

**Process Evaluation of the Community Engagement Alliance Consultative Resource  
(CEACR)**

by

**Nadia Lena Jones**

Bachelor of Arts, University of Pittsburgh, 2016

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This essay is submitted

by

**Nadia Lena Jones**

on

June 23, 2023

and approved by

**Essay Advisor:** Patricia Documet, MD, DrPH, Associate Professor and Director of the Doctoral Program, Behavioral and Community Health Sciences, School of Public Health, University of Pittsburgh

Essay Reader: Patricia Documet, MD, DrPH, Associate Professor and Director of the Doctoral Program, Behavioral and Community Health Sciences, School of Public Health, University of Pittsburgh

Essay Reader: Mylynda Massart, MD, Ph.D., Associate Professor, Family Medicine, School of Medicine, University of Pittsburgh

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# **Process Evaluation of the Community Engagement Alliance Consultative Resource (CEACR)**

Nadia Lena Jones, MPH

University of Pittsburgh, 2023

## **Abstract**

The Covid pandemic affected racial/ethnic minorities and underserved communities disproportionately, highlighting the pervasive structural inequities within the United States. The NIH Community Engagement Alliance (CEAL) reflects the partnership of 21 academic institutions and community-based organizations to combat mistrust and disseminate community-engaged best practices to ensure representation of communities of color in health research focused on Covid prevention and treatment.

The Community Engagement Alliance *Against Covid-19 Disparities* Consultative Resource (CEACR) is a consulting system to aid in the timely delivery of best practices by providing tailored recommendations to NIH-funded research teams. This essay is a process evaluation that examines each step of the CEACR consultation process. The CEACR Senior Project Coordinator reviewed the number and type of consultation requests, client surveys, and other data. This essay describes the barriers and facilitators to programmatic activities' fidelity, dose, and reach and captures iterations to the consultation process to date.

CEACR was expected to create an asset map of CEAL resources to support consultation services, develop tools to facilitate consultations, average three consultations per month, and measure satisfaction with services and the utility of recommendations.

CEACR created a CEAL Asset Map totaling over 1,000 resources like community-based partners and organizations working with each CEAL site's academic/research institution. CEACR created a roster of 152 experts. In launch, CEACR facilitated 39 service requests and completed 33, meeting its objective of averaging 3 consults per month. CEACR hosted 15 expert panel sessions guided by 56 subject matter experts. The recommendations delivered to six national Covid research teams represented academic and community-based expertise. Consultation tools created included three REDCap forms to facilitate the consultation process and four REDCap surveys for evaluation; surveys were sent to six of 17 consultees and five completed surveys were received. The 30-, 90- and 180-day surveys were administered to fewer consultees.

Client feedback suffered due to inconsistent evaluation activities. Improved evaluative efforts should include an internal activity log, dedicated evaluation staff, and continuous quality improvement (CQI) to detect problems mid-course. An invigorated evaluation will aid in CEACR's goal to improve the inclusion of ethnic and racial minority individuals in research.

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## 1.0 Introduction

Black, Native American, and Hispanic people often referred to as BIPOC, experience a myriad of social and economic inequities that increase their risk of disease (1). At the height of the Covid pandemic, engagement of these racial and ethnic minority groups in clinical trials was deemed critical to diversify representation (1). Data suggests that ethnic/racial minoritized groups are not represented in early Covid vaccine trials (1), and many structural interventions were put in place to increase diverse participation in all Covid research.

The Covid pandemic exacerbated existing health disparities amongst ethnic/racial minority groups and underserved communities. BIPOC individuals experience a host of stressors across the socioecological framework while discrimination decreases their quality of life. The pandemic's effect on minority groups was evident with a higher rate of sickness and death observed in Black, American Indian, and Hispanic/Latino populations compared to those who identify as White (3). The involvement of BIPOC communities in research is essential for capturing generalizable data and improving trust in the research outcomes and eventual acceptance of treatments and interventions developed from the research (2).

Community-based participatory research (CBPR) is a research approach that brings community members into each step of the process (10). Its design addresses health disparities and improves health outcomes in marginalized communities. Community engagement in research spans a range of activities including outreach to shared leadership and beyond (3). Effective community-engaged research requires skill and adequate resources. Community involvement in each step of the scientific process enhances the effectiveness of the intervention and serves as a

bridge to equity. Community assets and needs are elevated in these approaches and reinforce reciprocity amongst multi-sector interest holders (10).

The NIH created the Community Engagement Alliance (CEAL) *Against COVID-19 Disparities* to apply a community-engaged approach to building trust in medical/research activities. CEAL was tasked with understanding and addressing factors that contribute to the disproportionate burden of Covid in underserved communities and applying community-engaged strategies to enhance awareness, education, access, trust, and inclusion in the science-based response to Covid. CEAL is comprised of 21 CEAL research teams working in tandem with community-based organizations in areas experiencing the disproportionate effects of Covid and other health disparities (3).

The NIH recognized the need to support the CEAL teams by offering technical assistance, resources, and best practices for community engagement amidst a public health crisis and an additional resource to help with the rapid development and implementation of best practices learned from CEAL applied to other national Covid clinical trials. This resource is called the CEAL Consultative Resource (CEACR). CEACR leverages and serves as an integral component of the overall CEAL Alliance to provide flexible and tailored guidance around (1) community engagement and (2) community-engaged research within underserved communities of color. CEACR was generated to coordinate and support a community of practice across the CEAL Alliance and to offer flexible and timely consultation services to increase inclusive participation through the dissemination of best practices. The objective of this essay is to review the implementation process of CEACR services against the NIH CEAL's original vision and goals for the consulting arm. The evaluation metrics captured throughout CEACR's implemented activities

since inception through year 1.5 are measured to determine the program's dose, reach, and fidelity aligns with NIH goals toward increasing inclusive participation in clinical trials related to Covid.

## **2.0 Background**

### **2.1 Establishment of the Community Engagement Alliance Against Covid-19**

The Community Engagement Alliance (CEAL) Against COVID-19 Disparities is a National Institute of Health (NIH) program that elevates community-based approaches to inclusive participation in health research and clinical trials related to Covid prevention and treatment. Hosted under the National Heart, Lung, and Blood Institute (NHLBI), the project was erected in 2020 to alleviate the burden of Covid on ethnic and racial minoritized communities by mobilizing trusted messengers to dispel misinformation, engage communities in vaccination uptake, and adequately reflect the country's diversity in Covid research. The Alliance combines academic and community-based partners in efforts to thwart health disparities exacerbated by the pandemic over the last few years. Misinformation and mistrust left swaths of underserved communities especially vulnerable as the coronavirus took its hold on communities of color (12). The NIH recognized that evidence-based information needed to be delivered by vehicles of trust, so they implemented 21 CEAL sites in major academic institutions across the United States with the expectation that together the academic sites and their community-based partners would level the playing field and combat mistrust in marginalized communities (10). These partnerships would eventually lead to a wealth of resources that would serve as a community of practice for academic and community-based efforts to improve inclusivity in research. Together the NIH CEAL teams work to provide trustworthy, science-based information through active community engagement and outreach to the communities affected most by health disparities. NIH CEAL's goal is to build long-lasting partnerships using a platform of tools and resources intended to increase the capacity of

communities to address health inequities. The platform supports stakeholders to systematically study and advance health equity and the field of community-engaged research.

## **2.2 The Importance of Diverse Participation in Research and the Need for CBPR**

Engagement of BIPOC communities in clinical research around Covid and all health concerns is critical in translating results to all populations and increasing confidence, acceptability, and uptake of treatments and interventions developed. Recent data highlight the relative absence of BIPOC communities in the early Covid vaccine clinical trials (1). Intentional and effective community engagement methods through CEAL were needed to improve BIPOC inclusion. Trials opening later in the pandemic benefited from strengthened community engagement efforts led by the CEAL Alliance, and greater and more diverse volunteer registry records (1). With appropriate resources, commitment, and community engagement expertise in research, the representation of BIPOC individuals in clinical research trials more closely mirrors population demographics (3). To ensure this goal, intentional efforts were needed to address and correct misperceptions, misinformation, and myths around research (1). Community-Based Participatory Research (CBPR) approaches emphasize the diversity of enrollment in clinical trials, the establishment of enrollment goals, ongoing robust community engagement, and conducting population-specific trials and research to inform best practices while increasing community awareness and knowledge (1).

### **2.3 The Establishment of CEACR to Support Community-Engaged Research**

CEACR was established to elevate best practices throughout CEAL and to provide customized expertise to optimize inclusive participation across the research ecosystem. The short-term goals for CEACR are: 1) to leverage the expertise from across the CEAL Alliance to provide rapid, flexible, tailored consultations to a variety of end-users, and 2) to establish sustainable community-academic collaborations that address the disproportionate impact of the pandemic and other health inequities on minority and underserved communities. Given the urgency of the pandemic, CEACR initially focused on Covid-related community engagement and outreach, such as promoting vaccination acceptance and uptake, addressing vaccine hesitancy, promoting public health mitigation strategies, promoting diagnostic testing, acceptance of effective treatments, and approaches to increase diversity and inclusion in Long Covid research. CEACR has since expanded to address inclusive participation and health disparities within communities of color for research beyond Covid priorities.

### **2.4 Intro to the Importance of Evaluation of Process Metrics**

Process evaluation is a systematic method of assessing a program's implementation and serves as an essential component of community-based approaches to public health (6). This process assesses the implementation of the intervention and identifies areas for improvement. Process evaluation involves several steps, including planning, data collection, analysis, and reporting, and provides valuable insights for future improvements and helps to ensure the success of the intervention. It involves monitoring and documenting the program's activities and outputs



to determine whether the program is being implemented as intended. In community-based public health approaches, process evaluation is important as it helps ensure that the program is responsive to the community's needs and priorities.

The key components of process evaluation in community-based approaches to public health include measuring community engagement in terms of program fidelity, dose delivered, dose received, and reach (13). Program fidelity refers to the extent to which the program is implemented as intended. The dose delivered refers to the program's amount delivered to the target population. The dose received refers to the extent to which the target population engages with the program. Reach refers to the proportion of the target population that is exposed to the program. A complex systems approach is needed to evaluate these components to answer evaluative questions such as:

“To what degree are they reaching their intended audience? What level of service (dosage) is necessary to attain desired behavioral effects?” (8)

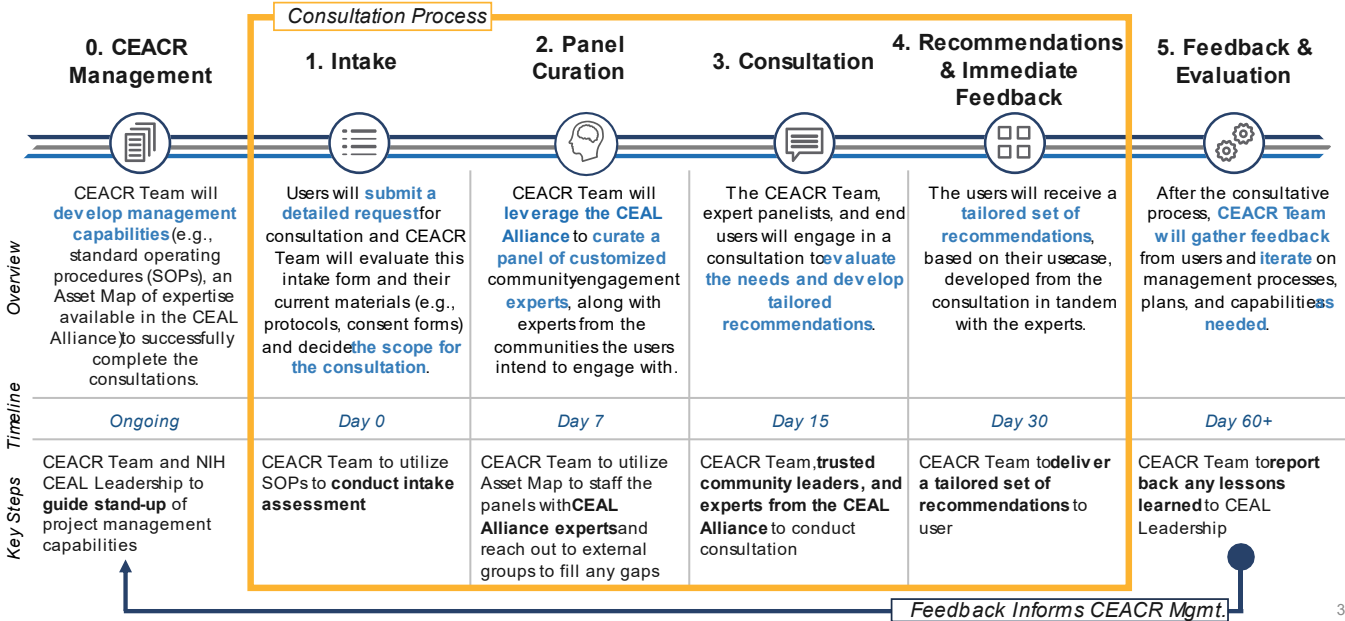
Process evaluation can be applied to various community-based approaches to public health, such as community health worker programs, participatory research projects, and community-based health promotion programs (13). For example, a process evaluation of a community health worker program would assess whether the program was implemented as intended, the number of community health workers trained and deployed, the number of people who received services from the community health workers, and the proportion of the target population that was reached. The evaluation would also identify any barriers to program implementation and provide recommendations for improvement (13).

## **2.5 Evaluation of CEACR as a Public Health Intervention**

Evaluating the implementation of CBPR interventions such as CEACR is essential to determine areas for improvement. (3). The process evaluation of public health interventions can help identify root causes for undesired effects and outcomes and help us understand a variety of factors that may contribute to the ultimate success or failure of the intervention. Process evaluation helps identify and learn why the activities succeed or fail to succeed and what factors contribute to their impact. This essay evaluates the process metrics of CEACR creation and implementation from inception through year 1.5 and describes the initial round of iterations implemented. Figure 1 highlights the NIH CEAL vision for CEACR activities, processes, and outcomes and serves as a baseline for fidelity.

# CEAL Vision for the CEAL Consultative Resource (CEACR)

The CEAL Consultative Resource (CEACR) was established to elevate best practices throughout CEAL and provide customized expertise to optimize inclusive participation across the research ecosystem.

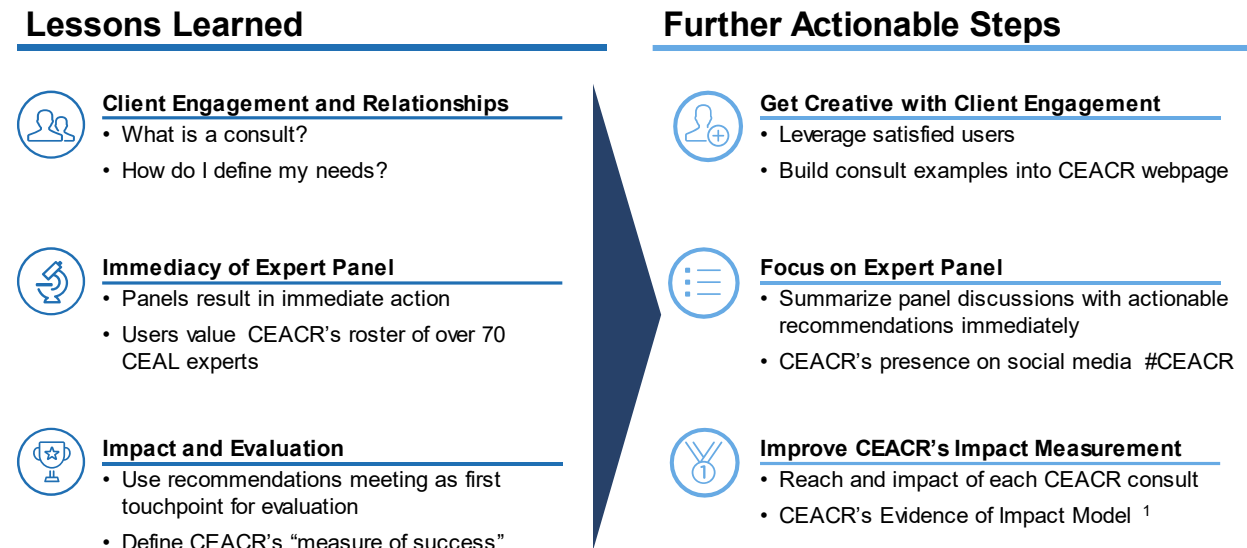


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Figure 1: CEAL Vision for the CEAL Consultative Resource (CEACR)

Figure 2 offers an overview of the lessons learned in CEACR’s first year of activities as well as suggested action steps to address discrepancies in reach, dose, and fidelity.

