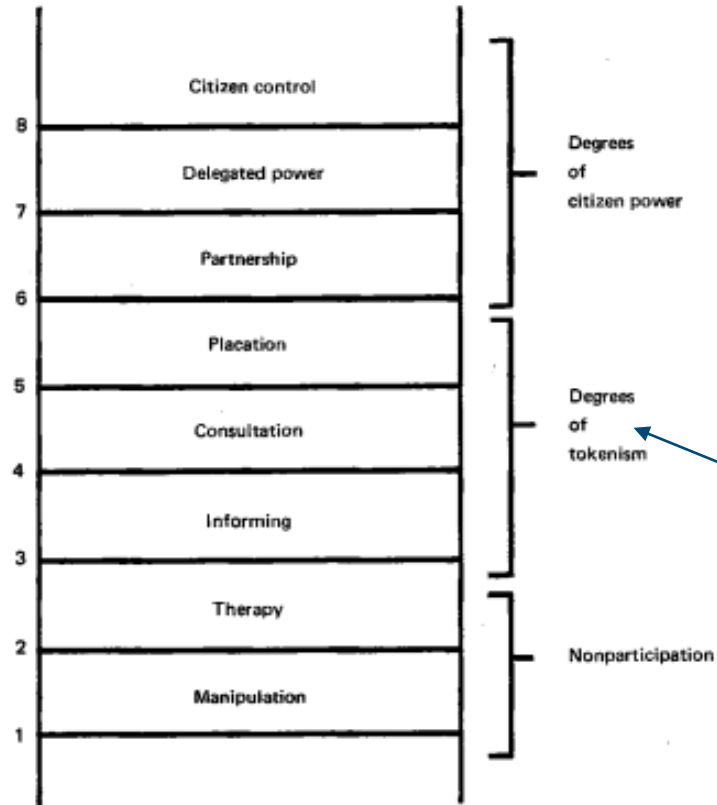
In this study, the positive effects of engagement were evident throughout the research lifecycle of comparative effectiveness research.

Forsythe LP, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute. Health Aff/ 2019 Mar;38(3):359-367.

See also: Geissler J et al. Ther Innov Regul Sci. 2017;51(5):612-619; Barber R et al. Health Expect. 2012;15(3):229-241. Wilson P et al. Southampton (UK): NIHR Journals Library; 2015. Crocker JC et al. Health Expect. 2017;20(3):519-528. Mann C et al. Res Involv Engagem. 2018;4:15. Forsythe L et al. Qual Life Res. 2018;27(1):17-31. Blackburn S, et al. Res Involv Engagem. 2018;4. Gordon J et al. Res Involv Engagem. 2018;4:11. Vale CL, et al. Syst Rev. 2012;1:23. Evans D, et al. Southampton (UK): NIHR Journals Library; 2014.



WHY IS POTENTIAL UNTAPPED?



Rather than being a universally deliberate process, engagement can be idiosyncratic or accidental – relying on the unique interest or expertise of individuals.

Notice here that a classical work on citizen participation considers “consultation” with stakeholders a form of tokenism (if stakeholders’ views are not actually incorporated).

FIGURE 2 *Eight Rungs on a Ladder of Citizen Participation*

Arnstein S. A Ladder of Citizen Participation. Journal of the American Planning Association. 1969;35(4):216-224.

FULFILLING THE POTENTIAL OF ENGAGEMENT

What is needed to fulfill the potential of engagement to achieve these goals?

COMPARATIVE

EVALUATION

ENGAGEMENT METHODS

“EVALUATION”

EVALUATION

“If we can’t measure it, then it doesn’t exist.”

Fortunately, work over the past decade has led to progress in the evaluation of engagement efforts:

- 22 item “Patient Engagement in Research Scale” (PEIRS) (Hamilton CB et al. Health Expect. 2021 Mar 17. doi: 10.1111/hex.1322)
- A quantitative assessment drawing on CBPR principles (Goodman MS et al. Content validation of a quantitative stakeholder engagement measure. J Community Psychol. 2019;47(8):1937-1951.)
- PCORI’s WE-ENACT <https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf>.
- Many others: see <https://ceppp.ca/en/about-us/>.

Still, multiple systematic reviews over the past few years have suggested a need to consolidate these measures into core items and asked questions about their rigor.

“ENGAGEMENT METHODS”

ENGAGEMENT METHODS



This Photo by Unknown Author is licensed under CC BY-SA-NC

Although we sometimes knee-jerk to creating advisory panels, having a single patient Co-Investigator, or even conducting qualitative research or surveys as part of “engagement,” we need to recognize the vast landscape of engagement methods.

