DELIVERABLE 15

California Reducing Disparities Project

Evaluation Guidelines for African American Pilot Projects

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African American Technical Assistance Provider

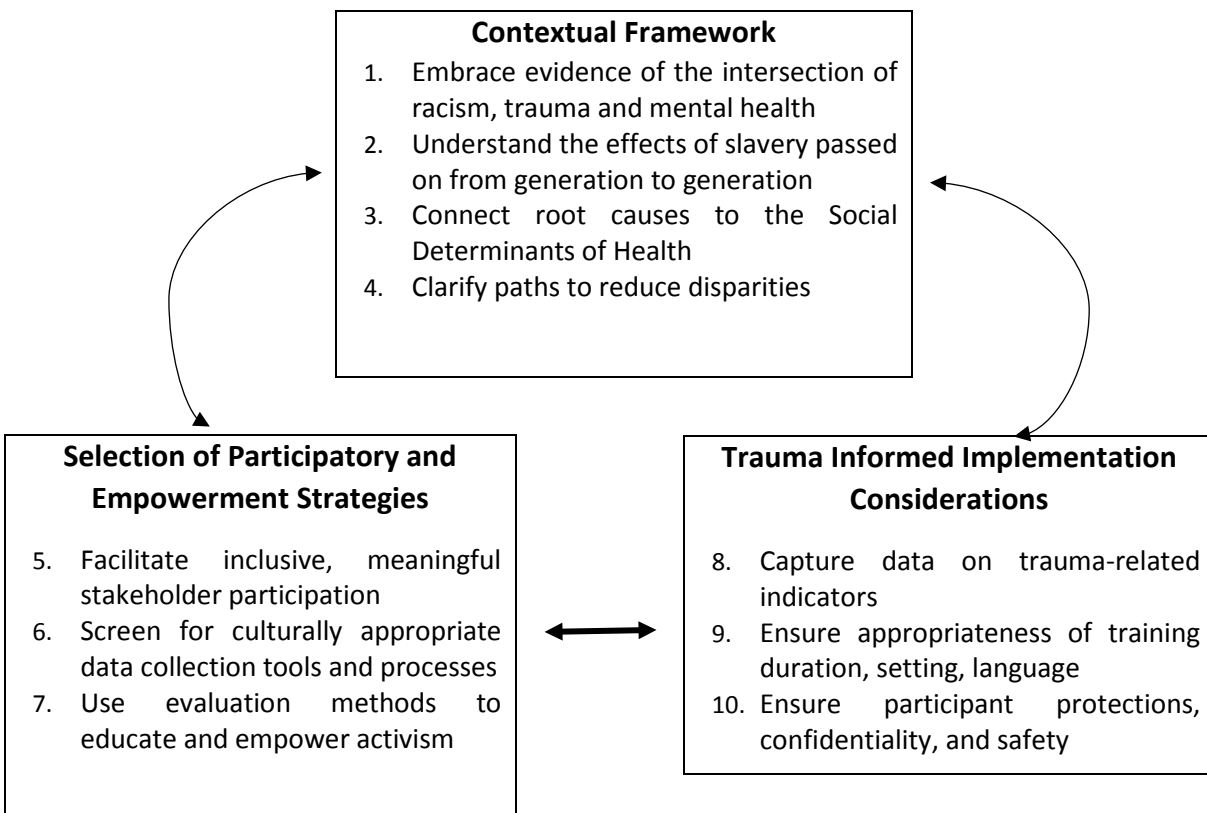Updated March 2017

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OVERVIEW

The CRDP African American Technical Assistance Provider (TAP), ONTRACK Program Resources (ONTRACK), prepared these population-specific Evaluation Guidelines to support Implementation Pilot Projects (IPPs) as they design and implement their local evaluations and also participate in the research designed by the CRDP Statewide Evaluator (SWE), PARC@LMU. In addition to providing ongoing support to individual IPPs, ONTRACK will develop a minimum level of consistency across the IPP evaluations. Even though each IPP will design an evaluation responsive to their own community, this document provides best practices and guidelines for conducting culturally and linguistically appropriate evaluation research in African American communities.

While each Implementation Pilot Project (IPP) may face unique evaluation challenges, the following five sections provide guidance on developing high performing, culturally relevant evaluations for the African American population CDEPs.

SECTION 1. SUMMARY OF GUIDELINES

Ten (10) guidelines are offered to provide culturally and linguistically appropriate approaches for the evaluation of African American IPPs. The guidelines are organized into three interrelated domains.

Contextual Framework

1. Embrace evidence of the intersection of racism, trauma and mental health
2. Understand the effects of slavery passed on from generation to generation
3. Connect root causes to the Social Determinants of Health
4. Clarify paths to reduce disparities

Selection of Participatory and Empowerment Strategies

5. Facilitate inclusive, meaningful stakeholder participation
6. Screen for culturally appropriate data collection tools and processes
7. Use evaluation methods to educate and empower activism

Trauma Informed Implementation Considerations

8. Capture data on trauma-related indicators
9. Ensure appropriateness of training duration, setting, language
10. Ensure participant protections, confidentiality, and safety

Just as CDEPs operate within a context of history and community, so must their evaluations. Like the interventions provided by IPPs, the evaluation cannot ignore the fact that they are operating in a pathological system that reflects and perpetuates the trauma that the African American community has, and continues to,

experience. The rigorous evaluations of the IPPs must start with an acknowledgement that over 400 years of systematic racism and trauma will not be erased by a six-month, a one-year, or even a five-year intervention. The old standards of social research will not always work. Culturally and linguistically appropriate measures of improved mental health and reduced stigma will need to be developed by these IPP evaluations. As James Baldwin said, "The American idea of racial progress is measured by how fast I become white." Thus, benchmarks and measures developed need to be realistic and appropriate, both culturally and logically.

Research strategies and data collection must acknowledge the entire person, and start from a spirit of resiliency, focusing on how people and communities have survived and thrived despite the trauma they and their ancestors have endured. Data collection tools and techniques must be consciously designed to ensure participants' comfort, to honor their trust, and reflect their truth. Finally, the evaluation must listen to the community, learn about the community, and collaborate to co-design research that speaks with the community, not just to it.

It is beyond the scope of this document to address every detailed element of evaluating community-defined evidence programs to address mental health in African American communities. These guidelines follow an African-centered philosophy,[1] which postulates that African epistemologies, ideals, and values must be at the center of any analysis involving African Black peoples. The principles and values that underpin the African-centered worldview (Akbar, 1976; Asante, 1987, 1990; Myers, 1988; Schiele, 1997) are the following:

- The interconnectedness of all things.
- The spiritual nature of human beings.
- Collective/individual identity and the collective/inclusive nature of family structure.
- Oneness of mind, body, and spirit.
- The value of interpersonal relationships.

Just as these principles are woven throughout each of the African American IPP's Community-Defined Evidence Programs (CDEPs), they can be included in the implementation of both the local and statewide evaluations. The evaluations of African American IPPs will not look like traditional or mainstream evaluations seen in the dominant white culture.

SECTION 2. COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

The California Reducing Disparities Project is community-driven at its core, from program design to evaluation, and requires incorporating community stakeholders in the evaluation. The desire to include community stakeholders in program design and evaluation is not new. In the early 1970s, the National Heart, Lung and Blood Institute established a program designed to increase minority participation. The most important strategy suggested by the report was soliciting contributions from community opinion leaders.[2]

Community engagement in the planning, implementation, and evaluation of health initiatives builds community capacity to create sustainable changes at all levels to achieve and maintain optimal health for those who bear the greatest burden of disease.[3]

Several models for community engagement in research exist, including community-based participatory research, empowerment evaluation, participatory or community action research, and participatory rapid appraisal. Some confusion exists about the definition of community engagement in research because the terms and models are sometimes used interchangeably.[4]

While not discounting other models, the methodological foundation of the statewide CRDP evaluation is the principles and practices of Community-Based Participatory Research (CBPR). The goal of this section is to assist IPPs in fulfilling the requirement for effectively incorporating community stakeholders in the full evaluation process. The following pages provide a general description of CBPR, along with a more detailed list of suggested guidelines for CBPR with African Americans.

What is Community-Based Participatory Research?

Broadly, Community-Based Participatory Research (CBPR) in health is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. The basic tenets are culturally responsibility, accountability, and reciprocity. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities (W. K. Kellogg Foundation's Community Health Scholars Program, 2001, p. 2). Researchers, community members, and program participants are partners in the research, all bringing their unique knowledge, skills, and experiences to the process.

CBPR emerges from the social justice and action research traditions, both of which recognize the unique strengths and perspectives of community partners and aim to produce tangible benefits for communities participating in research.[5] The principles of CBPR have been adapted from Minkler & Wallerstein, (2008) and the table on the next page presents questions to consider, especially as you engage in ongoing refinement and implementation of your CDEP.

Community-Based Participatory Research Principles[6]

CBPR Principle	Questions For Your Project
1. CBPR **brings researchers and community members together** during all parts of the research process.	How can all group members become involved?
2. CBPR **balances research *and* action** for the benefit of all partners.	What actions might come out of your research?
3. CBPR **recognizes the community** as a whole.	How do you define your community for this project?
4. CBPR uses the opportunities and talents within the community, recognizing that **everyone has something to offer.**	What are the opportunities and talents in your community?
5. CBPR allows researchers and community members to **learn from each other and get results**.	What do you hope to learn from the community/researcher?
6. CBPR is a **long-term process** that requires commitment and dedication.	What type of commitment and dedication do you expect from each team member?
7. CBPR focuses on **issues in the local community**. CBPR pays attention to the many factors that contribute to those issues.	What issue in your local community will you be addressing? What factors impact it?
8. In CBPR, community research partners **share information** obtained from the research for the benefit of all people involved.	Who will benefit from your research?
9. CBPR tries to improve the health care system through **open and consistent communication** between researchers and the community.	How will your project improve the (mental) health care system?
10. CBPR **promotes the rights of community members** to	How can leaders empower group

make their own choices and in many ways empowers all persons involved in the process.	members? How can group members become empowered? How can this project empower the larger community?

The questions (and the answers) might change over the course of the CRDP, but considering these questions on an on-going basis can help keep the community at the center of your service delivery and program evaluation.

