Examining the Representation of Racial and Ethnic Minority Groups in Preventive Intervention Research

Pamela R. Buckley, PhD, Institute of Behavioral Science, University of Colorado Boulder

Velma McBride Murry, PhD, Departments of Health Policy & Human and Organizational Development



Vanderbilt University Medical Center and Vanderbilt University

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University of Colorado Boulder

Background – How did this project originate?

- Talk in June 2019 given to faculty and students at CU Boulder.
- Title: Scaling up Evidence-Based Programs in Community Settings – Balancing Fidelity and Real-World "Adjustments" to Model Implementation
- Key take-aways:
 - Developers must help facilitators make appropriate modifications to cultural contexts and social trends.
 - Modifications cannot interfere with effectiveness.
 - Discussed how to maintain fidelity to theoretical foundations and core components while modifying experimentally-proven programs to meet participants' needs.
 - Go here to view the talk.

Implications of Diversity Explosion for Prevention Science

• Preventive interventions must be responsive to the cultural practices and worldview of subgroups for whom the interventions are intended (Resnicow et al., 2000)

BUT

- Continued arguments center around whether adaptations to be responsive to varying culture
 - Is necessary
 - Is feasible

The Presenting Issue

- While intervention programs have been shown to be effective and ready for large-scale implementation, most programs have been tested on Caucasian population
- Lack of sufficient evidence that many existing EBI are effective for preventing or reducing behavioral disorders in non-Caucasian populations.
- Do EBIs need to be adapted and tailored to be effective for implementation in diverse racial/ethnic group?

- What does cultural adaptation, cultural tailoring mean?
- How do we know it matters? What are the evidence?
- How much adaptation can occur before compromising the fidelity of the program? Or changing the program to "something else"?
- Adaptations may transcend ethnicity and race to address issues based on SES or sexual orientation, or geographic context

Culture vs Ethnicity and Race

- Culture describes the characteristics of a particular group of people
 - \odot Including language, religion, cuisine, social habits, music and arts.
 - "having a culture," means that its members share a collective system of values, beliefs, expectations, and norms, including traditions and customs, as well as sharing established social networks and standards of conduct that define them as a cultural group (Betancourt & Lopez, 1993).
- Research on cultural adaptation equates culture with ethnicity and race.
- Focusing and race is often based on assumptions of homogeneity, without regard for heterogeneity that exist based on nationality, SES, religious background, geographic residence, immigration status, and other issues that can complicate "cultural" adaptation

For whom do the interventions developed in our field work or not work?







Many interventions were developed and tested in one population...

...but now users would like to implement them in other populations.



- Should we assume that the intervention will not work without adaptation?
- Or should it be implemented <u>exactly as designed</u> in the new community with high fidelity?





18 May 2021 Boulder, Colorado / Zoom Prevention Science Methodology Group Webinar

Addressing Health Equity and Social Justice within Prevention Registries: Blueprints for Healthy Youth Development

Karl G. Hill, PhD Director, Prevention Science Program Co-PI, *Blueprints for Healthy Youth Development* Professor Psychology and Neuroscience Institute of Behavioral Science University of Colorado Boulder

Pamela Buckley, PhD

PI, Blueprints for Healthy Youth Development

Senior Research Associate Institute of Behavioral Science University of Colorado Boulder

Review of Previous Talk (May 2021)

- Presented an overview of Blueprints for Healthy Youth Development, and online registry of effective prevention programs for youth.
- Discussed concerns regarding adaptation/cultural relevance that registry staff and users encounter.
- Previewed a research project that begins to address these concerns within Blueprints.
 - Go <u>here</u> to view the recorded talk.
- Today's talk provides preliminary findings of this project.
- But first, a quick review of Blueprints.

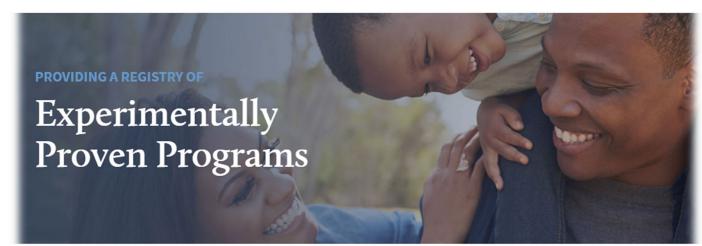
Key Stakeholder Groups

- Researchers: How can we ensure that our intervention is producing the most positive impact for each community who elects to adopt it?
- Community Members: *How can we effectively address youth drug use and violence? How do we support positive youth development?*
- Policymakers/Agency Staff: *How can we know that we are funding and implementing the most effective programs for our communities?*

Blueprints!