Only by understanding this landscape can we overcome some of the more vexing problems in engagement:

- Tokenism...by using methods that elicit authentic input and partnerships
- Diversity and Inclusivity...by using methods that are accessible and culturally appropriate to all
- ETC.

“COMPARATIVE”

COMPARATIVE

Once we have agreed upon measures of engagement – and a sense of the full toolbox of engagement methods – we can pursue the “holy grail” of engagement in research:

Comparative Effectiveness Research on engagement methods themselves – to develop a robust evidence base for engagement.

CONCLUSIONS

- **A growing body of literature suggests that engagement works, and it matters,** but there is a need for comparative evaluation of different engagement methods.
- **Note that this presentation was intentionally vague about “which” engagement stakeholder** – it implied patients/families/communities – and this vagueness suggests another dimension of engagement: tailoring engagement methods to different stakeholder types (health system leaders, industry, and so on).

One effort to begin filling these voids, funded by the University of Colorado’s Data Science to Patient Value (D2V) Program, is the Stakeholder Engagement Navigator Webtool – the subject of the rest of this session.

Contact us

- If you have questions or would like more information about the Stakeholder Engagement Navigator, please contact Kate Ytell at kate.ytell@cuanschutz.edu.



Thank you!

Choosing Appropriate Stakeholder Engagement Methods: The Stakeholder Engagement Navigator Webtool

- Matt DeCamp, MD, PhD; Brad Morse, PhD; Kate Ytell, MPH



COPRH Con

Colorado Pragmatic
Research in Health
Conference



ACCORDS

UNIVERSITY OF COLORADO
CHILDREN'S HOSPITAL COLORADO

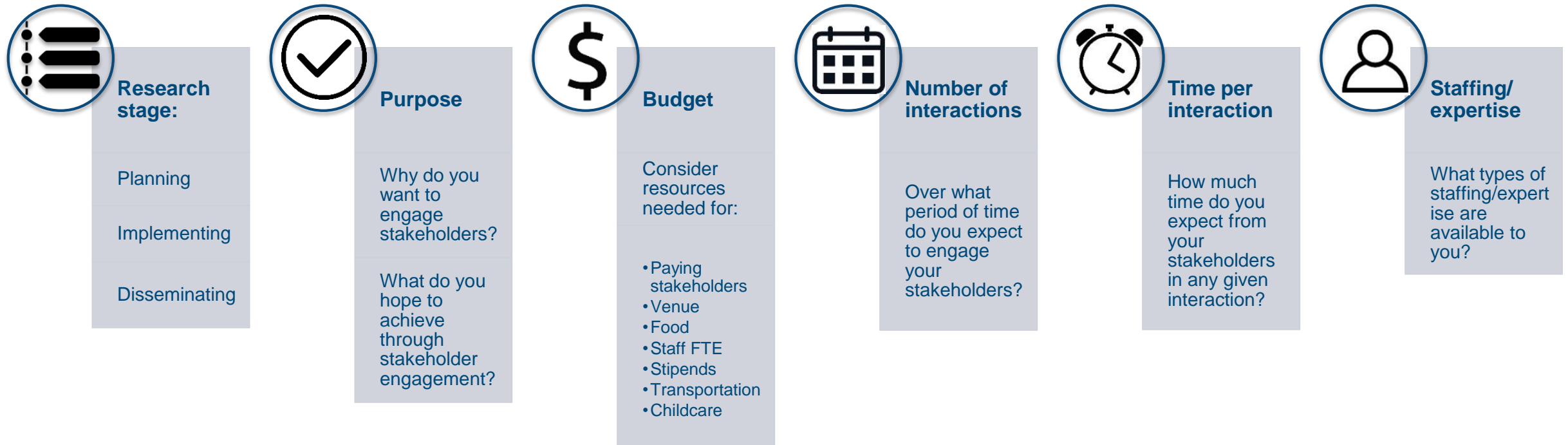


Colorado Clinical and Translational
Sciences Institute (CCTSII)

UNIVERSITY OF COLORADO DENVER | ANSCHUTZ MEDICAL CAMPUS

Using the Stakeholder Engagement Navigator to plan your engagement strategy

- Considerations:



Contact us

- If you have questions or would like more information about the Stakeholder Engagement Navigator, please contact Kate Ytell at kate.ytell@cuanschutz.edu.



Thank you!