How to Use Community-Based Participatory Research

There are many different ways to use CBPR. The table below lists a few different ways to use the CBPR process in the evaluation of your CDEP. [7]

Research Element	CBPR Application
Research design	Researchers communicate the need for specific study design approaches and work with community to design more acceptable approaches
Participant recruitment and retention	Community representatives guide researchers to the most effective way to reach the intended study participants and to keep them involved in the study
Formative data collection	Community members provide input to intervention design, barriers to recruitment and retention, etc. via focus groups, structured interviews, narratives, or other qualitative method
Measures, instrument design and data collection	Community representatives involved in extensive cognitive response and pilot testing of measurement instruments before beginning formal research
Intervention design and implementation	Community representatives involved with selecting the most appropriate intervention approach, given cultural and social factors and strengths of the community
Data analysis and interpretation	Community members involved regarding their interpretation of the findings within the local social and cultural context
Manuscript preparation and research translation	Community members are included as coauthors of the manuscripts, presentations, newspaper articles, etc.

The previous descriptions of CBPR provide good general guidelines for including any community members in the evaluation process. The next sections present best practices for conducting Community-Based Participatory Research within the African American community more broadly, and with Black or African American women, specifically. The final section provides guidance and suggestions for including youth in Community Based Participatory Research and local evaluation of the CDEP.

Community-Based Participatory Research with African Americans

In addition to the specific suggestions for working with youth and women, in 2004, the National Black Leadership Initiative on Cancer (NBLIC), housed at Morehouse Medical School, worked with community

coalitions to develop a set of CBPR principles that are friendlier to non-academics, and are presented in terms familiar to African Americans, more broadly. [8]

The NBLIC developed a set of principles that resonate well in the African American community and, because they reflect familiar themes, are readily committed to memory. They are fewer in number than the principles listed in other compilations, but nonetheless capture the important points. Since they **emphasize trust and solidarity**, they support the CBPR approach without necessarily specifying details.

Like other sets of CBPR principles, the NBLIC's seven guidelines do not represent a recipe for conducting community-based research. Rather, these principles, and others, help define the approach that researchers and community partners take in designing and implementing research projects. They may be consulted as protocols are drawn up and, subsequently, they may be used as criteria against which a project may be measured to determine the extent to which it is truly community-based (or community-centered) and participatory. [9]

The National Black Leadership Initiative on Cancer (NBLIC)'s **Seven Guiding Principles**, including with abridged verbatim descriptions by Smith, et. al., are presented below, along with our suggestions for application to the California Reducing Disparities Project, in italics.

1. **We are Family**—This 1977 hit song recorded, by the group Sister Sledge, is a classic in the pop music world, perhaps because it is a kind of theme song for community solidarity. It thus represents research that is community-based (not community-placed) and supported by the community as a whole. This resonates with the historical context of the Black community. This principle is similar to Principle #1 of Israel, et al. (1998)[10] "Recognizes community as a unit of identity." CBPR provides a cooperative framework for working toward a common goal. Similar to a family, CBPR is based on an understanding of and respect for divergent interests within partnerships and communities. Mutuality allows researchers and communities, despite their differences, to address a health problem important to both.

> *Some of your CDEP community partners might vary in size and composition. Some partners might be large, with formal structures comprised of professionals and practitioners, while others might be small, grassroots, and primarily represent consumers. Including a diverse group of partners and stakeholders is critical to understanding different facets of the issues you are researching. Some stakeholders might be more important during planning stages, others during implementation, but all are working towards a common goal: to reduce stigma and improve mental health.*

2. **It Takes a Village**—The African proverb, "It takes a village to raise a child" became well known as the title of a book written by then-First Lady Hillary Rodham Clinton in 1996. In the context of CBPR principles, it represents the mutual trust established between investigators, stakeholders, and the community so that all partners function as if they constituted a village. The 'village' facilitates co-learning, shared decision-making, and mutual ownership of the problem and its solutions. This is similar to Community-Campus Partnerships for Health (CCPH) Principle #2: "The relationship between partners is characterized by mutual trust, respect, genuineness, and commitment." A growing consensus is that, for translation of evidence-based interventions, they must be implemented with methods engaging partners and stakeholders that treat their expertise and perspectives with equal weight to those of researchers. The principle of 'village,' as defined in NBLIC collaboration, includes organizational partners and community stakeholders (i.e., church, clinic, and community site).

> *Your CDEP likely includes some sort of Community Advisory Board, comprised of individual partners, stakeholders, and consumers. In addition to creating equality amongst members of this important group, identify other agencies with whom you can align for your mutual benefit. Perhaps your agency can help support a local community center where you hold meetings by showing up at a funding hearing.*

3. **Come as You Are**—This phrase, originally a party invitation, has been used in popular as well as gospel music. It describes our call to the community and indicates the willingness of academic researchers to meet their community partners on their own turf and on their own terms. It rejects the proposition that the community must assume a posture of "readiness" in order to participate equitably in the research process. For scientists and community leaders, the goal is to enhance communities by empowering them to become full participants in research. This principle can be viewed as similar to CCPH Principle #3: "The partnership builds upon identified strengths and assets, but also addresses areas that need improvement." This principle is demonstrated by facilitators, which include community health educators (CHEs) (i.e., agency staff with degrees in a health profession) or community health workers (CHWs) (i.e., community health advisors, natural helpers, and frontline workers without college or graduate school education in a health profession).

> *Consider how your agency can provide training workshops to introduce basic vocabulary, concepts, and methods of community-based mental health services (including your specific CDEP) and program evaluation to individuals of varying health literacy. Asking people to participate as equal partners in the process requires time and effort to ensure that everyone is starting from the same basis of general knowledge in order to full share their unique talents, information, and skills.*

4. **Just Stand**—This is a refrain from a gospel song. In the CBPR context, it points out that current research 'stands on' or is grounded in past research. With each new research cycle, new questions are expected to emerge from the research itself. Such an approach is cyclic, converging on a better understanding of processes as well as outcomes. This principle is comparable to Principle #6 of Israel, et al. (1998): "Involves a cyclical and iterative process," which suggests that the process is not stagnant, but one that involves rounds of review, reflection, and revision before researchers and communities are satisfied with the outcomes.

> *The groundbreaking "not business as usual" nature of the California Reducing Disparities Project lends itself easily to formative evaluation, where the evaluation research helps inform the program, and changes in program are reflected in the evaluation. Over the five years of the CRDP, both your local and the Statewide Evaluation will likely evolve based on lessons learned and adapt to changing contextual factors. While some of the core measures will remain constant, a willingness to engage in an iterative process will be critical. Participating community members, both advisors and consumers, will need to be kept informed about interim findings and changing processes and rationales.*

5. **Health, Wholeness, and Healing**—This reflects the fact that most communities have little interest in being studied; however, they are concerned about education, jobs, health care, and other services – entities that will improve community health. Research must ensure that individuals have the opportunities, knowledge, attitudes, and skills needed for optimal health. Researchers who wish to conduct observational studies must be able to describe how their research will lead to an intervention or policy change that will improve community health.

This resembles Principle #4 of Israel, et al (1998): "Integrates knowledge and action for mutual benefit of all partners," promoting an ecological approach to health, emphasizing physical, mental, and social well-being.

> *Although your CDEP focuses on mental health, you may include additional modifiable behaviors (i.e., dietary intake and physical activity) in the intervention curriculum. You may partner with other providers based on the needs of your specific communities. You might integrate your CDEP into other organizational efforts. For example, you might work with a new organization to share a small portion of your CDEP, bringing awareness to new partners and constituencies.*

6. **Go Tell it on the Mountain**—This is old spiritual reminds us of the role of the community in disseminating the results of CBPR, including scientific publications (which may be of less interest to the community), the popular media (e.g., newspapers, radio, organizational newsletters, and magazines), and policymakers. It reflects Principle #8 of Israel, et al. (1998): "Disseminates findings and knowledge gained to all partners." For years, community members have participated in studies from which they did not see results or experience benefits. Information needs to be shared through relevant community channels appropriate to its communities. For researchers, this means peer-reviewed publications, scientific presentations, books, and reports; for communities, popular magazines, radio, church gatherings, and word-of-mouth. A shared data plan promotes co-ownership of data between researchers and communities.

> *It is vitally important to share results with the community to address the perception that "research findings rarely benefit the African American community because they do not see the results of studies [or that] research usually is conducted for the benefit of others, specifically, Whites."[11] A series of focus groups with African Americans who have participated in medical research studies found that "many participants believe that confusion about research and medical care stems from the lack of education and dissemination to the public. When information is presented, it is rarely done in way that is understandable, and therefore its use is limited. Additionally, participants suggested that doctors, researchers, and others in health care do not always present information in a way that is respectful and understandable."*
>
> *Participants in the focus group study emphasized that when study findings are communicated back to the community, they should be presented in an understandable way, and also from a sense of interest and concern about the community. Nicholson and colleagues found that African Americans respond negatively to cancer disparity information and positively to messages of hope.[12] Similarly, Teal and colleagues describe a framework for culturally competent communication, which includes communication repertoire, situational awareness, adaptability, and knowledge about core cultural issues. Researchers should indicate how studies can potentially benefit the African American community.[13] To close the loop, investigators can work to ensure that minority communities reap benefits from new research findings.*
>
> *Communication of study findings has also been shown to positively influence attitudes about participation and willingness to consider participation in future trials, even when the results are negative or inconclusive. In addition to providing feedback and review opinions, you might ask at least one community coalition leader to contribute to and serve as a co-author on all publications and materials.*

7. **We Shall Overcome, Someday**—The civil rights anthem brings to mind the overriding goal of CBPR in the African American community: reducing and eliminating the health disparities that plague this community.

Mortality rates for African Americans are higher than those for other racial and ethnic groups for major causes of death. This must be overcome. This principle is relatively unique, partly because it reflects outcome rather than process and partly because it focuses particularly on racial/ethnic health disparities.

> *From intervention development to testing and dissemination, the fundamental component of CRDP is addressing a disparity in mental health services that leads to preventable morbidity and mortality in the African American community. This guiding principle of CBPR in the African American community is at the heart of the California Reducing Disparities Project and permeates through each component of the project.*

Community-Based Participatory Research with African American Women

In addition to acknowledging and addressing trauma and exclusion in the history of conducting research within the broader African American community, the IPPs focusing their efforts on reducing mental health disparities for Black and African American women (California Black Women's Health Project: *Sisters Mentally Mobilized*, and Healthy Heritage Movement: *Broken Crayons…Still Color Project*) will need to also consider the stressors, perspectives, and expertise that women bring to the research process. Specifically, "the authoritative knowledge that women of color have about their lives and their health should form the basis for collaboration between researchers and study participants."[14] Women are the experts of their own lives and communities, and evaluation tools and analyses need to consider the multiplicative effects of race, class, and gender on mental health.