FIND PROGRAMS BLUEPRINTS CERTIFICATION NEWS & EVENTS FAQS ABOUT BLUEPRINTS





The Blueprints for Healthy Youth Development mission is to promote interventions that work. We do this by providing a comprehensive, trusted registry of evidence-based interventions (programs, practices and policies) that are effective in reducing antisocial behavior and promoting a healthy course of youth development and adult maturity. We also advocate for evidence-based interventions locally and nationally and produce publications on the importance of adopting.

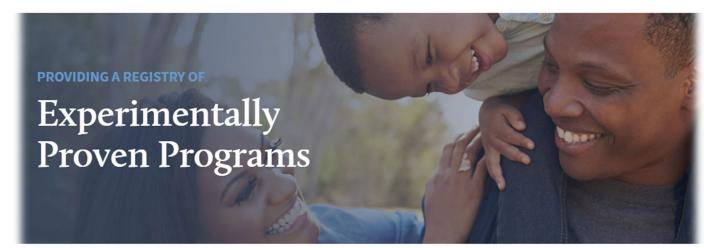
www.blueprintsprograms.org

A web-based registry of *experimentally proven programs* (EPPs) promoting the most rigorous scientific standard and review process for certification.

What is Blueprints for Healthy Youth Development?



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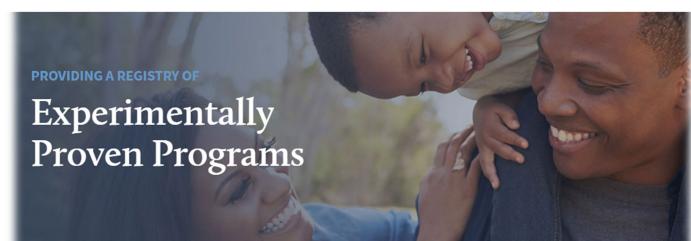
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Goal:

To provide researchers, communities and policymakers/agencies with a trusted guide to interventions that work.



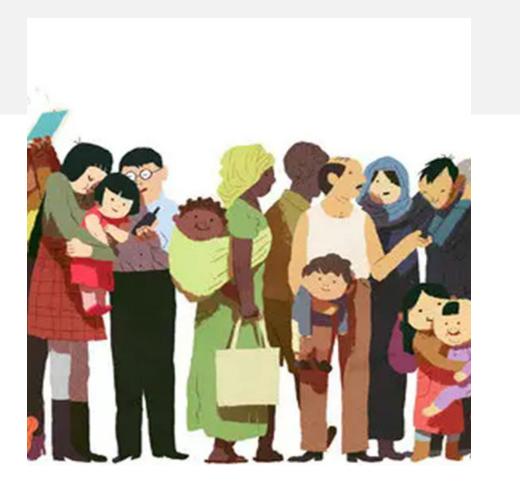
Each Certified Intervention has a Fact Sheet including

- Program Name and Description
- Developmental/Behavioral Outcomes
- Risk/Protective Factors Targeted
- Risk/Protective Factors Impacted
- Contact Information/Program Support
- Target Population
- Program Rating and Effect Size
- Operating Domain: Individual, Family, School, Community

- Logic/Theory Model
- Program Costs: Unit Costs, Start-Up, Implementation, Fidelity Monitoring, Budget Tool
- Cost Benefit/Return On Investment (When Available): Net Unit Cost-Benefit, Benefits
- Funding Overview, Financing Strategies
- Program Materials
- References

Purpose: To ensure the evidence-based intervention is implemented with fidelity (i.e., as intended)

Addressing Health Equity and Social Justice within Prevention Registries



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- The question is not only how do you implement interventions with fidelity, but with whom have these interventions been tested?
- If there is a need for adaptation, can we (Blueprints) provide some guidance from the developers?
- In order to inform the debate, we need to know for which populations have these interventions been:

 \circ Developed?

o Tested on?