## CEACR: Converting Lessons Learned to Further Actionable Steps



<sup>1</sup>Appendix

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**Figure 2: CEACR: Converting Lessons Learned to Further Actionable Steps**

CEACR activities were reviewed to measure its effectiveness as a community-based intervention to increase minority participation in NIH-funded clinical trials. The CEACR Project Coordinator, author of this essay, conducted a process evaluation of CEACR consultative activities carried out since launch; this evaluation reviewed each step of the consultation process and the implemented iterations necessary to improve implementation fidelity. The process evaluation weighed the NIH CEAL's original vision for CEACR against the first 1.5 years months of program activities to determine if the intervention launched and progressed in a way the NIH CEAL initially envisioned. Data was collected on the fidelity of the program developed, the dose of deliverables, the reception to the deliverables, and the program's overall reach.

The following logic model (Table 1) details the components of this process evaluation of the CEACR program including both the process metrics and their iterations documented within the rest of this essay. The process evaluation was carried out during the first year of activities and continued throughout the second year of program activities. The gathered program metrics are indicative of how well the program was implemented according to the NIH's original vision. Consultee participation, expert panel diversity metrics, and exposure to services were tracked to understand the level of diverse opinions of thought included in expert recommendations (expert panelist) as well as satisfaction with client requests. Participant data, satisfaction surveys, program debriefing, and REDCap tools were reviewed to track how closely CEACR consult activities were implemented as described in the project's defined statement of work. The upcoming Methods section details steps taken to implement CEACR consultation activities.

**Table 1: Logic Model CEACR Year 0 – 1.5**

Assumptions	Inputs	Activities	Outputs	Short-Term Outcomes	Long-term Outcome
<p>COVID-19 has affected marginalized communities disproportionately.</p> <p>Marginalized communities receive misinformation about COVID-19 &amp; mistrust the medical system.</p> <p>Community-based participatory research</p> <p>-Enables community to take the lead in solving their own problems.</p> <p>-Fosters trust</p>	<p>CTSI and CCPH partnership</p> <p>Funded grant</p>	<p>Prepare asset map (resources &amp; experts)</p> <p>Develop REDCap tools</p> <p>NIH refers internal and external consultees</p> <p><u>Consultation</u> Phase 1: Receive request &amp; conduct intake session Phase 2: Host expert panel session Phase 3: Team staff apply HCD and conduct Recommendation Session</p>	<p>Asset map</p> <p><u>REDCap Tools</u></p> <p>-Consult Request Form</p> <p>-Intake Form</p> <p>-Internal Tracking Form</p> <p>-Satisfaction, 30-, 90-, &amp; 180-day Surveys</p> <p>12 organizations request consultation per year</p> <p><u>Consultation</u></p> <p>-Phase 1: Completed Consult Request Form, 60-minute Intake Meeting</p> <p>-Phase 2: CEACR Panelists, Tailored Recommendations</p> <p>-Phase 3: Recommendations PowerPoint, 60-minute Recommendation Session with Consultee</p>	<p>Consultees will gain knowledge about best practices to community-engaged approaches to research recruitment</p> <p>Consultees apply/disseminate best practices</p>	<p>Ethnic and racial minority participation increases in consultees' projects</p>

### **3.0 Methods**

This section describes the steps taken to organize, implement, and evaluate CEACR consulting services. I am going to explain the organization of CEACR, and then I will describe the evaluation methods.

#### **3.1 CEACR Structural Organization**

The CEACR team is led by Principal Investigator, Dr. Mylynda Massart and Co-Investigator Dr. Elizabeth Miller from The University of Pittsburgh Clinical and Translational Science Institute (CTSI) Community PARTners (Partnering to Assist Research and Translation) core. CEACR is co-led by the Community-Campus Partnerships for Health (CCPH) directed by Mr. Al Richmond. CCPH is an international, nonprofit membership organization that supports individuals and organizations in their efforts to form authentic, equitable partnerships in the pursuit of policy, practice, and systems-level changes that support the health of our communities and eliminate health disparities. In the Spring of 2021, both Pitt CTSI and CCPH applied to the Research Opportunity Announcement OTA-21-016 Community Engagement Research Alliance (CEAL) Against COVID-19 Disparities: Consultative Resource. NIH CEAL leadership suggested that both teams work together as CEACR bringing together the resources of a major academic research institution and a community-based organization with proven success in engaging underrepresented populations. CEACR began activities in the Fall of 2021 upon hiring a Senior Project Coordinator (author of this essay) to join CEACR leadership, a Project Manager, and an

Evaluation lead. Additional team members were added during Year 2 of the project including two student workers, one research assistant, one evaluation member, and a new project manager. CEACR activities began with the standardization of processes as detailed in multiple standard operating procedures (SOPs). These SOPs defined the consultation and evaluation processes throughout the first 18 months (about 1 and a half years) of activities; each SOP defined the specific roles and communication activities necessary to facilitate, including the CEACR consultation process workflow by both internal CEACR staff and external programmatic staff within CETAC/WESTAT. CEACR. The National Institutes of Health funded Community Engagement Technical Assistance Center (CETAC) in the Public Health Sector of WESTAT, serves as the coordinating center that houses the Community Engagement Alliance's (CEAL) portfolio of programs. The Community Engagement Alliance Consultative Resource (CEACR) is a CEAL program supported by CETAC. In addition, a communication plan was established as well as meeting cadence both internal to the CEACR team and with the WESTAT/CETAC and NHLBI leadership. CEACR also worked closely with CETAC staff to identify existing CEAL site resources that contributed to the bulk of the CEAL Asset Map content.

### **3.2 Asset Map Design**

CEACR's ability to rapidly deploy CEAL resources was a critical component of CEACR activities. An asset map was created to capture existing resources available within the CEAL network which allowed for rapid identification of experts and resources for deployment in the consultative process. The map was developed during an extensive passive process where data was captured from all CEAL websites, NIH CEAL website, and prior CEAL monthly project reports



and social media. CEACR uses this resource to quickly identify and leverage CEAL resources to support all CEACR activities. This asset map feeds client requests for resources/assets i.e. rapid consult requests. These resources are organized into the following eight categories: population, tools, methodologies, partners, engagement strategies, reciprocity assets, disseminated resources/materials, CEAL subject matter experts, lived experience experts, and funding source (Appendix Figures 3-4).

### **3.3 REDCap Tool Development**

During the first year of activity, CEACR created the tools needed to facilitate the consultation process from intake to evaluation. REDCap is the primary data management tool used in the consultation process. CEACR used REDCap to create the following forms and surveys: Consult Request form, Intake form, Internal Tracking form, Satisfaction survey, 30-Day survey, 90-Day survey, and 180-day survey. These tools are used across the four phases of the CEACR consultation process (See Appendix C & D).

### **3.4 CEACR Consultative Process**

A four-phase consultation process was mapped during the launch of the CEACR project with one month per consultation and a workload of up to three consults per month (Appendix Figures 1-2). Consult activities are described throughout each of the four phases below from receipt of the consultation request to the evaluation of client satisfaction.

### *Phase 1*

Phase 1 begins the CEACR consultation process with a consultation request and intake session. NHLBI leadership facilitates and directs prospective consultation requests to the CEACR team. The first step of the CEACR Consultation process is to learn more about the client and their needs. During this stage, CEACR assesses the client's request: Is the client seeking resources, speakers, and/or contacts i.e., a “rapid” consult, or does the ask necessitate a deeper level of insight requiring a panel of experts to brainstorm ideas to assist client needs? The Senior Project Coordinator uses the consultee’s contact information from the received Consult Request form (Appendix Figure 5) to schedule an “Intake” meeting between the consulting team and CEACR. During the “Intake Meeting,” CEACR meets with the client to learn more about where they are in their project, their challenges, successes, and goals for the consultation. CEACR’s Senior Project Coordinator documents the details of the meeting including the consultee’s requests, timeline, and any initial feedback delivered, and outlines next steps and action items. This information is sent to the consultee within two days of the “Intake Meeting” to confirm client needs and programmatic expectations.

### *Phase 2*

Phase 2 consists of the internal processing, panel curation of experts, and hosting of the expert panel session. The CEACR team holds an internal debrief to review the information discussed during the “Intake”. CEACR discusses the next steps and begins sourcing relevant expertise to invite to the panel session essential to offering implementable recommendations. CEACR created a roster of experts in REDCap using the CEAL Panel Expert Interest Form (Appendix Figure 7). CEACR disseminated a REDCap link to the CEAL Panel Interest Form that captures contact information, affiliation, expertise, and availability. Any interest submitted

through the survey link populates in a REDCap dashboard, and the Senior Project Coordinator receives an email notification for each submission. The CEAL Panel Interest Forms are the primary source from which perspective panelists are identified. The panel discussion brings together a range of experiences that include both academic and community-based expertise. They are designed to allow space for guided dialogue on the real-world challenges facing research teams and attempt to integrate humanity into the research process. CEACR's expert panels allow traditionally silenced voices to be heard and put lived experiences alongside institutional practice. CEACR panelists inform the recommendations provided back to the consultee, and the vital importance of diverse representation in the discussion of strategies to increase inclusive participation is prioritized. The Senior Project Coordinator carefully plans the panel sessions to reflect the flexibility in approach needed to engage community-specific solutions. Expert panelists are sourced through a variety of channels: the CEAL Asset Map, CETAC Liaisons, CEAL site PIs, and internal CEAL meetings. CEACR hosts a roster of 151 expert panelists sourced to date and growing. This roster of expertise includes a range of CEAL-affiliated individuals from across the nation from both community- and academic-based backgrounds. Since its inception, NIH leadership has called upon CEACR to balance the diversity in perspective within CEACR Expert panels that offer community-based solutions to public health issues. CEACR continues to source interest from experts across the CEAL network many of whom have demonstrated success with the engagement and recruitment of ethnic and racial minority groups in clinical trials. Panel curation is critical to service quality and requires the ability to source panelists, confirm availability across multiple stakeholders, schedule across multiple time zones, and ensure the timely completion of panel participant payments.

The expert panel sessions are held virtually using Microsoft Teams and last between 60-90 minutes (about 1 and a half hours). Panel participants are sent an introductory email detailing the upcoming panelist opportunity. Panelists who confirm interest are subsequently sent a follow-up FindTime poll to survey their availability to attend. Meeting dates/times are offered to accommodate work schedules and time zones. Four to six interested participants are invited to ensure a minimum of at least three panelists per panel session. The FindTime poll is checked over a week, and reminders are self-generated to prompt non-responsive invitees to submit their availability to attend. Once three or more panelists confirm availability for a date/time, the Senior Project Coordinator schedules the CEACR Panel Session including the consulting research team members and CEACR staff. One facilitator arranged these discussions, and 2 CEACR staff facilitated the panel sessions. CEACR lead, Dr. Mylynda Massart, facilitates these virtual discussions using a *community engagement studio* model (9). Each expert panel session includes a facilitator from CEACR, at least one representative from the consultee's research team, and at least three subject matter expert panelists. The session begins with participant introductions before the consultee's team provides an overview of project activities and goals. The consultee representatives are present for the entirety of the session to offer clarity in project activities as needed. Guiding prompts are displayed as the CEACR facilitator moderates the discussion. Each panel session lasts from 60-90 minutes in comparison to the *community engagement studio* model's duration of 2 hours (9). All expert panel attendees are compensated \$100 an hour for their participation, double the compensation rate of the *community engagement studio* model (9). CEACR staff record the sessions, generate a transcript, and import the session chat. All session materials are uploaded to the consultee's folder in Microsoft Teams and analyzed for recurring themes/takeaways that inform subsequent "Recommendations". Only the consulting research team

is prompted for feedback on their experience with CEACR services differing from the *community engagement studio* model that prompts both the research team and contributing experts for feedback via paper.

### *Phase 3*

Phase 3 includes applying a human-centered design (HCD) approach to synthesizing panel session takeaways and themes using a virtual whiteboard to affinity cluster and organize the recommendations provided during the expert panels. These are then reviewed by the team, reported in a PowerPoint which serves as a durable resource for the consultee, and delivered to the consulting team in a “Recommendations Session”. The Satisfaction Survey (Appendix Figure 9) is provided at the end of the report-out meeting to allow the consultee to complete the REDCap survey offering any feedback on their immediate experience with CEACR. The recommendation power point is emailed to the consultee immediately following the “Recommendations Session”.

### *Phase 4*

Phase 4 of the consultation captures any feedback on the consultee’s experience, the utility of recommendations, and impact metrics. See the upcoming evaluation process for expanded details. Note, impact metrics will not be discussed in this essay and are currently under draft for publication.

## **3.5 CEACR Process: Evaluation Tools/Approach**

Consultee feedback is critical to measure the dose and reach of provided consultation services. Consultees are prompted for feedback on their experience with CEACR and asked to rate the utility of the recommendations delivered. All surveys are built and disseminated using

REDCap. Four surveys were developed to capture immediate, short-term, and long(er) term impact; an initial satisfaction survey, followed by a 30- Day, 90- Day, and 180 -Day (Appendix D). Each follow-up survey is tailored to measure the consult-specific recommendations that were provided by the expert panel. The survey instruments attempt to capture whether recommendations were implemented, why recommendations were/not implemented, the period in which the recommendations were implemented, and the overall utility of the offered recommendations. The Satisfaction Survey prompts consultees to rate their level of satisfaction with the overall experience of CEACR services up to the delivery of recommendations; timeliness, approachability, and confidence in applying discussed content are scored. The Satisfaction survey is administered immediately following each Recommendations Session (< 2 Days). The 30, 90, and 180-Day surveys are customized to include each consultee's delivered recommendations and prompts feedback on overall usefulness of recommendations, whether recommendations were implemented, and reasons why recommendations were not implemented. The 30-Day survey is sent 30 days post-delivery of recommendations i.e., Recommendations Session (Appendix Figure 10); the 90-Day survey is sent 90 days post-delivery (Appendix Figure 11), and the 180-Day survey is sent 180 days post-delivery (Appendix Figure 12). The Senior Project Coordinator sent a follow-up email reminder to non-responsive consultees including the consult-specific REDCap link within the body of the email; the frequency and consistency of these reminders varied with most reminders sent within 7 days of the initial prompt for feedback. All received survey responses were reviewed with the CEACR leadership team during standing biweekly meetings. No additional evaluative functions/tools were needed to assess the results of the received feedback. Survey responses were downloaded from REDCap and stored in each consultee's file in Microsoft Teams.

The process evaluation informing this essay captured implementation data from January 2022 through March 2023. Process metrics included expert panelist backgrounds, number of incoming consultation requests, populations of interests, topics of interest, and efforts to rate client satisfaction all of which contribute to project dose, reach, and fidelity and ultimately insight into the project's utility as a public health intervention. The results of these efforts are highlighted in the upcoming section.

