

### Health Research Alliance

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## Reaching Consensus on Principles of Stakeholder Engagement in Research

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#### Abstract

**Background:** Stakeholder-engaged research is an umbrella term for the types of research that have community, patient, and/or stakeholder engagement, feedback, and bidirectional communication as approaches used in the research process. The level of stakeholder engagement across studies can vary greatly, from minimal engagement to fully collaborative partnerships.

**Objectives:** To present the process of reaching consensus among stakeholder and academic experts on the stakeholder engagement principles (EPs) and to identify definitions for each principle.

**Methods:** We convened 19 national experts, 18 of whom remained engaged in a five-round Delphi process. The Delphi panel consisted of a broad range of stakeholders (e.g., patients, caregivers, advocacy groups, clinicians, researchers). We used web-based surveys for most rounds (1–3 and 5) and an in-person meeting for round 4. Panelists evaluated EP titles and definitions with a goal of reaching consensus (>80% agreement). Panelists' comments guided modifications, with greater weight given to non-academic stakeholder input.

**Conclusions:** EP titles and definitions were modified over five Delphi rounds. The panel reached consensus on eight EPs (dropping four, modifying four, and adding one) and corresponding definitions. The Delphi process allowed for a stakeholder-engaged approach to methodological research. Stakeholder engagement in research is time consuming and requires greater effort but may yield a better, more relevant outcome than more traditional scientist-only processes. This stakeholder-engaged process of reaching consensus on EPs and definitions provides a key initial step for the content validation of a survey tool to examine the level of stakeholder engagement in research studies.

#### Keywords

Community health partnerships; evaluation studies; outcome and process assessment (health care); community-based participatory research; process issues

Stakeholder-engaged research is an umbrella term for the types of research (e.g., patientcentered outcomes research, community-based participatory research) that have community, patient, and/or stakeholder engagement, feedback, and dialogue as core principles. Two key elements of stakeholder-engaged research are 1) stakeholder engagement and involvement throughout the research process and 2) selection and measurement of outcomes that the population of interest cares about and that can inform decision making about the research topic.<sup>1,2</sup> Stakeholder engagement is a powerful vehicle for effectuating changes that can improve health.<sup>3</sup> Engaging community health stakeholders in the research process is often the missing link to improving the quality and outcomes of health promotion activities, disease prevention initiatives, and research studies.<sup>4,5</sup> Stakeholder engagement requires a long-term process (e.g., time and effort from all partners) that builds trust, values all stakeholders' contributions, and generates a collaborative framework.<sup>6</sup>

The benefits of engaging stakeholders—as consumers of health care and active partners in the full spectrum of translational research—include, for instance, identifying community health needs and priorities, providing input on research questions, contributing to appropriate research design and methods, developing culturally sensitive and ethical proposals, enhancing the recruitment and retention of research participants, and implementing and disseminating research findings more effectively.<sup>7–11</sup>

Most stakeholder engagement in research occurs during the recruitment and dissemination phases of translational research, so there is less experience on how to identify and involve stakeholders from the early research stages (e.g., research question and hypothesis development) and throughout the translational continuum (e.g., data analysis and interpretation). Because the optimal ways to involve relevant communities in each stage of the translational process have not been defined, stakeholder engagement needs to be addressed as a scientific problem—to identify best practices in an experimental, data-driven fashion.<sup>12</sup>

Although the usefulness of stakeholder-engaged health research has been well-established, <sup>7–11</sup> measurement and evaluation of non-academic stakeholder engagement in research activities has primarily been done using qualitative research approaches.<sup>13–19</sup> This is particularly true in assessments of how engaged the patient/stakeholder feels about the benefit of collaborations.<sup>20</sup> Although qualitative methods are effective at assessing engagement, 1) they can be time consuming, 2) they do not easily scale up for the evaluation of large-scale or multisite research projects and intervention trials engaging multiple settings or stakeholders, and 3) the results cannot be easily compared over time and across programs or institutions.

To determine the level of stakeholder engagement in research studies, it is necessary to reach consensus on what determines how engaged stakeholders are in a project. Here, we discuss a stakeholder-engaged approach to reach consensus on each stakeholder engagement principle (EP) and definition.