• We need basic baseline data.

Present Study

- Using the Blueprints database, we conducted a systematic review of the representation of ethnic minority groups in preventive intervention research.
- Aims:
 - Code samples of studies by race, ethnicity, gender, and economic disadvantage.
 - Descriptive analysis of these codes to examine the representation overall, and by subgroup (e.g., geographic location of the study, outcomes reported, target age).
 - Identify additional considerations of importance to inform preventive intervention research (e.g., cultural adaptation, competence, modification, and responsiveness).

Co-authors

Pamela R. Buckley, PhD, PI: Blueprints Charleen Gust, PhD student, Blueprints Staff Fred C. Pampel, PhD, Research Professor Emeritus, Blueprints Staff

Amanda Ladika, Blueprints Manager Velma McBride Murry, PhD, Blueprints Advisory Board Member

Acknowledge Blueprints Team Members: Karl G. Hill, PhD, Christine Steeger, PhD, Jennifer Balliet, PhD

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 - Institute of Behavioral Science Prevention
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 - Karl G. Hill (Director, Prevention Science Program, Institute of Behavioral Science, CU Boulder; Co-PI and Board Chair, Blueprints for Healthy Youth Development).

Background

- Lack of representation of racial and ethnic minority groups in health-related research studies is well-documented (Turner et al., 2022).
- A critical evaluation of this omission in the prevention science literature has not been undertaken.
- Necessary for prevention or intervention efforts focused on social, behavioral, and educational outcomes to identify for whom do interventions work and under what conditions?



- If researchers do not specify target populations, practitioners are vulnerable to misinterpreting relative strength of evidence even if it is well-defined.
- Misinterpretation risks over- or under-ascribing an intervention's utility to be scaled up or implemented across settings.

Research Questions

- 1. How prevalent are preventive interventions for youth that were developed for a specific population based on race, ethnicity, gender, economic disadvantage, and/or geographic location (i.e., urban vs. rural)?
- 2. What percent of evaluation studies reported sample characteristics by race, ethnicity, gender, economic disadvantage, and location where the program was tested?
- 3. How well represented are race, ethnic, gender, economic disadvantage, and rural-urban groups in samples of evaluation studies?

Systematic Search Strategy

- Target studies in the grey literature AND journal articles.
- Use Boolean operators to create multiple search terms:
 - o Several clauses are used to select academic journals.
 - Search terms are applied to locate outcomes for youth relating to physical and mental health, delinquency, education, prosocial behavior, and problem behavior.
 - Boolean operators are entered into the Web of Science search engine (multiple academic disciplines).
- Search blogs, other registries, and research sites.
- Accept self-nominations from developers and researchers.

Racial Composition Codes

- US Census Bureau requires 5 categories:
 % Asian or Asian American
 - \circ % Black or African American
 - o % Native American or American Indian or Alaska Native
 - $\,\circ\,$ % Native Hawaiian or Pacific Islander
 - \circ % White
- Additional codes:
 - o % Multi-racial (must clearly be specified this way)
 - \circ % Not Specified
 - ✓ "Other" category
 - ✓ Racial groups collapsed cross Census race categories
 - ✓ Latino/Hispanic

Ethnicity Composition Codes

- Race and Ethnicity are distinct identities according to the US Census.
 - In general, ethnicity has historically referred to a person's cultural identity (eg, language, customs, religion).
- Hispanic or Latino origin asked as a separate question on the US Census.
 - o % Hispanic or Latino.
 - o % Not Hispanic or Latino (remainder of sample).

