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Toxic Stress Among Black and African American Oregonians

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Toxic Stress Among Black and African American Oregonians
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Project Overview

Toxic stress is a reaction to ongoing adversity such as abuse, neglect, poverty, racism, discrimination, and exposure to violence; it is powerful enough to change brain chemistry and architecture. Toxic stress and associated changes to the brain can lead to poor health outcomes later in life. Adverse childhood experiences (ACEs), racism*, and discrimination can trigger toxic stress and have long term consequences for the health of many people, particularly those in the Black and African American community.

The current project examined toxic stress and its impact on the health of Black and African American Oregonians. We looked at two indicators of toxic stress: reports of adverse childhood experiences (ACEs) and recent experiences of racism among adults. Data from the Behavioral Risk Factor Surveillance System (BRFSS) were analyzed, followed by a series of focus groups with Black and African American Oregonians. Our goal was to assess whether experiences of racism as an adult exacerbate the negative effects of ACEs on the health of this community.

Three focus groups of Black and African American community members were conducted in Northeast and East Portland. Each group was co-facilitated by Dr. Hunte and Alexis Phillips, two members of the African American community. A total of 38 individuals participated in the focus groups. Participants were given information about the concept of toxic stress and BRFSS findings related to perceived racism and ACEs in the Black community. They were asked to reflect on the meaning of BRFSS findings in relation to their community, the efficacy of how the BRFSS is administered, and reactions to the survey’s ACEs and perceived racism questions.

Key Findings

We analyzed data from the 2015-2017 Oregon BRFSS racial/ethnic oversample focusing on ACEs, distress from perceived racism, and health conditions and health risk behaviors among Black and African American respondents. Nearly one third (30%) of respondents reported four or more ACEs, the threshold over which severe and negative health outcomes are more likely to occur. Distress

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* We understand racism as “the state-sanctioned or extralegal production and exploitation of group-differentiated vulnerability to premature death.” This definition originates in Gilmore RW. Golden Gulag: Prisons, Surplus, Crisis and Opposition in Globalizing California. 2007.
from perceived racism was more prevalent among Black and African American respondents (32% reported emotional distress and 18% reported physical distress) than any other racial/ethnic group. Additionally, ACEs and distress from perceived racism were independently associated with health risk behaviors of smoking, binge drinking, and inadequate sleep. The prevalence of these health risk behaviors was highest among respondents who reported both ACEs and distress from perceived racism. Similar associations between mental health outcomes and toxic stress (e.g. ACEs and distress from perceived racism) were not observed. Finally, we identified potential questions and concerns about the overall BRFSS methodology and the validity of certain survey questions relating to mental health, racism, and ACEs. These questions and concerns informed the focus groups.

Focus groups resulted in feedback on the BRFSS data collection methods and ways to refine ACEs and perceived racism questions. Participants offered broad themes to consider in conceptualizing these questions and interpreting findings. Their comments included specific ways to refine questions and reflections on the lived experiences and impacts of racism and ACEs.

**BRFSS Data Collection Methods**

- Multiple factors may lead to participant disinterest or distrust in the BRFSS. These include: reluctance to answer anonymous phone calls and intrusive questions from an outsider of one’s community; a lack of incentive to complete the lengthy survey; and concern that small sample sizes may not reflect the robust experiences of Black communities in Oregon.
- Other methods of data collection may gather a more representative sample. These include: having culturally specific organizations administer the survey; potentially utilize health professional and medical offices to offer the survey; randomly offer the survey at Black cultural events; and incentivize the survey.

**General Considerations for Perceived Racism and ACEs Questions and Analysis**

- Families have multiple configurations.
- People want to racially classify themselves.
- Questions related to the impact of structural systems need to be included in both sets of questions.
- Generational differences and length of time in Oregon are important factors.
- Racism happens over time and is not limited to discrete instances.
Specific Considerations for ACEs Questions and Analysis

- How people think about ACEs has changed over generations.
- Institutional responses to ACEs trauma in the home further puts people at risk.
- What happens in the home stays in the home. There are strong cultural messages in the African American community about not telling outsiders what is happening within the home. This can result in not seeking outside help or discussing trauma with health professionals.

Specific Considerations for Perceived Racism Questions and Analysis

- Definitions of discrimination are not universally understood; therefore, deeper explanation of what is meant by discrimination is necessary.
- Collective experiences of racism matter - racism is experienced as an individual and collective phenomenon.
- Racism is experienced in a variety of ways, including: being put in random racially threatening situations; feelings of lack of belonging in one’s city; stress related to acting as a lone Black community advocate; generational medical racism; and the particularity of racism in Oregon.

Cumulative Impacts of ACEs and Racism Experiences

The cumulative impacts of ACEs and racism contribute to mental health concerns that both the community and medical providers do not adequately address.

- Mental health care is not commonly understood.
- The lack of recognition and care for Black mental health concerns results in both institutional and community neglect of Black mental health.
- Discussing mental health can have institutional repercussions.
- An inability to talk meaningfully with healthcare providers about trauma - be it from racism, ACEs, or other experiences - compounds mental health issues.
- Limited culturally competent and/or Black mental health counselors alienates people from seeking mental health care.

Overarching Lessons and Recommendations for Action

Anonymous phone calls are a problematic method for collecting data among Black participants.

- Recommendation(s): Limit or stop anonymous phone calls and diversify who administers the survey.
Black people care about the data and want to participate in data collection.

- Recommendation(s): Incentivize the survey to increase participation and utilize culturally specific/culturally trusted organizations to administer it to Black clientele.

Survey questions need to make space for multiraciality and multiple family forms.

- Recommendation(s): Include a question related to multiraciality that would allow respondents to self-identify how they racially categorize themselves. Be cognizant of different family forms in the research questions.

As currently written, Perceived Racism and ACEs questions do not address economic insecurity, community violence, and institutional involvement with corrections or Child Protective Services.

