

# 2018 Online KT Conference: Engaging Ways to Engage Stakeholders

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Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

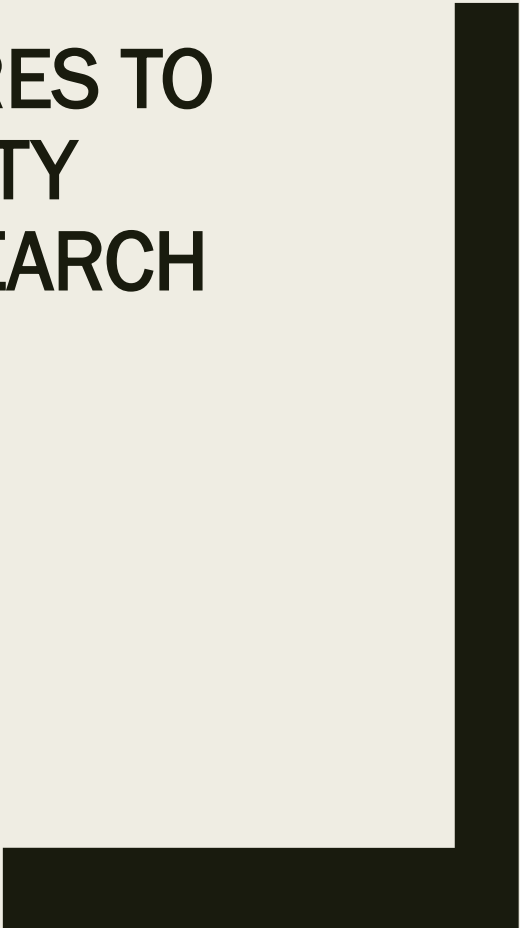
at American Institutes for Research ■



# QUANTITATIVE MEASURES TO ASSESS COMMUNITY ENGAGEMENT IN RESEARCH

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# Community Engagement Working Definition

- “....the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.”

Source: Centers for Disease Control and Prevention. (1997). *Principles of community engagement* (1st ed.). Atlanta, GA: Author. As cited in Agency for Toxic Substances and Disease Registry. (2015). What is community engagement? Retrieved from [https://www.atsdr.cdc.gov/communityengagement/pce\\_what.html](https://www.atsdr.cdc.gov/communityengagement/pce_what.html)

# Why do community engagement?

- Ensure patient/community centered work
  - *Communities provide unique perspectives on needs*
- Increase relevance to stakeholders (from patients to communities to policy makers)
- Sustainability of interventions post-funding
- Capacity/trust building
- Leverage existing resources within the community
- Reciprocal relationship between researchers and communities

# Why Measure Community Engagement?

The extent to which stakeholders in research partnerships *feel engaged* has not received sufficient attention.

It is important to understand:

- *How engagement level in a partnership is developing.*
- *To what extent engagement level is a predictor of outcomes in the larger study.*

# Elements of our approach

- Systematic review
- Initial development of new measure
- Psychometric properties of new measure

# Systematic review to identify measures

- Started by thinking that such measures existed and that they had properties that were understood
- Found that lots of people had measured something
- But really did not know what they had measured, in large part
- Field was “not very strong methodologically”



# Existing measures came in two camps

- One, in which investigators simply counted the attendance in various events and activities, and assumed engagement
- Two, in which investigators measured some construct that was possibly related to engagement
- Neither way has been validated or corroborated
- Mostly not related to outcomes or progress in project
- Not tracked over time

# Examples of counting method

- Number of people who attended a board meeting
- Counts of attendees at community meeting
- Frequency of attendance at process reports

# Examples of construct measurement method

- Degree to which participants felt they were part of a positive community
- Degree to which participants felt comfortable sharing their thoughts and opinions
- Level of confidence regarding their neighbors' willingness to participate in neighborhood problem solving process