Additional Codes

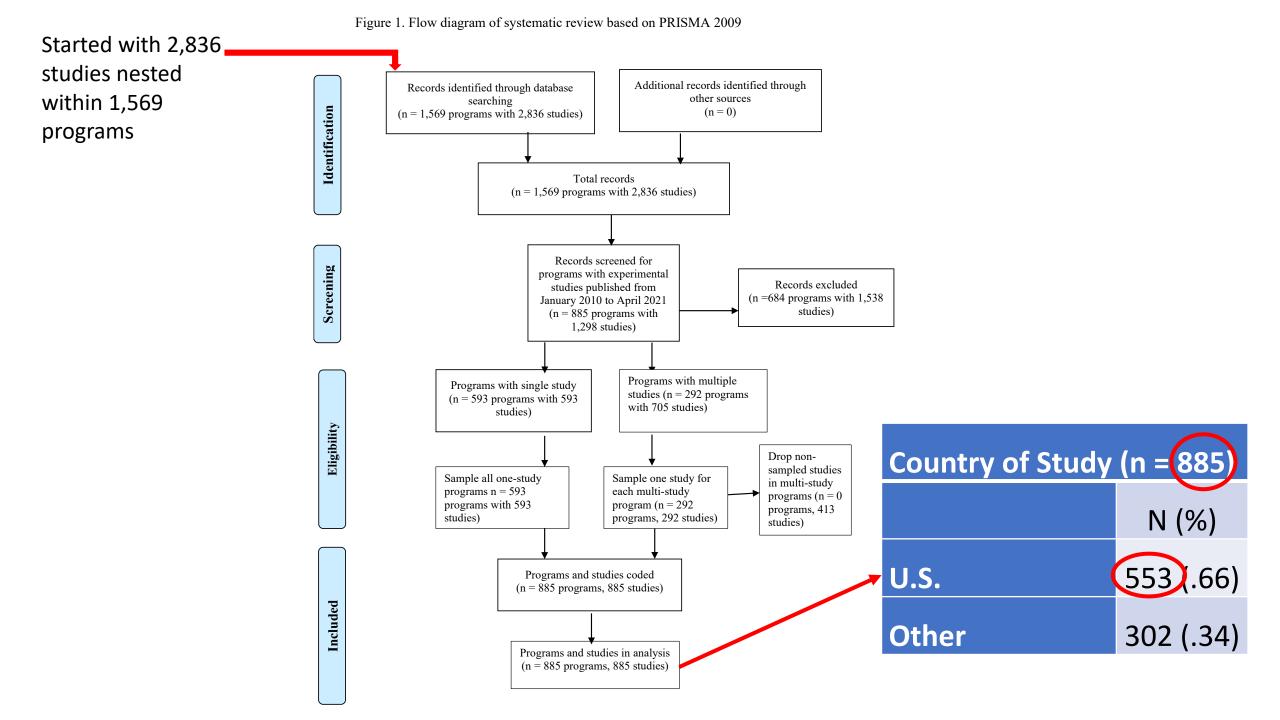
- Gender
 - o % Male
 - o % Female
 - \circ % Other
- Economic Disadvantage (e.g.):
 - \circ % Qualifies for free/reduced lunch (FRL) program
 - o % Receives Medicaid
 - \circ % Pell-Eligible
 - % Qualify for the Children's Health Insurance Program (CHIP)

Sample

- Reports (peer-reviewed articles, non-published reports).
- Many reports are part of the same evaluation, because they examine the same intervention with the same sample but have several reports publishing different outcomes, follow-up periods, etc.
- Blueprints combines "reports" into a single <u>study</u> (i.e., same study subjects/sample).
- Coding occurred at the study (not report) level.
- For programs with more than one study, we randomly selected one study within that program to code.

Eligibility Criteria

- Preventive intervention studies in the Blueprints database.
 - No treatment programs (sole focus).
 - No medical or pharmacological interventions.
- Universal, selective and indicated preventive interventions.
- Focus on youth (ages 0-25 years)
- Exception: interventions designed to reduce recidivism that follow typically young offenders to older ages.
- Group design studies (RCT, QED, cluster-RCT)
- Evaluation completed between 2010 to April 2021.