- Recommendation(s): Include questions in the ACEs and Racism sections about exposure to direct violence and community violence; these questions should ask about both the individual and the wider community. Include questions related to economic insecurity, justice involvement and CPS involvement; these questions should ask about both the individual and close family.

Racism is both interpersonal and systemic. Current Perceived Racism questions don’t go far enough in capturing factors related to racialized experiences.

- Recommendation(s): Expand the timeframe of perceived racism questions; explain what is meant by discrimination; include questions pertaining to hate crimes; and include a question about perceived racism that speaks directly to Oregon.

Mental health concerns affect Black people in Oregon and need more attention.

- Recommendation(s): Ask explicit questions about mental health, including references to depression and anxiety related behaviors.

ACEs is not a universal concept; culturally relevant questions related to ACEs could be beneficial.

- Recommendation(s): Develop culturally relevant ACEs questions with community members, and analyze ACEs responses by age group.

Punitive institutional responses to ACEs trauma in the home further put people at risk. Shift how the data is understood and collected to provide a more accurate picture of how ACEs affect communities.

- Recommendation(s): Participants note that institutional responses to ACEs in the home can get them caught up with CPS and threaten their families.
ACEs data must be used to support prevention resources; ACEs questions should aim towards prevention.

**Perceived racism questions in the BRFSS are an important element of the survey. Updating these questions would be beneficial with an eye to addressing the impacts of systemic racism and issues of belonging.**

- **Recommendation(s):** Update the perceived racism questions. Questions should include themes related to belonging, connection, experiences of stereotype threat, displacement, and direct and indirect racism related violence. Updated perceived racism questions should account for the effects of racism over time. When asking about health, include questions beyond diagnosed chronic illnesses, such as stress related ailments like headaches, stomachaches, body aches and pains.
Introduction to Issue: Toxic Stress, ACEs, and Racism

Toxic Stress

Toxic stress can be described as a response to experiences - particularly childhood experiences - that affect brain architecture and brain chemistry. Toxic stress is the “strong, unrelieved activation of the body’s stress management system” in the absence of protective factors like positive support and relationships.* In other words, constant stress stemming from ongoing adversity such as abuse, neglect, poverty, racism and discrimination, and exposure to violence can actually “weaken the architecture of the developing brain, with long-term consequences for learning, behavior, and both physical and mental health.”†

ACEs and Toxic Stress

Research has shown that certain traumatic experiences during childhood can trigger this prolonged toxic stress response, leading to poor health outcomes in later life.‡ These events, often called adverse childhood experiences (ACEs), include childhood sexual or physical abuse, witnessing household violence, incarceration of a parent or other household member, and growing up with a caregiver who has a mental health or substance abuse problem. Evidence suggests that ACEs have a cumulative effect on health: the more ACEs a person experiences, the more likely they are to engage in certain health risk behaviors (e.g., substance abuse, smoking) and develop serious health conditions (e.g., diabetes and heart disease).§ The accumulation of at least four ACEs appears to have the largest impact on the risk of developing these serious conditions.

Racism and Toxic Stress

Additional social factors like racism and discrimination can also trigger toxic stress and lead to poor health outcomes. Research indicates that everyday discrimination - that is, experiences of discrimination that are integrated into the

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† Ibid.
daily lives of individuals* - has profound impacts on health and well-being. For Black and African American people, there are significant connections between higher reports of everyday discrimination and increased prevalence of chronic illnesses like high blood pressure and coronary artery calcification, as well as poor sleep, lower birth weight, and mortality.†

### Racism, ACEs, and Toxic Stress

Together, racism and ACEs are a double threat to the health and well-being of people in the Black and African American community. Black and African American children are likely to experience significant early childhood adversity including many ACEs (i.e., household violence, household member with mental illness or substance abuse problem, parental incarceration) as well as persistent racism and discrimination.‡ Black and African American children are also likely to experience trauma in the form of financial hardship, death of a parent, and being a victim or witness of community violence - all of which can lead to toxic stress. In sum, adversity and toxic stress are not randomly distributed across communities; rather, they are concentrated within areas with larger populations of people of color, such as Black communities. This, in turn, contributes to health disparities and early death among Black and African American people in the United States.§

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The current project contributes to the conversation about toxic stress and health by examining its relationship among Black and African American Oregonians. As work progressed, the project expanded into an opportunity to demonstrate the critical value of partnering with community members on the analysis and interpretation of public health data.

We examined two indicators of toxic stress: reports of adverse childhood experiences (ACEs) and recent experiences of perceived racism among adults. Our goal was to assess whether experiences of racism as an adult exacerbate the negative effects of ACEs on the health of Black and African American Oregonians. The project included a quantitative analysis of data from an existing statewide public health survey (i.e., the Behavioral Risk Factor Surveillance System or BRFSS) followed by a series of focus groups with Black and African American adult Oregonians. Focus group participants reflected on BRFSS survey questions and methodology and co-interpreted the findings from the quantitative analysis. The quantitative findings provided a good starting place for the focus groups, where rich and more impactful information was gathered.

Measuring Perceived Racism and ACEs in Public Health Surveys

Careful attention must be paid to how racism and toxic stress in the form of ACEs are assessed among community members. In Oregon, public health officials rely heavily on the BRFSS to assess health-related risk factors like ACEs and racism. The Oregon BRFSS is also one of the most frequently used sources of data on the prevalence of chronic health conditions, the use of healthcare and preventive services, and other social determinants of health (e.g., employment, education level, housing stability, and food security).

The BRFSS is an anonymous telephone-based survey conducted by the Oregon Public Health Division in partnership with the United States Centers for Disease Control and Prevention (CDC). The BRFSS is a national survey that started in 1984. Oregon has participated since 1988. The survey covers a number of different topics, including physical activity, diet, smoking, whether people are getting screened for diseases like cancer, and other factors that can affect health. The BRFSS allows Oregon and the CDC to collect data on risk behaviors and preventive health practices that are associated with chronic illnesses, injuries,
and preventable diseases. Oregon uses the results of the annual BRFSS survey to design programs that meet the health needs of Oregonians.