Single-risk explanations for health disparities (e.g., race <u>or</u> gender) obscure discoveries of the complexities of day-to-day existence that imperil health.[15] Engagement in CBPR must provide opportunities for expressions of the unique gendered identities, roles, and experiences of oppression among women of color. This includes also encouraging women to validate their lived experience within and across the boundaries of presumed class categories. While this disaggregation may seem to divide, acknowledging the diversity of lived experience can provide connection and inclusion for all participant-partners.

Community-Based Participatory Research provides an opportunity for Black and African American women to ensure that their realities and lived experiences are reflected in the design, delivery, and evaluation of the CDEP. Focus groups can be an effective way for women to share their stories and be collaborative and authoritative partners in all aspects of research, from the conceptualization of research questions, the implementation of research procedures, and, most importantly, the sustained application and dissemination of research findings within their community.

Community Based Participatory Research with Youth

The Implementation Pilot Projects (Catholic Charities of the East Bay: *Restorative Trauma-Informed Practice Project*, Safe Passages: *Law and Social Justice Life Coaching Project*, The Village Project: *the Emanyatta Program*, West Fresno health Care Coalition: *Sweet Potato II Project*) working with youth will need to include the unique language, culture, concerns, and resilience of youth in their Community Based Participatory Research processes. Although definitions vary, for the purposes of this section, "youth" refers to the population of people under age 21 with whom the IPPs are working. For most of the IPPs, this refers mostly to high-school aged youth (14-18).

Representing the key community constituents for these projects, youth bring unique strengths and perspectives, and their participation in the research process can increase community buy-in for the CDEP, overall. Youth might

help review program and/or evaluation materials to ensure cultural and linguistic appropriateness for youth audiences. Youth might also be helpful in program design, delivery, or engagement, as well as disseminating results among their peers and with stakeholders. How youth participate in CBPR depends on what works best in the CDEP community and more importantly, what works best for participating youth.

In addition to representing younger community members, youth can also play a deeper role in implementing the evaluation of your CDEP. The ways in which youth can/will be engaged will vary from IPP to IPP and depends on the CDEP, the workplan, and the local evaluation plans. This section provides examples and best practices, but cannot dictate exactly what roles youth will play in the evaluation, if any. A few examples of the ways youth can participate in the evaluation with the guidance of adult allies include, but are not limited to:

- **Advising**: Youth can provide feedback on CDEP evaluation data collection tools and/or methods. Youth can help ensure questions and language are relevant to and reflect their lives and experience.
- **Advocacy**: Youth voices can be a powerful part of sharing evaluation findings, particularly to elected officials and other stakeholders.
- **Analysis**: Youth can be valuable partners in making sense of evaluation data, especially interpreting qualitative data gathered from youth.
- **Data Collection**: Youth can conduct peer-to-peer interviews or focus groups, or engaging in participant observation of CDEP services.
- **Recommendations**: Youth voice and perspective should be included whether and how change should be made in the CDEP based on evaluation findings.

There is a continuum of youth involvement in evaluation, presented below. The level at which will vary depending on the CDEP elements, the local evaluation plans, and the ability and capacity of IPP and local evaluator staff to include youth in the evaluation. I

A Continuum of Youth Involvement in Evaluation and Research[16]

Youth Involvement	Process
Highest	Youth-led research/evaluation is part of organizational planning cycle; experienced and trained youth act as peer trainers and are paid
High	Youth participate in research design, data collection, and analysis; youth report findings, implement change
Medium-High	Youth design and administer research instruments; adults analyze results, develop findings, implement changes
Medium-Low	Youth give input on process
Low	Youth collect data
Very Low	Information is collected from youth

None	Outside adult conducts research without collecting information directly from youth

The American Evaluation Association supports a Youth-Focused Evaluation (YFE) Topic Interest Group (TIG) specifically focusing on engaging youth in evaluation practices in a meaningful way. Katie Richards-Schuster, Chair of the TIG, suggests evaluators consider the following questions to explore how to expand the roles of young people in evaluation, in order to move higher along the continuum of youth involvement.[17]

- What are the role or role(s) young people should play in evaluation?
  - What is needed to prepare young people for these roles?
- What are the roles of adults?
  - What is needed to prepare adults as allies in evaluation?
- What supports and facilitates youth engagement?
  - What are some of the challenges and barriers?
- What are the best practices for engaging young people? For engaging adults?
- What more needs to be known about the development of youth-adult partnerships as a vehicle for youth-focused evaluation efforts?
- What are the contexts in which youth-focused evaluation is occurring?
  - Where is it happening? Where is it not? Why?
- What is the impact of youth participation in evaluation on youth? On programs? On communities?
- What knowledge needs to be developed to further the field? What are the critical questions for the future?
- What are the forms this knowledge should take? What are strategies for co-learning?
- What are the possibilities for cooperation, collaboration, and co-learning in various contexts?

These questions will need to be answered by each IPP and its local evaluator as they collaboratively determine the extent of the role youth will play in the evaluation. No matter the depth or extent of the role, youth will need to be prepared to participate in the evaluation, and accommodations may need to be made to make youth feel comfortable. The same youth engagement principles that guide service delivery – providing education and training, meeting people where they are, using language that is familiar and comfortable, including them in a meaningful way – all apply to participating in the evaluation, as well. For example:
- **Meetings** may need to be shorter and scheduled during out-of-school time, in the late afternoon or on weekends, so that youth can attend.
- **Transportation** is an issue for many youth, so arranging carpools or providing bus passes can help youth remain engaged.
- Like anyone learning a new skill, youth will need to receive **age-appropriate training** about evaluation principles, practices, and methods, in a language and at a pace that works for them.
  - Training youth to engage in the highest level of participation in the evaluation process is likely beyond the scope of most IPPs. If the IPP and local evaluation staff decide to conduct formal "Evaluation 101" trainings with youth, there is no need to reinvent the wheel: many resources and toolkits[a] exist to train youth in basic evaluation concepts, skills, and methods.

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[a] ACT For Youth has compiled an excellent list of Youth Participatory Evaluation resources that can be found here: http://www.actforyouth.net/youth_development/evaluation/resources.cfm

- Just as professional researchers get paid, the youth participating in the CDEP evaluation should receive some sort of **stipend or other compensation**, as the IPP budget allows.
- Finally, the best way to engage youth is to feed them. Have **food and drinks** at every meeting, especially if meeting after school.

According to a review of four projects that included active youth participation in research efforts to engage youth in research will work best if care is taken to address the following key considerations:[18]

- All researchers need **time** to learn, practice, and improve their craft.
    - o Participatory research, which often unfolds in an iterative, cyclical manner, is ideal for this kind of learning and particularly well-suited to engaging adolescents. Just as adult researchers receive training, IPPs and their local evaluators must educate and train youth to participate in the evaluation.
- The timeframe needs to be **realistic**—long enough for the development, testing, and revision of new skills, but not so long that young people are unable to see it through to completion because of their own developmental changes.
    - o This may mean that youth are highly involved in one aspect of the evaluation, such as a specific piece of data collection that has a finite beginning and end, so that they can participate in every stage, from question development, administration, analysis and findings. It is also important to acknowledge school calendars: youth will be more available for longer-term projects during the summer months, and/or you may need to schedule a short-term project during Spring Break.
- The work of youth researchers needs to be **supported** with appropriate human, financial, and logistical resources.
    - o Adult allies are critical in providing support and encouragement to youth participating in the evaluation. Adult-youth partnerships provide new insights and learnings for both parties, but it is the responsibility of the adult ally to be the "guide on the side," supporting youth in their learning and development. As partners in the evaluation, if adults are financially compensated to conduct research, so should the youth. And meetings and workplans need to be scheduled by consensus, in order to accommodate both the adults' and youth's schedules and competing demands.
- Young people need to be engaged in and informed about the **rights and responsibilities** involved in "human subjects" research.
    - o In three of the four examples described by Powers and Tiffany (2006), this did not take place; in the fourth, young people not only completed human subjects training but also contributed substantially to making sure that confidentiality concerns were addressed in an effective, context-specific manner.
- Organizations that engage youth in participatory research and evaluation need to take youth voice seriously by **listening to and acting upon youth recommendations**.
    - o At the same time, youth recommendations should not be endorsed uncritically—the reflection and decision process involving youth generated recommendations need to be no less rigorous.
- **Multiple modes of participation** are important.
    - o A wide range of youth (not just youth who are "stars") should be engaged, and youth should have an opportunity to adapt their level of participation to their changing developmental needs. It is important to provide incentives or pathways to "ramping up" participation and assuming increasingly complex responsibilities, as well as ways for youth to reduce their involvement, while maintaining significant relationships with the project, as their developmental needs change.

Suggested Resource: A Step-by-Step Guide to Community-Based Participatory Research

For a step-by-step discussion of conducting Community-Based Participatory Research, we recommend the Chicago Reducing Disparities Project's *Inspiring Change Workbook,*[19] a Community-Based Participatory Research workbook for involving African Americans with serious mental illness in research. The workbook contains explanations and fillable worksheets for every stage of research.

SECTION 3. CULTURALLY AND LINGUISTICALLY APPROPRIATE EVALUATION

The evaluation of the California Reducing Disparities Project (CRDP) is multi-faceted, including both local and statewide evaluation across five priority population groups. The goal of this section is to help IPPs ensure the evaluation is culturally and linguistically appropriate for the individuals that will be served by the population, including addressing any cross-population issues. The following pages present tips, suggestions, ideas, examples, and recommendations on how to strengthen or tailor your local evaluations to your prioritized African American communities. The discussion includes culturally and linguistically appropriate services (CLAS) standards for African Americans in your data collection, data entry, and overall evaluation process.

Culturally and Linguistically Appropriate Services (CLAS) Standards

The Culturally and Linguistically Appropriate Services (CLAS) Standards are a set of 15 mandates, guidelines, and recommendations originally developed in 2001 by the Department of Health and Human Services, Office of Minority Health, to inform, guide, and facilitate organizations in their efforts to improve culturally and linguistically appropriate health services.