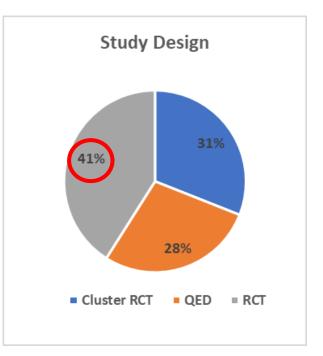


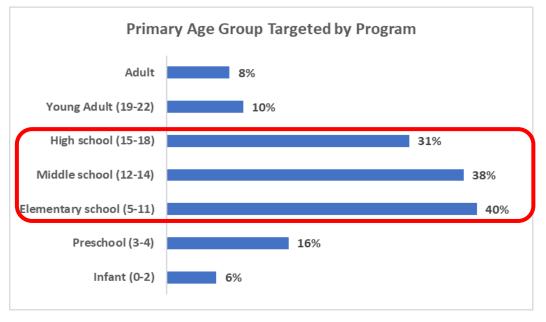
Methods

- Each report coded in rotating dyads, so all coders worked together.
- Reviewers independently coded reports and entered their codes into an online form.
- Codes within each dyad were compared, discrepancies resolved through consensus among all coders.
- Inter-rater reliability (ICCs for continuous, Kappa for dichotomous) = .82 (good; .9 or greater excellent).
- 4/20/21 to 10/12/21 double (36% of sample, n = 208)
- 10/18/21 to 03/07/22 single (64% of sample, n = 375)

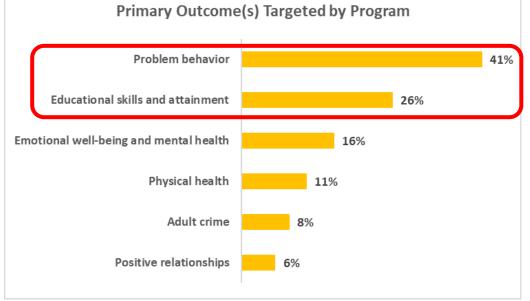
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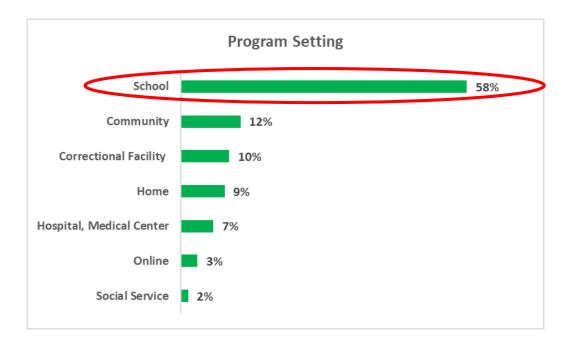
Sample Characteristics





Note: Percentages add to more than 100, as programs may targe multiple groups.





Note: Percentages add to more than 100, as programs may targe 2 or more primary outcomes.

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Results

RQ 1:

How prevalent are preventive interventions for youth that were developed for a specific population based on race, ethnicity, gender, economic disadvantage, and/or geographic location (i.e., urban vs. rural)?

Note: Percentages add to more than 100, as programs may target multiple groups.

Group	Percent (n=583)
Race	
Asian or Asian American	0.03
Black or African American	0.02
Native American, American Indian, or Alaska Native	0.09
Native Hawaiian or Pacific Islander	0.02
White	0.00
Ethnicity – Hispanic or Latino	0.04
Gender	0.07
Economic Disadvantage	0.05
Location	
Rural	0.05
Urban	0.02
No Specific Group	0.78

RQ 2:

What percent of evaluation studies reported sample characteristics by race, ethnicity, gender, economic disadvantage, and location where the program was tested?

Characteristic	Percent (n=583)
Race	.77
Ethnicity – Hispanic or Latino	.64
Gender	.87
Economic Disadvantage	.29
Location (rural, urban)	.73

RQ 3:

How well represented are race, ethnic, gender economic disadvantage, and rural-urban groups in samples of evaluation studies?

Note: US studies reporting group percentages (n=168-509). Percentages for location add to more than 100, as programs may target multiple locations.