## 4.0 Results

CEACR launched in October 2021 and began consultation activities in January 2022. This essay will focus on CEACR results in the initial 1.5 years since launch as it relates to the project's fidelity, dose, and reach. The upcoming sections review the results of the process metrics measured throughout this time frame beginning with a review of consult activities, evaluation metrics to determine client satisfaction, the diversity of thought utilized within CEACR activities, and ends with a revised evaluation plan guided by the iterations described within the essay. The following evaluation table (Table 2) summarizes the components of the process evaluation for CEACR's first 18 months of activities.

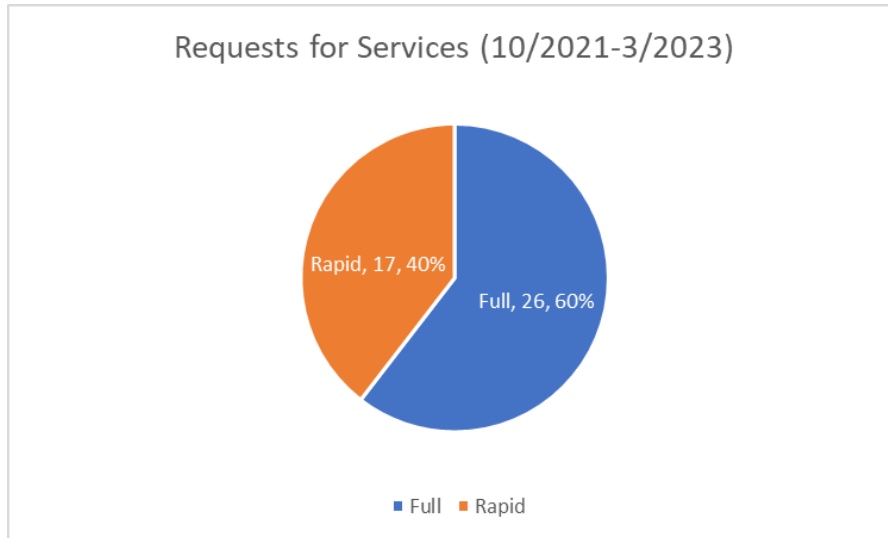


**Table 2: Summary of Process Evaluation Metrics for CEACR Yr 0-1.5**

<b>Process Evaluation Questions</b>	<b>Expected Output</b>	<b>Data Sources</b>	<b>Timing</b>
<p><b>Fidelity</b></p> <ul style="list-style-type: none"> <li>-To what extent is the program implemented consistently with the initial scope of work?</li> <li>-What types of engagement techniques are being used?</li> </ul>	<ul style="list-style-type: none"> <li>-# of completed asset maps</li> <li>-# of consultation instruments developed</li> <li>-# of evaluation tools developed</li> <li>-Consultee follow-up ≤ 48 hrs</li> <li>-≥ 3 panel attendees per session</li> <li>-Equal representation of community/academic panelists per session</li> <li>-Panel sessions yield topic-specific, actionable recommendations</li> <li>-Coordinator ensures completion of all activities from scheduling Intake Meeting &gt; Recommendations Session</li> <li>-PI reviews all recommendations ahead of delivery to consultee</li> </ul>	<ul style="list-style-type: none"> <li>-Tracking</li> <li>-Spreadsheet</li> <li>-Data Dashboard</li> <li>-REDCap instruments</li> <li>-Activity logs</li> </ul>	Biweekly
<p><b>Reach</b></p> <ul style="list-style-type: none"> <li>-Was CEACR able to reach enough potential consultees?</li> <li>-Was CEACR able to reach enough panelists?</li> <li>-Did CEACR recommendations address populations of interests (Covid-specific, ethnic/racial minority groups)?</li> </ul>	<ul style="list-style-type: none"> <li>-# Scheduled Intake Meetings</li> <li>-# of panelists and representatives from the CEAL teams and their partners</li> <li>-# of end users focused on ethnic/racial minority recruitment in Covid research</li> </ul>	<ul style="list-style-type: none"> <li>-Consult Request Form</li> <li>-Priority Ranking</li> <li>-Intake Meeting Notes</li> <li>-CEAL Panel -Interest Forms</li> </ul>	As needed throughout the consultation process
<p><b>Dose Delivered</b></p> <ul style="list-style-type: none"> <li>-Was CEACR able to average 3 consultations a month?</li> <li>-Do panel sessions yield topic-specific, actionable recommendations?</li> </ul>	<ul style="list-style-type: none"> <li>≥ 3 consults per month</li> <li># Scheduled Recommendations Sessions</li> </ul>	<ul style="list-style-type: none"> <li>-Coordinator Emails</li> <li>-Internal Tracking Form (REDCap)</li> </ul>	As needed throughout the consultation process
<p><b>Dose Received (Exposure)</b></p> <ul style="list-style-type: none"> <li>-How do consultees interact with CEACR services?</li> <li>-To what extent do consultees interact with CEACR services?</li> </ul>	<ul style="list-style-type: none"> <li>-Consultees are satisfied with CEACR services</li> <li>-Consultees find recommendations useful</li> <li>-Consultees report multilevel application of CEACR recommendations</li> <li>-Consultees report they interacted with CEACR as much as needed</li> </ul>	<ul style="list-style-type: none"> <li>Emails Completed</li> <li>-Satisfaction Survey</li> <li>-30-Day Survey</li> <li>-90-Day Survey</li> <li>-180-Day Survey</li> </ul>	<ul style="list-style-type: none"> <li>Post Recommendations Session</li> <li>-0 days</li> <li>-30 Days</li> <li>-90 Days -180 Days Post Consultation</li> </ul>

CEACR activities since launch resulted in the creation of a CEAL Asset Map totaling over 1,000 data points, half of which included community-based partners and organizations working in conjunction with each CEAL site's academic/research institution. The CEAL Panel Expert Form created in REDCap helped CEACR create a roster of 152 subject matter experts to pull from for consultations. CEACR received 43 requests for services and held 15 expert panel sessions that guided the recommendations delivered to six Covid research teams across the United States. CEACR delivered tailored recommendations for each asset request including lists, links, takeaways, and toolkits. 32 requests for services were completed including requests for CEAL-affiliated resources, formalized requests for guidance on outreach and recruitment strategies, and requests for presentation of findings and workshop facilitation. CEACR received 17 requests for resources including 14 Asset Map requests for CEAL-affiliated resources like assistance sourcing subject matter expertise for speaking engagements and lists of population-specific organizations and three requests for workshop/listening sessions (Figure 3).

Panel discussions included topics such as equitable partner compensation, cultural appropriateness of recruitment materials, and best practices for engaging rural residents in Covid research activities. CEACR panels included 56 academic and community-based experts from across the country. 46% percent of the subject matter experts were representative of community-based organizations/expertise, and the remaining 54% of panelists were academic-affiliated (Table 3).



**Figure 3: Rapid VS Full Service Requests**

**Table 3: CEACR Activities Since Launch (Completed)**

<b>October 2021-March 2023</b>	
<b>Total Requests Received</b>	43
<b>Requests for services</b>	32
<b>Requests for resources</b>	17
<b>Expert panels held</b>	15
<b>Panelists engaged</b>	56
Community-based organizations (%)	46
Academic-affiliated (%)	54

Three REDCap forms were developed to facilitate the consultation process and four REDCap surveys were created to facilitate the evaluative processes necessary to determine CEACR’s quality of services. The following section reviews the results of CEACR evaluation efforts since launch and detailed in the accompanying Table 4.

**Table 4: Evaluation Attempts to Measure User Satisfaction**

Consultee	Date of Consult	Satisfaction	30 Day	90 Day	180 Day	Email Follow Up	Consultee Response to Follow Up
ACTIV-6 (Duke)	1/21/2022	1/25/2022	3/16/2022	N/A	8/24/2022	10/13/2022	<a href="#">10/28/2022</a>
CEAL (Texas)	7/29/2022	8/1/2022	9/15/2022	N/A		11/9/2022, 2/9/2023, 4/25/2023	N/A
ACTIV-6 (Pitt)	9/16/2022	9/16/2022		N/A		2/9/2023	<a href="#">2/20/2023</a>
ACTIV-6 (SAC)	9/7/2022	11/8/2022		N/A		2/9/2023	<a href="#">2/9/2023</a>
RECOVER VCU_Long Covid, Rural	9/22/2022			N/A		9/30/2022, 2/9/2023	<a href="#">9/30/2022, N/A</a>
RECOVER VCU_Long Covid, CE Best Practices	9/22/2022			N/A		9/30/2022, 2/9/2023	<a href="#">9/30/2022, N/A</a>
RECOVER_NYU_Long Covid, Latinx	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Indigenous/Tribal	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Age 65+	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Committee Reps.	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Covid (+) Pregnancy	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Pediatric	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Covid (+) Pregnancy, Latinx	10/10/2022	<a href="#">10/14/2022</a>		N/A			
RECOVER NYU_Long Covid, Pediatric, Latinx	10/10/2022	<a href="#">10/14/2022</a>		N/A			

RECOVER NYU_Long Covid, Indigenous/Tribal	12/19/2022			N/A			
RECOVER NYU_Long Covid, Black, African American	12/22/2022			N/A			
RECOVER NYU_Long Covid, Latinx	12/20/2022			N/A			
MCRU_NINDS	Apr-23						
UCSD (M2B/HMB)	Apr-23						
UCSD (M2B/HMB)	Apr-23						
ACTIV-6 (Duke)	Apr-23						
Home Test to Treat	Apr-23						
ACTIV-6 (Duke)	Apr-23						
Pediatric Trials Network	May-23						
Pediatric Trials Network	May-23						
Home Test to Treat	May-23						
RECOVER_UCSF	Jun-23						
U of Illinois Urbana-Champaign (UIUC)	Jun-23						

During the first 1.5 years, CEACR met with each consultee requiring a panel session at least twice; one 60-minute meeting for Intake and one 60-minute meeting to deliver the Recommendations. One consultee was unable to meet to discuss recommendations due to availability, so a report was sent via email. Out of the 17 eligible instances for consultees to rate their immediate satisfaction with CEACR services, 6 surveys were sent, and 5 were received. Only two of the 30-day surveys were sent; 1 was received. The second survey was sent in error before editing to capture consult-specific feedback. No 90-Day surveys were successfully created or sent, and one 180-Day survey was sent and received. All survey recipients received an email prompt for survey completion if nonresponsive after 7 days (Table 4).

#### **4.1 Iterations**

The CEACR consultation process has required many iterations since its inception to ensure adherence to the evolving scope of activities planned by NIH leadership. All enacted revisions to the CEACR process are documented along with the corresponding activity for improvement and process metric correlation to dose, reach, and/or fidelity. Continuous quality improvement efforts like this evaluation of activities maintain the rigor of community-based approaches to public health interventions. The following section will detail the various iterations to the CEACR consultation processes including steps taken to strengthen the intake process, panel curation, and evaluation tools needed to relay the impact and utility of the service. In the next section, I will describe CEACR's adjustment to maintain the timeliness of consultation services.

## **4.2 Intake Iteration and the CEACR Time Clock**

The Consult Request form gathers basic information needed to schedule an initial meeting between the consultee and CEACR. Many initial consultees did not have a grasp of the rapid turnaround required of the CEACR process and did not respond to requests to meet as promptly as NIH Leadership had anticipated. Additionally, early consultees needed to understand a bit more about the CEACR process and gain approval from their project leadership before committing to service requests. This delayed the start of the CEACR consultation and prolonged the time clock as approval was achieved (1). To mitigate the delay, CEACR established “soft” intake meetings to confirm consultee appropriateness for services and allow time for the consulting team to confirm availability and interest in moving forward. Once all approvals were gained, a formal “Intake” session was held, and the date of this meeting is documented as the start of service. This iteration helped reflect a more accurate time to completion for each consultation increasing fidelity in the consultation process. This next section describes how the widening of services increased CEACR’s range, scope, and reach of programmatic services.

## **4.3 Scope and Prioritization of Request Iteration**

CEACR clients were initially limited to extramural (not employed at the NIH), NIH-funded research teams centered around the mitigation of the effects of the Covid pandemic limiting the project’s reach. As CEACR gained footing, NIH leadership expanded the scope of services to include consideration for requests from intramural clients (NHLBI, NINDS) and other federally funded teams addressing Covid and while expanding the reach of services to address health

disparities more broadly. In addition, the CEACR team and NIH leadership recognized that while the CEAL sites were intended to be a resource for CEACR, they too needed consultative support. Additionally, several prior consultees became repeat users upon successful completion of their initial consultation. Consultation requests increased from an average of 0-3 consult requests per month to a peak of 9 active requests at once. This increased business necessitated the adoption of tracking tools and a prioritization or ranking system which CEACR developed with NIH leadership (Figure 4). NIH leads expanded CEACR's scope to aid federally funded Covid research efforts more broadly. This expansion allowed more incoming requests that addressed the urgency of the Covid pandemic thus increasing CEACR's reach and dose of activities. A tracking spreadsheet was developed to help the Senior Project Coordinator document and monitor consult activity (Appendix Figure 13). The data in this spreadsheet is used to populate a data dashboard built with Power BI (Appendix Figure 14). This tracking mechanism helped CEACR staff organize, classify, measure, and display the dose delivered and reach of CEACR activities.

- |   |
|---|
| <p style="text-align: center;"><b><u>Priority Ranking</u></b></p> <ol style="list-style-type: none"><li>1. NIH funded, Covid related</li><li>2. NIH funded, Not Covid related</li><li>3. Federally funded, Covid related</li><li>4. Federally funded, not Covid related</li></ol> |
|---|

**Figure 4: Priority Ranking for Incoming CEACR Consult Requests by Funding Source and Public Health Significance**

All incoming requests were documented, sent to NHLBI programmatic leads, assigned a priority ranking, and reviewed for approval during biweekly meetings with NIH leadership (Figure 4). The new triage system elevates priority requests and deprioritizes others. All consultees are



updated with any changes in the timeline and priority status via email. This next section discusses the importance of preparing CEACR's expert panelists whose expertise contributes to the overall quality of consultee recommendations.

#### **4.4 Expert Panel Orientation and Implementation Iteration**

Successful panels also require the careful preparation of subject matter experts. In the fall of 2022, there was a panel session held for the RECOVER community engagement team on the best approaches to sourcing research committee members from the community. The panel was extremely excited to share and discuss, however, each panelist drifted from the topic and the other panelists followed the organic flow of discussion. After the panel session was completed, the review demonstrated significant feedback and recommendations on engaging minoritized populations but did not yield recommendations on the topic request for how to recruit community members to serve on the national research committees. The CEACR team debriefed and decided to generate a "Panelist Orientation PowerPoint" presentation to help panelists prepare for the virtual brainstorming sessions (Appendix Figure 17). This significantly improved fidelity of the panelist responses in subsequent sessions and the importance of this orientation slide deck was re-demonstrated during a subsequent panel in winter 2023, when it was accidentally omitted again leading to a disorganized off-topic panel session. In addition, we have found that the panelists are much better equipped to offer tailored, project-specific recommendations during CEACR panel discussions when only one discussion question/prompt is displayed at a time during the virtual sessions.

These iterations address the intended fidelity, dose received, and reach of program activities. This second iteration improved the panelists' adherence to the topic and the overall utility of the advice offered. The integration of these iterations helped ensure that the client's questions were addressed. The panelists' contributing thoughts and suggestions centered around the specific need for actionable strategies targeted around the client's population of focus. Panelists' adherence to CEACR panel expectations directs panelist efforts and expertise where it is needed the most. Panelist adherence to and focus on individual discussion prompts ensures that each client's need is addressed. CEACR recommendations are, in turn, more robust and tailored for client implementation. The more specific and targeted the feedback, the more relevant CEACR recommendations harness more potential for implementation and impact (Appendix Figure 15). Measurement of the quality of recommendations requires a complete overhaul of CEACR's current evaluation tools and activities. The next section details the steps taken to understand and measure the dose delivered by CEACR recommendations.