The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care[20] (The National CLAS Standards) aim to improve health care quality and advance health equity by establishing a framework for organizations to serve the nation's increasingly diverse communities. The Principal Standard is to "*Provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs.*" The comprehensive application of The National CLAS Standards provides guidelines in the following core domains: Governance, Leadership and Workforce; Communication and Language Assistance; Engagement, Continuous Improvement and Accountability.

The 15 CLAS Standards are as follows:

PRINCIPAL STANDARD
1)   Provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs.

GOVERNANCE, LEADERSHIP AND WORKFORCE
2)   Advance and sustain organizational governance and leadership that promotes CLAS and health equity through policy, practices and allocated resources.

3)   Recruit, promote and support a culturally and linguistically diverse governance, leadership and workforce that are responsive to the population in the service area.

4)   Educate and train governance, leadership and workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.

COMMUNICATION AND LANGUAGE ASSISTANCE

5) Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.

6) Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.

7) Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.

8) Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

ENGAGEMENT, CONTINUOUS IMPROVEMENT AND ACCOUNTABILITY

9) Establish culturally and linguistically appropriate goals, policies and management accountability, and infuse them throughout the organizations' planning and operations.

10) Conduct ongoing assessments of the organization's CLAS-related activities and integrate CLAS-related measures into assessment measurement and continuous quality improvement activities.

11) Collect and maintain accurate and reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes and to inform service delivery.

12) Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.

13) Partner with the community to design, implement and evaluate policies, practices and services to ensure cultural and linguistic appropriateness.

14) Create conflict- and grievance-resolution processes that are culturally and linguistically appropriate to identify, prevent and resolve conflicts or complaints.

15) Communicate the organization's progress in implementing and sustaining CLAS to all stakeholders, constituents and the general public.

The CLAS Standards come into play in the local IPP evaluation and the statewide CRDP evaluation mostly around the last section, Engagement, Continuous Improvement, and Accountability (Standards number 9 through 15).

Culturally Competent Evaluation

The Centers for Disease Control developed a widely-used *Practical Strategies for Culturally Competent Evaluation*[21] guidebook to provide guidance on evaluation approaches and methods, relevant examples, and additional resources. It provides many similar suggestions presented in these guidelines, along with specific guiding questions for evaluators. The following two pages present the full "Program Evaluation Tip Sheet" excerpted verbatim from pages 31 and 32 in that guidebook.

Program Evaluation Tip Sheet: Integrating Cultural Competence into Evaluation

This Tip Sheet contains important excerpts from the *Practical Strategies for Culturally Competent Evaluation,* an evaluation guide designed for programs and partners funded by the Centers for Disease Control and Prevention's (CDC) Division for Heart Disease and Stroke Prevention and Division of Environmental Hazards and Health Effects' National Asthma Control Program. The guide highlights the prominent role of culture in the work of evaluators and provides important strategies and guiding questions for enhancing cultural competence in evaluation.

What Is Cultural Competence?

Cultural competence is "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enables effective work in cross-cultural situations."[1] Cultural competence is an essential and ethical obligation for all evaluators.

Applying a critical cultural lens to evaluation will ensure that efforts have cultural relevance and will generate meaningful findings that stakeholders ultimately will value and use. This Program Evaluation Tip Sheet contains tips and guiding questions aligned with the six steps of CDC's *Framework for Program Evaluation in Public Health.*[2]

Self-Reflection Questions for Evaluators

To help explore your own identity, ask yourself
* Where am I from (nationality, region, and heritage)?
* What are my beliefs, values, and religious and political orientation?
* What is my biological sex and gender identity?
* What is my age group?
* What is my social class?
* Which of the above factors are significant to me?
* What do I see as potential opportunities, challenges, or conflicts for this evaluation?

* What stereotypes do I hold?

Evaluations cannot be culture free.

Cultural competence requires reflection on one's own cultural position.

Competence in one context is no assurance of competence in another.

Cultural competence fosters trustworthiness.

Ensuring Cultural Competence in Evaluation

Tips	Guiding Questions
Engage Stakeholders • Assess cultural self-awareness. • Request that stakeholders who reflect the diversity of the community be included throughout the evaluation. • Lay clear ground rules for participation to establish equality. • Build trust by talking openly with the community about the evaluation.	• Does the stakeholder group fully represent the diversity of the program's participants and others affected by the program? • Are meaningful roles planned for stakeholders throughout the evaluation? • Is there a distribution of power among stakeholders? To other distinctions related to status and social class? • Are there multiple voices in planning, implementing, interpreting, and decision making?
Describe the Program • Conduct key informant interviews to clarify stakeholders' perspectives of the program. • Hold an information-gathering session for stakeholders about the social and historical context of the program. • Use models that resonate with the community.	• Are stakeholders' perspectives appropriately reflected? • What is known about the strengths, assets, challenges, and barriers of the community, including the talents and expertise that individual community members or organizations bring? • Are there "gatekeepers of knowledge" within the community that can help describe the social and political context of the program/community?
Focus the Evaluation Design • Engage an experienced facilitator familiar with the community who can guide the development of evaluation questions that reflect stakeholders' values. • Develop a visual chart that describes evaluation design options in such a way that all stakeholders understand the choices and the implications.	• What/whose values and perspectives are represented in the evaluation questions? • Is the design appropriate to the evaluation questions as well as the cultural context and values of the community? • Is the evidence considered credible by the community and stakeholders?
Gather Credible Evidence • Select culturally appropriate data collection instruments. • Develop data collection methods that factor in cultural and linguistic distinctions. • Adapt data collection processes to the stakeholder context.	• Whose perspectives are accepted as credible evidence? Credible to whom? • Are the language, content, and design of the instruments culturally sensitive? Have the instruments been validated with their intended audiences? • Have verbal and nonverbal communication been addressed?
Justify Conclusions • Prior to developing final conclusions, discuss cultural implications during data analysis. • Involve diverse stakeholders in interpreting data. • Ensure that many stakeholders' voices are heard when making judgments.	• How are different stakeholders' perspectives and values addressed in the analysis and interpretation of the evaluation findings? Are conclusions validated by participants? • Are conclusions balanced with culturally appropriate recommendations and community capacity?
Ensure Use and Share Lessons Learned • Generate recommendations through an inclusive process by providing a role for various stakeholders to implement the evaluation findings. • Tailor dissemination of evaluation results to stakeholder needs. • Encourage the use of evaluation information by holding an inclusive meeting about developing an action plan for evaluation use.	• Are communication mechanisms culturally appropriate? • Does the reporting method meet stakeholder needs (both the message and the messenger)? • Are the data presented in context, with efforts made to clarify issues and prevent misuse? • Has the community benefited as anticipated? How?

[1]Anderson LM, Scrimshaw SC, Fullilove MT, Fielding JE, Normand J, Task Force on Community Preventive Services. Culturally competent healthcare systems: a systematic review. *Am J Prev Med.* 2003;24(3S):68–79. www.thecommunityguide.org/social/soc-AJPM-evrev-healthcare-systems.pdf.

[2]Centers for Disease Control and Prevention. Framework for program evaluation in public health. *MMWR*. 1999;48(RR-11):1–40.

Addressing Cross-Population Issues

While the California Reducing Disparities Project is divided into five priority population groups, these groups are not monolithic. Implementation Pilot Projects will work with individuals who may represent multiple racial/ethnic groups, such as people who identify as Afro-Latinx[b] (African and Latino/a ancestry), Blasian[c] (African and Asian ancestry), and/or represent the LGBTQ population. The Statewide Evaluator is developing data collection tools with set demographic questions, and it is important to consider challenges that may arise in evaluation research with people who cross the five CRDP priority population groups.

The CRDP LBGTQ Technical Assistance Provider, Center for Applied Research Solutions (CARS), will be providing technical assistance and training about engaging and working with participants across the four ethnic priority populations. A few issues to consider with evaluation research in Black and African American LGBT communities[22] are to:

- Engage in a deliberate self-awareness process to not put any participants in an "other" role.
- Consider whether research tools and methods, including your consent form, create an "us-them" dichotomy. For example, does the consent form serve to protect subjects or spell out the researchers' obligations and commitments to potential participants.
- Partner with cross-population agencies and/or individuals, especially in advisory or CBPR roles.
- Explore the full range of potential participants and seek breadth to the extent possible.
- Consider using more than one measure of sexual identity, if appropriate (i.e., a sexual orientation, a sexual label, and a behavioral component).
- Share research findings broadly in important sources of information in the community, including in the popular and contemporary media.
- Include the voices of all participant-partners.

Evaluating your CDEP with Black and African American LGBT communities will require additional openness to listen to and include diverse, and possibly dissenting, voices. Evaluators and program staff will need to engage in open and honest dialogue to gain entry, provide support, and build trust within this community of participants and partners.

Universal Design for Evaluation

In addition to the consideration of cross-population issues, high quality evaluations need to pay attention to the diversity of all populations being served. To assist in evaluation planning, Jennifer Sullivan-Sulewski, & June Gothberg developed the *Universal Design for Evaluation Checklist*,[23] a short planning tool that helps evaluators include people of all ages and all abilities in evaluations.

Universal Design for Evaluation Checklist (4th ed.)
Developed by Jennifer Sullivan Sulewski & June Gothberg

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[b] Afro-Latinx is a term to describe people of African and Latino descent. "Latinx" is a less sexist and more inclusive and indigenous term than "Latino."
[c] Blasian is a term to describe people of African and Asian descent. These are important terms to include given the cross-population/ intersectionality focus of the CRDP.

The purpose of this checklist is to provide support for program evaluators who design, develop, implement, and disseminate evaluations. This checklist is designed to assist the evaluator to include all individuals in the evaluation process; people of all ages and all abilities. To do this, evaluators are encouraged to use the seven principles of Universal Design.[1] "Universal design asks from the outset how to make the design work beautifully and seamlessly for as many people as possible. It seeks to consider the breadth of human diversity across the lifespan to create design solutions that work for all users". This checklist is best implemented during the planning phase of the evaluation project in order to ensure full participation for all populations.

Principle One: Equitable Use *The design is useful and marketable to people with diverse abilities.*

☐ To the greatest extent possible, the evaluation plan represents the participant population, known or anticipated, as staff, advisers, and/or co-researchers.[2]

☐ Evaluation plan prepares for locating diverse study participants and providing accessible recruitment materials.