#### **METHODS**

#### **Evaluation of Stakeholder Engagement**

The Program for the Elimination of Cancer Disparities (PECaD) at Siteman Cancer Center was established in 2003 in response to known racial/ethnic and socioeconomic cancer disparities in the St. Louis region. PECaD includes a community advisory board, the Disparities Elimination Advisory Committee (DEAC), which provides programmatic leadership. DEAC members represent multiple community interests and perspectives: survivors, community-based organizations, faith-based organizations, community physicians, and the media.<sup>21</sup> PECaD began administering a biennial evaluation survey in 2011 to evaluate PECaD's implementation of community EPs.<sup>22</sup> Although this initial survey was informative in assessing PECaD's adherence to the community EPs, it lacked specificity about how adherence was achieved and how this impacted PECaD's research studies.<sup>22</sup>

To address this issue, the DEAC and PECaD researchers formally developed an evaluation team using a community–academic partnered framework. The evaluation team comprised PECaD staff (three investigators, the data manager, and the program coordinator) and the DEAC community co-chair. The evaluation team's work was continuously reported back to DEAC; the team met individually and used DEAC meetings to obtain feedback at each stage of measure development. The evaluation team developed and pilot tested a survey tool on community engagement pertaining to 11 EPs.<sup>23</sup> The EPs came from the literature<sup>11,13,19,24,25</sup> and were selected based on feedback from the DEAC. These EPs were based on the principles of community-based participatory research<sup>9,11,19,26–28</sup> and community engagement.

The Patient Research Advisory Board (PRAB) was developed from a PECaD program that provides research literacy training to community health stakeholders.<sup>32</sup> The PRAB works with researchers to develop and implement community-engaged and patient-centered research studies. The DEAC and PRAB both serve as advisory boards to the project and have dedicated several meetings for discussion of the project's updates and to provide feedback to project investigators.

#### **Delphi Panelists**

Delphi panelists were recruited by email using a convenience snowball sampling approach based on the networks of the project team members (community-engaged researchers). Members of the panel were selected from the DEAC (n = 2) and the PRAB (n = 3) as key connections to both advisory boards for the project. Panelists were selected from each of the project team members' institutions: Washington University in St. Louis (four stakeholders, two academics; including five from DEAC and PRAB), New York University (two stakeholders), and the University of Washington (two academics). In addition, nationally recognized scholars in community engagement were selected (n = 3) as well as nationally recognized community health stakeholders (n = 2). There was one academic who was also the director of a community–academic partnership, we considered her an academic on the Delphi panel. After initial selection, there was approximately an equal mix of academics and

community health stakeholders. The list of panelists was shared with the funder to obtain additional recommendations for panelists. No specific panelists were suggested, but the funder requested greater representation from non-academics on the panel. To address this request, we asked academic panelists to identify community partners they worked with to be recruited to the panel. An additional three community health stakeholders joined the panel through this process.

Nineteen panelists were recruited to participate in the Delphi process. Most panelists were female (90%), African American (63%), and had some college or more education (100%). The panel consisted of 8 (42%) academic researchers and 11 (58%) community health stakeholders, including 4 (21%) current and 5 (26%) former direct services providers. The mean age of panelists at the start of the project was 55 years (range, 26–76 years). Panelists had an average of 10 years of research experience (range, 0–35 years) and 10 years of community-based participatory research experience (range, 0–30 years). We included one community health stakeholder panelist who had no research experience to provide the perspective of someone new to this type of work. One panelist dropped after completing the first round of the Delphi process, leaving 18 (95%) panelists who remained engaged throughout the entire five-round process. Table 1 displays the name, affiliation, partner type, and location of these panel members, who are patients, caregivers, advocacy group members, clinicians, and researchers.

#### **Reaching Consensus on the Engagement Principles**

To identify the strongest EPs possible, we used a consensus process with the group of 19 national experts, in a five-round modified Delphi process (Figure 1). We used web-based surveys (via Qualtrics survey platform for rounds 1–3 and 5) and an in-person meeting (round 4). Panelists unable to attend the in-person meeting could participate in real time via webinar (using the GoToMeeting platform) or in advance via web-based survey. Synchronous voting for in-person and webinar attendees was conducted using mobile devices and the Poll Everywhere web survey platform. A professional editor participated in the in-person meeting, a final edit of the EP titles and definitions was done. These edited versions were voted on in round 5 (final consensus). This study was approved by two institutional review boards: the University Committee on Activities Involving Human Subjects, Office of Research Compliance at New York University and the Human Research Protections Office at Washington University in St. Louis.