#### **4.5 Improving the Capture of Evaluation Metrics**

CEACR recognizes the importance of consultee feedback and the failure to achieve successful evaluation over the initial 1.5 years of implementation. CEACR is undergoing an overhaul of the current evaluation processes, activities, and tools to improve these outcomes. Current iterations seek to address the evaluation metrics critical to assessing fidelity, dose delivered/received, and reach. Two issues were identified, the first being the issue of consistently deploying surveys promptly which is a fidelity failure to our process. The second was the need to improve the response rate to the surveys sent out. To increase consistent deployment of the surveys

and improve fidelity to the survey evaluation procedure, a new process is being developed to automatically alert the project manager and evaluation team for each consult to trigger customization and sending of the relevant survey. To increase the survey response rate, CEACR has added built-in time for consultees to privately complete their satisfaction surveys during the recommendations report-out session. This additional, real-time evaluation effort attempts to capture the received dose of CEACR services. The information gleaned from the Satisfaction Survey captures insight into the client’s experience of the CEACR process (dose delivered). This immediate survey also seeks to understand whether the recommended feedback can be implemented (dose received). This information helps CEACR understand if the panel discussion yielded feedback that resonates with the target population and can be easily implemented (reach). Subsequent evaluation tools address the client’s initial question(s) as well as whether the recommended actions were implemented. The evaluation team also developed a script to deploy oral interviews as an alternative to the REDCap surveys for consultees who prefer that method. If adequate feedback cannot be solicited within the 30, 90, or 180-day intervals, a brief interview will be requested by the CEACR Evaluation team. Iterations to date have resulted in an enhanced evaluation plan (Table 5).

**Table 5: CEACR Evaluation Plan\_Year 3**

<b>Deliverable</b>	<b>Timeline</b>	<b>Milestones</b>	<b>Metric</b>	<b>Impact</b>
Process Metrics	Completed Year 1	-Increase survey responses -Process metrics paper for CEACR	# of surveys completed # process metrics # overall scoring in >80% satisfied	Inform actual consult process around customer satisfaction with consult service

Impact Metrics	Completed Year 2	-Ongoing capture of impact metrics with each consult -Impact metric paper for CEACR	# Cumulative increase in impact from expert panel recommendations	Demonstrate the overall impact of expert panel recommendations
Data Dashboards	Year 2/Year 3	Dashboards for each of the three Evaluation Methods		Ease dissemination of data, work completed, and findings

As these iterations to process evolve, CEACR will be able to measure the dose delivered and received through CEACR services; this data is not captured in this essay but will prove useful to understand whether additional revisions to CEACR activities are warranted. This next section addresses the NIH's decision to track and monitor process metrics to maintain project fidelity.

**4.6 Development of Dashboards to Display Data**

Using the Power BI program, CEACR can review program progress with enhanced data visualization. CEACR has developed and iterated several dashboards to rapidly display data. These dashboards display a range of metrics including incoming consult requests, active requests, completed consult requests, consult priority levels assigned, consultee trends, topics of interest, populations served, and panelist affiliation. CEACR activities are displayed to capture fidelity, dose, and reach at-a-glance. NIH leadership now can access these program metrics for reporting needs (Appendix Figure 14)

#### **4.7 Increasing Staff for Programmatic Support**

Additional staff have been hired to support CEACR activities, project management, data management, and reporting. Additional staff will help CEACR increase the dose of activities delivered by contributing to project activity input and increase the project's fidelity by increasing the delivered dose of survey tools to increase consultee feedback on the dose received (Figure 3). Project management support for current CEACR staff is underway to assist with quality control measures, tracking milestones and deliverables, progress reports, and regular maintenance and organization of project materials. These actions will help flag any deviations to process/protocol strengthening fidelity in the process. Additional evaluation staff was hired for the development of the dashboards and to support the capture of the evaluation metrics going forward.

## 5.0 Discussion

Researchers have tested a range of interventions that incorporate behavioral strategies to improve research participant recruitment and retention (5). Common strategies include building trust between research teams and participants and improving participant comprehension of trial objectives and procedures (5). Widening the accessibility of research opportunities is not enough for successful implementation, and interventions with active knowledge translation are critical to turning research into practice (13). The process evaluation activities described in this essay help to understand how the CEACR design and process serve as barriers or facilitators to the implementation of the intervention as originally anticipated (13).

The CEACR consultation process infuses strategies to enhance minority participation in Covid research activities through trust-building and reciprocity. CEACR mobilizes CEAL resources, partnerships, and relationships built through academic and community collaboration. CEACR consultation services move consulting research teams past asking why communities are hesitant to trust science, research, academia, and medical institutions, and instead, ask what research teams are doing to address and overcome the fear and mistrust prevalent in the marginalized communities that stand to gain the most from research participation (3). CEACR suggests that the responsibility of trust should not be solely on the prospective research participant but instead ask the researcher to earn the trust of the participant. Participation in research activities often requires more effort on behalf of the participant rather than the researcher, yet researchers are often ill-equipped to reciprocate the resources asked of the participants (5). Researchers ask people for their identities, information, time, brain space, body, safety, trust, and power, and in return, you receive what has already been predetermined to be of fair value. The ask typically

always outweighs what is returned, and the power imbalance ensues. Researchers must approach participants with respect by “promoting a setting of equality rather than one of authority” (11). “Recruitment etiquette” is based on the Belmont Principles and enhances an ethical recruitment approach that “focuses on sensitive demeanor, astute observation, cultural and ethnic awareness, appreciation for the overall research environment and a polite manner in approaching the recruitment process” (11). CEACR helps researchers assess their approach to recruiting minoritized communities by inviting a range of experts including the population(s) of interest into the conversation to review and guide the research project’s outreach and recruitment strategies. CEACR offers researchers alternative recruitment approaches that are rooted in reciprocity and trustworthiness. CEACR activities foster an alternative approach to doing science that bolsters the efficacy of community-partnered responses that address health disparities research. CEACR’s ultimate goal is to assist researchers to increase ethnic/racial minority participation in health research; this review of the process enhances the understanding of the factors affecting the intervention (6).

The process evaluation of the CEACR consult explores “the mechanisms behind the intervention’s success or failure” (7). A systematic approach is necessary for evaluative rigor with evaluators ready to follow the pathway of emergent findings (8). A complex systems perspective could help CEACR understand the nonlinear way(s) in which consult-specific services may lead to impact within a larger system (7).

Findings suggest areas of strength thus far as well as opportunities for capacity building to support implementation and overall project fidelity. While CEACR experiences positive feedback in the form of multiple repeat customers, this indicates a decrease in reach. Increased fidelity efforts should focus on the collection of survey data from consultees and a clear activity log. To

date, CEACR has captured very little insight outside of the consultee’s immediate experience with the CEACR process, inadequately capturing the data needed to measure the dose received. Initial REDCap tools had several measurement errors and nonresponse errors deterring the adequate measurement of client satisfaction and quality of services delivered (15). Early survey data collected from Satisfaction surveys suggest that the consultee experience is Satisfactory, but there is not enough follow-up data to measure the utility or impact of the offered recommendations or measure the dose of the received activities. This lack of data deters insight into the intervention’s received dose. The CEACR team recognizes that the challenge of evaluation has been two-fold with the need for improved dissemination of the survey process and for capturing survey completion from the consultees. A consistent evaluation plan should be developed and adhered to for the successful measurement of project inputs and outcomes. CEACR is increasing the amount of dedicated evaluation staff to assist with increasing input; additional staffing will increase timely data and survey management, tracking process metrics, impact data (not discussed in this essay), quality control, and prompts for feedback from non-responsive consultees. CEACR has also drafted a model to capture outcome metrics including the immediate, short, and long-term impact of CEACR services.

Since launch, CEACR has pivoted to enhance project fidelity; CEACR activities have undergone a constant evaluation and iteration process to ensure adherence to scope and achieve intended goals. To ensure the 30-Day completion of consults, CEACR changed the official consultation start date to align with the completed “Intake Session” rather than “starting the clock” upon receipt of the Consult Request Form. We learned that many consultees required a “soft” intake to learn more about the CEACR process and the appropriateness of services. CEACR also



needed time to present consultee request info during biweekly meetings with NIH leadership for review/approval to proceed.

With a total of 45 consultation requests to date, CEACR is on track to average 2.5 consultations per month, signaling a 47% increase in output since launch. CEACR continues to expand its roster of expertise by increasing the reach and dose of programmatic activities; this includes extending panel opportunities more broadly through regular outreach to CEAL workgroups/interest groups and leaning on partner affiliate CCPH to source relevant expertise from their network of community-based colleagues. In addition to increased effort from colleagues CCPH, three additional staff members have been added to the CEACR team to assist with project activities and oversight; additional staff will assist in achieving fidelity upon reaching the project's goal of facilitating 3 consults per month.

CEACR services were initially limited to consultees from NIH-funded Covid research teams and have now expanded the project reach to offer consultancy services to federally funded research teams working to address health equity more broadly. As the scope broadened, so did the project reach, and the number of requests increased requiring a prioritization of incoming requests by finding source and topic/population of focus. Four priority levels were assigned to incoming requests for services, and all external (extramural) NIH-funded projects relevant to Covid were prioritized over others. This triaging of requests allowed CEACR to prioritize Covid-related projects yet continue to serve other research teams requesting CEACR service.

As of March 2023, all consultation requests requiring a panel session have received tailored expert guidance except for the pilot consultation. CEACR's first panel session addressed equitable partner payment practices. This consultation has yielded favorable results that will be published, has led to a national webinar activity, and will continue to serve as a durable resource to inform

future requests seeking guidance on this topic. CEACR panel sessions have discussed increasing inclusive participation in NIH-funded health research including discussions around building relationships with community partners, community outreach and engagement, recruitment and enrollment, and research material/asset review for cultural appropriateness. CEACR was enacted to deploy CEAL resources to assist NIH-funded Covid researchers reach and engage ethnic and racial minority populations. CEACR clients represent major academic, medical, and community-based partnerships leading community-engaged research that touches the lives of millions of individuals. In CEACR's first year and 6 months in operation, the consulting arm provided consults to help NIH-funded research teams increase diverse participation in Covid research activities. CEACR activities have produced recommendations to help national clinical trialists reach and engage the anticipated underrepresented populations of focus such as ethnic and racial minority groups including Hispanic/Latino, American Indian, and Black/African American individuals (Appendix Figure 16). CEACR increased its reach by hosting additional panel sessions to address underrepresented groups including older adults/Age 65+, pediatric, pregnant, and rural populations. This diversity was also represented in the panels themselves. Each of the 15 expert panel sessions was guided by national representatives from equal parts academic and community-based backgrounds with most individuals representing CEAL affiliations.

CEACR's Panelist Orientation helps maintain fidelity and increases the dose delivered during the panel sessions (Appendix Figure 17). When supporting materials are sent within 48 hours of the session, panelists are better prepared, stay on topic, and offer higher-quality recommendations serving to increase the activity's delivered dose. We anticipate that panelists' contributions to each panel session address the client's specific asks. When panelists were prepared to stay on topic, the panel sessions yielded better results and more actionable recommendations.

Iteration to the panel session display prompts helps ensure fidelity, enhances the delivered dose, and increases the received dose. When one prompt is displayed at a time, panelists maintain focus on the question in front of them rather than the complete list of discussion questions. This helps maintain the anticipated actions by keeping the recommendations/advice tailored to the consultee's needs yielding recommendations that the consultee will find useful. CEACR panels are curated to reflect the population(s) at the focus of the conversation. Panelists are invited based on relevant experience working with the population(s) of focus and/or self-identify with the population(s) of focus. This helps incorporate a vantage point and perspective in recruitment and outreach strategies typically omitted from the research process thus enhancing the utility/reach of CEACR services as well as the dose delivered. CEACR panels reflect a balance of both the academic- and community-based CEAL expertise needed to advance community-based approaches to research inclusivity. Diverse panelist representation supports the utility of applying community-based approaches to improve health outcomes and warrants further tracking per NIH leadership request. A community-based participatory evaluation (CBPE) approach “advances the importance of bilateral engagements with consumers and academic evaluators” and may serve as a viable method to assess community-level reach (8).

In addition to the tracking of panelist demographics, affiliation, and participation trends, NIH leadership has requested consult data by topic, priority, and consultee. CEACR has developed dashboards using Microsoft’s business intelligence tool, Power BI offering NIH leadership instantaneous access to real-time updates and data visualization functionality (Appendix Figure 14). The dashboard captures CEACR reach detailing repeat customers, populations of focus, topics of interest, and diversity metrics of CEACR panels to date. The dashboard displays the number of incoming consults, active consults, and completed consults. These fidelity metrics forecast

adherence to the project's scope of maintaining at least three consults per month. This information helps both CEACR staff and NIH leadership monitor the fidelity of the program, the dose of services delivered, and the reach of CEACR services.

## 6.0 Conclusion and Future Work

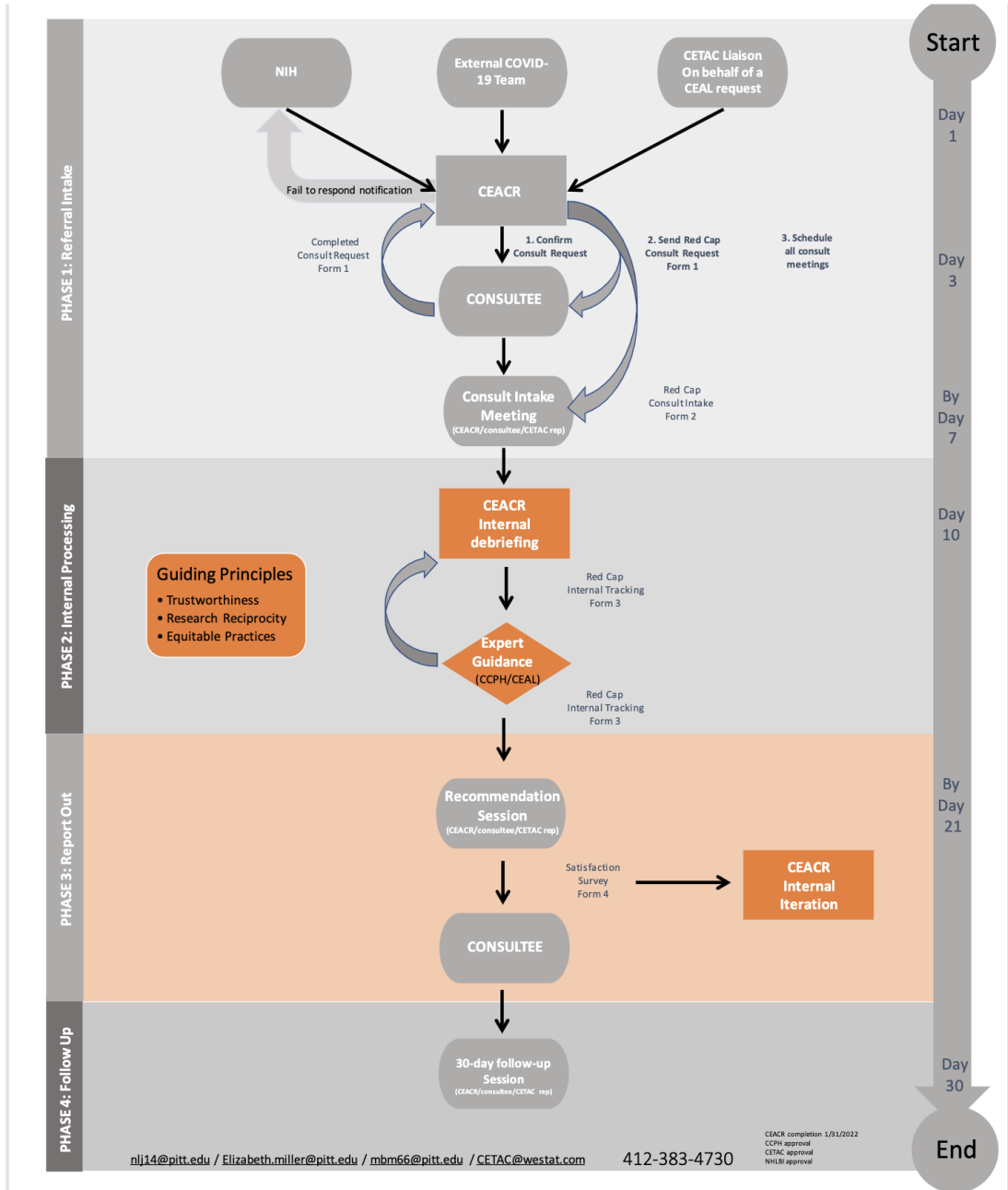
Overall CEACR has thus far demonstrated success and impact culminating in two articles in progress, four poster presentations for the 2023 APHA conference, and an invitation to speak at a national conference in 2023. The CEACR team continues to evaluate and iterate the consultative process and workflow to best serve consultee needs. CEACR has discussed implementing a panelist survey to understand more about the panelist experience. Informal panelist feedback indicates that most expert panel participants find value in these activities. These conversations mobilize power and knowledge transfer between researchers, academics, and communities. The researcher hears from the target demographic. The academic learns more about the lay experience of research. The community members learn more about the research study and contribute to better practice. As CEACR strengthens program evaluation and increases the number of metrics captured, these needs will become more evident. Panelists have informally offered positive feedback via email suggesting that there is a need for CEACR to develop and disseminate surveys to capture the CEACR panelist experience (Appendix Figure 7). The inclusion of multiple sources of feedback can help reduce bias and offers another data source to strengthen evaluation efforts (8). As the scope of requests expands past the Covid pandemic, CEACR will need to expand its reach of resources to support inclusive participation in research on topics such as maternal-child health, climate change, and closing healthcare disparity gaps in primary care.