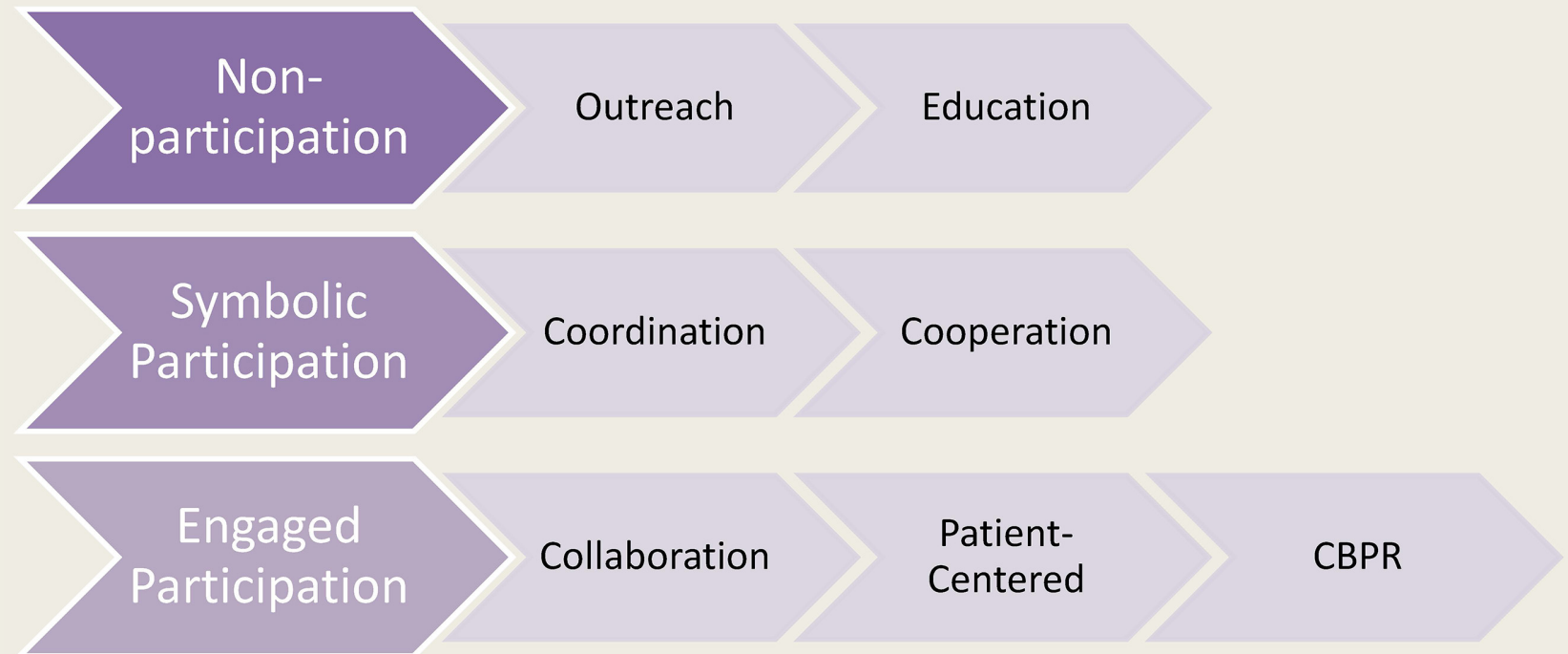
# Community Engagement Measure

New community engagement measure is based on 11 engagement principles previously developed in the literature.

## ■ 11 Engagement Principles

- 1) Focus on local relevance and determinants of health
- 2) Acknowledge the community
- 3) Disseminate findings and knowledge gained to all partners
- 4) Seek and use the input of community partners
- 5) Involve a cyclical and iterative process in pursuit of objectives
- 6) Foster co-learning, capacity building, and co-benefit for all partners
- 7) Build on strengths and resources within the community
- 8) Facilitate collaborative, equitable partnerships
- 9) Integrate and achieve a balance of all partners
- 10) Involve all partners in the dissemination process
- 11) Plan for a long-term process and commitment

