



# OUR HEALTH



# HEALTH ASSESSMENT & RESEARCH PROJECT

**Santa Clara County  
African/African Ancestry  
Research Project & Demographic Study**



# Ken Yeager

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To the Residents of Santa Clara County:

We are proud to present the **Status of African/African Ancestry Health: Santa Clara County 2014**, a report that focuses on five areas of inquiry that the County's African/African Ancestry community identified as most important because of their influence on the health, well-being, and quality of life in their community. These five areas include: the African/African Ancestry community definition of health, wellness, and illness; healthcare access; experiences with the healthcare delivery system; chronic disease; and the effects of racism and discrimination on health.

Members of the African/African Ancestry community in Santa Clara County experience disproportionately higher rates of illness and premature mortality than other racial/ethnic groups in our county. Despite efforts to address disparities in health status and outcomes, many challenges remain. Through a partnership with community stakeholders and the Public Health Department, this assessment seeks to provide a deeper understanding of the root causes and contributing factors to poorer health outcomes, and to spotlight the community's assets and historically strong networks and institutions.

The Public Health Department worked collaboratively with community stakeholders to ensure that the assessment was developed and conducted within an Afro-centric framework. An important component of the Afro-centric framework is the shared knowledge through the lived experiences of members of the African/African Ancestry community. We wish to acknowledge the important leadership role that the assessment's steering committee – comprised of community leaders with expertise in health and healthcare issues – played in ensuring fidelity to this framework.

It is our hope that the findings from this report will support ongoing and future community action, program development, and resource allocation to address the health and social inequities facing the African/African Ancestry community. We also wish to recognize and celebrate the strengths and assets of Santa Clara County's African/African Ancestry community.

Special thanks to the members of the assessment's steering committee, representing the Black Leadership Kitchen Cabinet of Silicon Valley, African American Community Services Agency, San Jose State University Departments of African American Studies and Urban and Regional Planning, Stanford University Office of Community Health, the Public Health Department, Social Services Agency, and Ujima Adult and Family Services, Inc. for their leadership and dedication to this project. We also wish to acknowledge the contributions of the many community leaders, partners, and residents who participated in all phases of the assessment.

Sincerely,

Supervisor Ken Yeager  
Board of Supervisors

Sara H. Cody, MD  
Health Officer

Dan Peddycord, RN/MPA/HA  
Public Health Director

### **Letter from Oscar Battle, Jr., Community Elder**

People of African/African Ancestry in the United States experience a wide range of inequities in health and healthcare. With few exceptions they experience higher rates of sickness and death than other racial/ethnic groups, often receive a lower quality of healthcare for many diseases and treatment for these diseases. According to the World Health Organization and other leading health organizations, health inequities are mostly a result of social conditions that affect individuals. The “social determinants of health” are the conditions in which people are born, grow, live, work and age, including the health system that responds to their needs. Many if not all of these social determinants that cause differences in the health status between groups of people, are responsible for health inequities and are unfair and avoidable.

This report is an attempt to identify the health and healthcare inequities that exist among the African/African Ancestry community in Santa Clara County and to understand the underlying conditions, circumstances, and experiences that perpetuate these inequities. Most importantly it helps to understand why African/African Ancestry communities suffer disease disproportionately when compared to other racial/ethnic groups. Current research helps us see the truth more clearly and explains the role social factors, such as racism and discrimination, have played in contributing to chronic stress and anxiety. Chronic stress and anxiety inhibits optimal immune system functions and wears on the body’s systems over time. Historically, African/African Ancestry community have experienced worse health outcomes than other racial/ethnic groups. Many reasons have been hypothesized as to why this occurs. Research now clearly shows how many social factors such as where we live and work, and how much income we earn give great insight into our health outcomes over the lifespan. Additionally, actions, whether intentional or unintentional that are based on race or skin color and that subordinates an individual or group directly affects health.

This report should leave every reader with this question: how can I help eliminate racism and discrimination in the systems in which I live and work. This report aims to challenge each reader to examine their own conscience and everyday practices that may be defined as acts of racism and discrimination. Acts of racism and discrimination undermine American values; such as the right to prosper and thrive economically, socially and physically. These values are important in that they define us in our own eyes and in the eyes of the world.

This report offers a special call to its readers. However, awareness does not necessarily changes behaviors; nor extensive knowledge of racism, discrimination and inequality automatically gives us the tools to make needed changes in our actions or environments. There must be commitment and understanding of how to eliminate racism and discrimination. This report begins the conversation and gives some insight on how to begin the process of addressing racism and discrimination as one of the several social determinants of health.

Any and every attempt at dismantling racism helps build a better world and improve the health of everyone.

Oscar Battle, Jr., DPA, MA, MPH

## **Letter to the Santa Clara County, African/African Ancestry Community**

The Black Leadership Kitchen Cabinet (BLKC) of Santa Clara County was established in 2005 with a mission to promote and establish initiatives, programs, policies and legislative reforms that improve public safety, educational outcomes, economic prosperity and the social well-being of individuals and families within the county's African/African Ancestry community. The BLKC membership is composed of community leaders that represent more than fifty organizations.


In keeping with the BLKC mission, about three years ago, through the leadership of Walter Wilson, African American Community Services Agency (AACSA) Board of Directors and Pastor Lee Wilson, Senior Pastor of Open Bible Church, the BLKC elected to conduct an updated Demographic Study on the lives of African/African Ancestry community members of Santa Clara County. The BLKC referenced the landmark Santa Clara County African American Demographic Study developed in 1999 by Mason Tillman Associates, for a baseline comparative for this study.