CEACR is currently applying for its third grant cycle to continue activities in collaboration with Community-Campus Partnerships for Health (CCPH). As CEACR enters its third year of activities, NHLBI leadership has introduced a cost-recovery model for repeat users. CEACR services will no longer be free of charge for repeat customers. CEACR will finalize virtual resource

packages available at no cost to internal and external end users. These “off-the-shelf” resources will be made available on the CEAL website and offer visitors best practices on a variety of topics to support health equity through inclusive participation in research and clinical trials. CEACR continues to operate under the CEAL umbrella as a consulting service serving the greater goal of health equity. As CEACR’s diversity and availability of resources increases in reach, the evaluation of the program must evolve beyond the early implementation phase (14).

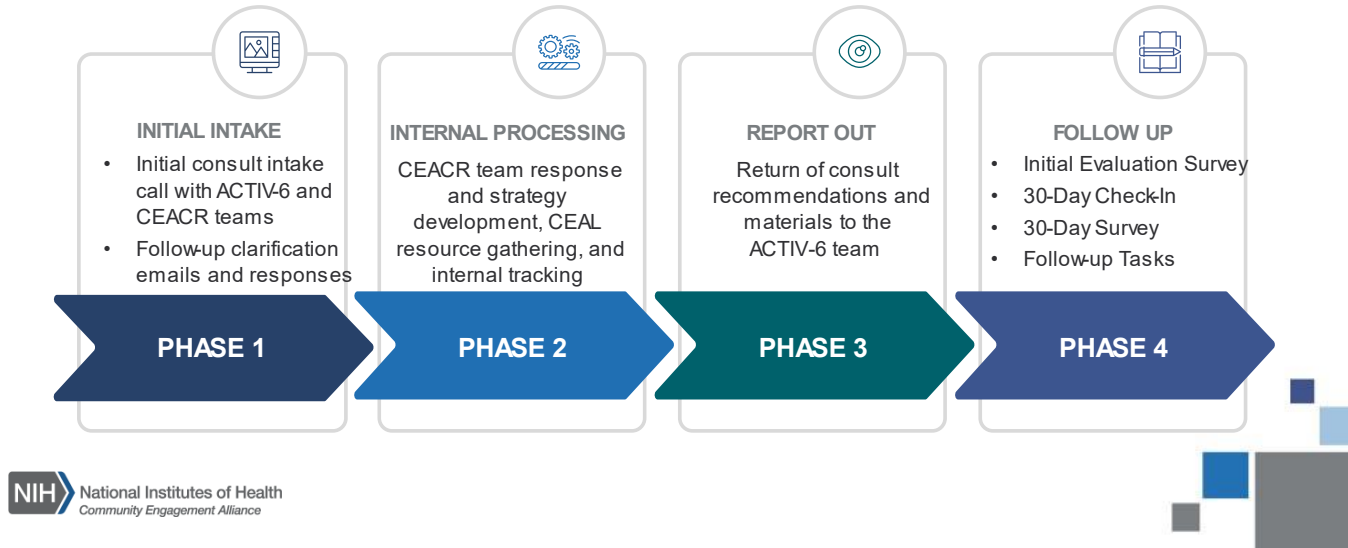
This process evaluation highlighted CEACR successes and areas for improvement indicating a critical need for improved evaluation efforts that successfully measure the dosage of interventional activities. Improved evaluative efforts that include dedicated staff, a clear activity log, and continuous quality improvement (CQI) plan will help CEACR identify potential causal mechanisms for breakdowns in service delivery throughout the grant cycle rather than post-intervention. A CQI plan will help CEACR build on what is working well and keeps activities relevant to the larger sphere of health equity efforts. A Plan-Do-Study-Act approach will help CEACR enact the necessary iterations to process throughout the project timeline enhancing the likeliness of timely quality improvement efforts (14).

# Appendix A



Appendix Figure 1: Consult Process Diagram with Phases 1 Through 4

## Example of Consult Timeline: **ACTIV-6**



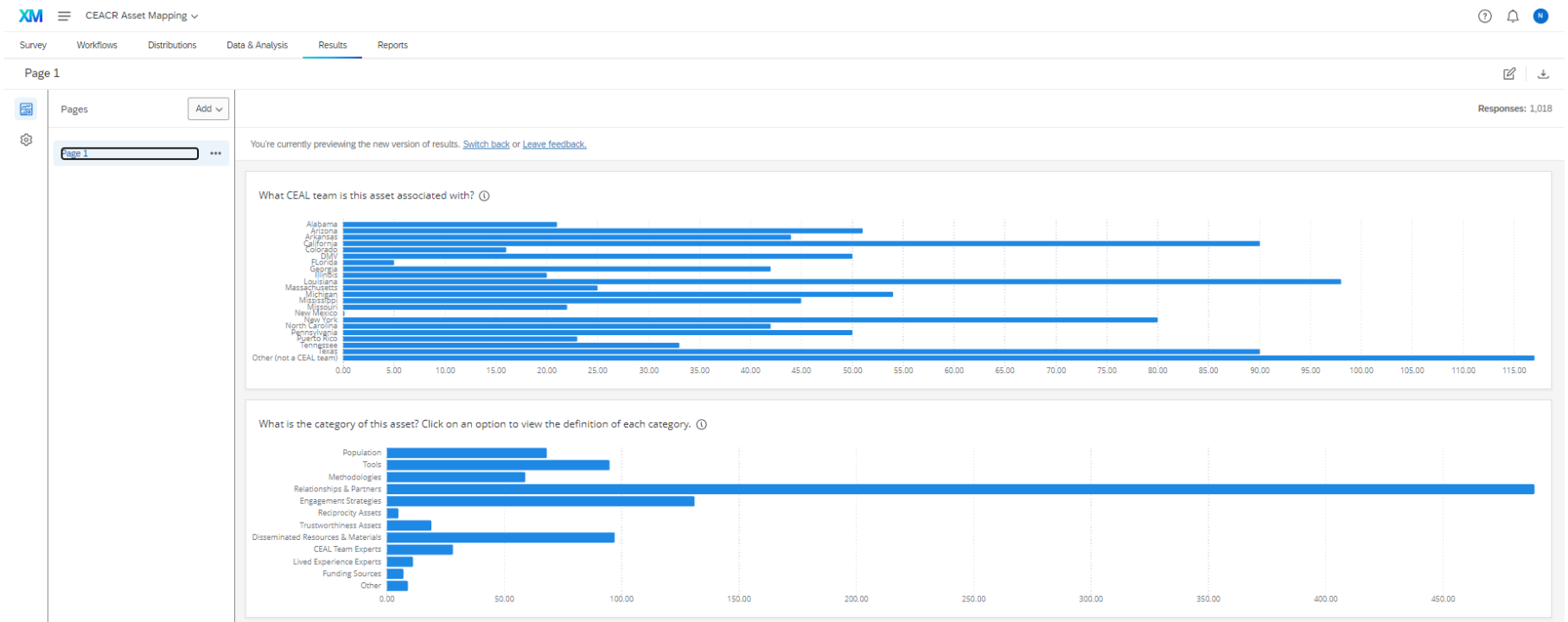
**Appendix Figure 2: CEACR Consult Phases 1-4**



# Appendix B

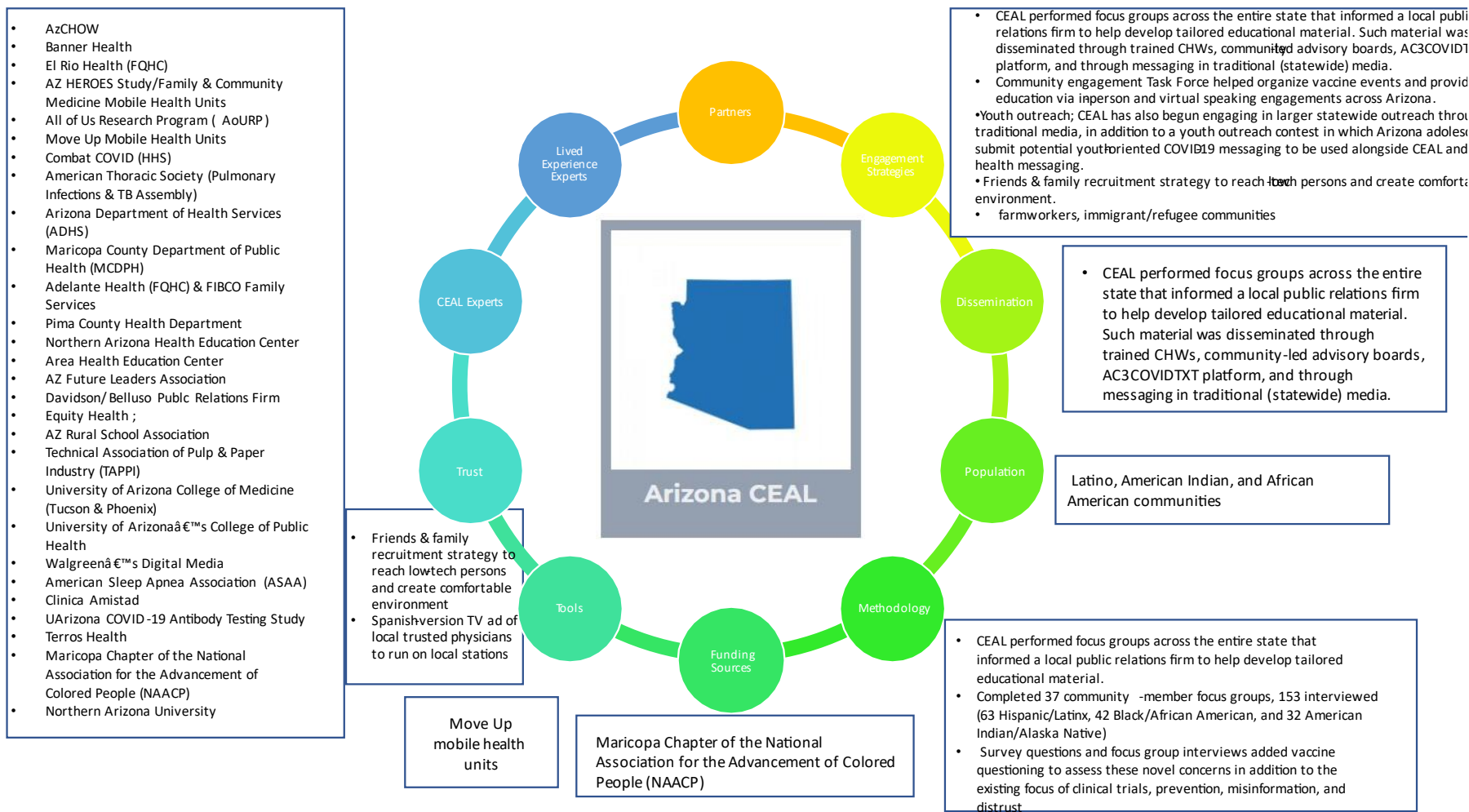
## 2: Asset Map

### Qualtrics Dashboard



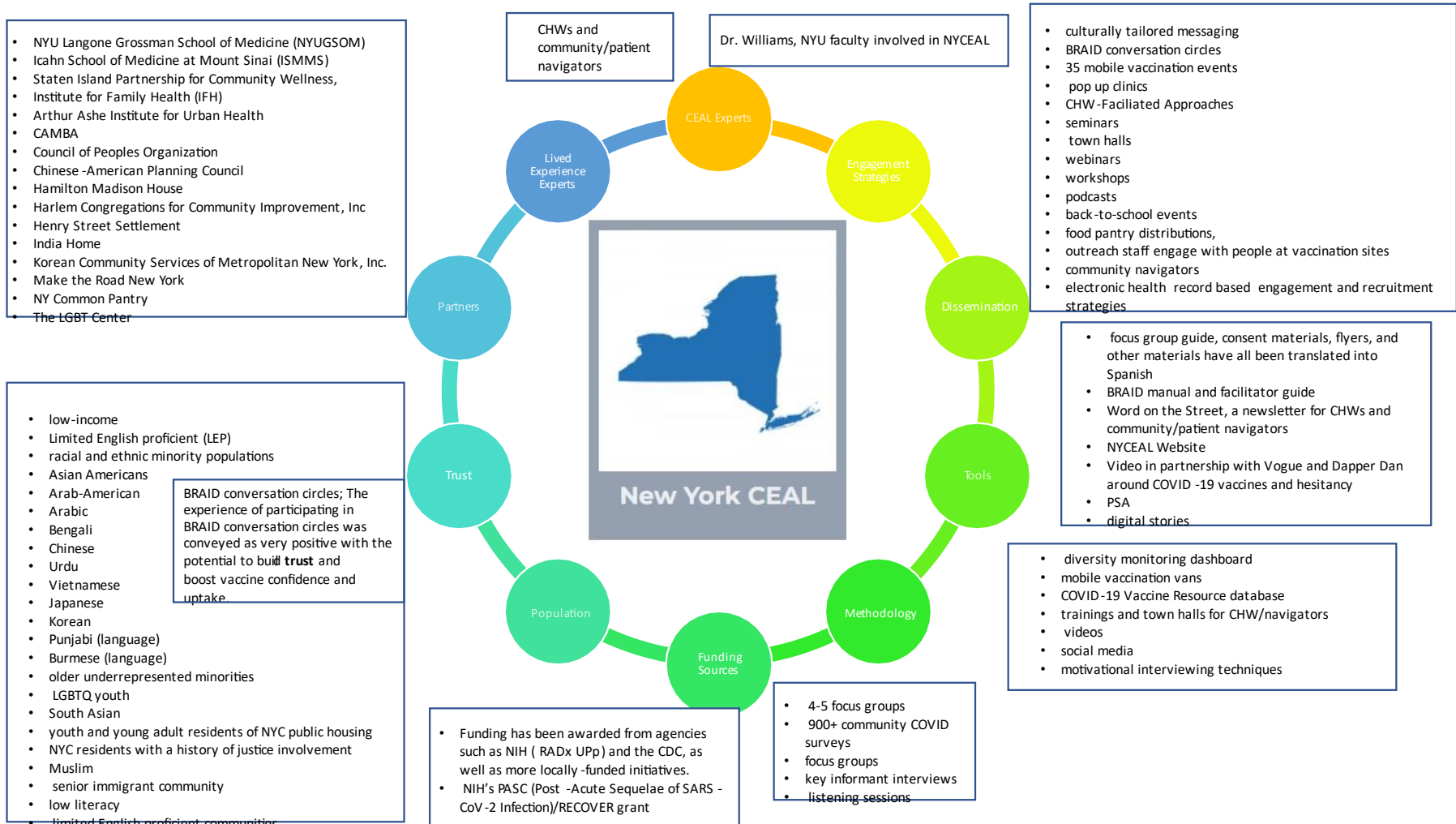
**Appendix Figure 3: Qualtrics Dashboard Example of CEAL Asset Map Data**

*Drafted Asset Maps for CEAL Teams*



**Appendix Figure 4: Drafted Asset Maps for CEAL Teams**

*Drafted Asset Maps for CEAL Teams (cont.)*



**Appendix Figure 4: Drafted Asset Maps for CEAL Team (cont.)**

# Appendix C REDCap Intake Forms

## Consult Request Form

### Consult Request Form

Page 1

Tell us a little about your project, how CEACR can assist, and please provide a follow-up contact for this request. Thank you!