# Categories and Classifications of Stakeholder Engagement



Source: Goodman, M. S., & Sanders Thompson, V. L. (2017). The science of stakeholder engagement in research: Classification, implementation, and evaluation. *Translational Behavioral Medicine*, 7(3), 486–491. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5645283/>

# PCORI Specific Aims (Goodman, Thompson et al. 2017)

- I. Examine the construct validity of each engagement principle on both scales (quality/quantity) and use a standardized Delphi process for expert validation, advocacy group/patient/family feedback and prioritization of domains.
- II. Examine the psychometric properties (reliability and sensitivity to change), correlative validity with the trust in medical researchers scale, and determine appropriate categorization cut-off for community engagement scores.
- III. Develop a shorter (condensed) version of the community engagement measure and revise the comprehensive community engagement measure.
- IV. Evaluate uptake and implementation of community engagement measure in PCOR/CER trials

# Progress of Project

- Delphi Panel Process
  - *4 web based surveys completed and in-person meeting convened*
  - *Multiple revisions of the measure have been made based on the 4 rounds of feedback from panelists*
  - *Final Delphi Panel consensus survey currently in progress*
  
- Participant Surveys
  - *Currently recruiting community engaged research participants*
  - *Surveys 1 – 3 (of 4 total) have been released and are in progress*
  
- Quarterly DEAC feedback
  
- Cognitive Interviews
  - *Currently creating interview guides*
  - *Recruitment & interviews to begin summer 2018*

# The Delphi Panel Process



# What is the Delphi Technique?

- The Delphi technique is a method for collecting and organizing informed opinions from a group of experts using an iterative process that is often used in survey instrument development
- This approach is most appropriate to ensure that feedback is obtained from all stakeholders with all experts being treated equal and everyone's voices being heard
- Web-based surveys used in rounds 1-3; for the final round 4 an in person meeting with polling software
- Delphi Technique afforded a stakeholder engaged measure development and validation (construct validity) process
- The responses to surveys were analyzed by the investigator team and returned to the Delphi panelist for further consideration and response

# More about the Delphi Process

- Subsequent iterations include items on which consensus was not previously reached accompanied with anonymous feedback from previous iterations.
- Panelists are encouraged to reconsider their previous responses, and if appropriate, to change their previous response in light of replies and comments from other panelists.
- The eventual outcome of the Delphi process is to obtain consensus with  $\geq 80\%$  agreement among experts.
- Consensus was not forced; items for which consensus can not be reached were discussed at the in-person meeting.
- On day 2 of the in-person meeting, live voting reached over 80% agreement on all items.