Each round (except the final round) was preceded by a presentation (recorded webinar in rounds 1–3 and in person for round 4) summarizing the results from the previous round and/or preparing panelists for the upcoming round. In addition, after rounds 1 to 3, panelists were provided with individual reports, which included each panelist's own responses and the aggregate responses and comments from other panelists. During the Delphi process, panelists evaluated EP titles and definitions with a goal of reaching consensus (>80% agreement). In rounds 1 through 3, panelists were presented each principle and definition (starting in round 2) and asked to keep, modify, or remove. If *modify* or *remove* was selected, panelists were asked a follow-up open-ended question on the reason for their

choice. In rounds 4 and 5, panelists were asked whether they agreed or disagreed with each EP and definition. The project team discussed them when consensus was not reached—that is, when more than four (21%) panelists suggested additions, deletions, or modifications.

Panelists' recommendations on deletion or modification of wording guided survey changes, with greater weight given to community health stakeholder input. Consensus percentage was calculated for the panel overall and then stratified by partner type (stakeholder/academic). Once panelists' responses were quantified, the study investigators and staff met to review quantitative data and panelists comments. Consistency in recommendations for wording change guided modifications, whereas the percentage in favor of *remove* guided decisions to delete. In cases where the team could not agree, items were retained and advanced to the next round to obtain additional feedback from panelists.

#### RESULTS

The Delphi process took approximately 1 year: round 1, July 2017 (n = 19); round 2, October to November 2017 (n = 18); round 3, February to March 2018 (n = 18); round 4, April 2018 (n = 16); and round 5, July to August 2018 (n = 18). The participation level varied during the 2-day, in-person meeting (round 4) from 11 to 16 participants (10 in person, 6 using a pre-meeting online survey [3 of these participating remotely]). We do not have any round 4 responses for 2 panelists (Figure 1).

#### **Delphi Round 1**

In round 1, panelists provided feedback on the 11 PECaD EPs.<sup>23</sup> Based on round 1 feedback from panelists, four EPs were dropped (i.e., "acknowledge the community," "disseminate findings and knowledge gained to all partners," "integrate and achieve a balance of all partners," "and plan for a long-term process and commitment"), and one EP was added (i.e., "build trust"). Two principles (EP 2 and EP 11) lacked consensus (79% overall; 91% stakeholder; 63% academic); both were dropped after round 1. The primary reasons for dropping EPs were that they were not applicable to a broad range of projects and that they overlapped other EPs. An additional principle was added because panelists stated that trust is a key component of stakeholder engagement that contributes to the success of partnerships, and this concept was not captured in any of the other EPs.

Two EPs were modified despite reaching consensus. The EP "seek and use the input of community partners" was changed to "seek and use the input of all partners." "Build on strengths and resources within the community" was modified to "build on strengths and resources within the community" was modified to "build on strengths and resources within the community/target population." Revisions were presented to panelists in round 2. Five EPs had consensus ( 90%) and were not modified after round 1; these EPs were excluded from the round 2 survey (Table 2). The EPs not modified after round 1 include "focus on local relevance and social determinants of health"; "involve a cyclical and iterative process in pursuit of objectives"; "foster co-learning, capacity building, and cobenefit for all partners"; facilitate collaborative, equitable partnerships; and "involve all partners in the dissemination process". Panelists' comments and edits about the EPs on the round 1 survey suggested the need to define each principle and reach consensus on the definitions.

#### **Delphi Round 2**

In round 2, panelists provided feedback on the new EP ("build trust") and the 2 EPs that were modified based on feedback from the previous round (Table 2). In addition, preliminary definitions based on the literature were provided for each EP for panelists' feedback (Table 3). Consensus was not reached (78% overall; 80% stakeholder; 75% academic) on the added EP; panelists felt the principle needed more description, but consensus was reached on two EPs modified after round 1 (90% overall; 90%–100% stakeholder; 75%–88% academic). However, lack of consensus on EP definitions required modifications of EP titles for clarity and consistency with the definition.