-CEACR Team

First Name:

\_\_\_\_\_  
{{Person filling out this form}}

Last Name:

\_\_\_\_\_

Email:

\_\_\_\_\_  
{{Email of person filling out this form}}

Affiliation/organization:

\_\_\_\_\_  
{{Name of academic institution, center, community organization, etc.}}

Location:

\_\_\_\_\_  
{{Which city and state is this project taking place?}}

Project Overview:

\_\_\_\_\_  
{{Please include the project title and a brief overview.}}

\_\_\_\_\_  
What are your goals for this consult? How can the CEACR team help?

\_\_\_\_\_  
Who/how should we contact to schedule an initial meeting about this request?  
{{Please include name and preferred contact method/info.}}

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### Appendix Figure 5: Consult Request Form

# Intake Form

Page 2

**Intake Form**

Please complete the survey below.  
Thank you!

9) Date of Meeting: \_\_\_\_\_

10) Consultee Name: \_\_\_\_\_

11) Project Title: \_\_\_\_\_

12) Project Location: \_\_\_\_\_  
(Address incl. Street, City, State, Zip)


13) Project Description: Please briefly summarize the nature of your project.  
\_\_\_\_\_  
(Include project aims/goals, communities of focus, outreach strategies, funding source, etc.)

14) Partners: Has your team partnered with any organizations to help reach project goals? Describe any partnerships.  
\_\_\_\_\_  
(Incl. CEOs, FBOs, academic/medical institutions, departments, agencies, etc. Do your partners aim to reach any specific populations? (ethnic/ancestral minority, LGBTQ+, rural, older adult, low SES))

15) Partners: Are you looking to partner with any other organizations?  Yes  No

16) If yes, who/why? \_\_\_\_\_

17) Would you be interested in learning about our START program or an Urban League collaboration? (May we offer?)  
 Start Program  
 Urban League  
 No, thank you.

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Page 3

18) Consider the role that research, medical, and academic institutions have played in culminating distrust in marginalized communities.  
\_\_\_\_\_  
Can you think any examples of how your team can incorporate principles of trustworthiness and/or research reciprocity in your research activities?  
\_\_\_\_\_  
Examples: advocating against institutional systems of oppression, acting as a connector to resources and gatekeepers, supporting community partner capacity development, and implementing creative solutions to institutional barriers that meet community expectations

19) Need/Request: Which research need are you hoping to address? How do you envision our team helping? Check all that apply: (How can we help?)  
 Engagement: Expand awareness of study/initiative, find new partners, develop trustworthiness or research reciprocity strategies  
 Recruitment: Increase participation, recruitment strategy  
 Retention: Retention strategy, increase volume of retained participants  
 Other \_\_\_\_\_

20) Need/Request: If other, please describe.  
\_\_\_\_\_

21) Is your team currently working with any NIH CEAL (Community Engagement Alliance) Against COVID-19 Health Disparities sites?  Yes  No  
(Can CEAL support?)


22) If Yes, which CEAL Site: \_\_\_\_\_

23) Assets:  
What kind of materials would be most beneficial for your team and/or organization? Check all that apply: (What do you need?)  
 Tangible (literature, posters, handouts)  
 Virtual (web-based information/links, social media content, online webinars)  
 Connection, contact, and/or introduction (person, organization, service)

24) Urgency: Please rate the urgency of this requested consult.  Low (within 2 months)  Medium (within 1 month)  High (within 1 week) (1, 1!, 1!!)

25) Timeline: How soon would you like to have these resources?  
\_\_\_\_\_  
(When do you need it?)

26) Timeline: How soon are you available to meet again?  
\_\_\_\_\_


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Page 4

27) Timeline: Please indicate general availability to follow up.  
\_\_\_\_\_  
(When can we follow up? AM, PM, weekly, 2x week)

28) Who should we contact to schedule a follow-up meeting?  
\_\_\_\_\_  
(Contact, preferred method, #/email)

29) Comments/Feedback: Any additional comments, questions, or concerns?  
\_\_\_\_\_  
(Anything else we should know!)

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Appendix Figure 6: CEACR Intake Form

CEAL Panel Interest Form

Confidential Page 1

## CEAL Panel: Interest Form

Please complete the survey below.  
Thank you!

1) Name \_\_\_\_\_

2) Email \_\_\_\_\_

3) Phone Number \_\_\_\_\_

4) CEAL Site Affiliation: \_\_\_\_\_  
(Which NIH CEAL (Community Engagement Alliance) Against COVID-19 Health Disparities site are you affiliated with? )

5) Area of Expertise  
(Do you consider yourself well-versed in any health topic or population(s) of focus? )  
\_\_\_\_\_

6) Assets:  
Would you like to share any of the following with other research teams providing COVID-19 relief efforts? Check all that apply:

- Tangible (literature, posters, handouts)
- Virtual (web-based information/links, social media content, online webinars)
- Connection, contact, and/or introduction (person, organization, service)
- Other

7) General Availability:  
(Please indicate your availability for the CEACR consultative process. )

- Once a week
- Once a month
- Once a quarter
- Once a semester
- Other Availability

8) If Other Availability, please describe: \_\_\_\_\_

Appendix Figure 7: CEAL Panel Interest Form

# Internal Consult Tracking Form

## Internal Consult Tracking

Page 5

Please complete the survey below.

Thank you!

30) Project Title \_\_\_\_\_

31) Date of Post-Intake Follow-Up \_\_\_\_\_  
(When was the INITIAL post-intake follow-up call, email, etc?)

32) CEACR Team Review \_\_\_\_\_  
(When did the CEACR team review the consultee information?)

33) Does CEACR need additional information?  
 Yes  
 No

34) If yes, what additional information is needed? \_\_\_\_\_

35) Initial Recommendations \_\_\_\_\_  
(Briefly describe initial feedback given to consultee.)

36) Date of initial feedback \_\_\_\_\_  
(When were initial recommendations communicated?)

37) Was a referral made?  Yes  
 No  
(Was the consultee referred to any contact/organization?)

38) Who was consulted/referred? \_\_\_\_\_  
(Who helped? Who was the referral to? If applicable, indicate compensation.)

39) Was a CEAL (Community Engagement Alliance) Against COVID-19 Health Disparities site referenced/involved for this consult?  Yes  
 No  
(Did CEAL support?)

40) If Yes, which CEAL Site: \_\_\_\_\_

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Page 6

41) Was the consultee referred to the START Program or an Urban League?  START Program  
 Urban League  
 No, none of these

42) Assets:  
Which assets were disseminated? Check all that apply: (What did the consultee receive?)  
 Tangible (literature, posters, handouts)  
 Virtual (web-based information/links, social media content, online webinars)  
 Connection, contact, and/or introduction (person, organization, service)  
 None

43) Resources/Assets \_\_\_\_\_  
(Which virtual and/or physical assets were used for this consult?)

44) Need/Request: Which research need was addressed? Check all that apply: (How did we help?)  
 Recruitment: Increase participation, outreach strategy, cultural awareness/inclusion  
 Retention: Increase volume of retained participants, decrease loss to follow-up, retention strategy  
 Education: Expand awareness  
 Engagement: Finding new community partners, developing trustworthiness or research reciprocity strategies  
 Other

45) Final Recommendations \_\_\_\_\_  
(What was CEACR's final feedback, advice, and/or recommendation?)

46) What resources were recommended?  CEAL expertise  
 CEAL educational material (fact sheet, one-pager)  
 CEAL webinar content  
 CEAL social media content  
 CEAL marketing material  
 CEAL website link  
 CEAL contact to Community Partner  
 Other CEAL-derived resource

47) If Other CEAL-derived resource was provided, please describe: \_\_\_\_\_

48) Date of Completion \_\_\_\_\_  
(When was the consult wrapped up?)

49) Send Satisfaction Survey?  
 Yes  
 No

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Appendix Figure 8: Internal Consult Tracking Form

# Appendix D REDCap Eval Forms

## Satisfaction Survey

### CTSI Services Satisfaction Survey (CEACR)

Page 7

Please complete the survey below. The survey has 2 sections: one relating to your service itself and another relating to the potential impact of that service on your awareness and implementation of research reciprocity and trust in research.

Thank you!

How did you find out about CEACR?

How satisfied were you with the service you received?

- Very Satisfied
- Satisfied
- Neither Satisfied nor Dissatisfied
- Dissatisfied
- Very Dissatisfied

What resources did you receive from the CEACR team?

- CEAL expertise
- CEAL educational material (fact sheet, one-pager)
- CEAL webinar content
- CEAL social media content
- CEAL marketing material
- CEAL website link
- CEAL contact to Community Partner
- Other

Other resource:

What was the most helpful piece of information you received from the CEACR team?

**Please rate the following statements about research reciprocity and establishing trust in research. We define research reciprocity as a consideration of what is not only taken from research participants, but also what is given to them. We define establishing trust in research as actions researchers can take to promote more trust amongst research partners, participants, and others in the community.**

	Low	Moderate	High
Familiarity with research reciprocity before I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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### Appendix Figure 9: CEACR Satisfaction Survey



*Satisfaction Survey (cont.)*

Familiarity with research reciprocity after I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Familiarity with how to establish trust in research with community partners before I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Familiarity with how to establish trust in research with community partners after I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confidence in deploying research reciprocity techniques before I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confidence in deploying research reciprocity techniques after I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confidence in establishing trust in research with community partners before I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confidence in establishing trust in research with community partners after I met with the CEACR team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

Please provide any additional comments or feedback you have about the CEACR service you received in the space below.

---

What additional information and/or actionable resources from the CEACR team would be helpful for your team to meet its objectives?

---

**Appendix Figure 9: CEACR Satisfaction Survey (cont.)**

# 30-Day Survey

## 30-Day Survey

Page 9

Please complete the survey below. This survey collects feedback on the utility of CEACR recommendations and the overall experience of the CEACR consultation process.

Your input is greatly appreciated. Thank you!

CEACR Team

Which CEACR Immediate Action Step recommendations were initiated/implemented? Check all that apply. ACTIV - 6 (Pitt) - 1

- Broaden payment methods.
- Avoid "repurposing" and use a word vetted by a community panel.
- Generate population-specific materials that are vetted by a community panel.
- Generate social media campaigns specific to populations and appropriate choice of social media based on age across the lifespan.

Which CEACR Immediate Action Step recommendations were initiated/implemented? Check all that apply. ACTIV - 6 (Pitt) - 2

- Focus on LGBTQIA+ and rural populations to ensure diversity, inclusivity, and outcomes data applicability.
- Consider a Human-Centered Design activity with the research team, SAC, and members.
- Provide educational seminars in the community from local clinicians around research-related topics.

Please indicate the reason(s) for not initiating/implementing any CEACR recommendations. Check all that apply.

- Not relevant
- Unsure how to implement
- Lack of time
- Lack of human resources
- Lack of financial resources
- Other

If Other, please describe:

Which CEACR recommendations were initiated/implemented? Check all that apply.

- Relay the urgency of the issue for institutional buy-in/support for alternative payment models
- Escrow fund to mitigate any financial burden imposed by delays in payment processing
- Ombuds(man/person) to facilitate the academic/CBO compensation process

Which CEACR recommendations were initiated/implemented? Check all that apply.

- Information/leads on snowball sampling
- Willing to explore different budgeting models for compensating community partners for assisting with recruitment efforts
- How to identify and engage trusted leaders

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Which CEACR Long-Term Action Step recommendations were initiated/implemented? Check all that apply. ACTIV - 6 (Pitt) - 1

- Consider a non-virtual arm of the study, like mobile vans or landlines.
- Re-budget for future components to match this standard
- Snowball sampling
- Marketing on home tests

Which CEACR Long-Term Action Step recommendations were initiated/implemented? Check all that apply. ACTIV - 6 (Pitt) - 2

- Hire a more diverse workforce for population-focused recruitment.
- Partner with barbershops, nail salons, hairdressers, and faith partners to build an ambassador program.
- Add local SACs.
- Consider regional coordination with other studies to strategize and prioritize engagement and recruitment efforts.
- Consider Cross-promoting studies in the region.

Please indicate the reason(s) for not initiating/implementing any CEACR recommendations. Check all that apply.

- Not relevant
- Unsure how to implement
- Lack of time
- Lack of human resources
- Lack of financial resources
- Other

If Other, please describe:

What was the most helpful piece of information you received from the CEACR team? ACTIV-6 (Pitt)

- Discussion of Trustworthiness & Research Reciprocity
- Discussion of Building Trustworthiness & Reciprocal Relationships with Partners Matters
- Immediate Action Step Recommendations
- Long-Term Action Step Recommendations

What was the most helpful piece of information you received from the CEACR team?

- Information/leads on snowball sampling
- Budgeting models for compensating community partners to assist with recruitment
- How to identify and engage trusted leaders

Which was the MOST helpful suggestion you received from the CEACR team?

- Relay urgency of the issue for institutional buy-in/support for alternative payment models
- Escrow fund to mitigate any financial burden imposed by delays in payment processing
- Ombuds(man/person) to facilitate the academic/CBO compensation process

Which recommendation did your team find least useful?

- Information/leads on snowball sampling
- Budgeting models for compensating community partners to assist with recruitment
- How to identify and engage trusted leaders

Appendix Figure 10: 30-Day Survey

30-Day Survey (cont.)

- Which recommendation did your team find LEAST useful?
- Relay urgency of the issue for institutional buy-in/support for alternative payment models
  - Escrow fund to mitigate any financial burden imposed by delays in payment processing
  - Ombuds(man/person) to facilitate the academic/CBO compensation process

**On a scale of 1-5, 1 being the least satisfied and 5 being the most satisfied, please rate your level of satisfaction with the CEACR service provided:**

	1	2	3	4	5
Responsiveness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow-through	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Approachability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relevance of feedback	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Actionable items	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you need additional information/assistance from CEACR?  Yes  No

Please select the reason for seeking additional CEACR services:  I would like further assistance with the initial request  I would like assistance with a new request

Would you recommend CEACR consultations to a colleague?  Yes  No

Do you have a colleague you would like us to contact?  Yes  No

Name \_\_\_\_\_

Email \_\_\_\_\_

Appendix Figure 10: 30-Day Survey (cont.)

### 180-Day Survey

CEACR would like to know if there has been any additional utility of the provided recommendations for your project/study. If you agree, a CEACR team member will follow up with a phone call. Please complete the survey below.