In addition to Pastor Wilson and Walter Wilson, the initial project planning committee included Andre Chapman, Unity Care Group; Reginald Swilley, Maranatha Christian Center; Everett Bobby Gasper, AACSA Board Chair; Milan Balinton, AACSA Executive Director; Sheila Mitchell, former Santa Clara County Chief of Probation; Lori Medina, Santa Clara County Department of Family and Children Services; and William Kendricks, 100 Black Men of Silicon Valley President. Later on, Dr. Ruth Wilson, Chair of the San Jose State University (SJSU) African American Studies Department and Rick Kos, SJSU Transportation and Urban Planning Department were recruited to participate as research leads on the project.

It was decided by the committee early on that this study would:

- Be of, for and by the African/African Ancestry communities of Santa Clara County
- Be a living document with regular updates
- Act as a "road map" with documented successes and challenges
- Provide accurate data on all aspects of the lives of the African/ African Ancestry community
- Adopt and implement "Best practices" throughout the African/African Ancestry communities
- Provide direction and information for policy makers that can be used when prioritizing services and resources for the African/African Ancestry community
- Act as the basis for a "Call to Action" for the community, policy makers, businesses and others that have a vested interest in the health and social well-being of the African/African Ancestry community in Santa Clara County





With support and direction from the Santa Clara County Board of Supervisors, the County Executive, and the Director of Public Health Department, a collaborative partnership began with the Santa Clara County Public Health Department to develop the health assessment component of the larger African/African Ancestry Demographic Study. Professional researchers from Research Development Associates (RDA) were also contracted to assist with the health assessment.

The first major event held was a “Stakeholders Forum” on Friday, November, 15th, 2013 at the AACSA. The data that was gathered from that event became the seeds to what is now a rich, data driven document that captures the heart and feelings of the Santa Clara County African/African Ancestry community.

The process developed during this health assessment will be used as a “template” for the remaining components of the African/African Ancestry Demographic Study. Other components of the African/African Ancestry Demographic Study will focus on education, social services, economic development, criminal justice and social/civic engagement and cultural arts.

As the Project Chair, I say thank you to everyone who has contributed to this health assessment and to those who will be involved in the upcoming components of the Demographic Study.

Walter Wilson *Walter Wilson*  
Board of Directors,  
African American Community Service Agency,

On behalf of the Silicon Valley Black Leadership Kitchen Cabinet

# Acknowledgements

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The Santa Clara County Black Leadership Kitchen Cabinet (BLKC) and the African/African Ancestry Health Assessment Steering Committee acknowledges the following individuals and organizations for their support in completing this component of a larger Santa Clara County African/African Ancestry Demographic Study.

## **Santa Clara County African/African Ancestry organizations**

First and foremost, thanks to a number of key local African/African Ancestry organizations, which contributed time, space, food, and other essential support. The African American Community Service Agency (AACSA) and Ujima Adult and Family Services, Inc. donated space for steering committee meetings, community conversations, and stakeholder gatherings. San Jose State University's African American and Urban Studies Department has also been an important partner, offering leadership and insight into research methods across various phases of this health assessment.

## **Research partners**

We are grateful to Walter Wilson, Project Chair from the BLKC for his persistent leadership and guidance, Yvonne Maxwell from Ujima Adult and Family Services, Inc., Project Co-chair for ensuring all efforts were immersed within an Afro-centric framework and that the voice of the community remained prominent, Dr. Ruth Wilson from San Jose State University, Project Co-Chair for giving clarity and sound research direction, Rhonda McClinton-Brown, from Stanford University School of Medicine for keen insight and the ability to "make it simple," and Anyika Nkululeko from Santa Clara County Social Services Agency for his passion and commitment to keeping everyone focused on the importance of our heritage. Alma Burrell, Project Co-Chair and Beverley White-Macklin, from the Santa Clara County Black Infant Health Program, and Milan Balinton, the Executive Director of the African American Community Services Agency, made sure that the health assessment was closely connected to the African/African Ancestry community at large and that community members had opportunities to participate throughout the process. Many thanks to Santa Clara County Public Health Department team including Resource Development Associates (RDA), the contractor hired to help with the health assessment, for their support and assistance with the extensive data collection and analysis that comprise this report.

Special thanks to the Santa Clara County Board of Supervisors for allocating resources for conducting this health assessment. We are thankful to Dan Peddycord, Santa Clara County Public Health Department Director for his support for this important work. The leadership and commitment of Public Health Department staff including Alma Burrell, Rocio Luna, Anandi Sujeer, and Beverley White-Macklin was critical for the successful completion of this health assessment. In addition, Mandeep Baath's extensive analysis of available public health data provided important information about the overall health and well-being of our community and Maritza Rodriguez's persistent communication and project management helped all partners stay on track throughout the health assessment. Brianna van Erp and Mandeep Baath undertook the massive task of report writing and many rounds of editing and incorporating team feedback in the report. Johanna Silverthorne helped with report formatting and Analilia Garcia provided her expertise working with the qualitative data.

At RDA, Mikaela Rabinowitz and Marcus Hunter worked closely with the steering committee and Public Health Department to ensure that this report reflects the guidance of the steering committee and the experiences of the African/African Ancestry community. Toward this end, Dr. Hunter, who is also a Professor of Sociology and African American studies at UCLA, provided his extensive expertise in African/African Ancestry community-driven research. Rajni Banthia, Alexandra Jacobs, Irine Onciano, Elena Reyes, Dant'e Taylor, Kelechi Ubozoh, and Karita Zimmerman also provided critical support for data collection, analysis, and reporting.