BRFSS participants are randomly sampled and contacted via random-digit dialing either on their landline or cell phone. Some people who are randomly selected for the BRFSS are more willing than others to participate. Historically, the BRFSS methodology has worked well to recruit older, white participants in Oregon and, likely due to the availability of the BRFSS in Spanish, participants from the Latinx community. The BRFSS approach has not worked as well with younger people* or those from other communities of color.† As a remedy, every few years Oregon conducts a BRFSS racial and ethnic oversample to increase the number of respondents from each of the following: the Black and African American community, the American Indian/Alaska Native community, and the Pacific Islander community.

The challenges with BRFSS participation rates raises concerns about how representative the data are of adults in Oregon, especially those from communities of color. There are also concerns about the validity of responses to sensitive questions (such as those about ACEs and perceived racism) given the changing perception of privacy among the general population and variability in cultural norms about privacy. Also, there has been an historic lack of engagement with communities of color to lead the analysis of BRFSS data, interpret the results for their people, or disseminate results to support their communities’ needs and priorities. Partnership with community members in the analysis, interpretation, and reporting of the data is critical for ensuring the accuracy and utility of the findings. Below, we touch briefly on the methodological approach for BRFSS quantitative analysis and focus groups, and then turn to our findings.

Methodology

BRFSS

BRFSS data were analyzed using Stata version 15.1 to account for the complex survey design. Data are weighted using standard raking procedures (also called iterative proportional fitting). Crosstabulations were conducted to estimate percentages of Black and African American respondents who reported four or more ACEs and recent experiences of perceived racism along with certain health conditions (i.e., depression diagnosis and reported frequent mental distress) and health risk behaviors (i.e., smoking, binge drinking, and inadequate sleep). All relevant BRFSS survey questions are presented in the Appendix. Estimates reported below are not age-adjusted in order to reflect actual burden.

* The median age of Oregon residents is 39 years whereas the median age of BRFSS respondents is 55 for men and 58 for women.
Focus Groups

The findings from our analysis of the BRFSS data led us to engage Black and African American community members in focus groups to unpack our findings. We hosted three focus groups with 38 community members who were recruited via social media, email listservs, and flyers posted in libraries and community centers in neighborhoods with large populations of Black and African American residents in Portland, Oregon. Community member participants ranged in age from 19 to 82 years old. Most participants were women (76%), but each focus group included at least one or two men. Participants attended a 2-hour meeting where they gathered, shared a meal, and were guided through a conversation about the BRFSS findings, methods, and survey questions. Participants were compensated for their time and meetings were audio-recorded and transcribed. Each group was co-facilitated by Dr. Hunte and Alexis Phillips, two members of Portland’s African American community.

The facilitators began each group by defining toxic stress and briefly describing evidence of its effects on the health of Black and African American people. Facilitators defined key terms like ACEs and described the purpose and significance of the BRFSS in Oregon. Participants were then provided with handouts highlighting the results of our quantitative analysis and were asked to reflect on the findings. Facilitators then asked the following guiding questions:

1. Is this what you would expect based on your life experiences?
2. Why do folks think that recent experiences of racism seem to heighten/exacerbate the negative effects of earlier traumatic experiences? And only for certain health conditions or behaviors?
3. Are these the right questions being asked on the BRFSS for the Black and African American community? By “these questions” we mean the ones about childhood traumatic experiences, racism experiences, and health conditions.
4. What are other questions that you think would better capture holistic information about the Black and African American community?
5. Is there a different way you feel like this information could be collected?
6. Do these ACEs ring true in your community?
7. What are other ACEs that impact your community?
8. What are other measures of toxic stress that could be considered other than ACEs and racism?
9. What is something that might capture your experience more?
10. What does wellness look like for you, for your community?
Comments and discussion in response to the questions were compiled and analyzed by the facilitators, who identified major themes and sub-themes. Quotes and stories to support each major theme and sub-theme are presented in the following sections.
Findings: BRFSS Analysis

ACEs

We analyzed data from the 2015-2017 racial/ethnic oversample of the Oregon BRFSS. First, we examined data on the number and type of ACEs* reported by Black and African American respondents. Results indicated that 30 percent of Black and African American respondents reported four or more ACEs (out of eight measured), the threshold over which severe and negative health outcomes are more likely to occur. Black and African American adults reported high prevalence of childhood sexual abuse (24%) and having lived with someone who used illegal street drugs or abused prescription drugs (25%). Having lived with someone who was incarcerated was also reported among Black and African American respondents (27%).

Distress from Perceived Racism

Second, we reviewed data on Black and African American respondents’ recent experiences of perceived racism. Perceived racism was assessed in the BRFSS via a series of questions, two of which asked respondents to report emotional (i.e., feeling angry, sad, or frustrated) or physical (i.e., upset stomach, headache, or pounding heart) reactions they had in the past 30 days as a result of how they were treated based on their race (i.e., experience of racism). Reports of emotional and physical distress caused by perceived racism were more prevalent among Black and African American adults (i.e., 32% reported emotional distress and 18% reported physical distress) compared to all other racial/ethnic groups. Responses to these two questions were combined into a single indicator of distress from perceived racism in the quantitative analysis.

ACEs, Racism, and Health

Finally, we examined relationships between Black and African American respondents’ reports of ACEs, distress from perceived racism, and certain health conditions (i.e., depression diagnosis and reported frequent mental distress) and health risk behaviors (i.e., smoking, binge drinking, and inadequate sleep). The data did not show links between ACEs, distress from perceived racism, and the health conditions we tested, but we did observe relationships with smoking, binge drinking, and inadequate sleep.