☐ Informed consent materials are simple and accessible with alternate forms available.[3]

☐ Informed consent materials allow participants to understand the plan for data use and dissemination.

☐ Evaluation plan is transparent with all steps understood; including proper procedures for publishing for community, cultural, and tribal participants.

☐ Evaluation plan is grounded in context with consideration for community and cultural appropriateness of methods used for gathering information.

☐ Evaluation plan follows all IRB processes including community, cultural, and tribal protocols.

Principle Two: Flexibility in Use *The design accommodates a wide range of individual preferences and abilities.*

Evaluation plan shows evidence of preparation to:

☐ Communicate with participants of diverse abilities, communication styles, and cultural backgrounds.

☐ Quickly solve problems in regards to individual needs.[4]

☐ Include a variety of data collection tools to accommodate communication preferences or needs.[5]

☐ Include extra time for participants with slower cognition or language barriers.

☐ Include extra time to observe cultural practices.

Principle Three: Simple and Intuitive *Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level. Eliminate unnecessary complexity.*

Data collection instruments and materials:

☐ Provide for different communication preferences or needs.[6]

☐ Are available to people with a variety of reading levels and backgrounds.[7]

☐ Use simple language, concrete questions, and show cultural competency.[8]

☐ Meet low vision and color blind requirements.[9]

☐ Are free from acronyms, jargon, slang, and colloquial terms.

Principle Four: Perceptible Information *The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.*

☐ Sensory issues are addressed.[10]

☐ Multiple media options are used to present information.[11]

☐ All printed publications are available immediately or in a timely manner in alternate formats.[3]

☐ A statement is included in all materials about procedures for requesting accommodations or assistance.

☐ Online materials adhere to web accessibility standards *(see: www.w3.org/WAI/).*

Principle Five: Tolerance for Error *The design minimizes hazards and the adverse consequences of accidental or unintended actions.*

Instruments and protocols:

☐ Are pilot tested with participants who resemble your target audience.

☐ Are easy to understand and responses intuitive, even if people don't read the instructions.[11]

☐ Avoid "skipping" *(e.g. "if you answer no please skip to number 17").*

☐ Avoid lengthy instructions keeping them to 12 words or less.

☐ Avoid confusing instructions.

☐ Allow different response options for different reading and/or cognitive levels.[12]

☐ Allow verbal or written responses outside the standard instrument.

☐ Include optional probes or explanations to make questions accessible to a wider audience.

☐ Online options provide a long time out period for those with dexterity and processing challenges.

☐ Online options are available to save and return later.

Principle Six: Low Physical Effort *The design can be used efficiently and comfortably, and with a minimum of fatigue.*

Location and meetings:

☐ Are accessible on a bus line, in a central location, close to building with parking, ramps, and elevators allowing access to wheelchairs.

☐ Are held at times and locations of the participants' choosing.

☐ Provide comfortable seating options

☐ Allow for break time, shortened time, or multiple sessions.

☐ Include options for collecting data, communicating, and/or sharing information online.

Principle Seven: Size and Space for Approach and Use *Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.*

Site:

☐ Ensures accessibility for interviews, focus groups, meetings, presentations, or other project-related gatherings

☐ Has accessible restrooms, the room is quiet, the space is well-lit, and provides enough space for sign language interpreters, readers, or personal assistants.

☐ Allows transportation accessibility, with event timed around transportation availability.[13]

☐ Allows for on-site accommodation (e.g., adding a reader or interpreter)

This checklist is being provided as a free service to the user. The provider of the checklist has not modified or adapted the checklist to fit the specific needs of the user and the user is executing his or her own discretion and judgment in using the checklist. The provider of the checklist makes no representations or warranties that this checklist is fit for the particular purpose contemplated by user and specifically disclaims any such warranties or representations.

1. Story, M.F., Mueller, J.L., & Mace, R.L. (1998). *Designing for people of all ages and abilities.* The Center for Universal Design.
2. all ages, gender, ethnicity, culture and ability
3. other languages, in Braille, at lower reading levels, large print, verbal, pictorial, electronic, and audio format
4. second language interpreters, sign language interpreters, readers, large text, and Braille.
5. interviews, focus groups, observations
6. choice of in-person, telephone, and online venues; written, drawn, or oral responses, and use of smart tools (smart phones, iPad, tablets)
7. having multiple versions for different respondent types, or having optional explanations or probe questions
8. types of scales, number of units, probes or explanations, keeping questionnaires short and simple, questions with cultural competency

The Safety First Initiative, funded by the Department of Justice, Office on Violence Against Women, prepared a Responding to Trauma: Creating inclusive, accessible, and responsive community services for people with developmental disabilities poster for an Association of University Centers on Disabilities meeting.[24] Safety First details the intersection of universal design and trauma-informed principles. They share the example that a person may benefit from plain language of a written document because the person has an intellectual disability or because the person has recently experienced trauma and is having difficulty processing. Regardless of the reason, transforming practices to be trauma-informed and universally designed go hand in hand. The examples on the poster focus on program development and implementation, but can easily translate into evaluation and data collection activities, as well.

Components of Trauma-Informed Services	Examples of Universal Design Considerations
Safety	Access to exit, line of sight, respect for personal boundaries
Trustworthiness	Respect for privacy, consistency of expectations, consistency of staff availability
Choice	Multiple ways to access information, information into group assignments, options for participation
Collaboration	Evidence of survivor-therapist partnership, peer-to-peer supports
Empowerment	Survivor-centered/strengths-based support, empowerment-focused therapy

Developing and Using Data Collection Instruments in African American Communities

The Tobacco Control Evaluation Center developed guidelines for the evaluation of tobacco control projects working with the African American community.[25] A few of their suggestions are included below.

- Ensure that participation in evaluation activities is done with **full consent** of each individual.
- Utilize existing surveys, questionnaires, and protocols that have been **validated** in samples similar to or the same as the community members. Make sure that the evaluation data collection protocol obtains information that is **relevant to African American communities**.
- Engage in **CBPR** to review surveys, questionnaires, and interviews (including the SWE Core measures) with community researchers to ensure that questions are understandable, respectful and effectively "get at" the evaluation objectives. Rely on the community researchers' expertise in regard to community participants' literacy skills and understanding and comfort with the interview process.
- Use **accessible and respectful language**, both in written documents and in conversations. Many community members, including African Americans, report difficulty in understanding informed consent procedures due to the technical language. Evaluation documents should be as simply written as possible and without technical jargon that distances the participant from the evaluation efforts. Informed consent should be discussed face-to-face with the participants in order to clarify any misunderstandings or misinterpretations.
- Face-to-face interviews and surveys are the preferable means of collecting data within African American communities. **Personalizing the evaluation data collection process** increases trust and honesty between and among the evaluators and the community participants. Moreover, face-to-

face interviews provide access to "high-risk" populations that may not have a telephone or Internet access at home.

- Any technical survey language can be addressed by **including the slang or street terms** in parentheses after the technical term. The respondent then reads the item or listens to the list read by the interviewer until the term they are most familiar with is named and they answer. In order to avoid diminishing slang or street terms, parentheses can be omitted and the technical or medical jargon terminology may appear last in the list of phrases. One result of this procedure is identification of the term occurs earlier in the question, striking a familiar chord that helps the respondent to remember particular situations connected with that type of act while the question is fresh in his/her mind.[26]

- Allow for **various means of communication** and responses to evaluation questions. Various means of responding increases participants' understanding of the evaluation questions and thus provides a sense of "communication equality", reduces embarrassment and resultant non- participation if community members have low literacy skills, and provides opportunities to gather rich and informative data as well as develop relationships.

- Let community leaders determine the "**time**" for data collection procedures. Many African American communities see time as a fluid construct, and evaluators who place constraints on time by having rigid scheduling and activities may likely reduce participatory behavior from the community.

IPPs will have the most flexibility in designing their own local evaluations, but some of the most successful research approaches in the African American community are those whose foundations are within the oral tradition.[27] These include participant observation, personal interviews, historical reviews, and focus groups. Participant observation provides an opportunity for the researcher to hear, see, and experience reality as the participants do by spending time in the setting.[28]

An Example of Culturally and Linguistically Appropriate Research

One example combining community engagement and culturally and linguistically appropriate research is a randomized trial to test the effectiveness of a therapeutic group via teleconference called Sisters Tell Others and Revive Yourself (STORY) for African American women with breast cancer.[29]

Knowledge of the target audience and an understanding of its culture are essential to successful social marketing. In laying the groundwork for patient recruitment, the authors consulted extensively with the African American community through patient and professional advisory committees. This core group chose the colors and logo design and endorsed the STORY acronym as the study name. In addition, the authors obtained feedback from a variety of African American consumer advocates and public relations professionals. The authors were very deliberative in building community and state support by involving hospital staff, politicians, church leaders, and others to help the authors tell the story of STORY. Also established was the STORY circle, an informal network of 98 volunteers, primarily African American women from health agencies, law firms, and churches who distributed STORY materials to churches and the community.

The authors deliberately chose words with STORY that reflected African American spirituality and story-telling, both strong features in the African American culture. These resonated with the African American community, helped increase public awareness of the project, and laid the groundwork for the recruiters. Also, the study's marketing message addressed lack of trust and knowledge of the Tuskegee Research

Project as possible factors that might decrease participation in the study; therefore, many recruitment pieces carried the tagline, "Our story is an open book."

General Tips for Data Collection and Data Entry

This section presents unique challenges in data collection from a review of mostly small, rural, predominantly African American Faith-Based Organization (FBOs) conducting tobacco prevention lessons for youth in Grades 4 through 6 while they were attending summer Vacation Bible School. [30]

Plan for evaluation in every aspect of the project. The local evaluation of your CDEP, as well as participation in the Statewide Evaluation, requires a continual focus on evaluation. Your program paperwork (intake, ongoing assessment, and closure) should also include evaluation data collection wherever possible. The more you can integrate evaluation into your daily program processes from the start, the easier the reporting requirements to CDPH will be.

Pilot-test everything. Pilot testing should involve giving the questionnaires and interview protocols to people who are the same age, gender, socio-economic situation, and literacy level as those intended for data collection. Test both local and statewide data collection tools with people who resemble your CDEP's priority population. Pilot testing can illuminate problems with instructions, reading levels, awkwardness in wording, and other problems that are difficult to anticipate. Pilot testing does not need to be extensive, but feedback from just a handful of people before you launch a survey can save you from hours of extra work, confusion, and most importantly, inaccurate data!