## **Community partners**

Thanks to the many members of Santa Clara County’s African/African Ancestry community who participated in data collection and strategy development. In particular, a number of Afro-centric volunteers gave their time to facilitate and scribe community conversations. In addition, more than 150 community members gave their time to participate in community conversations, key informant interviews, and community stakeholder meetings. Without them, this report would not exist.

Lori Medina, the Director of the Department of Family and Children’s Services at Santa Clara County Social Services Agency approved release time for African/African Ancestry staff to participate and contribute to this health assessment. Other contributors include Kool World Media, Back-a-Yard Restaurant, and Lillie Mae’s House of Soul Food.



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# Executive summary

Santa Clara County is home to a vibrant African/African Ancestry<sup>a</sup> community. In 2012, 49,013 or 3% of the county's more than 1.8 million residents identified themselves as African American. Despite many strengths and assets, Santa Clara County's African/African Ancestry community faces disparities in health outcomes, relative to other racial/ethnic groups in the county. While in recent years some health indicators have improved and disparities between African/African Ancestry community members and other racial/ethnic groups residing in the county have decreased, the persistence of several health disparities indicates a need to address the underlying issues behind these disparities.

People from the African/African Ancestry community in the United States experience a wide range of inequities in health and healthcare. Research suggests that for some indicators, African/African Ancestry individuals experience worse health outcomes than other racial/ethnic groups and that unfair treatment contributes to many of these inequities.<sup>1</sup> Health inequities that are avoidable and unjust, often arise among groups already experiencing lower levels of social advantage.<sup>2,3</sup> Social advantage is often conferred in the environments in which people are born, grow, live, work, and age, also known as the social determinants of health. Healthcare is an example of a social determinant of health since healthcare access, resources, and quality are shaped by social policy.<sup>3</sup>

The aim of this report is to identify the health and healthcare inequities that exist among members of the African/African Ancestry community in Santa Clara County and to understand the underlying conditions, circumstances, and experiences that may contribute to the root causes of these inequities. The report provides information that helps build understanding about salient contributing factors for disproportionately higher rates of sickness and death in the African/African Ancestry community compared to other racial/ethnic groups. Moreover, this report describes the role that social factors, such as racism and discrimination, have played in contributing to poorer health outcomes among the African/African Ancestry community. Five key domains of inquiry, developed by the community stakeholders and the steering committee, define the structure and direction of this health assessment.

## ***Key domains of inquiry***

- **African/African Ancestry community definition of health, wellness, and illness**
- **Healthcare access**
- **Experiences with the healthcare delivery system**
- **Chronic disease**
- **Effects of racism and discrimination on health**

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<sup>a</sup> African/African Ancestry: At the beginning of this project, the steering committee elected to use the term "African/African Ancestry" to refer to all African people, whether they are recent African immigrants or have been in the U.S. for multiple generations. This terminology was chosen over the more commonly used terms "Black" or "African American" to underscore the connectedness among all African people as well as the importance of uniquely cultural norms, beliefs, and practices among African people in the U.S., from the African continent and throughout the Diaspora. Throughout this report, African/African Ancestry is used to refer to all African people, although there are instances where "African immigrant" is used to refer specifically to individuals who were born in Africa, and also the Caribbean, Mexico, South America, and other parts of the world and immigrated to the United States. In addition, when discussing data that uses Black or African American, this report mirrors that language in order to accurately report what the data conveys and to accurately reflect the language of participants.

## **Community engagement and participation**

Santa Clara County's African/African Ancestry community played a critical role in guiding and implementing this health assessment. The health assessment has been led by a steering committee, comprised of community leaders who are knowledgeable about health and healthcare issues among the African/African Ancestry community in the county. In addition, many other stakeholders participated via a number of key forums, including a Stakeholder Forum in November 2013, a Health Summit in June 2014, and 25 topic-specific key informant interviews. Finally, more than 140 African/African Ancestry community members participated in a series of 15 small-group discussions called "community conversations," and had the opportunity to share information about their health needs, concerns, and experiences as well as those of the community overall.

## **Findings<sup>b</sup>**

The report focuses on several aspects of health in the African/African Ancestry community in Santa Clara County and presents findings from quantitative and qualitative data on several health and healthcare-related themes. The report highlights community strengths and assets identified by community conversation and key informant interview participants. The report also presents community health data and discusses findings related to cultural (in)competence, racism and discrimination, (mis)information and avoidance, barriers to better health and well-being, lack of support for the most vulnerable, and (dis)empowerment and the power of choice.

### ***Community strengths and assets***

African/African Ancestry community participants identified various strengths and assets prevalent in the community that empowers the community members to aim for better health and well-being. Salient protective factors identified by the community members are:

- Community based institutions including churches, mosques and other places of worship
- Community support networks
- Commitment to greater community well-being
- Resiliency through the ability to draw strength from prior struggles

### ***Community health overview***

Although disparities between the health status of African/African Ancestry community and other racial/ethnic groups in the county have decreased in recent years, these disparities continue to exist. The report reveals continued disparities in several areas:

- Despite an overall increase in life expectancy countywide, the African/African Ancestry community in the county has a life expectancy of 78.9 years. This is lower than other racial/ethnic groups and the county overall.
- A higher rate of African/African Ancestry infants die in their first year of life (6.1 infant deaths per 1,000 live births) than other racial/ethnic groups and the county overall.

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<sup>b</sup> For more details, please read the 'African/African Ancestry Health Assessment' report or check Santa Clara County Public Health Department website for detailed data tables.