	Group	Percent
	Race	
	Asian or Asian American	0.03
	Black or African American	0.28
	Native American, American Indian, or Alaska Native	0.02
r,	Native Hawaiian or Pacific Islander	0.00
	White	0.35
	Multi-Racial	0.01
	Not Specified	0.31
	Ethnicity – Hispanic or Latino	0.32
	Gender – Female	0.50
	Population is Low-Income	0.66
for	Location	
s.	Rural	0.32
<i>.</i>	Urban	0.90

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Summary

583 preventive intervention evaluation US studies (2010- 2021):

- Less than 1/4th (22%) targeted a specific group.
- Dichotomous reporting (1=reported; 0 = did not report)
 - 77% reported racial characteristics of their sample.
 - 64% reported ethnic characteristics of their sample.
- When examining by category:
 - Most tested programs on samples of White youth (27%), African American youth (22%), or youth coded as "not specified" (24%).
 - Several racial groups were not represented (Asian American, Native American, American Indian, Alaska Native, Native Hawaiian or Pacific Islander).
 - 33% of samples included Hispanic youth.
- 32% of evaluations were conducted in rural communities.

Guidance in Reporting Race and Ethnicity

Flanagin et al. (2021).

- Though race and ethnicity have no biological meaning, the terms have important, albeit contested, social meanings.
- "Terminology, usage, and word choice are critically important.... when discussing race and ethnicity. Inclusive language supports diversity and conveys respect. Language that imparts bias toward or against persons or groups based on characteristics or demographics must be avoided."
- Language must be accurate and precise, and must reflect fairness, equity, and consistency in use and reporting of race and ethnicity.

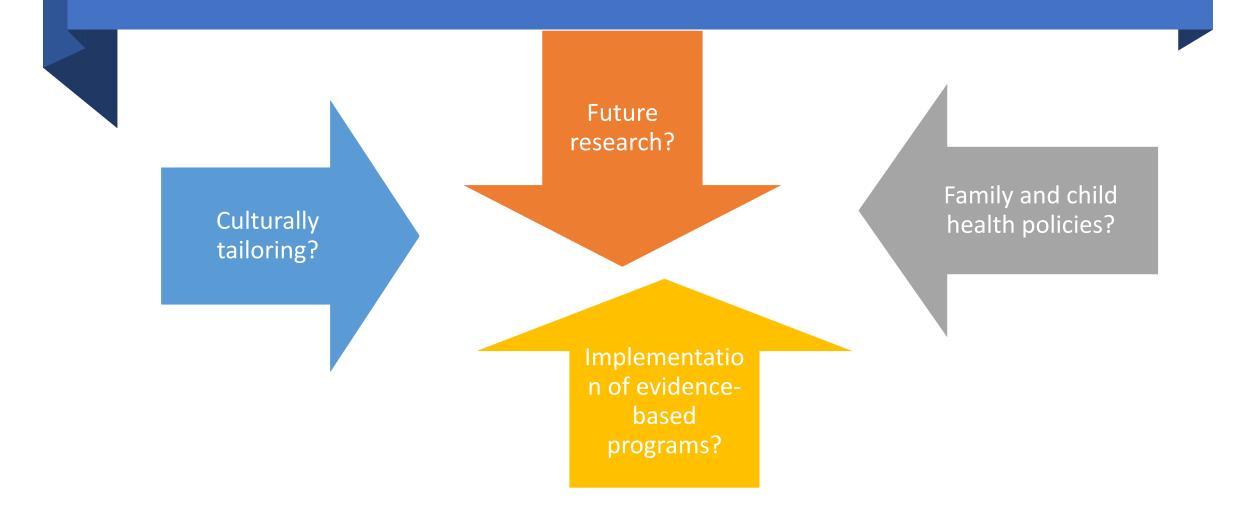
Not Reporting Race and Ethnicity

- Disregards the reality of social stratification, injustices, and inequities and implications for population health and well-being.
- May conceal disparities.
- Inclusion of race and ethnicity in research to address and further elucidate health disparities and inequities remains important at this time.
- Reporting of race and ethnicity should not be considered in isolation and should be accompanied by reporting of other sociodemographic factors and social determinants.
- If any demographic characteristics that were collected are not reported, the reason should be stated.

"Not Specified" for Race

- "Other" is uninformative and may be considered pejorative.
- Sometimes used for comparison in data analysis when the numbers in some subgroups are too small.
- The term should not be used as a "convenience" grouping or label unless it was a prespecified formal category in a database or research instrument.
- If the numbers in some categories are so small, the specific numbers and percentages do not need to be reported provided this is noted.
- Specific racial and ethnic categories are preferred over collective terms.
- Categories included in groups labeled as "other" should be defined.

Call to Action and Future Directions



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