Based on responses in round 2, all three principles presented in this round required additional modification. "Seek and use the input of all partners" was changed to "partnership input is vital." "Build on strengths and resources within the community/target population" was modified to "build on strengths and resources within the community/patient population." "Build trust" was changed to "build and maintain trust in the partnership." In addition, two other EPs were modified for clarity related to their definition. "Focus on local relevance and social determinants of health" was changed to "focus on community perspectives and determinants of health." "Involve a cyclical and iterative process in pursuit of objectives" was changed to "partnership sustainability to meet goals and objectives." Definitions for EP 1 (67% overall; 80% stakeholder; 50% academic), EP 2 (78% overall; 90% stakeholder; 63% academic), EP 5 (72% overall; 80% stakeholder; 63% academic), EP 7 (78% overall; 90% stakeholder; 63% academic), and EP 8 (78% overall; 100% stakeholder; 50% academic) lacked consensus. Despite three EP definitions (EPs 3, 4, and 6) reaching the consensus threshold (Table 3), all of the preliminary definitions were modified based on panelists' feedback and presented again in round 3. For example, for EP 1, panelists commented on missing "local relevance" in the definition, using a word other than "biomedical," and that social determinants of health may not be what is currently most important to a certain community. For EP 5, panelists commented on disagreeing with the use of the term "target population." For EP 8, panelists commented on the need to include historical context and understand the history of the community.

#### **Delphi Round 3**

In round 3, panelists reached consensus on three ("partnership input is vital," "build on strengths and resources within the community or patient population," and "build and maintain trust in the partnership") of five EPs presented in this round (Table 2). Consensus was not reached on "focus on community perspectives and determinants of health" (78% overall; 90% stakeholder; 63% academic) and "partnership sustainability to meet goals and objectives" (72% overall; 80% stakeholder; 63% academic).

Consensus was reached on six EP definitions (Table 3). The panelists did not reach consensus for the definitions of "foster co-learning, capacity building, and co-benefit for all partners" (72% overall; 80% stakeholder; 63% academic) and "facilitate collaborative, equitable partnerships" (78% overall; 90% stakeholder; 63% academic). EPs and definitions for which consensus was not reached in round 3 were put on the agenda for the in-person meeting (round 4).

#### **Delphi Round 4**

Round 4 took place in person over 2 days, but only some panelists could attend (n = 10). This meeting was facilitated by the two project co-principal investigators, who have experience facilitating group discussions and stakeholder-engaged research. Facilitators kept the discussion focused and worked toward reaching consensus or understanding why consensus could not be reached. A professional editor attended the meeting to help ensure consistency, language clarity, and proper grammar. After a vibrant, thoughtful, and insightful discussion on each EP and definition, which was followed by editing for cohesion and clarity, all attending panelists reached consensus on eight EP titles and definitions on day 2. Given the reduction in participation for this round, the variable levels of participation of webinar attendees, and the editor's final edits, we decided to add an additional round to reach final consensus.

#### **Delphi Round 5**

In round 5, the panel reached consensus (> 80%) on eight EPs and definitions (Table 4). One academic panelist disagreed with some titles (EPs 1–3). However, the community health stakeholder panelists had total consensus. Two academic panelists disagreed with the EP 1 definition, and one academic panelist disagreed with two definitions (EPs 4–5; Table 4). The final EPs and definitions are listed in Table 4.

#### DISCUSSION

The Delphi process allowed for a stakeholder-engaged approach for reaching consensus on EPs and definitions. This approach is particularly significant in light of the Institute of Medicine Committee report highlighting stakeholder engagement as an integral component in all phases of clinical, translational, community, and public health research to identify health needs, set priorities, and promote diverse participation in research studies.<sup>33</sup> The work presented here on reaching consensus on EPs and definitions would not have been so comprehensive without the input of stakeholders in the process. It became clear after round 1, that if we wanted to reach consensus on the EPs, we were also going to have to reach consensus on how each EP was defined. The discussion of engagement has been different across the many types of stakeholder-engaged research literature, requiring the need to assure agreement on what we meant by each EP.

Stakeholder engagement in research is time consuming and requires greater effort, but may yield a better, more relevant tool to assess stakeholder engagement in research than more traditional scientist-only processes. This became most evident during the in-person meeting where key components of language and meaning needed to be discussed to reach consensus. For example, the definitions of *partnership, partners*, and *stakeholders* were important in finalizing the EP definitions. This initial step—reaching consensus on what is to be measured—lays the foundation for content and construct validation of a quantitative stakeholder engagement measure.