- The African/African Ancestry community in the county experiences a higher overall cancer mortality rate (248 per 100,000 adults) than other racial/ethnic groups and the county overall. One in 4 African/African Ancestry county resident died due to cancer.
- A higher percentage of African/African Ancestry adults in the county (40%) have high blood pressure than other racial/ethnic groups and the county overall.
- One in 10 African/African Ancestry adults in the county (10%) have diabetes. This is higher than most other racial/ethnic groups (except Latino) and the county overall.
- Among newly diagnosed HIV cases, African/African Ancestry community members experience a higher rate of new case diagnosis (27.5 cases per 100,000 people) than other racial/ethnic groups and the county overall.

### **Cultural (in)competence**

Research suggests that a lack of cultural competence contributes to disparities in healthcare access and health outcomes. Findings from key informant interviews and community conversations reveal the impact of cultural incompetence on health and well-being of the community:

- Participants cite a lack of cultural competence as a contributing factor to poor experiences with the healthcare delivery system.
- Health services do not sufficiently meet the needs or address the cultural practices and experiences of African/African Ancestry community members.
- LGBT African/African Ancestry community members and African immigrants residing in the county expressed particular concerns regarding a lack of cultural competence and professional mistreatment in healthcare settings.

*“There is not a specific system for African or African American. Everything is very vanilla, which makes it cookie cutter. They do not address specific issues for a community, given diseases and mental health, skin diseases from where you came from, TB... Maybe they know a little, classes in tropical medicine, they are not aware of specific issues for our community... by Vanilla I mean general treatment, not race related.”*

(Ethiopian community conversation participant)

### **Racism and discrimination**

Experiences with racism and discrimination negatively impact health and well-being. Research suggests that stress and anxiety associated with exposure to racism and discrimination is a risk factor for poor health outcomes. A higher percentage of African/African Ancestry adults (10%) reported being treated worse than people of other races in social settings such as work or when seeking healthcare compared to most racial/ethnic groups and the county overall. Eleven percent (11%) of African/African Ancestry adults reported frequent mental distress in the past 30 days, which is higher than most other racial/ethnic groups and the county overall. Findings from key informant interviews and community conversations reinforce the negative consequences of these experiences on overall health:

- Racism and discrimination are a pervasive source of stress and anxiety that directly impacts the mental and physical health of African/African Ancestry community members.
- Differential access to resources and opportunities that can accumulate over lifetime and across generations negatively affect health outcomes for the African/African Ancestry community.

- The effects of racism and discrimination have created a structural and institutional context in which African/African Ancestry community members are overrepresented in a series of institutions associated with poor outcomes such as the criminal justice system, foster care, and special education.

*“Think about the things that are related to discrimination for being African American and some of those issues have manifested themselves in a lot of depression, anxiety, substance use, and other stress related illnesses such as heart disease, diabetes, etc. Things that get exacerbated by the stress people are under living in a society that doesn’t respect African Americans on the same level as other individuals in the community.”*

(Mental health professional key informant)

### **(Mis)information and avoidance**

Many African/African Ancestry community members reported challenges with regards to obtaining accurate information about health, healthcare services, and the broader healthcare delivery system. The lack of accurate information in these areas impacts the ability to manage their health and to access needed healthcare. Key informant interviews and community conversations identified several areas of concern:

- Limited knowledge and information about health and health related issues within the African/African Ancestry community contributes to negative health outcomes.
- There is a lack of information about available services related to health and well-being in the county, leaving individuals to frequently rely on word of mouth to obtain information about these services. Barriers such as limited language skills and unfamiliarity with American systems of care makes navigation through the county’s healthcare delivery system particularly challenging for African immigrants.
- Historical experiences of medical abuse have led to high levels of mistrust of medical professionals serving the African/African Ancestry community.
- Among African immigrants, cultural differences and lack of familiarity with the American healthcare delivery system may exacerbate mistrust and an unwillingness to disclose important health information to providers.

*“What prevents women from getting healthcare? Mistrust. I don’t know about fear, maybe some fear, but definitely mistrust. As a race we typically don’t trust the medical system. For all the reasons above. We have a lot of history, Tuskegee Experiment, Henrietta Lacks, all those things that have affected us in the past.”*

(African/African Ancestry health expert key informant)

### **Barriers to better health and well-being**

The African/African Ancestry community in the county experiences unique challenges in accessing healthcare services such as barriers to accessing preventive care. Findings from key informant interviews and community conversations revealed several barriers to better health and well-being:

- Challenges with navigating the complexity of the healthcare delivery system are exacerbated by a lack of services for and outreach to the African/African Ancestry community in the county.



- The county needs more healthcare providers to serve as community resources, educators, and liaisons to the African/African Ancestry community.
- The high cost of healthcare can be prohibitive and prevent community members from seeking needed care.

*“For African immigrants in particular, a lot of it has to do with not having knowledge of the system and the cultural differences. Our systems are disjointed; in particular, for the Valley Health system, you may have to go to two or three places to get services you need so it is not a seamless system and a lot of times they don’t know what questions to ask because they’re not familiar with the whole system and so they are totally confused.”*

(African/African Ancestry health expert key informant)

*“Illness to someone who has money isn’t the same as to someone that doesn’t have money.”*

(Pastors community conversation participant)

### ***Lack of support for the most vulnerable***

The most vulnerable populations within the African/African Ancestry community face challenges accessing services in the county. Key informant interviews and community conversations identified several areas of vulnerability:

- There are limited services for the county’s most vulnerable populations, such as homeless people and individuals involved in the criminal justice system.
- Because African/African Ancestry community members are overrepresented within these populations, the inability of homeless and incarcerated individuals to get the services and support they need disproportionately impacts the health and well-being of the African/African Ancestry community as a whole.