Use reminders judiciously. Maintain communication with your local evaluator, CDPH Contract Manager, Technical Assistance Provider, and the Statewide Evaluator to keep up-to-date with the CRDP data collection schedule. Consider agency and CDEP calendars, such as trips, personal leave, and other agency requirements to ensure that data collection timelines are met. Automating your data collection process can help ensure a smooth quarterly, semi-annual, and annual data collection process throughout the life of the CRDP. For example, try collecting data at regular intervals and/or on memorable milestone dates, establishing automatic reminders, and engaging multiple owners of the data collection process so that the responsibility is shared.

Ensuring timely data collection by external partners can be challenging. A reasonable time to start calling to remind partners of the upcoming evaluation is 1–2 weeks beforehand. A longer lead time reduces the value of the reminder. A shorter lead time reduces the chances of reaching someone. Reminders work optimally if they have a personal touch, which may take enormous patience and dogged persistence.

Make backup plans at every step. Unfortunately, it is impossible to anticipate all problems that will occur during data collection. While you may attempt to collect pre- and post-assessments from every participant, attrition is a normal component of service delivery. However, back-up plans can help reduce the loss of follow-up data. For example, even if a participant misses the last session when post-tests are administered, you might respectfully contact the individual directly to complete the assessment anyway.

Personally collect data in a nonthreatening way. Engaging partners to assist with evaluation data collection can be challenging, especially with pre- and post-tests in group settings. Errors arise when facilitators do not pay attention to the instructions, do not realize that the pre-test questions must come before the post-test questions, and do not understand that the pre-testing must occur before the

training or group sessions. It is essential that instructions are clear and bold, that pre-tests are on the top of the envelope, and that pre-tests are in a different color from that of the post-tests. It is a good idea to include a question about the date as a built-in check to ensure that pretesting actually occurred before post-testing. If you are trying to match individual pre- and post-tests for individuals, you will need to create a unique identifier, keeping confidentiality concerns in mind. The SWE has developed an extensive system for the collection of core measures.

Throughout these guidelines, we have discussed the concerns of many African Americans, especially, about privacy and the motivations behind data collection. Scharff et. al. (2010) found that "in view of widespread mistrust and suspicion in their community, African Americans in a qualitative study about participating in medical research indicated that they tend to be reluctant to provide information about themselves. Many discussed the fear that personal information may be used against them at some later date. This belief has a historical etiology that has been sustained throughout the generations."[31] Explaining why the data elements in both your local CDEP evaluation and the CRDP statewide evaluation are important can help increase acceptance and participation in the data collection process.

Safeguard data entry. As previously mentioned, the CRDP Statewide Evaluator has created a system for de-identifying individual responses on the core measures. Keeping the master list of individual names secure is both ethically and programmatically critical. Each IPP has created a Data Plan to ensure safeguarding of data, and this should include the process for data entry. For example, if a form contains identifying information (even if it is not entered into a database), the person doing the data entry must be screened and trained in your agency's confidentiality practices.

Along the same lines, data entry is often relegated to new staff members, who can be overconfident of their ability to enter data, who can lack investment in entering data correctly, or who can be unaware of simple strategies to check their data entry. Therefore, systematic quality control for data entry is crucial.

Quality control, accountability, and some simple steps available in most data analysis programs can diminish data contamination and reduce inevitable human error. A two-step quality control process of numbering all completed questionnaires, and relatively early in the data entry process, randomly selecting a few questionnaires allows a person other than the data entry person to check that data are entered correctly. In addition, a data entry tracking log can increase accountability by tracking who entered which surveys, when, and any comments that he or she has about the data.

Once data is entered, checking for outliers and empty boxes in Microsoft Excel, or using the frequencies option in SPSS, is critical. Trust your intuition about how you think the data "should" look. If the frequencies option in SPSS or Excel produces averages or charts do not make sense, go back to the raw data. Look for typos or erroneous entries (such as 8, not 88). The time taken early in the data entry process to clean the data is well worth it when the evaluator analyzes the data.

Tips on Assessing Evaluation Outcomes for At-Risk Youth

Several of the African-American Implementation Pilot Projects focus on providing mental health PEI to "at risk" youth. In addition to the previous considerations about engagement and data collection, it is important to consider the unique challenges of program participants when assessing evaluation outcomes.

Allan Porowski from ICF International and Heather Clawson from Communities In Schools (CIS) shared their lessons learned[32] from a five-year, comprehensive, mixed-method evaluation of Community In Schools, which surrounds students with a community of support, empowering them to stay in school and achieve in life. While the students in the following example were not specifically adjudicated youth, many of the risk factors are similar for the students prioritized in IPPs such as TRIBE, Sweet Potato II, Safe Passages, and RTIPs for Teens.

Sometimes, you have to catch falling knives: The students coming into CIS were targeted for services because they were on the strongest downward trajectories on a number of factors (e.g., academics, behavior, family issues, attendance, etc.). There's an old adage in stock market trading that you should "never catch a falling knife" – but that's what CIS and other dropout prevention programs do every day. This has implications for how you evaluate the relationship between dosage and outcomes. A negative relationship between dosage and outcomes doesn't necessarily indicate that services aren't working – it can actually be an indication that services are going to where they are needed the most.

 Look for the "Nike Swoosh": The general pattern of outcomes among CIS students looked like Nike's "swoosh" logo: There was an initial downward slide followed by a longer, more protracted period of improvement. Reversing that initial downward slide takes time, and this pattern is worth investigating if you're evaluating programs for at-risk youth.

"All we need is just a little patience": It takes a long time to make significant changes. So many evaluations of at-risk students don't have a long enough time horizon to show improvements, which may in part explain why we see such low effect sizes in dropout prevention research relative to other fields of study.

These three lessons learned are even more salient for CDEPs, which do not have established measures or definitions for "success." The determination of measures of successes in CDEPs will occur in partnership with program and community stakeholders.

Suggested Resource: Trauma-Informed Data Collection

The Substance Abuse Mental Health Services Administration (SAMHSA) developed a guide to GPRA data collection using trauma-informed interviewing skills.[33] This extensive guide provides strategies and resources for interviewing and data collection using a trauma-informed approach, identifying and handling post-trauma responses from interviews, self-care for program staff, and supervising trauma-informed programs.

SECTION 4. STATEWIDE EVALUATION TIMELINE

The LMU@PARC's draft Statewide Evaluation Guidelines 1.0 present a general reporting timeline for IPPs to follow. The goal of this section is to link the SWE's timeline to the TAP's timeline of providing technical assistance across seven IPPs.

Evaluation Plan

According to the SWE's draft Guidelines, IPPs must submit their CDEP Evaluation Plan to the SWE using the SWE's Qualtrics template within 60 days of the project start. The SWE will provide feedback within 4-6 weeks for revision prior to submission to the CDPH.

The exact timeline and schedule is under review, but the TAP will also provide guidance and feedback about evaluation plans to the IPPs.

Semi-Annual Reporting

IPPs must submit their Semi-Annual Evaluation Reports to the SWE using the SWE's Qualtrics template according to the following timeline. The SWE will provide instructions for completing the reports 30 days prior to submission (October 1, 2017). The following reporting schedule is included in the PARC@LMU's Statewide Evaluation Guidelines 1.0:

SWE Semi-Annual Reporting Schedule

Semi-Annual Reporting Periods		Semi-Annual Submission to the SWE		SWE Summary Reporting of Semi-Annual Data to CDPH
#1: 4/1/2017 – 9/30/2017	TAPs, EOAs, & IPPs have 1 month to prepare their reports & submit to SWE	#1: 11/1/2017	SWE has 2 months to analyze data	#1: 1/1/2017
#2: 10/1/2017 - 3/31/2018		#2: 5/1/2018		#2: 7/1/2018
#3: 4/1/2018 – 9/30/2018		#3: 11/1/2018		#3: 1/1/2018
#4: 10/1/2018 - 3/31/2019		#4: 5/1/2019		#4: 7/1/2019
#5: 4/1/2019 – 9/30/2019		#5: 11/1/2019		#5: 11/1/2019
#6: 10/1/2019 - 3/31/2020		#6: 5/1/2020		#6: 7/1/2020
#7: 4/1/2020 – 9/30/2020* tentative		#7: 11/1/2020		#7: Data to be included in SWE Final Evaluation Report

SECTION 5. IMPLEMENTING STATEWIDE EVALUATION GUIDELINES

The cross-population evaluation conducted by the California Reducing Disparities Project Statewide Evaluator (SWE) will be critical to understanding the impact of the project across populations, throughout the state. The SWE developed the Statewide Evaluation Guidelines 1.0, including common Core Outcome Measures and indicators that will be implemented across all 35 Implementation Pilot Projects. The SWE has collected input and feedback from each of the population-specific Technical Assistance Providers, and the evaluation plan is designed to cover all five priority populations. This goal of this section is to help the IPPs implement the Statewide Evaluator's Guidelines in a manner that is culturally and linguistically appropriate. The following pages present population-specific strategies and points to consider in implementing the Statewide Evaluation Plan, specifically for the African American priority population.

Recruitment & Retention

Recruitment of participants in the CRDP statewide evaluation might be a challenge during the IPP phase. In order to implement both your local evaluation and the Statewide Evaluation plan, you might need to consider formal recruitment strategies for research, beyond just your recruitment activities to provide services.

Engaging participants in extensive evaluation data collection can be extremely challenging. Knowledge of the unethical research conducted during the U.S. Public Health Service Tuskegee Research Project syphilis study often is cited as a reason for non-participation by African Americans. However, Heiney, Parrish, Hazlett, Wells, and Johnson (2008) found that 68 percent of African American participants felt that they received the same quality of health care as other ethnic groups and only 38% were aware of the Tuskegee Research Project. [34]

The Heiney-Adams Recruitment Framework (H-ARF) has been demonstrated as effective in recruiting African American women for a random clinical trial. The major elements of H-ARF include **social marketing** and **relationship building**. While this may seem obvious given the community-driven nature of your programs, the relationships you build in service delivery can also support the evaluation:

- Establishing a trusting bond.
- Approaching the participants in a genuine and empathetic manner.
- Being participant-focused and sensitive to issues of time, fatigue, and family obligations.
- Inquiring about the participants' well-being prior to discussions about the project.
- Empathizing with the participants' experiences.
- Listening in a respectful manner.