# Expert Review Panel Members

## PCORI DELPHI PANEL

| First Name                          | Last Name      | Affiliation   | Title  | Partner   | Location           |
|-------------------------------------|----------------|---|--|-----------|--------------------|
| Elizabeth                           | Baker          | Madison, TN   | Professor and Chair of Behavioral Science and Health Education | Academic  | St. Louis          |
| One panelist dropped after survey 1 |                |   |  |           |                    |
| Sylvia                              | Burns          | St. Louis Patient Research Advisory Board (PRAB)            | Registered Nurse   | Community | St. Louis          |
| Nell Meade                          | Fields         | UK Mountain Air Project                                     | Community Engagement Specialist                                | Community | Whitesburg, KY     |
| Sheila                              | Grigsby        | University of Missouri–St. Louis                            | Assistant Professor of Nursing                                 | Academic  | St. Louis          |
| Fern                                | Herzberg       | ARC XVI Fort Washington, Inc                                | Executive Director   | Community | NYC                |
| Denise                              | Hooks-Anderson | St. Louis DEAC/Saint Louis University School of Medicine    | Assistant Professor, Family and Community Medicine             | Academic  | St. Louis          |
| Melvin                              | Jackson        | Strengthening the Black Family                              | Program Director   | Community | Raleigh-Durham, NC |
| Sherrill                            | Jackson        | St. Louis DEAC/ Breakfast Club Breast Cancer Support Group  | Founder  | Community | St. Louis          |
| Loretta                             | Jones          | Healthy African American Families II                        | Founder & CEO  | Community | Los Angeles        |
| Alison King                         | King           | Washington University School of Medicine                    | Assistant Professor, Pediatrics                                | Academic  | St. Louis          |
| Danielle                            | King           | Kentucky River Community Care                               | Intensive Assertive Community Team Case Manager                | Community | Hazard, KY         |
| Danielle                            | Lavallee       | University of Washington, Surgical Outcomes Research Center | Research Assistant Professor                                   | Academic  | Seattle            |
| Chavelle                            | Patterson      | St. Louis PRAB  | Community Engagement Coordinator, BRAND of St. Louis           | Community | St. Louis          |
| Rosita                              | Romero         | Dominican Women's Development Center                        | Executive Director   | Community | NYC                |
| Nancy                               | Schoenberg     | University of Kentucky College of Medicine                  | Professor of Behavioral Science                                | Academic  | Lexington, KY      |
| Kate McGlone                        | West           | University of Washington                                    |  | Academic  | Seattle            |
| Consuelo                            | Wilkins        | Meharry-Vanderbilt Alliance                                 | Executive Director   | Academic  | Nashville          |
| Jackie                              | Wilkins        | St. Louis PRAB  | Co-Chair STL PRAB  | Community | St. Louis          |

19 members: 11 community health stakeholders, 8 academic researchers

# Community Engaged Research Participant Surveys

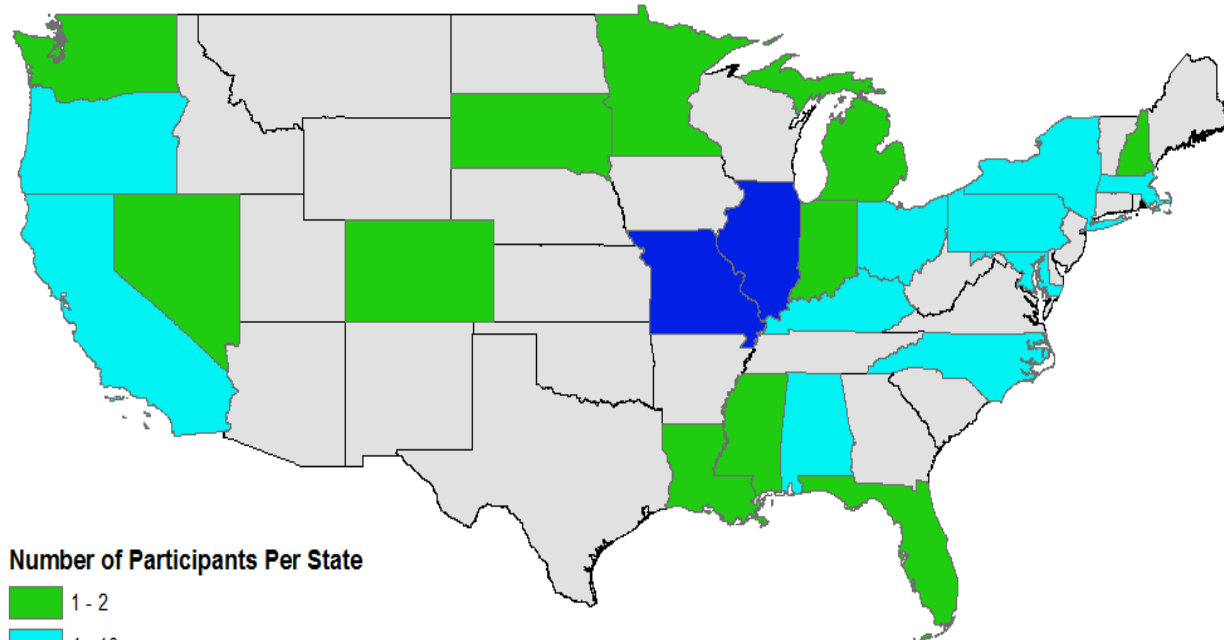
# Participant Recruitment (Target N = 500)