*A lot of these individuals [in the criminal justice system] have mental health issues but don’t have other stabilizing issues with respect to community – housing, employment, and access to social services. So I think it needs a combination not only mental health but also collateral like housing, employment, job situation, and other services that will support their well-being and mental health and long term.”*

(Public defender key informant)

### ***(Dis)empowerment and the power of choice***

Many African/African Ancestry community members report that many of the issues described earlier in the report contribute to an overall sense of a lack of personal choice in their experiences with the healthcare delivery system. Findings from key informant interviews and community conversations highlight several examples of disempowerment:

- There is a lack of choice in healthcare service providers as a result of underrepresentation of African/African Ancestry community members in the healthcare professions and provider assignment system.

- Many African/African Ancestry community members have healthcare providers who lack cultural competence and the ability to understand and assist with their health and well-being needs, often depriving them of their ability to make informed choices.
- African/African Ancestry healthcare seekers are not empowered to advocate for their own health and healthcare needs.

## Strategies and recommendations

Throughout the health assessment, one of the primary objectives of the steering committee and the larger stakeholder group has been identification of strategies to address the disparities highlighted in this report. The need to develop a plan of action has informed all aspects of this health assessment, from the steering committee meetings to the community conversations and key informant interviews to the June 2014 Health Summit. Throughout these processes, all of the stakeholders and community members who participated in the health assessment has had the opportunity to be part of planning the next steps, thus the strategies and recommendations are community-driven. Moreover, in recognition of the multiplicity of actors and institutions whose actions impact the health and well-being of any community, these strategies and recommendations are intended to encompass a wide variety of organizations and individuals.

### *Collaborative strategies*

The strategies described here involve partnerships between local African/African Ancestry organizations and several partners, including government agencies and private sector organizations. The following strategies and recommendations cut across major topic areas:

- **Develop an online resource center.** An online resource center would provide culturally relevant information about the health needs and concerns of the African/African Ancestry community. This center could also provide directories of African/African Ancestry health professionals in the county as well as individuals who have received the African/African Ancestry Skills and Knowledge Certification (discussed in the next strategy).
- **Require African/African Ancestry Skills and Knowledge Certification for all health and social service professionals.** Local African/African Ancestry community organizations and leaders should work with health and social service organizations and providers in Santa Clara County to update the African/African Ancestry Skills and Knowledge Certification criteria and require it for all health and social service providers who work with African/African Ancestry patients or clients. The certification program should also be available on a voluntary basis to professionals who are not required to become certified.
- **Train Afro-centric health coaches and employ them at public and private healthcare service locations.** Health coaches will assist health seekers to better understand their health needs as well as the healthcare delivery system, including recommendations of healthcare providers. African/African Ancestry health coaches will be employed at public and private healthcare service centers.
- **Establish an African/African Ancestry Health Week.** Establishing an African/African Ancestry Health Week would provide an opportunity for government agencies, healthcare providers, community-based organizations, and African/African Ancestry health services consumers to all come together to promote the health and well-being of the African/African Ancestry community.
- **Bring health resources into the community.** Establishing health resource centers within existing community organizations, including churches, mosques, and other places of worship, will help overcome many of the most commonly cited barriers to better health and well-being. These centers can serve as hub for seeking information and knowledge about health and healthcare services. Health coaches will be available at these resource centers to provide services to community members.

- **Initiate community-driven messaging campaign.** The Black Leadership Kitchen Cabinet (BLKC) and other local African/African Ancestry organizations should collaborate with other entities to develop a messaging campaign that is directed towards the African/African Ancestry community using images, language, and media that resonates with African/African Ancestry community members. This campaign should address both health and the healthcare system.
- **Develop and promote an Afro-centric definition of health. Use this definition as a measure of health and well-being of the African/African Ancestry community.** In order to promote a more accurate definition of what health means for African/African Ancestry community members, local African/African Ancestry organizations should work together to establish Afro-centric definition of health and well-being and to identify indicators by which to measure the definition.
- **Implement health consumer satisfaction surveys at public and private healthcare settings.** In order to assess the healthcare satisfaction among African/African Ancestry health services consumers compared to other racial/ethnic groups, hospitals, clinics and other healthcare settings should create customer satisfaction surveys that explicitly ask about consumer's race/ethnicity and the cultural relevance and competence of the services they receive. These data should be published annually and made available on the online African/African Ancestry resource center and other healthcare related websites.
- **Establish an Afro-centric Health Clinic.** Establishing an Afro-centric Health Clinic with services that are tailored for African/African Ancestry community members in the county would go a long way towards addressing many of the issues identified throughout the report. This health clinic should strive to employ a predominantly African/African Ancestry staff who are *African/African Ancestry Skills and Knowledge* certified. The clinic should train and employ Afro-centric health coaches. This clinic should provide both physical and mental health services from an Afro-centric perspective to address client needs in a holistic way.


## **Individual strategies**

In addition to identifying strategies at the organizational and institutional levels, stakeholders, key informants, and community conversation participants identified a number of strategies that African/African Ancestry community members should implement to improve their health and well-being:

- **Take someone with you to healthcare appointments.** Take someone with you to make it easier to ask questions and advocate for yourself.
- **Engage and advocate.** These issues will not get better on their own. African/African Ancestry community members must continue to advocate for their needs and those of the whole community to make sure that the health and social service providers in the county address them.
- **Teach children to own their health and bodies.** Educate children about their bodies and health so that they can advocate for their health needs.
- **Be a health ambassador.** Work with other African/African Ancestry community members to teach them about health and the healthcare delivery system.

## **Conclusion**

This report is the first part of a more comprehensive study to document and understand the various health disparities and inequities that exist in the African/African Ancestry community. This health assessment intends to provide elected leaders, county agencies, and community organizations, advocates, and community members with information, inspiration, and ideas for improving the health and well-being of the African/African Ancestry community in Santa Clara County. With this goal, the report lays the framework for



developing a call to action and solutions that will benefit the community and especially those who are underserved, underrepresented, and most in need of services to support their health and well-being.