The results of the Delphi process presented here should be considered in light of the study limitations. The sample of Delphi panelists was recruited using a convenience snowball

sampling approach based on the networks of the project team members. The resulting sample was majority female (90%), non-Hispanic (95%), African American or Black (63%), with some college or higher education (100%) and resided in the Midwest or Southern region of the United States (72%). The views of other ethnic groups or gender identities, particularly those with no representation in the sample (e.g., Asian, Native American, and transgender) might be inadequately reflected in the Delphi process. In addition, other relevant identities were not queried (e.g., sexual orientation, health status), and those with limited English proficiency, from some health professions, and from other disciplines were not included; the impact of their presence or absence is unknown. Despite these limitations, we recruited a diverse national sample of Delphi panelists with a range of experience in community engagement and research.

Several panel members (n = 8; 44%) were not able to attend the round 4 in-person meeting. We were able to have six of these panel members complete a web-based survey that provided feedback in advance of the meeting, and three of these panelists participated via webinar or phone during part of the meeting. To address this issue and to reach final consensus, an additional web-based round was added to the Delphi process in which 18 panelists participated.

The results of this Delphi process make several significant contributions to communityengaged science.<sup>34</sup> It is important to reach consensus on key principles (and definitions) of stakeholder engagement in research that studies should measure to determine the influence of community–academic partnerships on the scientific process and scientific discovery. The project originated from a community–academic partnership, used a stakeholder engaged Delphi process, and integrated different approaches to engagement (e.g., community-based participatory research, patient-centered outcomes research) to determine key EPs across approaches. In future work, the authors intend to conduct content validation of items used to measure each EP and examine their psychometric properties. The results will be used to refine and validate a quantitative stakeholder engagement measure that can be used to identify crosscutting best practices and tailored strategies for engaging specific populations.

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Round 1	Round 2	Round 3	Round 4	Round 5
Kick-off Webinar June 28, 2017 -Introduction to the project -Preparation for Round 1	Webinar 2 October 4, 2017 - Review of Round 1 results -Preparation for Round 2	Webinar 3 January 31, 2018 -Review of Round 2 results -Preparation for Round 3	In-person Meeting April 26-27, 2018 - Review of Round 3 results - Facilitated discussion N=10	No webinar
Survey 1 EP titles July 2017 N=19	Survey 2 EP titles and definitions October - November 2017 N=18	Survey 3 EP titles and definitions February - March 2018 N=18	Survey of those unable to attend in person EP titles and definitions April 17-25, 2018 N=6	Final consensus survey EP titles and definitions July - August 2018 N=18
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Individualized reports with Round 1 results October 5, 2017	Individualized reports with Round 2 results January 31, 2018	Individualized reports with Round 3 results April 9, 2018	No individualized reports	No individualized reports

#### Figure 1.

Implementation of Modified Delphi Process and Timeline

Table 1.

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Members of the Delphi Panel

Name	Affiliation	Partner Type	Location
Elizabeth Baker	Saint Louis University	Academic	St. Louis, MO
Sylvia Burns	St. Louis Patient Research Advisory Board	Stakeholder	St. Louis, MO
Nell Meade Fields	UK Mountain Air Project	Stakeholder	Whitesburg, KY
Sheila Grigsby	University of Missouri—St. Louis	Academic	St. Louis, MO
Fern Herzberg	ARC XVI Fort Washington, Inc.	Stakeholder	New York, NY
Denise Hooks-Anderson	St. Louis DEAC Saint Louis University School of Medicine	Academic	St. Louis, MO
Melvin Jackson	Strengthening the Black Family	Stakeholder	Raleigh-Durham, NC
Sherrill Jackson	St. Louis DEAC Breakfast Club Breast Cancer Support Group	Stakeholder	St. Louis, MO
Loretta Jones	Healthy African American Families II	Stakeholder	Los Angeles, CA
Alison King	Washington University School of Medicine	Academic	St. Louis, MO
Danielle King	Kentucky River Community Care	Stakeholder	Hazard, KY
Danielle Lavallee	University of Washington, Surgical Outcomes Research Center	Academic	Seattle, WA
Chavelle Patterson	St. Louis Patient Research Advisory Board	Stakeholder	St. Louis, MO
Rosita Romero	Dominican Women's Development Center	Stakeholder	New York, NY
Nancy Schoenberg	University of Kentucky College of Medicine	Academic	Lexington, KY
Kate McGlone West	University of Washington, Institute for Public Health Genetics	Academic	Seattle, WA
<b>Consuelo Wilkins</b>	Meharry-Vanderbilt Alliance	Academic	Nashville, TN
Jackie Wilkins	St. Louis Patient Research Advisory Board	Stakeholder	St. Louis, MO