- We are interested in community health stakeholders who have participated in previous community-engaged research studies. Each participant will be asked to complete 4 web-based surveys.
- Each web-survey will take approximately 30-60 minutes to complete.
- Participants will be able to complete these surveys on any mobile device with an internet connection at a time and in a place convenient to them.
- Participant survey incentives (\$65 maximum total compensation):
  - *Surveys 1 & 2: earn \$10 per survey, or \$25 for both*
  - *Surveys 3 & 4: earn \$15 per survey, or \$40 for both*

# Participant Surveys - Progress

- Number Enrolled: 123
- Number Completed Survey 1: 114
- Number Completed Survey 2: 108
- Number Completed Survey 3: 90
- Number Completed Survey 1, 2, and 3: 82

# Community Engagement Measures - Participants who Completed Survey 1, 2, or 3\* (n=123)



Number of Participants Per State

- 1 - 2
- 4 - 10
- 19 - 36
- None

0 470 940 1,880 Miles

\*As of June 25th, 2018



# Participant Survey - Universities

- Which universities are represented among the research participants who have completed the survey?
- Universities listed have 5 or more participants reporting.

| University                            | Number of Participants |
|---------------------------------------|------------------------|
| Washington University<br>in St. Louis | 30                     |
| St. Louis University                  | 9                      |
| University of Missouri                | 9                      |
| New York University                   | 9                      |
| Northwestern                          | 8                      |
| University of Washington              | 7                      |
| Penn State                            | 7                      |
| University of North Carolina          | 6                      |
| University of Illinois at Chicago     | 5                      |



# Preliminary Results – Participant Surveys

- Internal Consistency of EPS
  - *Represented by Cronbach's Alpha*
  - *Measured on a 0 to 1 scale*
  - *Values above 0.7 are considered acceptable in many fields*
- Measure correlations
  - *Pearson's correlation coefficient and P-Values comparing to other measures of engagement*

# Internal Consistency by EP Participant Survey 1

| Engagement Principle | Number of Items | Participant Survey 1 – Version 1 of measure |       |          |       |
|----------------------|-----------------|---|-------|----------|-------|
|                      |                 | Quality                                     |       | Quantity |       |
|                      |                 | N   | Alpha | N        | Alpha |
| EP1                  | 4               | 114   | 0.94  | 113      | 0.93  |
| EP2                  | 4               | 114   | 0.95  | 113      | 0.96  |
| EP3                  | 5               | 114   | 0.95  | 112      | 0.95  |
| EP4                  | 5               | 113   | 0.94  | 111      | 0.93  |
| EP5                  | 5               | 114   | 0.96  | 111      | 0.94  |
| EP6                  | 5               | 114   | 0.95  | 110      | 0.94  |
| EP7                  | 4               | 114   | 0.95  | 111      | 0.95  |
| EP8                  | 5               | 112   | 0.94  | 110      | 0.94  |
| EP9                  | 4               | 114   | 0.94  | 112      | 0.93  |
| EP10                 | 4               | 114   | 0.95  | 112      | 0.95  |
| EP11                 | 3               | 113   | 0.94  | 111      | 0.94  |