* Please refer to the Appendix for a list of all relevant BRFSS survey questions.
**Smoking**

Figure 1 shows the results for smoking. The data indicated that 26 percent of all Black and African American adult Oregonians reported currently smoking. The percentage jumped to 37 percent among those who reported four or more ACEs. Among those who reported four or more ACEs and recent distress from perceived racism, 59 percent were current smokers - more than double the rate of current smokers within the overall population of Black and African American adults in Oregon.

![Figure 1: Toxic stress and smoking behavior among Black and African American Oregonians](image)

**Binge Drinking**

The results were similarly striking for binge drinking. Figure 2 shows that 15 percent of all Black and African American adult Oregonians reported binge drinking.

![Figure 2: Toxic stress and binge drinking among Black and African American Oregonians](image)
drinking in the previous 30 days. Again, the prevalence of binge drinking was higher among Black and African American adults who experienced four or more ACEs (26 percent), and even higher for those who experienced four or more ACEs and recent distress from perceived racism (32 percent).

**Sleep**

Finally, Figure 3 shows findings from the data on ACEs, perceived racism, and inadequate sleep, defined as six hours or less in an average 24-hour period. Overall, inadequate sleep was reported by 48 percent of Black and African American adults. This figure jumped to 56 percent among Black and African American adults who experienced four or more ACEs, and 62 percent of those who reported four or more ACEs and recent distress from perceived racism.

![Figure 3: Toxic stress and inadequate sleep among Black and African American Oregonians](image)

**BRFSS Findings Generated more Questions than Answers**

Our analysis of Oregon BRFSS data suggested that toxic stress in the form of ACEs and perceived racism had substantial associations with risk behaviors like smoking, binge drinking, and inadequate sleep among Black and African American adults. Experiencing four or more ACEs and recent distress from perceived racism were not only independently associated with these risk behaviors but the combination of these two forms of toxic stress appeared to have a cumulative effect on their likelihood.

We found it interesting, however, that the data did not show similar associations between toxic stress and diagnosis of depression or reports of frequent mental distress. This led us to wonder about the validity of BRFSS survey questions.
Specifically, was the question about depression limited in that it asked only about official diagnoses? What if a respondent felt depressed but had not visited a doctor for a diagnosis? It is likely such respondents would not have been included in our analysis due to a lack of formal diagnosis.

Similarly, we wondered whether the BRFSS questions about perceived racism truly captured a meaningful range of experiences associated with racism. The two survey questions we considered in our analysis specifically asked about physical and emotional distress caused by treatment based on the respondent’s race. In other words, these questions asked about individual experiences of perceived racism directed at the respondent. None of the survey questions asked about physical or emotional distress caused by observations of racism, discrimination against the respondent’s community because of race, repeated police brutality toward Black people, community violence, institutional bias, or other experiences directly tied to race.

We also wondered whether the BRFSS survey questions pertaining to ACEs were culturally appropriate and reflective of the traumatic experiences faced by Black and African American adults during childhood. We were already aware of prior research suggesting that the inclusion of “parents’ divorce” as a traumatic childhood event may not be as appropriate in the Black and African American community where parental relationships are more diverse. We were also aware of prior research suggesting that exposure to discrimination and racism should be included as an ACE.

Finally, we questioned the overall validity and utility of the findings given the BRFSS methodology’s limited effectiveness in reaching respondents from the Black and African American community and other communities of color. Through focus groups, described in the following sections, we were able to explore the questions raised by our analysis of the BRFSS data as well as other key questions in depth.
Findings: Focus Groups

Focus group participants offered a few observations related to our BRFSS analysis, but the bulk of their feedback centered on a) the BRFSS data collection methods and b) ways to refine both ACEs and perceived racism questions. Participants were highly critical of the use of anonymous phone calls to administer the survey and as a result felt that findings were not as representative of the larger Black community in Oregon. The remainder of this section describes each theme of the focus groups narratively.

BRFSS Data Collection Methods

Factors That Lead to Disinterest or Distrust

Participants voiced concerns about anonymous phone calls as means for administering the survey. Participants said that survey respondents sense that the person on the other end of the phone is not from their community and are immediately suspicious of them. The length of the survey, the lack of incentive to take the survey, and the lack of investment in the community after completion of the survey also contributes to respondent disinterest. Participants expressed some distrust of the data as the number of respondents was significantly lower than expected. Regarding participants’ reticence to participate in anonymous phone surveys, one person said:

“Do I want to spend 20 minutes of my time to talk to some stranger about some stats, and I’m not getting anything for it? But I got kids to feed or other things that I can be doing with my time ... Chances are, I won’t ever hear from you again.”

Participants voiced concern about the intrusiveness of calls. Having someone who works for the government call to ask intimate details about one’s home can be perceived as invasive. One said:

“We all know how suspicious Black homes are. So somebody calling me, asking “How many people in your house? I work for the CDC.” “The government? How many people’s in my house? Click! Asking questions about me!” So I think that’s a big barrier right there with participation.”
Other Methods of Data Collection May Gather a More Representative Sample

Participants suggested the following strategies: having the surveys administered by culturally specific organizations to Black clientele; having surveys administered by health professionals at medical offices; offering random surveys in places where Black people receive resources, services, and/or do business; having surveys administered at Black culture events such as Good in the Hood or Juneteenth in Portland; and face to face meetings. Some participants also liked the idea of surveys being administered on social media. It would also be useful to incentivize the survey to gain greater participation.

Opportunities for Refining ACEs and Perceived Racism Questions

General Feedback

Participants offered general feedback on the ACEs and perceived racism questions asked in the survey. Feedback offered points to consider to enhance specific questions and a discussion of who was left out of the data.

- **Families have multiple configurations:** For people whose parents were never married, the ACEs question “Were your parents separated or divorced?” is hard to answer. This question could be revised.