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# Introduction

People from the African/African Ancestry<sup>c</sup> community in the United States experience a wide range of inequities in health and healthcare.<sup>d</sup> Research suggests that for some indicators, African/African Ancestry individuals experience worse health outcomes than other racial/ethnic groups and that unfair treatment contributes to many of these inequities.<sup>1</sup> Health inequities that are avoidable and unjust, often arise among groups already experiencing lower levels of social advantage.<sup>2,3</sup> Social advantage is often granted in the environments in which people are born, grow, live, work, and age, also known as the social determinants of health. Healthcare is an example of a social determinant of health since healthcare access, resources, and quality are shaped by social policy.<sup>3</sup>

This report is an attempt to identify the health and healthcare inequities that exist among the African/African Ancestry community in Santa Clara County and to understand the underlying conditions, circumstances, and experiences that may contribute to the root causes of these inequities. The report provides information that helps build understanding about salient contributing factors for disproportionately higher rates of sickness and death in the African/African Ancestry community compared to other racial/ethnic groups. In addition, this report describes the role that social factors, such as racism and discrimination, have played in contributing to poorer health outcomes among the African/African Ancestry community.

## Community engagement and participation

Santa Clara County's African/African Ancestry community has played a critical role in guiding and completing this health assessment in a number of ways. The health assessment has been led by a steering committee, comprised of African/African Ancestry community leaders who are knowledgeable about health and healthcare issues among the African/African Ancestry community in the county. In addition, various stakeholders participated via a number of key forums, including the Stakeholder Forum held in November 2013, the Health Summit held in June 2014, and 25 issue-specific "key informant interviews" conducted throughout the health assessment. Finally, more than 140 community members participated in a series of 15 "community conversations," during which they had the opportunity to share information about their health needs, concerns, and experiences and those of the African/African Ancestry community.

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<sup>c</sup> African/African Ancestry: At the beginning of this health assessment, the steering committee elected to use the term "African/African Ancestry" to refer to all African people, whether they are recent African immigrants or have been in the U.S. for multiple generations. This terminology was chosen over the more commonly used terms "Black" or "African American" to underscore the connectedness among all African people as well as the importance of uniquely cultural norms, beliefs, and practices among African people in the U.S., from the African continent and throughout the Diaspora. Throughout this report, African/African Ancestry is used to refer to all African people, although there are instances where "African immigrant" is used to refer specifically to individuals who were born in Africa, and also the Caribbean, Mexico, South America as well as other parts of the world and immigrated to the United States. In addition, when discussing data that uses Black or African American, this report mirrors that language in order to accurately report what the data conveys and to accurately reflect the language of participants.

<sup>d</sup> The World Health Organization (WHO) defines health inequalities as the "differences in health status or in the distribution of health determinants between different population groups. For example, differences in mobility between elderly and younger populations or differences in mortality rates between people from different social classes." Health inequities are avoidable inequalities in health between groups of people. These inequities arise from inequalities within and between societies. According to the WHO, "some health inequalities are attributable to biological variations or free choice and others are attributable to the external environment and conditions mainly outside the control of the individuals concerned. In the first case it may be impossible or ethically or ideologically unacceptable to change the health determinants and so the health inequalities are unavoidable. In the second, the uneven distribution may be unnecessary and avoidable as well as unjust and unfair, so that the resulting health inequalities also lead to inequity in health." (<http://www.who.int/hia/about/glos/en/index1.html>)

## ***Steering committee***

The steering committee has been the key driving force behind this report and has been involved in critical decision making throughout the course of this health assessment. At the beginning of the health assessment, the steering committee hosted a half-day Stakeholder Forum to give community members the opportunity to identify questions of greatest importance to them, as well as to discuss methodology for data collection and participant recruitment for this health assessment. Based on the input from this forum, the steering committee worked closely with the Santa Clara County Public Health Department team to develop data collection protocols (available in Appendix A), identify health experts to interview about specific health issues, and identify African/African Ancestry sub-groups to recruit for community conversations.

The steering committee also met on a biweekly basis to track data collection progress, recruit additional participants, review preliminary findings, and plan for next steps.

## ***Health stakeholders***

A number of key community stakeholders provided their support and expertise through their participation in the November 2013 Stakeholder Forum, 25 key informant interviews about specific health issues relevant to the African/African Ancestry community, and a Health Summit in June 2014.

At the November 2013 Stakeholder Forum, stakeholders identified the following five key domains of inquiry, which guided all the subsequent health assessment activities:

- African/African Ancestry community definition of health, wellness, and illness
- Healthcare access
- Experiences with the healthcare delivery system
- Chronic disease
- The effects of racism and discrimination on health

Through their participation in key informant interviews, stakeholders also provided critical insight into the following key issues:

- African immigrant concerns and perspectives
- Aging and chronic disease
- Community perspectives on health and healthcare
- Family health and well-being
- Healthcare provider perspectives
- Health, well-being, and the criminal justice system
- Mental health and substance use
- Social services
- Women's health issues, including maternal and infant health
- Youth and young adult concerns and perspectives

Finally, at the June 2014 Health Summit, stakeholders convened to review preliminary findings and to develop strategies and recommendations for moving forward.

## Community Participation

More than 140 African/African Ancestry community members (n=143) participated in 17 community conversations as a part of this health assessment. These conversations targeted a diverse array of African/African Ancestry community members in order to develop a comprehensive understanding of the health needs, concerns, and experiences of the community. The table below demonstrates the diversity among the community conversation participants.