# Internal Consistency

## Participant Surveys 2 & 3

| Engagement Principle  | Survey 2 – Version 2 of measure |         |       |          |       | Survey 3 – Version 3 of measure |         |       |          |       |
|-----------------------|---------------------------------|---------|-------|----------|-------|---------------------------------|---------|-------|----------|-------|
|                       | Number of Items                 | Quality |       | Quantity |       | Number of Items                 | Quality |       | Quantity |       |
|                       |                                 | N       | Alpha | N        | Alpha |                                 | N       | Alpha | N        | Alpha |
| EP1                   | 4                               | 103     | 0.90  | 106      | 0.85  | 4                               | 84      | 0.90  | 85       | 0.84  |
| EP2 (prev. EP4)       | 5                               | 102     | 0.95  | 104      | 0.89  | 5                               | 82      | 0.91  | 81       | 0.85  |
| EP3 (prev. EP5)       | 6                               | 106     | 0.96  | 106      | 0.94  | 4                               | 86      | 0.92  | 85       | 0.88  |
| EP4 (prev. EP6)       | 5                               | 106     | 0.93  | 105      | 0.90  | 4                               | 85      | 0.92  | 83       | 0.87  |
| EP5 (prev. EP7)       | 5                               | 106     | 0.93  | 105      | 0.91  | 4                               | 86      | 0.93  | 82       | 0.89  |
| EP6 (prev. EP8 & EP9) | 9                               | 100     | 0.96  | 102      | 0.95  | 7                               | 81      | 0.95  | 85       | 0.93  |
| EP7 (prev. EP10)      | 5                               | 104     | 0.94  | 104      | 0.93  | 4                               | 83      | 0.91  | 85       | 0.80  |
| EP8 - Added           | 4                               | 103     | 0.93  | 103      | 0.91  | 4                               | 84      | 0.93  | 83       | 0.89  |

# Correlative Validity – Survey 1

| Other Measures  | Our Measure – Quality* |                             |         | Our Measure – Quantity* |                             |         |
|---|------------------------|-----------------------------|---------|-------------------------|-----------------------------|---------|
|   | N                      | Pearson's R                 | P-Value | N                       | Pearson's R                 | P-Value |
| <b><i>Participant Survey 1</i></b>  |                        |                             |         |                         |                             |         |
| <b><i>Medical Mistrust<sup>1</sup></i></b>  | 114                    | 0.16 – Weak Correlation     | 0.094   | 113                     | 0.13 – Weak Correlation     | 0.159   |
| <b><i>Trust in Medical Researchers<sup>2</sup></i></b>                                      | 113                    | 0.34 – Weak Correlation     | <0.001  | 112                     | 0.31 – Weak Correlation     | 0.001   |
| <b><i>Partnership Assessment in community-based Research (PAIR) Measure<sup>3</sup></i></b> | 114                    | 0.52 – Moderate Correlation | <0.001  | 113                     | 0.60 – Moderate Correlation | <0.001  |
| <b><i>Kagan Measure<sup>4</sup></i></b>   | 111                    | 0.67 – Moderate Correlation | <0.001  | 110                     | 0.74 – Strong Correlation   | <0.001  |

<sup>1</sup>Mainous, A. G., Smith, D. W., Geesey, M. E., & Tilley B. C. (2006). Development of a measure to assess patient trust in medical researchers. *Annals of Family Medicine*, 4(3), 247–253.

<sup>2</sup>Hall, M. A., Camacho, F., Lawlor, J. S., DePuy, V., Sugarman, J., & Weinfurt, K. (2006). Measuring trust in medical researchers. *Medical Care*, 44(11), 1048–1053.

<sup>3</sup>Arora, P. G., Krumholz, L. S., Guerra, T., & Leff, S. S. (2015, Winter). Measuring community-based participatory research partnerships: The initial development of an assessment instrument. *Progress in Community Health Partnerships*, 9(4), 549–560. doi:10.1353/cpr.2015.0077.

<sup>4</sup>Kagan, J. M., Rosas, S. R., Siskind, R. L., Campbell, R. D., Gondwe, D., Munroe, D., . . . Schouten, J. T. (2012, Fall). Community-researcher partnerships at NIAID HIV/AIDS clinical trials sites: Insights for evaluation and enhancement. *Progress in Community Health Partnerships*, 6(3), 311–320. doi:10.1353/cpr.2012.0034