- **People want to racially classify themselves:** The BRFSS offers no questions about multiracial identity. Participants shared that they did not feel represented in the data if they identified as more than one racial category. They wanted a place to self-identify. A question in the survey could be “How do you classify yourself?”

- **Questions related to the impact of structural systems need to be included:** Participants noted that exposure to community violence - whether it happened to them directly or to others in their community - was traumatic. This could be gang related, gunfire, drug addiction, police involvement, the experience of a hate crime, and/or loved ones, including one’s children, involved in community violence. Participants said that economic insecurity was neglected as an ACE or an experience of perceived racism despite the fact that a higher percentage of Black people experience low income and the realities of poverty. Participants gave examples of gentrification, a parent losing a job, housing insecurity, food shortages, and utilities being cut off. Within the study there were not questions about being justice involved or involved with DHS. These are forms of structural violence that directly impact people’s basic needs and survival.
• **Generational differences and length of time in Oregon are important:** In relation to both ACEs and perceived racism there is little asked about participants’ age in relation to events. Participants brought up generational concerns around this, namely that both community and personal understanding of these phenomena were experienced differently generationally. Participants were interested in having this explored more. One participant said:

("In the ACEs there is nothing about exposure to community violence and then thinking about what you said about length of time in Oregon but also [...] there is nothing about age in relation to the everyday experiences of racism or ACEs.")

• **Racism happens over time:** Participants identified multiple ways in which the perceived racism questions should be revised. These include the following:

  » The 30-day time frame was too short to illuminate systemic discrimination.

  » Experiences of discrimination needed to be broken down so that people could understand more what is being implied.

  » The areas focused on did not reflect the intensity of the experiences of discrimination.

  » The perceived racism questions were offensive and trite for people who have personally experienced hate crimes or have loved ones who have experienced hate crimes.

**Feedback Specific to ACEs Questions and Analysis**

Participants reflected on the ACEs findings from the survey. They noted the significance of generational differences in how ACEs are understood. Talking about ACEs is sensitive and can expose people to institutional harm. People shared how institutional responses to ACEs from groups like Child Protective Services have harmed Black families. Participants also explored the theme of privacy within the Black community and its impact on ACEs.

• **Generationally how people think of ACEs has changed:** Participants noted that some of the things listed as ACEs were things that were acceptable in their families. Only now as parents do they identify certain behaviors as problematic, such as yelling at children. A participant said:

("They’re saying this is called ACEs, if your parents talked to you like this ... We always thought it was normal.")
• **Institutional responses to ACEs trauma in the home further put people at risk:** Participants note that institutional responses to ACEs in the home can get them enmeshed with Child Protective Services where they feel they will not be treated fairly. A participant said:

> “I know two of my friends have been almost at the jail, just for a simple spanking of the kids, because they put so much of that there.”

• **What happens in the home, stays in the home:** Participants shared that in African American homes you do not tell outsiders what is happening within the home. One participant said:

> “Culturally, African-Americans won’t talk about trauma. That’s not something you share. You don’t go out into the community and talk about what’s going on in your household, your family.”

This results in people not seeking outside help or discussing trauma with health professionals. This is a cultural message that is pervasive throughout the African American community. In terms of ACEs this theme is particularly pertinent. Participants noted that they were told by their elders to not discuss abuse or distress that was happening in the home with outsiders. A participant said:

> “If you be too honest, something can happen when you share. Like my parents was older, it was like, “Don’t tell nobody too much. They come in and try to take your property. […] We just not gonna share no information. When we do, you use it against us. So that was the whole thing. So that’s why we gonna keep information to ourselves within our family dynamic, right. Go outside the family dynamic, anything can happen.”

**Feedback Specific to Perceived Racism Questions and Analysis**

Systemic racism - racism experienced from institutional neglect, inequality, discrimination, and exclusion - occurs over time and is a key contributor to racism related stress. Systemic racism takes into account both interpersonal and institutional racism. Participants pointed to the need to include questions related to systemic racism in the survey. For them this would paint a clearer picture of how racism is affecting Oregonians. Participants questioned the wording of survey questions, particularly regarding the framing of perceived racism. Some themes included:

• **Definitions of discrimination are not universally understood:**
  A participant who was a housing advocate made an observation about the systemic experiences of discrimination. She noted that talking with her clients about discrimination required some explanation of what discrimination might look like. Being Black does not mean that people...
understand the ways that they may experience discrimination or that they will admit to it on an anonymous survey. She states that people need examples of discrimination to help them understand what it is. She said:

“Maybe re-wording the questions so that they are able to answer it. Because I deal with housing discrimination, that’s my job title, so I see it. I have thirty participants on my caseload and at least twenty of them have experienced this. So if we’re asking the right questions, I think the numbers will definitely go up. ... So when I’m screening someone for housing discrimination, the first thing I’ll say is, “Do you know what discrimination looks like?” And so then they’ll break it down to me. Then I’ll be like, “Well, have you experienced that?” And then I’ll say, “What made you feel that you experienced that?” And so then they’ll break it down and I take notes on everything they say. Even if they’re just giving me general information of their history, I still take the note down.”

• Collective experiences of racism matter: Participants talked at length about experiences of racism that focused on collective, community-wide issues affecting Black communities. They began with sharing interpersonal experiences and moved to discussing collective issues including: gentrification; hate crimes; economic inequality; and community violence, including police brutality, gangs, and drug addiction.

• Racism is experienced in many ways: Participants offered descriptions of racism that were not reflected in the perceived racism questions. Some of these experiences included being put in random racially threatening situations; feelings of not belonging in their community or when they left Portland; stress related to being the only Black person advocating for their community; experiences of generational medical racism; and the particularity of racism in Oregon. Narratives illustrating these points are shared below:

  » Racially threatening situations: Participants talked about navigating potentially threatening situations in everyday encounters where they notice that they could be exposed to violence from random individuals due to their skin color. A participant said of an experience where she felt threatened because of racial discrimination:

  “I didn’t know what to do. I just made sure I didn’t get in trouble, and I took myself home. I don’t know what people’s capable of doing, to anybody and everybody.”