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		ř.	Round 1 $(n = 19)$	-	R	Round 2 $(n = 18)$	-	R	Round 3 $(n = 18)$	_
Uriginal Er	New EF	Total	Stakeholder Academic	Academic	Total	Stakeholder Academic	Academic	Total	Stakeholder	Academic
1	-	18 (94.7%)	11 (100.0%)	7 (87.5%)	MN	MN	MN	14 (78.0%)	6 (90.0%) 6	5 (62.5%)
2		15 (79.0%)	10 (90.9%)	5 (62.5%)						
ю		18 (94.7%)	11 (100.0%)	7 (87.5%)			I			
4	2	17 (89.5%)	10(90.1%)	7 (87.5%)	16 (88.9%)	6 (90.0%) (	7 (87.5%)	17 (94.0%)	10 (100.0%)	7 (87.5%)
5	3	19 (100.0%)	11 (100.0%)	8 (100.0%)	MN	NM	MN	13 (72.0%)	8 (80.0%)	5 (62.5%)
9	4	19 (100.0%)	11 (100.0%)	8 (100.0%)	MN	NM	MN	MN	NM	MN
7	S	18 (94.7%)	11 (100.0%)	7 (87.5%)	16 (88.9%)	$10\ (100.0\%)$	6 (75%)	18 (100.0%)	10(100.0%)	8 (100.0%)
8	9	18 (94.7%)	11 (100.0%)	7 (87.5%)	MN	NM	MN	MN	NM	MN
6		16 (84.2%)	11 (100.0%)	5 (62.5%)			I			I
10	٢	17 (89.5%)	11 (100.0%)	6 (75%)	MN	NM	MN	NM	MN	MN
Π	I	15 (79.0%)	10 (90.9%)	5 (62.5%)	Ι	I	I	I	I	
	8				14 (77.8 %)	8 (80.0%)	6 (75.0%)	16 (89.0%)	9 (90.0%) 6	7 (87.5%)

## Table 3.

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Ē		Round 2			Round 3	
-	Total $(n = 18)$		Academic $(n = 8)$	Total $(n = 18)$	Stakeholder $(n = 10)$ Academic $(n = 8)$ Total $(n = 18)$ Stakeholder $(n = 10)$ Academic $(n = 8)$	Academic $(n = 8)$
_	12 (66.7%)	8 (80.0%)	4 (50.0%)	15 (83.3%)	10 (100.0%)	5 (62.5%)
7	14 (77.8%)	9 (90.0%) 9	5 (62.5%)	15 (83.3%)	9 (90.0%)	6 (75.0%)
3	15 (83.3%)	10 (100.0%)	5 (62.5%)	16 (88.9%)	9 (90.0%)	7 (87.5%)
4	17 (94.4%)	10 (100.0%)	7 (87.5%)	13 (72.2%)	8 (80.0%)	5 (62.5%)
2	13 (72.2%)	8 (80.0%)	5 (62.5%)	16 (88.9%)	10 (100.0%)	6 (75.0%)
9	16 (88.9%)	10 (100.0%)	6 (75.0%)	14 (77.8%)	9 (90.0%)	5 (62.5%)
2	14 (77.8%)	9 (90.0%)	5 (62.5%)	16 (88.9%)	10 (100.0%)	6 (75.0%)
~	14 (77.8%)	10 (100.0%)	4 (50.0%)	16 (88.9%)	6 (90.0%)	7 (87.5%)

