Answers to Questions Asked During the Webinar

Provided by: Melody S. Goodman, Ph.D. New York University Methods: Mind the Gap March 25, 2020

- 1. I would appreciate hearing more about the [Community Research Fellows Training] CRFT program with teens you recently piloted. My research focuses on the adolescent population and partnering with them to design interventions from a user-centered design approach. Thus, I would enjoy hearing more [about] how you partnered [with] and included teens as fellows!
 - a. Please see our publication that describes the program adaptation with youth entitled <u>Adaptation, implementation, and evaluation of a public health research methods</u> <u>training for youth</u>.
 - b. If you have any further questions this publication does not address, please reach out.
 - c. Thank you for your question!
- 2. When making research materials, what literary level should we be aiming for, based on what you are observing in your community outreach training program?
 - a. We try to aim for an 8th grade reading level; most of our participants have at least some college education, but there are some with lower levels of education.
 - b. For further information on the CRFT program curriculum, please see our book:
 - i. Goodman, MS and Thompson, VS. *Public Health Research Methods for Partnerships and Practice.* New York, NY: Routledge, Taylor & Francis Group; 2018.
 - c. Thank you for your question!
- 3. Have you engaged participants from IDeA states (historically low funding), and parents of child participants?
 - a. We have engaged participants from IDeA states:
 - i. Our Delphi panel included three members from Kentucky.
 - We had participants engage in our longitudinal web-based surveys from Puerto Rico, Alaska, Arkansas, Delaware, Kentucky, Louisiana, Maine, Mississippi, Nebraska, Nevada, New Hampshire, New Mexico, Rhode Island, and South Dakota.
 - iii. So far, in our implementation study, we have teams from Louisiana and Kansas.
 - b. We have not specifically recruited parents of child participants. We are still looking for more project teams to implement the REST as part of our implementation phase, and are open to any suggestions you may have.
 - c. Thank you for your question!

4. How can we obtain copies of the longer (32-item) survey and the shorter (nine-item) survey?

- a. Please see our most recent publication on the measure entitled <u>Content validation of a</u> <u>quantitative stakeholder engagement measure</u>.
- b. The list of 32 items can be found in Table 5. This version of the items was before the cognitive interviews mentioned in the presentation—we have since modified the

wording and language of several items. This manuscript is still in progress, and this is the version of the items we are currently using in the implementation study.

- c. The shorter nine-item version is still a work in progress.
- d. Please feel free to contact us if you need it immediately and let me know if you have any questions.
- e. Thank you for your question!

5. If a researcher wants to use the measure of engagement, how does one proceed?

- a. We are still currently recruiting teams who may be interested in working with us to implement the measure (REST) and provide feedback (this includes research partner and project team member incentives for participating). If you would be interested, please feel free to reach out to our project manager, Nicole Ackermann, at nackermann@wustl.edu, and she can send you more information.
- b. Please feel free to contact us if you need it immediately and let me know if you have any questions.
- c. Thank you for your question!
- 6. Can you talk more about how you formed your Delphi panel? Specifically, how did you avoid including just a convenience sample of folks your team already knew versus achieving broad representation? Also, on a related note, does your measure address this issue of stakeholder selection/representativeness in evaluating engagement?
 - a. We used a convenience sample for the Delphi panel recruitment; we recruited panelists by reaching out to those we knew were in the field via email, using a snowball sampling approach based on the networks of project team members.
 - i. We also used the networks of recruited academic panelists who recommended community partners they worked with.
 - We ended up with a nationally representative sample of panelists, many of whom are well known in the community engagement space as researchers (e.g., Consuelo Wilkins, Elizabeth Baker) and as research partners (e.g., Melvin Jackson, Lorretta Jones).
 - b. There are a few items within the measure that address the issue of stakeholder selection/representativeness in evaluating engagement including:
 - i. The team includes representation from the local community or patient population.
 - ii. The team works with existing community groups and organizations.
 - c. Thank you for your questions!
- 7. Are these measures readily usable among community-based participatory research (CBPR) in different subpopulations (e.g., rural folks, racial/ethnic groups, sexual and gender minorities)?
 - a. We have not tested the measure among different subpopulations yet. We are hoping that after we have the initial validation of this measure complete, we can continue future work in this area. We have also received feedback desiring the measure in other languages, specifically Spanish, so we plan to pursue funding to work on this in the future with appropriate collaborators.
 - b. As part of the measure validation process, we are also looking into how the measure functions in different groups, by age, education, sex, and race, and hope that if we do find differential functioning, we can use a computer-adapted algorithm to address some