### Demographic characteristics self-reported by community conversation participants

Ancestry	N	%
<b>African/African Ancestry (unspecified)</b>	32	22
<b>African American</b>	92	64
<b>Cameroonian</b>	10	7
<b>Caribbean</b>	3	2
<b>Ethiopian</b>	11	8
<b>Nigerian</b>	3	2
<b>South African</b>	1	1
<b>Other African (country not specified)</b>	5	3
<b>American Indian or Alaska Native</b>	8	6
<b>Asian</b>	1	1
<b>Arab/Arab American</b>	1	1
<b>Hispanic/Latino</b>	4	3
<b>White</b>	6	4
<b>Prefer not to answer</b>	1	1

Note: Because percentages are rounded and some participants selected more than one answer option, percentages do not sum to 100%. While all participants identified as African or African Ancestry, 14% of participants also identified as another racial/ethnic group.

In addition, participants lived in 8 different cities within Santa Clara County, including San Jose, Santa Clara, Milpitas, Mountain View, Campbell, Palo Alto, Morgan Hill, and Sunnyvale. Participants ranged from ages 14 to 89 years. Ninety-two percent (92%) of the participants identified as heterosexual; 5% identified as lesbian, gay, or bisexual; and 3% preferred not to state their sexual orientation. Fifteen percent (15%) of the participants were born in Santa Clara County, 30% were born elsewhere in California, 35% were born elsewhere in the United States, and 19% were born outside of the United States.





# Methods

The findings presented in this report are drawn from qualitative and quantitative data sources. Qualitative data sources include small group discussions called “community conversations” with members of the Santa Clara County’s African/African Ancestry community, and key informant interviews with community leaders, experts, and service providers. Quantitative data sources include a variety of existing data sources. Qualitative and quantitative data collection and analysis methods are presented in greater detail in this chapter.

## **Qualitative data collection**

As discussed earlier, the key domains of inquiry for the qualitative data collection were identified through a collaborative process that drew on the experiences and interests of a broad spectrum of African/African Ancestry community members and stakeholders. After identifying the key domains of inquiry at the November 2013 Stakeholder Forum, the steering committee began the outreach process, recruiting community members to participate in conversations about their health-related needs and experiences, and recruiting local African/African Ancestry community members and health experts to participate in key informant interviews about their areas of expertise. This recruitment occurred through various avenues, including social and professional networks of steering committee members, and local African/African Ancestry organizations. Data was collected during the short period of 6 weeks spanning from March to April 2014.

### ***Selecting key domains of Inquiry***

To begin the process of selecting key domains of inquiry for this health assessment, the steering committee, along with its partners, hosted a Stakeholder Forum in which more than 60 African/African Ancestry leaders, health professionals, service providers, and other stakeholders participated. At this forum, stakeholders engaged in a series of small group discussions focused on key issues for the health assessment, including understanding the primary health and healthcare issues of interest to the African/African Ancestry community, identifying the key subgroups to engage, and strategizing modes of outreach to engage the widest possible range of community members. Responses from these discussion groups and across topics covered during the forum were analyzed and triangulated with existing public health research and local public health data in order to come up with a final list of key domains of inquiry. These domains were presented to the steering committee for final review and approval prior to the development of data collection tools.

### ***Tool development***

Consistent with other aspects of this health assessment, the tools used to guide the key informant interviews and community conversations were developed through a collaborative process that drew on the expertise of steering committee members and other community stakeholders. Members of the steering committee were invited to submit proposed questions and/or interview protocols; Santa Clara County Public Health Department (SCCPHD) also developed a series of interview protocols organized around the key domains of inquiry discussed above. The steering committee then reviewed all protocols, assessing their alignment with the priorities that emerged out of the Stakeholder Forum and their relevance for the African/African Ancestry community. Based on this review, SCCPHD revised and finalized the protocols, which are available in Appendix A.

## ***Community outreach and recruitment***

The African American Community Service Agency led the community outreach process, with support from other steering committee members. Most outreach drew on existing African/African Ancestry organizations in the county, including local churches, mosques and other places of worship, pastors' groups, a variety of African/African Ancestry fraternities and sororities, and community based organizations, such as the Ethiopian Community Center and Ujima Adult and Family Services, Inc. Steering committee members also drew on their personal and professional networks to engage hard to reach groups and individuals. Posters were developed to increase community awareness about the ongoing Demographic Study and encourage participation in the health assessment. These posters were widely distributed within the community and announcements were made at social gatherings and community meetings. In addition to these direct outreach methods, steering committee members and partner organizations also recruited community members through newsletters, email outreach, and social media.

## ***Community conversations***

The primary purpose of the community conversations was to understand the health needs, concerns, and experiences of Santa Clara County's African/African Ancestry community. In order to ensure that the health assessment represented the diversity within the African/African Ancestry community, the steering committee identified a number of groups within the community to target for these conversations. These included:

- Adult mental health consumers
- African/African Ancestry women
- Black Infant Health advisory board
- College students
- Ethiopians
- Elders
- Foster parents
- Homeless men
- Individuals in the reentry system
- Lesbian, Gay, Bisexual, Transgender (LGBT) individuals
- Local pastors group/ faith & spiritual leaders
- New moms (mothers of infants and young children)
- Professionals
- West Africans
- Young adults

In addition, to ensure that these conversations were facilitated and recorded in a way that was centered on African/African Ancestry cultural norms, practices, and history, the steering committee also came up with a set of criteria for selecting facilitators and scribes for the community conversations. The resulting guidelines and interview questions were used to recruit facilitators and scribes for the community conversations. Examples of these criteria included, "ability to articulate historical understanding of African/African Ancestry people in the U.S., the continent of Africa and throughout the Diaspora with specific knowledge of African experiences with health systems and medical experimentation" and "ability to use various terminologies within an African American dialect and translate". The full criteria are available in Appendix C of this report.