One participant shared an experience of having her belongings stolen by a white woman and no one came to her aid as a Black woman. She felt particularly vulnerable in that moment.
» **Lack of belonging:** When asked about feelings of belonging in Oregon, a participant noted that he felt that he belonged and would travel widely. He noted that friends of his would not travel to certain parts of the state as a safety precaution.

> “*I feel like I belong to Oregon. And a lot of my friends will not go with me to a whole lot of places. They say hey, you just take too many chances.*”

This fear of going to certain places in the state and city were echoed by other participants. This feeling of not belonging is also reflected in discussions about gentrification. Participants said that people ‘welcomed them’ to their neighborhoods in inner Northeast Portland, even though they had been residents there for decades.

> “*A lady told me, “Welcome to the neighborhood.” I looked at her and I was thinking, “My older son’s ma went into labor off of 60th. I was like, born down the street. Like, lady, I’ve been here way before you even thought about it.”*”

» **Cultural racism:** Not belonging was also reflected by cultural racism such as disciplining or monitoring children for ethnic hairstyles in schools. A participant shared the story of sending her child to a predominately white school. Her daughter was scrutinized because of her different hairstyles. This type of scrutiny would not happen in a predominately Black and Brown school.

» **Generational medical racism:** Participants shared generational experiences of medical racism. The legacy of this distrust is passed down generationally. It can feed into a fatalism that racism is simply the way things are. For example, one person shared that his father had a stroke and because he did not trust doctors would not seek treatment:

> “*My father had a stroke. Because he didn’t trust the hospital, he didn’t go to the hospital. So I know the people came in and prayed for him, did whatever. And we just thought that was the norm, right? … Going to the doctor, you might not come back. Your organs might disappear.*”

» **Particularity of racism in Oregon:** Participants noted that racism in Oregon looked worse than in other parts of the country. No survey questions asked about experiences of racism in Oregon in particular. One participant stated that experiences of racism were worse in Oregon than in other places she has lived. This assertion was supported by others in the group.
Reflections on the Cumulative Impacts of ACEs and Racism Experiences

Participants emphasized the challenges of mental health in the Black community. Their analysis was that the cumulative impact of ACEs and racism contributed to mental health concerns and that both the community and medical providers did not adequately address them. The section below highlights elements of this discussion around mental health.

• **Mental health care is not commonly understood:** In relation to learning more about the impact of mental health on the Black community, participants said that interview questions needed to specifically speak to mental health. Some people may not know what mental health is or how they are impacted by it. For example, to clarify the meaning of depression one participant suggested:

  “So maybe asking a question, ‘have you experienced feelings of depression in the last 30 days?’ Followed by a more detailed description of what depression looks like.”

• **The lack of recognition and care for Black mental health concerns results in both institutional and community neglect of Black mental health:** A participant said:

  “I think a lot of Black people are depressed, anxiety filled and don’t even recognize it. They just consider their everyday struggle, “The struggle is real.” You know? They keep going. They don’t realize, “Okay, I’m having some mental barriers or some challenges behind the struggle.” And then you hear the message - “The strong survive” - we got all these messages that keep us going in the struggle. So, taking time to really embrace our mental health and what we’re going through is something that we’re still working on, that still has to be taught.”

• **Discussing mental health can have institutional repercussions:** In considering the impacts of mental health in the Black community, participants shared that discussing mental health with healthcare providers could cause them to be deemed mentally unfit by social workers and result in them becoming involved with Child Protective Services. One person said:

  “I’ll tell you just enough where I can keep going because I don’t want to turn around and go home and have a CPS worker talking about, “Well the doctor informed us that there is something wrong with you mentally.”
This distrust of healthcare providers around mental health creates a double bind for participants who expressed that they want to be able to talk about mental health, but feel that talking about it will create more vulnerability to institutional racism. This means that people who would be open to seeking mental healthcare do not. A participant shared:

“But just feeling not safe to tell anybody that I’m depressed, I’m sick right now because of what the consequences might be from saying that. ... Like you were saying CPS taking your kids or just anything can happen, and just feeling like, “Dang, if I say this, I’m going to be labeled crazy or I’m going to be labeled as schizophrenic or anything.” So, we just keep it inside and harbor it until it kills us.”

Participants acknowledge that there is a generational distrust of mental healthcare in general. Older generations are reluctant to participate in mental health services and deem them unnecessary. They may invalidate or undermine efforts of younger people to address mental health concerns.

- **An inability to talk meaningfully with healthcare providers about trauma - be it from racism, ACEs, or other experiences - compounds mental health issues:** A participant said:

  “I have a younger sister who has bipolar; and the thing is she’s not open with what has happened through her childhood, but it’s because she feels like the person she’s talking to can’t relate.”

This perception of not relating to mental healthcare providers also results in people feeling unseen and that they are being treated for symptoms but not getting at the root causes of their stress:

“I don’t want you to treat my symptoms - I want you to get at the root of it and remove what’s causing the stress.”

- **Limited culturally competent and/or Black mental health counselors alienates people from seeking mental healthcare:** Social service providers in the focus groups noted that it was challenging for them to get their clients seen for mental healthcare. One participant said:

  “Me and my supervisor have to be strategic in our plan on mental health, with the mental health agencies that’s here, to get our people in. Because it’s not as easy for us to go and get mental health done, or talk about getting it, us being African American.”
Recommendations for Action

Several overarching lessons and related recommendations emerged focusing on improving BRFSS data collection among Blacks in Oregon and the impacts of racism and ACEs on Black mental health. Participant and researcher recommendations will be shared in two sections: first, recommendations directly related to the BRFSS, and second, emergent recommendations related to mental health stress and needs for support.