of these issues. Unfortunately, we did not collect detailed data regarding sexual and gender minorities so that is a limitation and area for future research.

c. Thank you for your question!

8. How did the research team address selection/sampling biases while measuring real engagement?

- a. We recruited very broadly and nationally in hopes that we would reach participants of projects among all levels of engagement; however, it is still possible that there may have been selection bias among respondents, with those more engaged being more likely to respond.
 - i. Although the data were skewed to the left (toward higher engagement), we did see a range of responses.
- b. Thank you for your question!

9. How do you measure the outputs and research engagement of community partners as CRFT participants following program completion?

- a. We currently measure this more informally. In CRFT-St. Louis (STL), we have a very strong alumni network. The first cohort of fellows developed the <u>Patient Research</u> <u>Advisory Board</u>, and they continue to meet monthly and are active in several projects (including our Patient-Centered Outcomes Research Institute (PCORI) project). They also reach out to fellows after graduating from CRFT and interact with fellows from all cohorts.
- b. We also keep in contact with alumni of the program who wish to remain actively involved via email and an alumni Facebook page.
- c. In 2018, we contacted all alumni inquiring about activities and updates. We maintain a database of active CRFT alumni contact information and alumni updates.
- d. We have written papers on two pilot projects, one from the Community Alliance for Research Empowering Social Change entitled <u>Brentwood community health care</u> <u>assessment</u>, and the other from CRFT entitled <u>Training community members in public</u> <u>health research: Development and implementation of a community participatory</u> <u>research pilot project</u>.
- e. Thank you for your question!

10. How are your eight principles similar to or different from the nine principles of CBPR?

- a. They are similar and overlap with one another. We modified the principles from the CBPR principles, community-engaged research (CER) principles, and patient-centered research engagement principles in the literature, and created measureable items from this. For development on the original 11 engagement principles measure, please reference the publication entitled <u>Evaluating community engagement in research</u>: <u>Quantitative measure development</u>, which describes the literature from which the principles were developed.
- b. For the refinement of the 11 engagement principles measure to the eight engagement principles measure, please reference the publication entitled <u>Content validation of a</u> <u>quantitative stakeholder engagement measure</u>.
- c. Our measure engagement principles are different from the CBPR principles in that we include a principle on trust, and our wording and definitions differ based on input from stakeholders during the Delphi process.
- d. Thank you for your question!