A series of focus groups with African Americans found that mistrust was the biggest barrier for participation in research, but that mistrust is multi-faceted and that there were no differences in mistrust, fear, and inadequate information by gender, education, income, or by prior participation in research. [35] For these participants, who had participated in medical research in the past, the term "medical research" is associated with terms that represent the negative connotations of research, such as experimentation, rats, and test tubes. Experimentation, it was said, is viewed in a particularly negative light, given the history of research in the African American community.

One particular challenge you might face is that much of the mistrust can be focused on the federal government as they recognize their role in the support of research studies such as the Tuskegee syphilis study. One participant said, "I think you have a lot of people who mistrust the government. You start looking at a lot of medical centers, there's always going to be some link up the chain to some government entity." Although the IPPs are grassroots community organizations, partnership with the California Department of Public Health could be perceived negatively.

Collective memory, characterized by shared beliefs and experiences within a community, may also contribute to African Americans' mistrust in medical research.[36] Although historical events such as Tuskegee foster mistrust, participants stressed that disrespect and discrimination towards African Americans continues to occur. Recent literature supports the view that current occasions of perceived or real racism or discrimination exacerbate mistrust.[37] Open, honest dialogue between clinicians or researchers and minority communities about these historical and sociocultural factors may help ease individuals' apprehension regarding biomedical research studies.[38]

Informing participants about the potential impact of study findings on mental health disparities as part of outreach and recruitment can help encourage cooperation with the evaluation research.

SWE Core Outcome Measures

As part of the CRDP Statewide evaluation, IPPs are required to collect specific data measures from their CDEP participants and submit them directly to PARC@LMU.

As outlined in the Statewide Evaluation Guidelines 1.0, the Core Outcome Measures are "the most meaningful measures of progress that could work simultaneously across 5 priority populations, their respective subpopulations and unique contextual realities." The SWE developed pre- and post- Core Outcome Measure tools, with specific instruments depending on participant age: under 11 years; 12-17 years old; and 18 years and older.

The SWE Core Outcome Questionnaire Items include the following:

1. Psychological Distress (K6)
2. Sheehan Disability Scale (SDS)
3. Social Isolation and Marginalization
4. Subjective Spirituality & Religiosity
5. Spiritual Wellness
6. Community/Social Connectedness
7. Cultural Connectedness
8. Health (optional)

Processes for submitting these Core Outcome Measures are presented in detail in the PARC@LMU Statewide Evaluation Guidelines 1.0. One challenge you might face is that some of the required Core Outcome Measures might be sensitive to your CDEP participants and/or your larger community. The next section provides suggestions for asking sensitive questions.

Asking Sensitive Questions

The SWE will provide training and guidance in the collection and reporting of the Core Outcome Measures, but as part of the evaluation, IPP staff will need to consider how to mitigate their own

discomfort in asking the questions, along with building a rapport of safety and comfort to encourage program participants to complete evaluation paperwork.

As mentioned previously in these guidelines, asking sensitive questions may be particularly challenging in working with African Americans who may be especially hesitant to share information with an agency they perceive to be aligned with the government. Challenges in asking questions about potentially stigmatizing topics affect any cultural and/or racial group, it is particularly a problem for a group that is easily physically identified, more frequently dependent on public facilities for their individual and family welfare, and who historically have suffered both informal and government-sanctioned discrimination.[39] All requests for personal information must acknowledge the personal and collective trauma particularly affecting African American participants.

The Institute for Child and Family Well-Being at the University of Wisconsin, Milwaukee developed an issue brief with suggestions for asking sensitive questions, in their example, about adverse childhood experiences.[40] Based on their research, they have learned that:

- Major adverse reactions to sensitive questions are less common than many professionals anticipate.
- The vast majority of clients can respond to sensitive questions without significant distress.
- Clients with a trauma history are more likely than clients without a trauma history to report discomfort with sensitive questions. However, clients with a trauma history also appear to be more likely to report that it is helpful to be asked these kinds of questions.
- Clients who report discomfort with sensitive questions often say it is important to ask these kinds of questions, either because it is a valuable experience for them or because they can help others by sharing their experiences.
- Some discomfort with sensitive questions is normative and even potentially therapeutic.

The Institute for Child and Family Well-Being's issue brief proposes a handful of practice implications to consider:

Safety first. Client discomfort with sensitive material can be mitigated by professionals who are able to establish a safe and supportive environment. A skilled professional can be able to develop a strong relationship with clients built on respect, trust, and unconditional positive regard.

Discomfort is a two-way street. Professionals can influence a client's level of discomfort with sensitive questions depending on when, where, and how they ask the questions. Professionals need to monitor their approach to sensitive topics and reactions to client disclosure.

Discomfort is not necessarily a bad sign. In fact, it is possible that "a moderate level of activation is often a good sign, indicating that the client is not in a highly avoidant or numbed state."

We may underestimate resilience. Out of concern and empathy for their clients, human service professionals may actually overemphasize survivors' vulnerability by avoiding their trauma histories.

We may be asking the wrong question. For professionals that serve disadvantaged and oppressed populations, adversity and trauma are nearly universal client concerns. We also know that, in the absence of appropriate support and intervention, adverse and traumatic experiences often continue to undermine health and well-being over the life course. Therefore, in addition considering what might

happen if they ask clients sensitive and personal questions, professionals should consider: What happens if I don't ask?

While IPP/participant rapport is critical in relationship-building and encouraging participants to complete the core measures, a few practical approaches recommended in the issue brief by the Institute for Child and Family Well-Being include:

- Prepare participants for sensitive nature of questions.
- Clarify goals of the questions and the evaluation: to measure the effectiveness of community-defined evidence programs to reduce disparity in mental health.
- Set aside enough time to talk as needed.
- Don't ask the questions too early or too late in the service term.
- Ensure privacy of the respondent at time of survey administration.
- Give client a copy of the survey.
- Record responses or ask respondent if he/she wants to complete the form.
9. Acknowledge adversity or trauma if it has been disclosed previously.

Studies on sensitive or stigmatizing issues, such as sexual beliefs and practices or mental health services or diagnoses, may serve to reduce cooperation even further among racial and ethnic group populations. Mays and Jackson argue that "this problem has to be addressed directly through sensitive designs, meaningful instruments, appropriate interviewers, assurances of confidentiality, and conveyance of a belief that cooperation will be of benefit to the larger community."[41]

As service providers and trusted organizations in the community, you have already-developed relationships with your participants, which can help in asking sensitive questions. You also might consider what other traditional gatekeepers in the community (i.e., the church, education, and business leaders) you can partner with to help in the collection of evaluation program data.[42] And again, engaging participants during the research process, through CBPR or other advisory roles, can increase credibility of the evaluation. Active engagement of participants in the evaluation can help create a climate of openness, respect, and shared information.

Identifying and Protecting Evaluation Participants

The SWE has developed the following protocol – presented verbatim from the Statewide Evaluation Guidelines 1.0 - to confidentially report individual Core Outcome Measures for CDEP participants:

To protect the identity of CDEP evaluation participants, IPPs will limit access to identifiable information by assigning a unique code to each participant. In order for an IPP and the SWE to link individual participants with their responses/data, each participant will be assigned an evaluation ID prior to collecting data. On a separate master code document/file, the IPP will maintain a file consisting of each participant's name along with their unique evaluation ID that will contain their Population Code (e.g., 1=African American), IPP Code (e.g., CBWHP=1.1) and Participant Code (e.g., 001). Codes for all population groups and IPPs are provided in Table 5.2. Each participant within a given IPP will receive their own 3 digit code. The example below shows how the codes would be assigned for 21 participants in IPP 1.1 (CBWHP).

Participant Codes Example (Pre/Post)	
1.1_001_PRE	1.1_001_POST
1.1_002_PRE	1.1_002_POST
…	…
1.1_021_PRE	1.1_021_POST

IPPs will store the master code file separately from actual participant data and they must have a clearly detailed plan for how this master list will be destroyed as soon as reasonably possible at the conclusion of the project. Evaluation data will be stored securely in locked cabinets or rooms at the IPP's location. The IPPs will insert the de-identified participant code into a specified field on the SWE pre-assessment and post-assessment measure. Each ID will be used only for that participant for the duration of the project. **It is imperative that each grantee follow this protocol to protect participant confidentiality and ensure consistency across all projects.** The final ID method will be developed in consultation with CDPH and a review of existing state/county agreements for ID protocols. Please work with your local evaluator to ensure that this matching and coding of participants is clearly developed.

Sample Priority Population Evaluation Codes for IPPs

Population Group	IPP Name	IPP Code
1= African American	California Black Women's Health Project	1.1
	Healthy Heritage Movement	1.2
	Whole Systems Learning	1.3
	The Village Project	1.4
	Catholic Charities	1.5
	West Fresno Health Care Coalition	1.6
	Safe Passages	1.7

Because IPP staff will need to maintain a list linking ID codes to individuals, this information cannot be considered "anonymous." Each IPP evaluation plan must include protocols for securely maintaining this list so that participant confidentiality is ensured, and that each participant uses the same ID number for their "_PRE" and "_POST" ID numbers. This is critical in order for the SWE to be able to match pre- and post- assessments. It can also be helpful to track PRE and POST dates on the confidential log. This provides a "double check" to ensure that both assessments are completed (only once), as well as provides another data point in case two participants have the same name. For example:

Participant ID	First Name	Last Name	_PRE Date	_POST Date
1.6_002	Tristina	Grey	6/1/17	12/27/17
1.6_003	Angela	Stribling	6/3/17	

The goal of the California Reducing Disparities Project is to evaluate and demonstrate the credibility of community developed evidence-based practices. To this end, the TAPs will work closely with the IPPs, providing a bridge between service delivery, local evaluation of the CDEP, and the statewide evaluation of the overall CRDP.

References

[1] Graham, M.J. (1999). The African-Centered Worldview: Toward a paradigm for social work. *Journal of Black Studies, 30,* 103-122.
http://journals.sagepub.com/doi/abs/10.1177/002193479903000106?legid=spjbs%3B30%2F1%2F103&patientinform-links=yes

[2] Lenfant C. Enhancing minority participation in research. The NHLBI experience. Circulation. 1995 Aug 1;92(3):279–280.

[3] Larson C, Schlundt D, Patel K, Goldzweig I, Hargreaves M. Community participation in health initiatives for marginalized populations. J Ambul Care Manage.2009; 32(4):264---270.