Participant Recommendations for BRFSS

Anonymous phone calls prove to be a problematic method for collecting data among Black participants. This limits Black peoples’ willingness to take the survey.

- Recommendation(s): Limit or stop the anonymous phone calls as a means of administering the survey. Consider administering surveys by health professionals at medical offices; offer random surveys in places where Black people receive resources, services, and/or do business; administer surveys at Black culture events such as Good in the Hood or Juneteenth in Portland; and administer surveys in face to face meetings.

Black people care about this data and would like to participate in the collection of it. This has a benefit for Black communities.

- Recommendations(s): Incentivize the survey to increase participation. Use community events as a means to invite people to take the survey. Hire diverse staff to administer the survey who reflect the communities you are trying to connect with. Participants suggested having the surveys administered by culturally specific organizations to Black clientele.

Multiraciality and varied family forms are a feature of Black life. Survey questions need to make space for this.

- Recommendation(s): Include a question related to multiraciality that would allow people the chance to self-identify how they racially categorize themselves. This does not mean they do not want to be counted as Black or want to be counted as a separate category; rather, this supports fuller participation in the survey as it reflects their lived experience.
Racism and ACEs questions as they stand do not address economic insecurity, community violence, and institutional involvement with corrections or Child Protective Services. These are disproportionately experienced among Black communities in Oregon.

- **Recommendation(s):** Include questions in the ACEs and Racism sections related to exposure to direct violence and community violence that asks if this happened to the individual or to others in their community. Ask about economic insecurity in regards to both ACEs and experiences of racism. Ask about justice and CPS involvement of the individual and their close family, as this directly impacts family trauma.

Racism is both interpersonal and systemic. Current perceived racism framing does not go far enough in capturing factors that impact the racialized experiences of discrimination, alienation, and direct and indirect violence felt by Black people in Oregon.

- **Recommendation(s):** Participants noted that the perceived racism questions need revision, as the time frame is too short to get at systemic discrimination. Experiences of discrimination need to be broken down so that people can better understand what is being implied; the areas focused on did not reflect the intensity of discrimination experiences. In addition, people experience discrimination but may not use the term “discrimination”. For people who experienced hate crimes directed at themselves, loved ones, or to people like them, the perceived racism questions were offensive and trite. Hate crimes terrorize whole communities whether they happen to the person directly or not. Finally, include a question about perceived racism that speaks directly to Oregon.

Mental health concerns affect Black people in Oregon and this needs more attention.

- **Recommendation(s):** Participants suggested that if researchers want to know about mental health, they should ask about it directly. This could include explicit references to depression or adding questions about depression and anxiety related behaviors and symptoms.

**Researcher Recommendations for BRFSS**

How communities understand and think of ACEs is not universal, thus answering questions about ACEs can be confusing. Developing culturally relevant questions related to ACEs could be beneficial.

- **Recommendation(s):** Develop culturally relevant ACEs questions with community members. Participants recognized generational differences in how ACEs are understood. One way to disentangle generational differences is to analyze ACE responses by age group.
Punitive institutional responses to ACEs trauma in the home further put people at risk. Shifting how this data is understood and collected is imperative to have a more accurate picture of how ACEs affect communities.

- **Recommendation(s):** Participants note that institutional responses to ACEs in the home can get them caught up with CPS and threaten their families. Data collection is never neutral. ACEs data must be used to support prevention resources. ACEs questions need to aim towards prevention.

**BRFSS questions about perceived racism are an important element of the survey. Updating these questions would be beneficial with an eye to addressing the presence and impacts of systemic racism and issues of belonging.**

- **Recommendation(s):** Update the perceived racism questions and pilot them with different groups. People appreciated that racism was addressed in the survey, but needed the questions to have greater depth. Questions should include themes related to belonging, experiences of stereotype threat, displacement, and direct and indirect racism related violence. Racism related stress manifests in participants’ lives and is not currently reflected in the survey. Three specific suggestions for reworking these questions are offered below.

  » Updated perceived racism questions should account for the effects of racism over time. Systemic racism impacts people directly and indirectly at different moments in one’s life. Trauma from racism can be experienced in the moment and after an event. The perceived racism questions as they stand do not address the allostatic load that results from racism-related stress that people experience after a racist incident. For example, if one has a discriminatory experience with an institution, the stress from that event can be easily triggered in future encounters with that institution and other institutions.

  » Add questions related to belonging and connection, as they can indicate both the impacts of discrimination and a strong protective factor to help people heal and thrive. These questions could include: Do they feel that they belong? Do they feel that they can connect meaningfully with people in their lives and community?

  » We learned that in general the Black community is not going to the doctor to address physical ailments in the same ways as white people because of histories of healthcare discrimination. Because of this, many Black people may not have specific clinical diagnoses for the illnesses they experience, which could be a reason why our quantitative analysis did not find direct links between experiences of perceived racism and diagnosed chronic conditions. Include questions beyond diagnosed chronic illnesses; include stress related ailments such as headaches, stomachaches, body aches and pains.
Unexpected Findings Related to Mental Health Stress as Related to Racism and ACEs

An unexpected finding from the focus groups was the impact of mental health distress on people who had reported high ACEs scores and experiences of perceived racism. In line with the findings, participants understood why data showed correlations between perceived racism, high ACEs scores, and sleep disturbances and substance use. They argue that the finding that mental health is not a concern for this population is incorrect. Mental health is of great concern within the Black community. Addressing stigma around mental health within the community and addressing institutional racism, discrimination, and lack of access to mental health resources is a deep need for the Black community. Limited therapists of color deters people from seeking care, as do negative racialized experiences when they access care. For the Black community there has been a historical and current experience that mental health care is hard to access, culturally alienating, and can result in harmful institutional involvement.

- **Recommendation(s):** Recruit more people of color for healthcare and provide a directory of mental healthcare providers in the state.