- 11. Although this is presented as a measurement tool, can the items also function as a guide for "how to" engage non-academic external partners in research?
 - a. Possibly—having partners respond positively to all items within the measure would indicate a higher level of partner engagement or a more developed partnership, so I suppose a team could use the items as a guide to follow. However, we have not tested the measure in this way. The engagement principles and definitions of these principles used to develop the measure (we have a paper in press about this) may be more helpful in partnership development.
 - b. Thank you for your question!
- 12. For the initial survey (you showed a map with respondents by state), how were survey participants identified?
 - a. We recruited survey participants through various methods, including our team members' networks, searching for researchers and organizations this could apply to and emailing them (including health departments, Clinical and Translational Science Awards Program, Prevention Research Centers, Transdisciplinary Research on Energetics and Cancer Centers, National Institute on Minority Health and Health Disparities Centers of Excellence, Community Networks Programs, Regional Health Equity Coalitions, and a general database of CER researchers we developed). We also used the recruitment resources at Washington University in St. Louis, including the Washington University Recruitment Enhancement Core, and <u>ResearchMatch</u>.
 - b. In addition to virtual recruitment, we also recruited in person by attending various events, including local health fairs and community partner meetings and national conferences related to community engagement.
 - c. Thank you for your question!
- 13. You mentioned that you had an editor who attended meetings and that this was very helpful. Can you tell us more about what the editor did and the value [she] added?
 - a. The editor reviewed everything we were modifying, including engagement principles and definitions, REST items, and levels of partner engagement definitions, and edited them for grammar and language consistency. She also was present at the in-person meeting and listened to panelists' conversations and provided alternative suggestions, which we were able to have panelists vote on and discuss on day 2 of the in-person meeting.
 - b. She helped with making sure the language we were using was consistent and clear.
 - c. Thank you for your question!
- 14. Did you run into situations where there was an area of engagement that is rated poorly but improvement was limited by resources, institutional barriers, etc.? Are there any engagement principles where this is more likely to be found?
 - a. We have not specifically looked into this. We are developing a measure and measuring other partnerships (not our own) for the most part, and did not ask information about context.
 - b. We are working on how to interpret the results in the implementation phase, but it is important that this happens in context of the partnership, including available resources and institutional barriers. There is no judgment in the measure about where a partnership should be; in some instances, minimal engagement may be most appropriate and/or feasible.

c. Thank you for your questions!

15. Once you assess engagement, how often would you recommend reassessing?

- a. We are hoping that one use of the measure will be to measure changes in the level of engagement in a project or partnership over time. In such cases, teams could potentially survey partners using the measure at a few time points across a partnership or project as the relationship develops. We do not have a specific timeline we recommend currently, and imagine this could look differently for different projects. We acknowledge that partnerships and relationships take time to develop, so it is unlikely that you would see a change in engagement level over a shorter period of time.
- b. This project developed from an annual assessment we were conducting among our partners. In our context, this was an appropriate frequency.
- c. Thank you for your question!
- 16. Currently, meeting attendance frequency is the only available metric to measure stakeholder engagement. Do you have any recommendations how to enhance that for right now? What is the best way (visually) to share those results with stakeholders?
 - a. We are hoping that our measure, REST, can enhance this and be used by teams to more accurately measure both the quality and the quantity of engagement.
 - b. We shared results with the Delphi panel via personalized reports. In these reports, we provided the panelists a brief summary (less than one page) of the results, followed by in-depth detailed tables containing all results, if they were curious and wanted to know more. We also preceded delivery of these reports with a webinar (that was also recorded for those who could not attend) in which we presented a PowerPoint of results. Project team members work hard to determine the best way to present information, which really depends on the message we are trying to communicate. We use graphs, maps, and figures as appropriate.
 - c. In the implementation phase currently in progress, we are working on developing report templates to provide results of the partner surveys to teams, but this is still a work in progress. We plan to follow up with teams after they receive the results via a web survey and phone interview to gather feedback on this, so we hope to have more information on this in the future.
 - d. Thank you for your questions!
- 17. There is substantial published literature about barriers and facilitators of policy-maker collaboration with researchers to identify policy-relevant research questions. To what extent is the first tool informed by that literature?
 - a. We modified the majority of the engagement principles from the existing literature on CBPR and CER. We did not have a specific focus on policy-makers or policy-relevant research questions. For development on the original 11 engagement principles measure, please reference the publication entitled <u>Evaluating community engagement in</u> <u>research: Quantitative measure development</u>, which describes the literature from which the principles were developed.
 - b. For the refinement of the 11 engagement principles measure to the eight engagement principles measure, please reference the publication entitled <u>Content validation of a quantitative stakeholder engagement measure</u>.
 - c. Thank you for your question!