		EP Titles				EP Definitions	
EP Title	Total $(n = 18)$	Stakeholder ( <i>n</i> = 10)	Academic ( <i>n</i> = 8)	EP Definition	Total $(n = 18)$	Stakeholder ( <i>n</i> = 10)	Academic ( <i>n</i> = 8)
1. Focus on community perspectives and determinants of health	17 (94.4%)	10 (100.0%)	7 (87.5%)	Community-engaged research addresses the concept of health from a holistic model that emphasizes physical, mental, and social well-being. It also emphasizes a community perspective on health that includes individual, social, economic, cultural, historical, and political factors as determinants of health and disease.	16 (88.9%)	10 (100.0%)	6 (75%)
2. Partner input is vital	17 (94.4%)	10 (100.0%)	7 (87.5%)	Meaningful participation is achieved through the collective efforts of all partners contributing to the generation of ideas. All partners understand each other's needs, goals, available resources, and capacity to develop and participate in community engagement activities. Structures and processes facilitate sharing information, decision-making power, and resources among partners.	18 (100.0%)	10 (100.0%)	8 (100.0%)
3. Partnership sustainability to meet goals and objectives	17 (94.4%)	10 (100.0%)	7 (87.5%)	Community-engaged research involves a cyclical, iterative process that includes partnership development and maintenance, where communications between the community partner(s) and the academic researchers are ongoing and bidirectional to meet mutually agreed-upon goals and objectives.	18 (100.0%)	10 (100.0%)	8 (100.0%)
<ol> <li>Foster co-learning, capacity building, and co-benefit for all partners</li> </ol>	18 (100.0%)	10 (100.0%)	8 (100.0%)	Community-engaged research is a co-learning and empowering process that facilitates all partners sharing and transferring knowledge, skills, capacity, and power so that findings and knowledge benefit all partners. It integrates knowledge and action for mutual benefit of all partners. There is a commitment to the integration of research results and community change efforts with the intention that involved partners will benefit.	17 (94.4%)	10 (100.0%)	7 (87.5%)
5. Build on strengths and resources within the community or patient population	18 (100.0%)	10 (100.0%)	8 (100.0%)	Community-engaged research seeks to identify and build on strengths, assets, resources, opportunities, and relationships that exist within identified communities to address their communal concerns. All partners appreciate the complementary assets and resources that communities and patients may provide.	17 (94.4%)	10 (100.0%)	7 (87.5%)
6. Facilitate collaborative, equitable partnerships	18 (100.0%)	10 (100.0%)	8 (100.0%)	Community partners and academic researchers share power and responsibility equitably. Diverse perspectives and populations are included in an equitable manner. Potential barriers to participation are addressed, communication and program activities are culturally appropriate, and all partners receive equal respect. Partners agree on who has access to research data and where the data will be stored. The addrenic researchers and the community partners commit to working in partnership toward achieving the study goals and to honor the commitments made to one another throughout the research process.	18 (100.0%)	10 (100.0%)	8 (100.0%)
7. Involve all partners in the dissemination process	18 (100.0%)	10 (100.0%)	8 (100.0%)	The partners establish appropriate policies regarding ownership and dissemination of results. With partner agreement, findings are disseminated to all partners and beyond the partnership in understandable and respectful language. All partners are invited to	18 (100.0%)	10 (100.0%)	8 (100.0%)

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Health Research Alliance Author Manuscript

# Table 4.

Engagement Principles (EP) and Definitions: Frequency and Percent Final Consensus (Round 5)

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Health Research Alliance Author Manuscript

		EP Titles				<b>EP Definitions</b>	
EP Title	Total $(n = 18)$	Total $(n = $ Stakeholder $(n = 18)$ = 10)	Academic (n = 8)	EP Definition	Total $(n = 18)$	Stakeholder ( $n$ Academic ( $n$ = 10) = 8)	Academic ( <i>n</i> = 8)
				review and be coauthors of publications and co-presenters at conferences as appropriate.			
8. Build and maintain 18 trust in the partnership (100.0%)	18 (100.0%)	10 (100.0%)	8 (100.0%)	Researchers and practitioners need to understand the cultural dynamics and history of specific groups and institutions in order to effectively identify ways to collaborate and to build respect and trust among all partners. This is an ongoing effort for all involved in the community engagement process and includes demonstrating one's own trustworthiness and the ability to follow through on promises and commitment.	18 (100.0%)	10 (100.0%)	8 (100.0%)