Areas of Future Study

Having members of the Black community review elements of the BRFSS tool and weigh in on the findings is very helpful. It would be good to do this periodically, as this both explains findings and challenges assumptions about how race and racism impact the experience of Black people in Oregon. The impacts of race and racism on mental health were an important finding from this research. Further study on mental health, how Black people access treatment, and how Black people envision ways to enhance treatment would be a beneficial public health intervention. More robust mental health supports for Black people are needed and desired in Oregon. Black community and our allies want to work on this.

Limitations of the Study

Though the focus groups were held around Portland, no participants represented other parts of the state. Interviews or focus groups on the BRFSS findings with people from other parts of the state would be beneficial, particularly around ways of increasing Black participation in the BRFSS survey and reflections on the perceived racism questions.
Appendix: Relevant BRFSS Survey Questions

Adverse Childhood Experiences (ACEs)

Questions related to adverse childhood experiences (ACEs) have been asked consistently on Oregon’s annual BRFSS survey since 2013. The list of questions is presented below, with response options in italics.

1. Did you live with anyone who was depressed, mentally ill, or suicidal? (Yes, No, Don't know, Refused)
2. Did you live with anyone who was a problem drinker or alcoholic? (Yes, No, Don't know, Refused)
3. Did you live with anyone who used illegal street drugs or who abused prescription medications? (Yes, No, Don't know, Refused)
4. Did you live with anyone who served time or was sentenced to serve time in a prison, jail, or other correctional facility? (Yes, No, Don't know, Refused)
5. Were your parents separated or divorced? (Yes, No, Parents were not married, Don't know, Refused)
6. How often did your parents or adults in your home ever slap, hit, kick, punch or beat each other up? (Never, Once, More than once, Don't know, Refused)
7. Before age 18, how often did a parent or adult in your home ever hit, beat, kick, or physically hurt you in any way? Do not include spanking. (Never, Once, More than once, Don't know, Refused)
8. How often did a parent or adult in your home ever swear at you, insult you, or put you down? (Never, Once, More than once, Don't know, Refused)
9. How often did anyone at least 5 years older than you or an adult, ever touch you sexually? (Never, Once, More than once, Don't know, Refused)
10. How often did anyone at least 5 years older than you or an adult, try to make you touch them sexually? (Never, Once, More than once, Don't know, Refused)
11. How often did anyone at least 5 years older than you or an adult, force you to have sex? (Never, Once, More than once, Don't know, Refused)

BRFSS participants who respond “yes” to question 2 and/or question 3 are coded as having experienced household substance abuse as a child. Similarly, those who respond “once” or “more than once” to questions 9, 10, and/or 11 are coded as having experienced childhood sexual abuse.
Perceived Racism

Questions about perceived racism were derived from the BRFSS question module “Reactions to Race,” which was developed in 2001 by Dr. Camara Phyllis Jones at the CDC.* Questions cover socially assigned race, perceptions of differential treatment based on race, and physical and emotional distress reactions to treatment based on race. All questions that appear in the module are listed below, with response options in italics. For this project, we examined questions numbered 3 and 4 in the following list.

1. How do other people usually classify you in this country? (White, Black, Hispanic or Latino, Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native, Some other group, Don’t know, Refused)

2. Within the past 12 months at work, do you feel you were treated worse than, the same as, or better than people of other races?† (Worse than other races, Same as other races, Better than other races, Worse than some races but better than others, Only encountered people of the same race, Don’t know, Refused)

3. Within the past 30 days, have you felt emotionally upset, for example angry, sad, or frustrated, as a result of how you were treated based on your race? (Yes, No, Don’t know, Refused)

4. Within the past 30 days, have you experienced any physical symptoms, for example, a headache, an upset stomach, tensing of your muscles, or a pounding heart, as a result of how you were treated based on your race? (Yes, No, Don’t know, Refused)

5. Within the past 12 months when seeking healthcare, do you feel your experiences were worse than, the same as, or better than for people of other races?‡ (Worse than other races, Same as other races, Better than other races, Worse than some races but better than others, Only encountered people of the same race, Don’t know, Refused)

6. How often do you think about your race? (Never, Once a year, Once a month, Once a week, Once a day, Once an hour, Constantly)

Questions Related to Selected Health Outcomes

Smoking

Smoking status is calculated based on BRFSS participants’ response to the following question: Do you now smoke cigarettes every day, some days, or not at

† Only asked of respondents who are employed.
‡ Only asked of respondents who received healthcare services in the past 12 months.
all? Respondents who choose “every day” or “some days” are coded as current smokers. Note that this only includes BRFSS respondents who report smoking tobacco cigarettes and does not include those who use e-cigarettes or cigars.

**Binge Drinking**

Binge drinking behavior is measured via BRFSS participants’ response to the following question: How many times during the past 30 days did you have X (X = 5 for men, X = 4 for women) or more drinks on an occasion? Respondents who answer “1 or more times” are coded as having recently participated in binge drinking.

**Sleep**

All BRFSS respondents are asked to report the number of hours they sleep on average via the following question: On average, how many hours of sleep do you get in a 24-hour period? Respondents who report sleeping 6 hours or less are coded as not getting enough sleep.

**Depression**

BRFSS respondents are asked whether they have been diagnosed with depression at any time during their lives via the following question: Has a doctor, nurse, or other health professional ever told you that you have a depressive disorder, including depression, major depression, dysthymia, or minor depression? Respondents who answer “yes” are coded as having a depression diagnosis. Information about the timing of the depression diagnosis is not collected, so respondents’ depression status at the time of the survey is unknown.

**Frequent Mental Distress**

Frequent mental distress is calculated based on BRFSS participants’ response to the following question: Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? Respondents who say their mental health was not good for at least 14 of the last 30 days are coded as having frequent mental distress.
You can get this document in other languages, large print, braille or a format you prefer. Contact Program Design and Evaluation Services (PDES) at 971-673-0589. We accept all relay calls or you can dial 711.