- **18.** Would any of this be utilized differently for researchers embedded within organizations and not an academic institution?
 - a. We hope that the measure can be used broadly and have some researchers embedded within organizations (although most are also affiliated with an academic institution) taking part in our implementation phase of the study. The language of the measure is purposefully broad so that many will be able to use it. We do not specifically mention academic institutions in the items language, but use the term partners.
 - b. Thank you for your question!
- 19. Thank you for sharing your psychometric process. For the engagement scale, you mentioned that removing an item related to co-authorship would marginally increase internal consistency. Was this item removed prior to larger implementation and IRT studies?
 - a. No—at this time we did not remove that item. In the 32-item version of the measure, this item is part of an engagement principle that only includes three items, and since the increase in internal consistency was marginal, we left it as is. We did remove this item and the corresponding engagement principle from the condensed nine-item version of the measure.
 - b. Thank you for your question!
- 20. You mentioned trust and power (I'd say perceived power) as factors in engagement. Can you elaborate?
 - a. We added the engagement principle "Build and maintain trust in the partnership" during the Delphi panel process as suggested by the panelists. The engagement principle includes five items in the full 32-item version of the measure related to trust. We define this as "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." (Source: Goodman M, Ackermann N, Bowen D, Thompson, V. Reaching consensus on principles of stakeholder engagement in research. Progress in Community Health Partnerships: Research, Education, and Action. [In press].)
 - b. Thank you for your question!

21. Can the research literacy measure be used by someone who has not taken the training?

- a. Yes—we also used the research literacy measure in our PCORI study with participants who had taken CRFT and participants who had not taken CRFT. The questions in the research literacy measure are broad in the hopes that the measure can be used as a general measure of research literacy, not just specific to the CRFT program.
- b. Thank you for your question!
- 22. I wanted to know more about the CRFT program. Is this offered online? Where would I find more information regarding this program?
 - a. The CRFT program is not currently offered online. In CRFT-STL, we have thought about offering the program online (especially now during the COVID-19 pandemic); however, we have found that one of the great benefits from the program is the in-person interaction among CRFT fellows and faculty, so we have kept to an in-person model.
 - b. For further information on the CRFT program curriculum, please see our book:

- i. Goodman, MS and Thompson, VS. *Public Health Research Methods for Partnerships and Practice*. New York, NY: Routledge, Taylor & Francis Group; 2018.
- c. Please visit the <u>CRFT-STL program website</u> for more information.
 - i. You can find many publications on the program listed at the bottom of the webpage.
- d. Please visit the <u>Jackson Heart Study Community Engagement Center website</u>, which mentions the CRFT Mississippi program. The CRFT Mississippi program has a publication entitled <u>Increasing research capacity in underserved communities: Formative and summative evaluation of the Mississippi Community Research Fellows Training Program (Cohort 1).</u>
- e. The youth CRFT has a publication entitled <u>Adaptation, implementation, and evaluation</u> of a public health research methods training for youth.
- f. Thank you for your questions!

23. How can I register for CRFT?

- a. Please see the answer to the above question (#22) for links to more information on the CRFT program. If you are in the St. Louis area and interested in the program, please email us at <u>crft@wustl.edu</u>.
- b. If you are interested in adapting the CRFT program for your area, please reach out and let us know if you have any questions!
- c. Thank you for your question!

24. You mentioned females were more likely to participate in research; do you have a solid citation for that? Many of us are struggling to balance our samples on sex assigned at birth; it would be nice to have a citation for it.

- a. Unfortunately, I don't have a citation for this. To be clear, I was referring to survey research and CER, not clinical trials for which there is a wealth of literature showing the opposite is true. I brought this up in the presentation because we are striving for more gender equity among Delphi panelists and survey participants but received anecdotal responses from Principal Investigators that most of their partners were women, which would suggest that our sample (despite the gender imbalance) is representative of this population.
- b. Thank you for your question!

25. How are the teams identified? Is there eligibility criteria to consider for participation in the implementation phase? How would a team express interest in participating?

- a. We reached out to teams or researchers involved in some sort of engaged research (CER, stakeholder-engaged, patient-engaged, etc.) via email and expressed the intent of our project and of REST. Outside of that, the only other eligibility criteria is having use for a tool in English, as that is currently the only available language right now. If a team is interested in participating, we encourage them to reach out to us. You can contact our project manager, Nicole Ackermann, at nackermann@wustl.edu and she will send you more information.
- b. Thank you for your questions!