[4] Ahmed SM, Palermo AGS. Community engagement in research: frameworks for education and peer review. American Journal of Public Health. 2010;100(8):1380–1387. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2901283/

[5] Braun, K. L., Nguyen, T. T., Tanjasiri, S. P., Campbell, J., Heiney, S. P., Brandt, H. M., … Hébert, J. R. (2012). Operationalization of Community-Based Participatory Research Principles: Assessment of the National Cancer Institute's Community Network Programs. American Journal of Public Health, 102(6), 1195–1203. http://doi.org/10.2105/AJPH.2011.300304 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3292685/

[6] Community-Based Participatory Research (CBPR) for African Americans with Serious Mental Illness http://www.chicagohealthdisparities.org/files/Inspiring_Change_CBPR_Workbook_Revised.pdf

[7] Carolina Community Network – CCN Fact Sheet
https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=0ahUKEwiWlZPj2OPRAhWpwlQKHXDxAvAQFggbMAA&url=https%3A%2F%2Fcarolinacommunitynetwork.org%2FPDFs%2Ffactsheets%2FCCN_Fact_Sheet-CBPRfinal.pdf&usg=AFQjCNGKkYyoTBaeV2k1yUXes6vLHJUqhQ&sig2=5phHBoYPQpKerhCCS-3v2g&bvm=bv.145393125,d.cGw

[8] Smith, S. A., Whitehead, M. S., Sheats, J. Q., Ansa, B. E., Coughlin, S. S., & Blumenthal, D. S. (2015). Community-based participatory research principles for the African American community. Journal of the Georgia Public Health Association, 5(1), 52–56. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4554535/

[9] Braun, K. L., Nguyen, T. T., Tanjasiri, S. P., Campbell, J., Heiney, S. P., Brandt, H. M., … Hébert, J. R. (2012). Operationalization of Community-Based Participatory Research Principles: Assessment of the National Cancer Institute's Community Network Programs. American Journal of Public Health, 102(6), 1195–1203. http://doi.org/10.2105/AJPH.2011.300304 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3292685/

[10] Israel, B.A ., Schulz, A .J., Parker, E .A . & Becker, A .B. (1998). Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173-202.

[11] Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: Understanding Mistrust about Research Participation. *Journal of Health Care for the Poor and Underserved*, *21*(3), 879–897. http://doi.org/10.1353/hpu.0.0323
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4354806/

[12] Nicholson RA, Kreuter MW, Lapka C, et al. Unintended effects of emphasizing disparities in cancer communication to African-Americans. Cancer Epidemiol Biomarkers Prev. 2008 Nov;17(11):2946–2953. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2660566/

[13] Teal CR, Street RL. Critical elements of culturally competent communication in the medical encounter: a review and model. Soc Sci & Med. 2009 Feb;68(3):533–543. [PubMed]

[14] Jackson, Fleda Mask. "Considerations for Community-Based Research With African American Women." American Journal of Public Health 92.4 (2002): 561–564. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447117/

[15] Hogan VK, Ferre CD. The social context of pregnancy for African American women: implications for the study and prevention of adverse perinatal outcomes. Matern Child Health J. 2001;5(2):67–69.

[16] ACT For Youth: Center of Excellence. "Youth Participatory Evaluation."
http://www.actforyouth.net/youth_development/evaluation/ype.cfm

[17] YFE TIG Week: Katie Richards-Schuster on Looking to the Future: Critical Questions for Youth-Focused Evaluation. AEA365 A-Tip-a-Day by and for Evaluators. October 11, 2015. http://aea365.org/blog/yfe-week-katie-richards-schuster-on-looking-to-the-future-critical-questions-for-youth-focused-evaluation/

[18] Powers, Jane L., Tiffany, Jennifer S. (2006) Engaging Youth in Participatory Research and Evaluation. Journal of Public Health Management Practice. November (Suppl), s79-S87. www.health.ny.gov/community/youth/development/docs/jphmp_s079-s087.pdf

[19] Chicago Reducing Disparities Project – Inspiring Change Workbook. http://www.chicagohealthdisparities.org/files/Inspiring_Change_CBPR_Workbook_Revised.pdf

[20] U.S. Department of Health and Human Services, Office of Minority Health. The National CLAS Standards. https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53

[21] Centers for Disease Control and Prevention. Practical Strategies for Culturally Competent Evaluation. Atlanta, GA: US Dept of Health and Human Services; 2014. https://www.cdc.gov/dhdsp/docs/**cultural**_competence_guide.pdf

[22] Wheeler, Darrell P. "Methodological Issues in Conducting Community-Based Health and Social Services Research Among Urban Black and African American LGBT Populations" in Research Methods with Gay, Lesbian, Bisexual, and Transgender Populations by William Meezan, James I. Martin

[23] Sullivan-Sulewski, Jennifer and June Gothberg, 2013. Universal Design for Evaluation Checklist, 4th Edition. http://comm.eval.org/Resources/ViewDocument/?DocumentKey=62107753-a359-40d1-96d7-2fc113ae9ba8

[24] Association of University Centers on Disabilities, Safety First. Responding to Trauma: Creating inclusive, accessible, and responsive community services for people with developmental disabilities. https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwifjKTptcz SAhXqyVQKHd2MCJAQFggaMAA&url=https%3A%2F%2Fwww.aucd.org%2Fmeetings%2F168%2F11404%2FAUCD% 2520Responding%2520to%2520Trauma%2520poster.pdf&usg=AFQjCNFPmIvVNTKnMCOVy1FKl95cC4JmEA&sig2= xeBjSNBXNPMXqgxbjCwtrA&bvm=bv.149093890,d.cGw

[25] Center for Program Evaluation and Research, Tobacco Control Evaluation Center. Culture in Evaluation #4: African American - Tobacco Control Evaluation with African American Communities

[26] Mays, V. M., & Jackson, J. S. (1991). AIDS Survey Methodology with Black Americans. *Social Science & Medicine (1982)*, *33*(1), 47–54. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4188856/

[27] Stanfield, J. H. IL 1994. Ethnic modeling in qualitative research. In Handbook of qualitative research, eds. N. Denzin and Y. Lincoln, 175-188. Thousand Oaks, CA: Sage.

[28] McAvoy, Leo; Winter, Patricia L.; Outley, Corliss Wilson; McDonald, Dan; Chavez, Deborah J. 2000. Conducting Research With Communities of Color. Society & Natural Resources. 13: 479-488. https://www.ncrs.fs.fed.us/pubs/jrnl/2000/nc_2000_McAvoy_001.pdf

[29] Heiney, S. P., Adams, S. A., Wells, L. M., & Johnson, H. (2010). Evaluation of Conceptual Framework for Recruitment of African American Patients With Breast Cancer. *Oncology Nursing Forum*, *37*(3), E160–E167. http://doi.org/10.1188/10.ONF.E160-E167. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2946071/

[30] Reinert, B., Carver, V., Range, L.M., & Pike, C. (2008). Collecting health data with youth at faith-based institutions: Lessons learned. *Health Promotion Practice, 9*, 68-75. https://www.ncbi.nlm.nih.gov/pubmed/18166668

[31] Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: Understanding Mistrust about Research Participation. *Journal of Health Care for the Poor and Underserved*, *21*(3), 879–897. http://doi.org/10.1353/hpu.0.0323 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4354806/

[32] Allan Porowski and Heather Clawson on Conducting Evaluation with At-Risk Youth. AEA365 – A Tip-a-Day by and for Evaluators. August 12, 2012. http://aea365.org/blog/allan-porowski-and-heather-clawson-on-conducting-evaluation-with-at-risk-youth/

[33] SAMHSA (2015) A Guide to GPRA Data Collection Using Trauma-informed Interviewing Skills. https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwifjKTptcz SAhXqyVQKHd2MCJAQFggaMAA&url=https%3A%2F%2Fwww.aucd.org%2Fmeetings%2F168%2F11404%2FAUCD%

2520Responding%2520to%2520Trauma%2520poster.pdf&usg=AFQjCNFPmIvVNTKnMCOVy1FKl95cC4JmEA&sig2=
xeBjSNBXNPMXqgxbjCwtrA&bvm=bv.149093890,d.cGw

[34] Heiney, S. P., Adams, S. A., Wells, L. M., & Johnson, H. (2010). Evaluation of Conceptual Framework for Recruitment of African American Patients with Breast Cancer. *Oncology Nursing Forum*, *37*(3), E160–E167. http://doi.org/10.1188/10.ONF.E160-E167. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2946071/

[35] Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: Understanding Mistrust about Research Participation. *Journal of Health Care for the Poor and Underserved*, *21*(3), 879–897. http://doi.org/10.1353/hpu.0.0323
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4354806/

[36] Reverby SM. More than fact or fiction. Cultural memory and the Tuskegee Syphilis Study. Hastings Cent Rep. 2001 Sep–Oct;31(5):22–8.

[37] Benkert R, Peters RM, Clark R, Keves-Foster K. Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care. J Natl Med Assoc. 2006 Sep;98(9):1532–1540.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2569718/

[38] McCallum, J. M., Arekere, D. M., Green, B. L., Katz, R. V., & Rivers, B. M. (2006). Awareness and Knowledge of the U.S. Public Health Service Syphilis Study at Tuskegee: Implications for Biomedical Research. Journal of Health Care for the Poor and Underserved, 17(4), 716–733. http://doi.org/10.1353/hpu.2006.0130
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1828138/

[39] Mays, V. M., & Jackson, J. S. (1991). AIDS Survey Methodology with Black Americans. *Social Science & Medicine (1982)*, *33*(1), 47–54. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4188856/

[40] The Institute for Child and Family Well-Being, University of Wisconsin, Milwaukee. Issue Brief: What Happens If I Ask? April 29, 2016. https://uwm.edu/icfw/what-happens-if-i-ask/

[41] Mays, V. M., & Jackson, J. S. (1991). AIDS Survey Methodology with Black Americans. *Social Science & Medicine (1982)*, *33*(1), 47–54. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4188856/

[42] McAvoy, Leo; Winter, Patricia L.; Outley, Corliss Wilson; McDonald, Dan; Chavez, Deborah J. 2000. Conducting Research With Communities of Color. Society & Natural Resources. 13: 479-488.
https://www.ncrs.fs.fed.us/pubs/jrnl/2000/nc_2000_McAvoy_001.pdf