# Correlative Validity – Survey 2

| Other Measures  | Our Measure – Quality* |                             |         | Our Measure – Quantity* |                         |         |
|---|------------------------|-----------------------------|---------|-------------------------|-------------------------|---------|
|   | N                      | Pearson's R                 | P-Value | N                       | Pearson's R             | P-Value |
| <b><i>Participant Survey 2</i></b>                                      |                        |                             |         |                         |                         |         |
| <b><i>Community Engagement in Research Index (CERI)<sup>1</sup></i></b> | 107                    | 0.33 – Weak Correlation     | <0.001  | 108                     | 0.40 – Weak Correlation | <0.001  |
| <b><i>Coalition Self-Assessment Survey – Trust<sup>2</sup></i></b>      | 105                    | 0.50 – Moderate Correlation | <0.001  | 106                     | 0.44 – Weak Correlation | <0.001  |

<sup>1</sup> Khodyakov, D., Stockdale, S., Jones, A., Mango, J., Jones, F., & Lizaola, E. (2013). On measuring community participation in research. *Health Education & Behavior, 40*(3), 346–354. doi:10.1177/1090198112459050.

<sup>2</sup> Peterson, J. W., Lachance, L. L., Butterfoss, F. D., Houle, C. R., Nicholas, E. A., Gilmore, L. A., . . . Friedman, A. R. (2006). Engaging the community in coalition efforts to address childhood asthma. *Health Promotion Practice, 7*(Suppl. 2), 56S–65S.

# Participant Survey Recruitment

- We need help with recruitment
- Please send the link to the screener around to potential participants:

FOR IRB USE ONLY  
IRB ID #: 201410117  
APPROVAL DATE:  
02/16/18  
RELEASED DATE:

Washington University in St. Louis  
SCHOOL OF MEDICINE

 NYU COLLEGE OF GLOBAL PUBLIC HEALTH

## PARTICIPANTS NEEDED

### DEVELOPING AND VALIDATING MEASURES TO ASSESS COMMUNITY ENGAGEMENT IN RESEARCH

WE ARE INTERESTED IN COMMUNITY MEMBERS WHO HAVE PARTICIPATED IN PREVIOUS COMMUNITY-ENGAGED RESEARCH STUDIES. EACH PARTICIPANT WILL BE ASKED TO PARTICIPATE IN 4 WEB-BASED SURVEYS.

EACH WEB-SURVEY WILL TAKE APPROXIMATELY 30-60 MINUTES TO COMPLETE. PARTICIPANTS WILL BE ABLE TO COMPLETE THESE SURVEYS ON ANY MOBILE DEVICE WITH AN INTERNET CONNECTION AT A TIME AND IN A PLACE CONVENIENT TO THEM. PARTICIPANT SURVEY INCENTIVES INCLUDE AMAZON E-GIFT CARDS (\$65 MAXIMUM TOTAL COMPENSATION):

- SURVEYS 1 & 2: EARN \$10 PER SURVEY, OR \$25 FOR BOTH
- SURVEYS 3 & 4: EARN \$15 PER SURVEY, OR \$40 FOR BOTH

### CONTACT US IF YOU'RE INTERESTED AND IF YOU:

- HAVE PARTICIPATED IN PREVIOUS COMMUNITY-ENGAGED RESEARCH PROJECTS
- CAN COMMIT TO A 10-MONTH STUDY (FEB. 2018 – NOV. 2018)
- HAVE ACCESS TO THE INTERNET

If you are interested in participating, please contact:  
Goldie Komaie at 314-747-2183 or [gkomaie@wustl.edu](mailto:gkomaie@wustl.edu)

*Funding provided by the Patient-Centered Outcomes Research Institute (PCORI).*

[https://wustl.az1.qualtrics.com/jfe/form/SV\\_5nmX3FWdEWUgQHH](https://wustl.az1.qualtrics.com/jfe/form/SV_5nmX3FWdEWUgQHH)

# Disclaimer

This work was supported through a Patient Centered Outcomes Research Institute (PCORI) Award (ME-1511-33027). All statements in this presentation, including its findings and conclusions, are solely the authors' and do not necessarily represent the views of PCORI, its Board of Governors, or its Methodology Committee.

# Disclaimer

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