Thank you!

---

Which CEACR recommendations were initiated/implemented in the last 3 months? Check all that apply.

- placeholder 1
- placeholder 2
- placeholder 3
- None

---

Please indicate the reason(s) for not initiating/implementing any CEACR recommendations over the last 3 months. Check all that apply.

- Not relevant
- Unsure how to implement
- Lack of time
- Lack of human resources
- Lack of financial resources
- Other
- Not Applicable

---

If Other, please describe:

---

Overall, what was the most helpful piece of information you received from the CEACR team?

- placeholder 1
- placeholder 2
- placeholder 3
- None
- Not Applicable (N/A)

---

Overall, which recommendation did your team find least useful?

- placeholder 1
- placeholder 2
- placeholder 3
- None
- Not Applicable (N/A)

---

Are you willing to be contacted by a CEACR team member for a brief telephone survey?

- Yes
- No

---

If you're willing to be contacted, please provide the best # to reach you: \_\_\_\_\_

### Appendix Figure 11: 90-Day Survey (Under Edit)

### 180-Day Survey

CEACR would like to know if there has been any additional utility of the provided recommendations for your project/study. If you agree, a CEACR team member will follow up with a phone call. Please complete the survey below.

Thank you!

---

Which CEACR recommendations were initiated/implemented in the last 3 months? Check all that apply.

- Information/leads on snowball sampling
- Willing to explore different budgeting models for compensating community partners for assisting with recruitment efforts
- How to identify and engage trusted leaders
- None

---

Please indicate the reason(s) for not initiating/implementing any CEACR recommendations over the last 3 months. Check all that apply.

- Not relevant
- Unsure how to implement
- Lack of time
- Lack of human resources
- Lack of financial resources
- Other
- Not Applicable

---

If Other, please describe:

---

Overall, what was the most helpful piece of information you received from the CEACR team?

- Information/leads on snowball sampling
- Budgeting models for compensating community partners to assist with recruitment
- How to identify and engage trusted leaders
- None
- Not Applicable (N/A)

---

Overall, which recommendation did your team find least useful?

- Information/leads on snowball sampling
- Budgeting models for compensating community partners to assist with recruitment
- How to identify and engage trusted leaders
- None
- Not Applicable (N/A)

---

Are you willing to be contacted by a CEACR team member for a brief telephone survey?

- Yes
- No

---

If you're willing to be contacted, please provide the best # to reach you:

\_\_\_\_\_



K	L	M	N	O	P	Q	R
Request	Focus	Panel	Internal Debrief Date	notes, recordings, etc.)	Panel Topic	Panelists Identified Date	FindTime Poll created/sent
(+) Inc. Part.	Underserved Pop.	Y					
(+) Inc. Part.	Underserved Pop.	Y					
(+) Inc. Part.	Underserved Pop.	Y					
Partner Compensation	Trustworthiness/Reciprocity	Y					
(+) Inc. Part.	Long Covid, Latins	Y					
(+) Inc. Part.	Long Covid, Indigenous/Tribal	Y					
(+) Inc. Part.	Long Covid, Age 65+	Y					
(+) Inc. Part.	Long Covid, Committee Reprs.	Y					
(+) Inc. Part.	Long Covid, Covid (+) Pregnancy	Y					
(+) Inc. Part.	Long Covid, Pediatric	Y					
(+) Inc. Part.	Long Covid, Covid (+) Pregnancy, Latins	Y					
(+) Inc. Part.	Long Covid, Pediatric, Latins	Y					
(+) Inc. Part.	Long Covid, Indigenous/Tribal	Y					
(+) Inc. Part.	Long Covid, Black, African American	Y					
(+) Inc. Part.	Long Covid, Latins	Y					
(+) Inc. Part.	Long Covid, Rural	Y					
(+) Inc. Part.	Long Covid, CE Best Practices	Y					
Req. to facilitate	CBOs	N					
Req. to facilitate	CBOs	N					
List of CEAL-affiliated efforts	Community Health Workers	N					
CE Toolkit	CE Best Practices	N					
Asset Map Request: List of CBOs	Maternal Health	N					
Asset Map Process/Req. to Facilitate	Asset Mapping	N					
Workshop Speaker	Underserved Pop.	N					
Speaker Request	Long Covid, Gender	N					
Speaker Request: Covid mitigation updates	Covid mitigation	N					
Speaker Request: Holiday safety, Spanish fluency	Covid mitigation, Latins	N					
HHS Interview Content	Best Practices Incl. Participation	N					
(+) Inc. Part.	Maternal Health	N					
Survey Tools	Vaccine Hesitancy, Pediatric, Caregivers	N					
(+) Inc. Part., Survey Dissemination	Long Covid	N					
Partner Compensation	Trustworthiness/Reciprocity	N					
(+) Inc. Part.	Latins	Y					
<b>Awaiting consultee response</b>							
Request for Asset Map data	Primary Care	N					
(+) Inc. Part.	Underserved Pop.	Y					
(+) Inc. Part.	Low SES	Y					
(+) Inc. Part.	Low SES	Y					
Return of Value (Community-based)		Y					
Increase minority part_ CEAL POV	Inclusive Part.	Y					
Return of Value (Researcher POV)		Y					
Partner Compensation		Y					
Partner Outreach		Y					
Increase minority part. TTT POV	Inclusive Part.	Y					

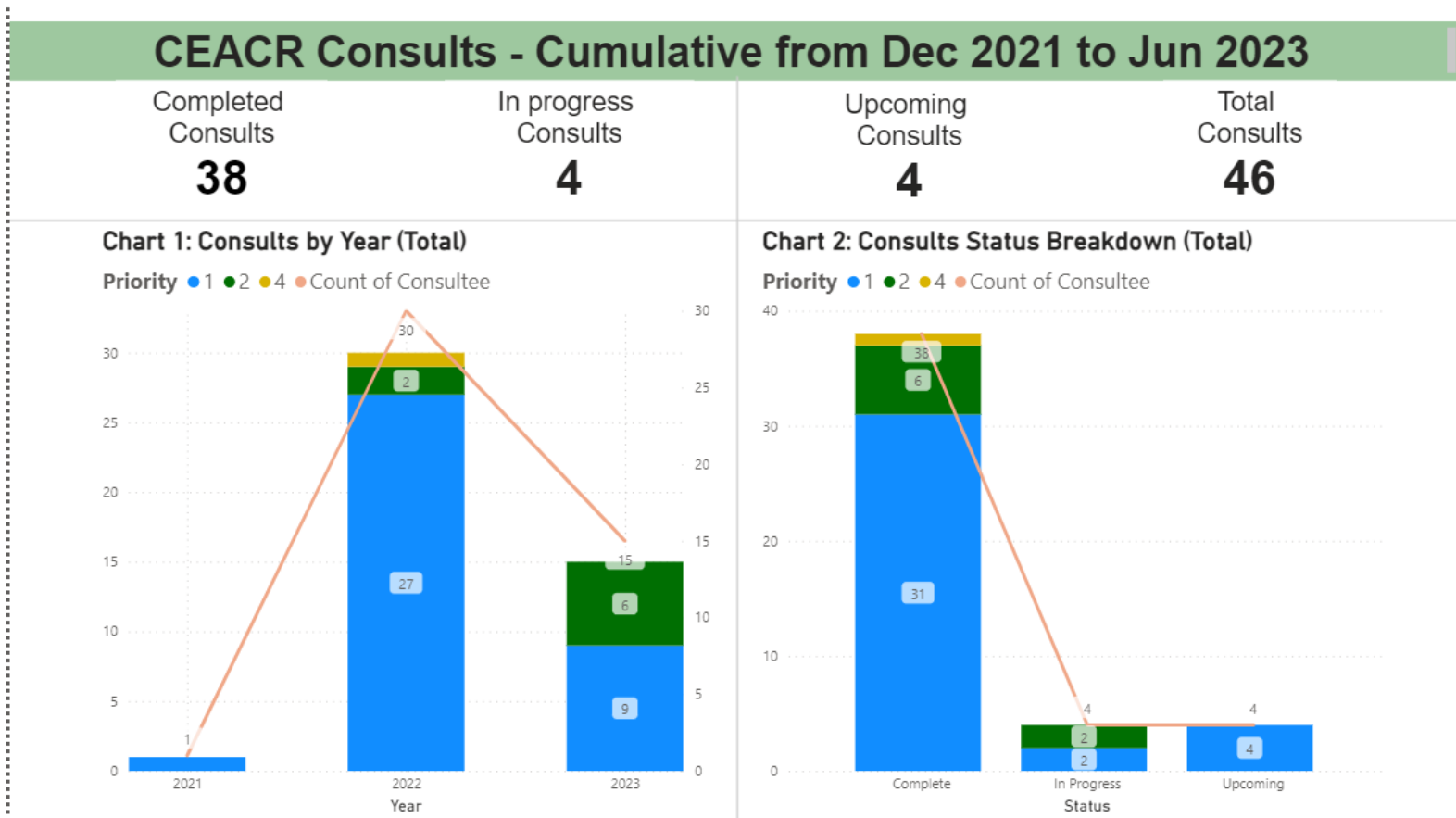
Appendix Figure 13: CEACR Tracking Spreadsheet (cont.)



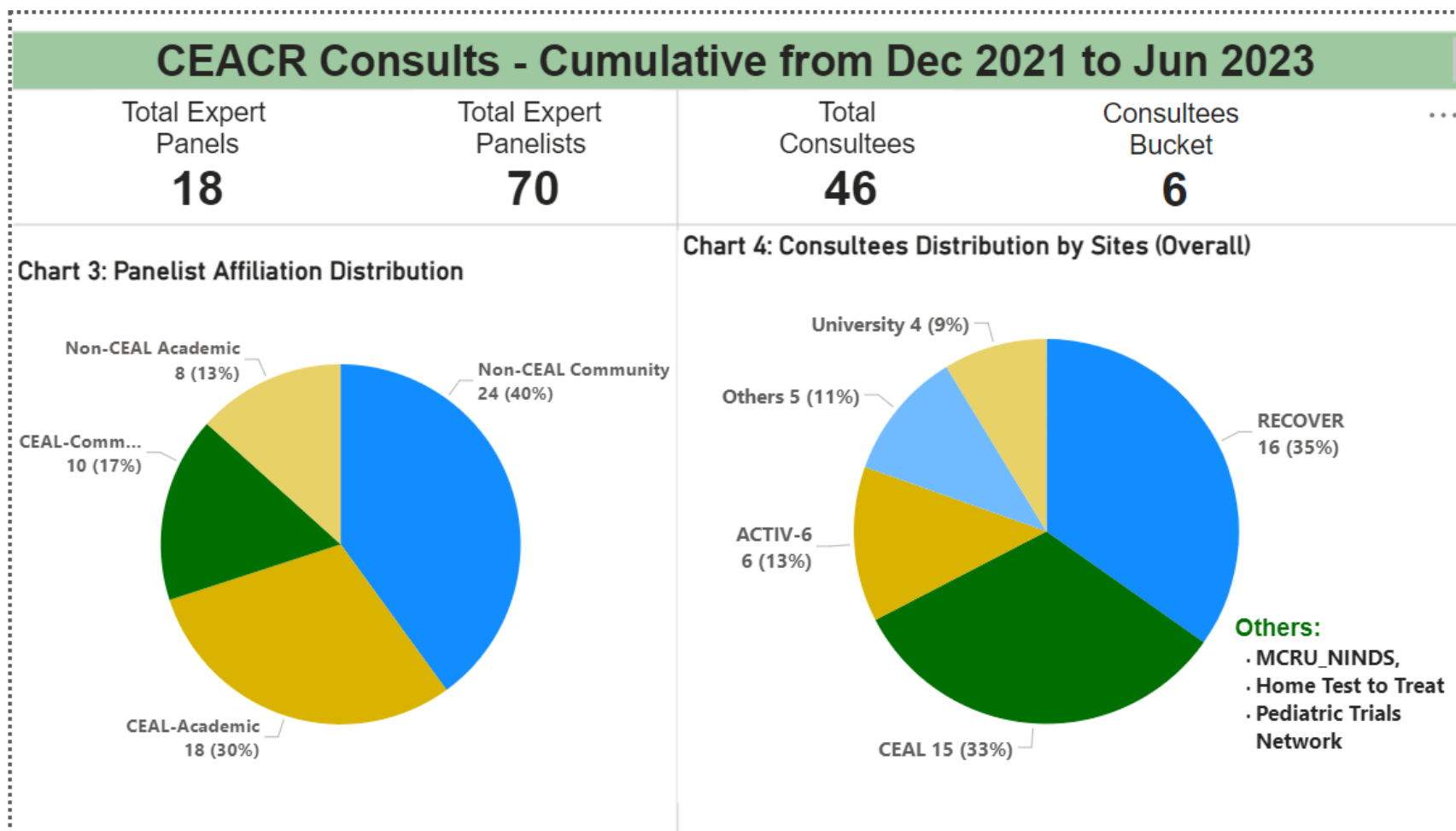


## Appendix F

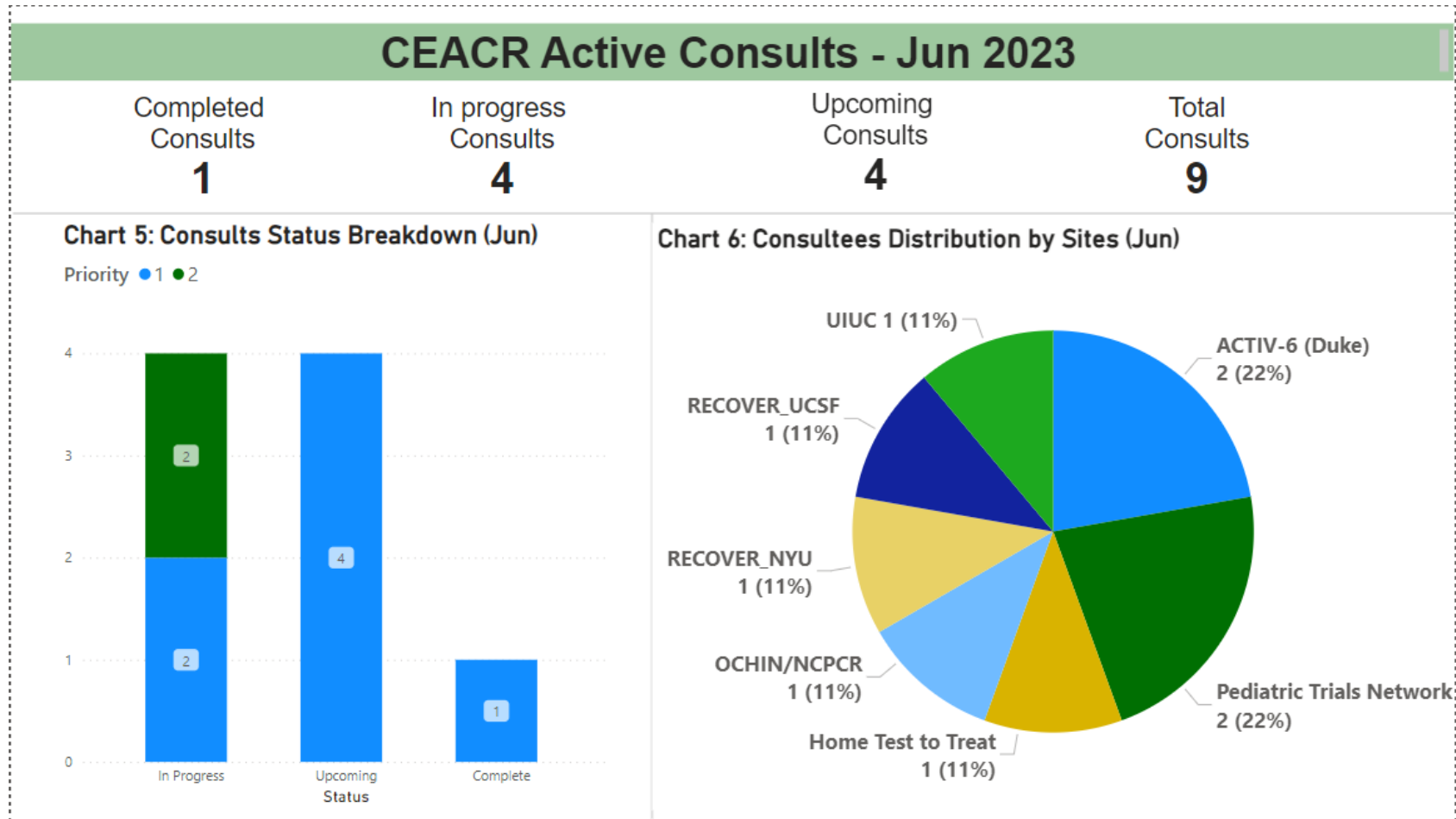
CEACR Dashboards (Power BI)