26. Are all engagement principles created equal—were there some seen as most critical by stakeholders?

- a. In the current way we calculate the overall measure score, all engagement principles are weighted equally. However, when we were narrowing down items for the condensed version of the measure, we did take into consideration the importance rankings of engagement principles from the Delphi panelists. Although the responses were varied among panelists, engagement principle seven "Involve all partners in the dissemination process" was consistently rated the lowest, so this was one of the reasons it was excluded from the condensed version of the measure we are developing. Panelists consistently rated engagement principle "Focus on community perspectives and determinants of health" as the most important.
- b. Thank you for your question!
- 27. Have you reviewed or come across work done on CBPR outcome measures by J Sandoval, J Oetzel, N Wallerstein, et al., for example, Process and outcome constructs for evaluating communitybased participatory research projects: A matrix of existing measures (2012)? If yes, how did it inform your current work?
 - a. Yes—in reviewing the literature and developing the original version of the measure, we cited several papers from Wallerstein and others. We did not cite this exact citation, but we did cite similar works.
 - Please see the reference entitled <u>Evaluating community engagement in research</u>: <u>Quantitative measure development</u>, which describes the literature from which the principles were developed.
 - c. We did review this article prior to the development of our longitudinal web surveys in which we included existing measures to compare REST to, and a few were included in our comparisons when we described the correlative validity of our measure.
 - d. Thank you for your questions!
- 28. Would this measure help to see the engagement shifts through something like COVID-19? For example, those teams in place prior to beginning stage engagement, if they took it now in the midst, and then after? Is it sensitive to change in those contexts?
 - We are hoping that the measure can be used by research teams to track engagement over time, assuming that at the beginning of a partnership, engagement scores would be lower, and as time goes on and the relationship develops, they would increase. However, we have not yet formally tested that.
 - b. Thank you for your questions!
- 29. I believe that you mentioned that participants in Delphi were primarily White and African American. Is this also the case in the implementation phase? Do you expect differences among different cultural groups?
 - a. Project team members who completed our baseline study are Non-Hispanic/Latino(a) White: 75%, Non-Hispanic Black: 11%, Hispanic: 5%, and Asian or Pacific Islander: 9%.
 - b. Partners of teams who have implemented REST are Non-Hispanic Black: 63%, Non-Hispanic White: 28%, Hispanic: 5%, Asian or Pacific Islander: 3%, and Other: 1%.
 - c. There may be differences among cultural groups and investigating this is an important next step.
 - d. Thank you for your questions!

- **30.** Have you thought about measures for research readiness of stakeholders (academic and/or community) that conduct CER?
 - a. We have not worked on measures of this topic, other than the research literacy measure, which may measure one aspect of research readiness in the form of research knowledge and understanding of research.
 - b. Measures of readiness for both academic and non-academic partners could make significant contribution to the literature.
 - c. Thank you for your question!
- 31. You used a variety of analytical approaches—Delphi method, internal consistency, etc. What kinds of conversations did you and your team have about mixed data validation and integration? Also, does the partnership combination (e.g., community-university) matter? Could it be used in multiple sectors?
 - a. Our research team has monthly phone calls and includes members with expertise in quantitative methods and qualitative methods. All investigators have experience with mixed-methods research. We had conversations throughout the process surrounding survey development and data collection methods, and triangulation of results across methods.
 - b. We think the measure could likely be used in multiple sectors. Please see our answer to question #18 for further explanation related to this topic.
 - c. Thank you for your questions!
- 32. I see that you've used PSAT. Did you use some of its questions and integrate its domains, such as synergy (partnership synergy), leadership, efficiency, management, resources, decision making, participation, and satisfaction?
 - a. We used PSAT as a measure to compare our measure to in terms of correlative validity (and discriminant validity) because we saw similarities between our measure and the PSAT. We did not specifically integrate any questions or domains from PSAT, although it is possible that the measure pulled from similar literature we used to develop our measure, so you can see the similarities across the domains and our engagement principles.
 - b. Thank you for your question!