Appendix Figure 14: CEACR Dashboards (Power BI)

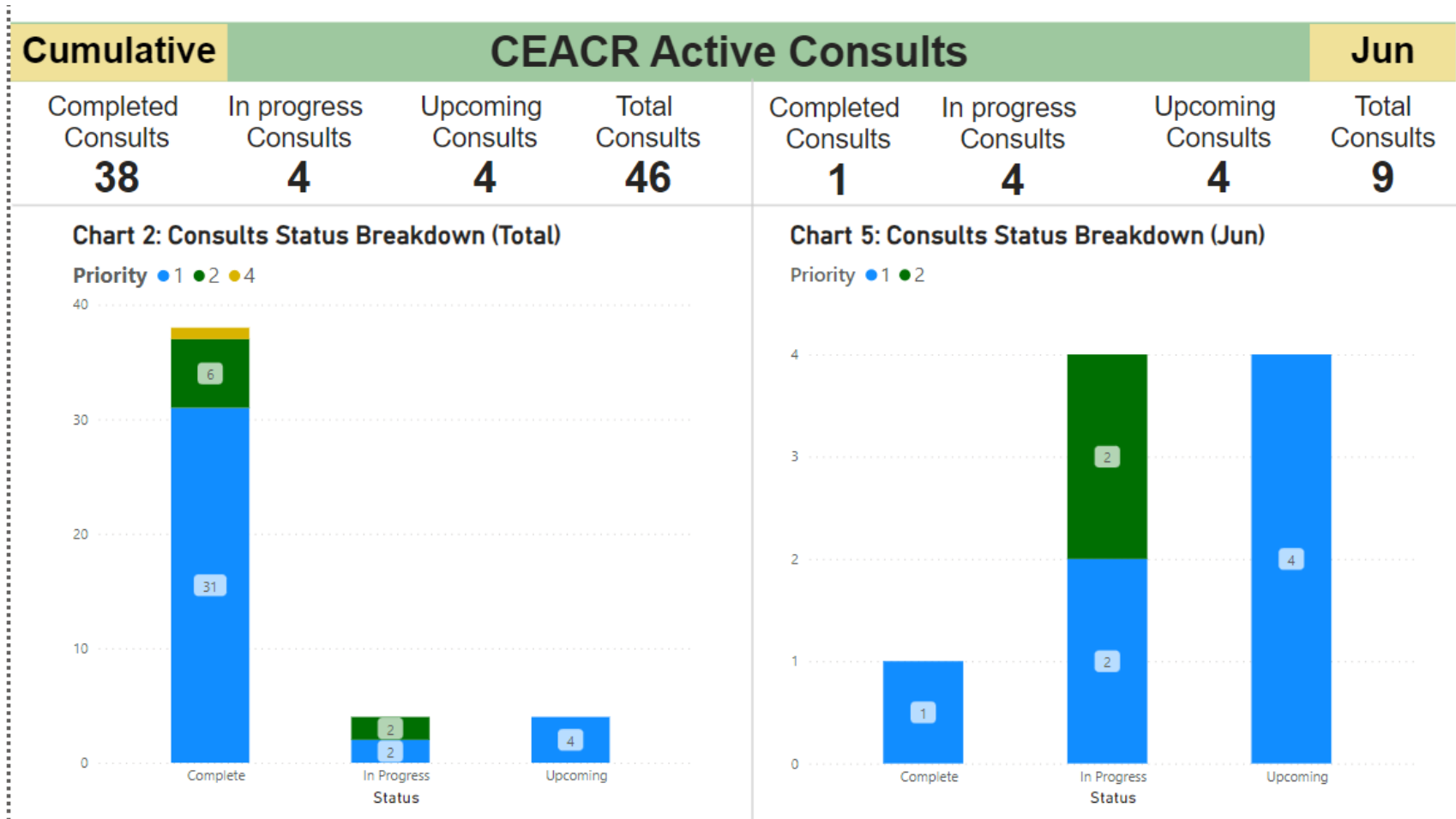


Appendix Figure 14: C EACR Dashboards (Power BI) (cont.)



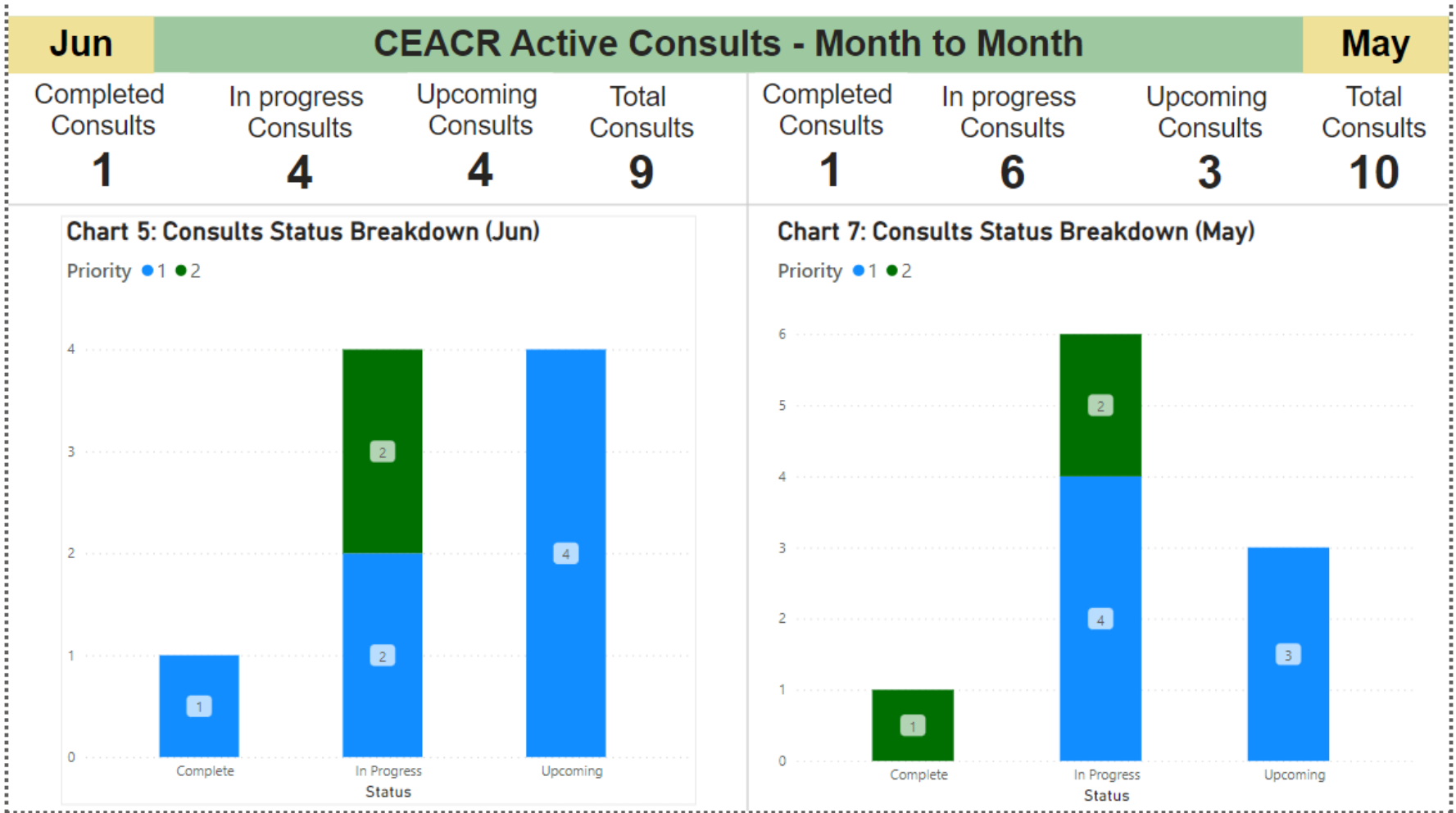
Appendix Figure 14: EACR Dashboards (Power BI) (cont.)

CEACR Dashboards (cont.)



Appendix Figure 14: EACR Dashboards (Power BI) (cont.)

CEACR Dashboards (cont.)



Appendix Figure 14: EACR Dashboards (Power BI) (cont.)

# Appendix G

## Sample Recommendations

The figure displays 18 sample recommendations from CEACR, organized in a grid. Each recommendation is presented on a slide with a title, content, and a number in the bottom left corner. The slides cover various topics such as Texas CEAL, Intake, Trustworthiness & Research Reciprocity, Building Trustworthiness & Reciprocal Relationships with Partners Matters, Panel, Recommendations, Leadership Buy-In, Ombuds (f-man, -person), Escrow Fund, Mini-Grants, Resources, Fiscal Equity, Post-Award Onboarding for Community Partners, Payment Delivery Models, Immediate Action Steps, Long-term Action Steps, Next Steps, and another Resources slide.

Appendix Figure 15: Sample of CEACR Recommendations

## Appendix H

### CEACR Success

**CEACR Success Stories**

**Partner with RECOVER to be a voice for people with COVID in your community**

RECOVER is looking for people to become Patient, Caregiver, and Community Representatives for American Indians/Alaskan Natives (AI/AN).

We need voices from within the AI/AN community to fully reflect the diversity of people who have Long COVID. By partnering with RECOVER, you can help us find answers to Long COVID that could make a difference in your community.

**RECOVER**  
Researching COVID-19 in Native Community  
An initiative funded by the National Institutes of Health

[RECOVERcovid.org](https://RECOVERcovid.org)

**What is RECOVER?**

RECOVER is a research project that aims to learn about the long-term health effects of COVID, called Long COVID. RECOVER's goal is to better understand, prevent, and treat Long COVID. It is a nationwide project funded by the National Institutes of Health (NIH).

**Who can be a RECOVER Patient, Caregiver, and Community Representative?**

Representatives are people who:

- Have Long COVID
- Have a family member or close friend with Long COVID
- Live or work in communities that have higher numbers of COVID or COVID-related problems, such as AI/AN communities
- Are respectful, kind to others, and open to sharing their experience


**What will Representatives do?**


Representatives will listen, talk, and share their thoughts with RECOVER researchers. For example, Representatives will:

- Attend and listen to meetings with RECOVER groups
- Review and give feedback to improve RECOVER studies
- Share their knowledge and personal experience with COVID and Long COVID
- Be paid for their time


 **MATERIAL AND ASSET REVIEW**

 **User: RECOVER**

 **Focus: Cultural appropriateness of outreach materials (Spanish, 65+, AI/AN)**

 **Recommendations**

- Easy-to-Understand
- Reading Level
- Clarify Nature of Trial

 **Impact:**

- Adjusted materials
- Requested consults for other demographics

63

Appendix Figure 16: Examples of CEACR Success

## CEACR Success Stories

### Immediate Action Step Recommendations:

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- Payment through amazon card is limiting to folks who have access to Amazon ordering, safe place for receiving shipping, or stores where it is accepted. Digital delivery can limit who can receive this card due to digital divide barriers.
  - Consider teaching payment methods and delivery of payment methods, consider local businesses within 1000 ft of health and transportation resources.
- The word "repurposing" has a negative connotation to certain populations.
  - Consider avoiding the word "repurposing" in future marketing iterations and using a word vetted by a community panel.
- Engagement/recruitment materials need to be population specific and sensitive to marginalized communities.
  - Consider generating population specific materials that are vetted by a community panel.
- Social media needs to be specific to populations and Hispanic.
  - Consider generating social media campaigns that are specific to populations and appropriate choice of social media based on age across the Western Facebook for older adults, Twitter for middle aged adults, TikTok for young adults.

BIG  
IMPACT  
Opportunity!!

- The Pitt ACTIV 2D team has offered to partner with the Pitt ACTIV 6 team to coordinate and collaborate on community engagement best practices.
- Nationally-the NIH should consider establishing regional quarterly sessions for all the large funded clinical trials to connect and collaborate.
  - PI session
  - Engagement team sessions

Overall sharing of best practices and lessons learned that are region specific

 TRIAL RECRUITMENT AND ENROLLMENT



User: ACTIV-6



Focus: Enrollment matches **prevalence of COVID** illness



Recommendations

- Inclusive language
- Non-web outreach
- Partner w/trusted community members



Impact:

- Implemented recs at Pittsburgh trial site
- Showcased recs at national-level

Appendix Figure 16: Examples of CEACR Success (cont.)



# Appendix I

## Expert Panel Orientation Slides

The figure displays 12 slides from an expert panel orientation presentation. The slides are arranged in a 3x4 grid and cover the following topics:

- Slide 73:** Community Engagement Alliance Consultative Resource (CEACR) Expert Panelist Orientation. Includes a collage of six diverse individuals.
- Slide 74:** Agenda. Lists: Introduction to CEACR (Meet our team, Goals & core services), The CEACR Consult (What to expect), and The CEACR Panelist (Role & responsibilities, What makes a good panelist?, Compensation).
- Slide 75:** Meet the CEACR team!. Features portraits of six team members: Joseph Miller, PhD; Myranda Stewart, PhD; Rachelle Jones, D. Public Health; Al Stewart, Executive Director, CCMH; Elyse Price, Program Coordinator, CCMH; and Anne Quinn-Rose, Deputy Director, CCMH.
- Slide 76:** Community Engagement Alliance Consultative Resource (CEACR) Best Practices and Innovations in Inclusive Participation in Research. Focuses on Core Services: Convene tailored Expert Panels, Feature CEAL Alliance assets, and Integrate principles of trustworthiness.
- Slide 77:** The CEACR Panel. Describes the purpose of CEACR Panels and lists activities like educational content development, tailored analyses, review of promotional assets, fiscal practices, and onboarding partners.
- Slide 78:** The Consult Process: What to Expect. A 4-step process from request to final summary.
- Slide 79:** Consult Participants. Lists attendees: CEACR Facilitator, CEACR Notetaker, Representative(s) from the research team, 3-4 expert panelists, and NIH Observer.
- Slide 80:** Post-Consult Follow-up. Details the human-centered design process, theme generation, sharing of action items, and post-consult feedback collection.
- Slide 81:** The CEACR Panelist: Roles and Responsibilities. Distinguishes between what panelists may include (Community Leaders, Lived Experience Experts, etc.) and what they are expected to do (Review materials, Active participation, etc.).
- Slide 82:** What Makes a Good Panelist?. Lists traits like being enthusiastic, listening closely, offering constructive critique, and respecting confidentiality.
- Slide 83:** What Makes a Good Recommendation?. Lists traits like being concrete, using tools/assets to fill gaps, sharing personal narratives, and providing accessible options.
- Slide 84:** Why Your Voice is Important. Emphasizes the value of community leaders' lived experience and academic experts' research insights.

Appendix Figure 17: Expert Panel Orientation Slides

*Expert Panel Orientation (cont.)*



**Appendix Figure 17: Expert Panel Orientation Slides (cont.)**

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