## ***Key informant interviews***

As part of the assessment, 25 interviews were conducted with individuals identified by the steering committee as experts in their particular fields or as key representatives of particular sub-groups within the African/African Ancestry community. As with the community conversations, the steering committee and local African/African ancestry organizations were actively involved in the identification and recruitment of these key informants. In accordance with the community-orientation of the health assessment, all key informants were individuals of African/African Ancestry who are residents of Santa Clara County and/or work with African/African Ancestry community in the county.

In contrast to the community conversations, which asked the same questions to each of the 15 different sub-groups, the key informant interviews focused specifically on informants' areas of expertise. Across these 25 interviews, the following topics were addressed:

- African immigrant concerns and perspectives
- Aging and chronic illness
- Community perspectives on health and healthcare
- Family health and well-being
- Healthcare perspectives
- Health, well-being, and the criminal justice system
- Mental health and substance use
- Social services
- Women's health issues, including maternal and infant health
- Youth and young adult concerns and perspectives

Because several key informants had expertise in more than one area, many of these interviews addressed more than one of these topics.

For more information on the qualitative data analysis and coding process, please see Appendix D.

## **Quantitative (secondary) data analysis**

Quantitative data included in the health assessment is secondary data that was already collected by various agencies. The Santa Clara County Public Health Department (SCCPHD) utilized secondary data from local, state, and national surveys, databases, and registries.

### ***Data selection***

Quantitative data sources were presented to the steering committee, including how the data is collected and processed, who manages the data sources, and whether these data sources represent the community. Next data were analyzed and presented to the steering committee. SCCPHD presented 165 data indicators from various sources to the steering committee. The steering committee met three times to review all the quantitative data and narrow down the list of indicators that were most relevant to the community. The steering committee ranked quantitative data domains based on the following criteria:

Magnitude of the issue

1. Relevance of the issue to social determinants of health

2. Availability of evidence-based interventions that are relevant to the African/African Ancestry community
3. Consequences of inaction

A score of 1 to 3 was given to each quantitative data domain; 1 being not important, 2 for unsure and 3 being very important issue for the community. Based on the scoring, domains were ranked in the following order:

1. Maternal, child, and adolescent health
2. Community assets
3. Racism and discrimination
4. Social determinants of health
5. Cancer
6. Lifestyle factors – food, nutrition, and physical activity
7. Health, wellness, and illness
8. Life expectancy and quality of life
9. HIV/AIDS
10. Healthcare delivery system
11. Risk taking behaviors
12. Violence
13. Injury

## **Definition of African/African Ancestry population**

For all data sources used in the health assessment, community members were classified as African/African Ancestry if they self-identified as being African American. Please refer to the footnote in the introduction chapter for details about why the term ‘African/African Ancestry’ was used throughout this health assessment.

## **Age adjustment**

Age-adjusted rate is a method used to make unbiased comparisons between groups with different age distributions in the population over time, or between different populations. For example, a county having a higher percentage of elderly people may have a higher death rate than a county with a younger population, mainly because the elderly are more likely to die. Age adjustment can make the different groups more comparable. A "standard" population<sup>e</sup> distribution is used to adjust rates. The age-adjusted rate is a rate that would have existed if the population under study had the same age distribution as the "standard" population. Thus, the age-adjusted rate is a summary measure adjusted for differences in age distributions.

To compare injury, emergency room visits, hospitalizations, cancer, and mortality outcomes among racial/ethnic groups in the county, direct age-adjustment method was used. The 2000 U.S. population was used as the standard population. For age adjustment, rates were calculated using data from the State of California, Department of Finance, Race/Ethnic Population with Age and Sex Detail, 2000–2010; State of California, Department of Finance, State and County Population Projection, 2010-2060.

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<sup>e</sup> Standard population is the age distribution used as weights to create age adjusted rates, serving as a uniform basis for the calculation of comparable measures. The National Center for Health Statistics recommends that the U.S. 2000 standard population be used when calculating age-adjusted rates.



## Limitations

Public health surveillance data (births, deaths, infectious disease, emergency room visits, and hospitalizations) utilized in the health assessment were subject to both misclassification and reporting bias; however, this bias is expected to be minimal.

Data on adolescents from the California Healthy Kids Survey (CHKS) 2007-08 and 2009-10 were subject to selection bias as well. Only public schools participate in the CHKS and participation is subject to both school district and parent consent.

Other data sources utilized in the health assessment were also subject to limitations. The telephone survey surveyed primarily individuals with landline telephones. Households without landline phones are more likely to include low-income and younger individuals as well as males.<sup>1</sup> The number of people who live in cell phone-only households has increased dramatically over the past several years.<sup>2</sup> The 2013-14 Behavioral Risk Factor Survey (BRFS) survey included a countywide random digit dial cell phone sample for the first time, but this sample accounted for only 7% of the total survey sample. Homeless individuals without landlines and residents who were too ill to speak on the phone or take the survey could not be interviewed, leading to a potential bias toward healthier individuals. All information on health and social indicators on surveys utilized in the health assessment was self-reported and so is subject to reporting bias. Although wherever possible the health assessment used validated survey questions from established sources, there is a possibility of measurement error for some indicators, including those not formulated to fit the cultural and religious norms and variations within the African/African Ancestry community. The 2013 BRFS survey was administered in English, Spanish, Mandarin, and Vietnamese. Santa Clara County residents who did not speak any of these languages were not interviewed. This may lead to some underrepresentation of immigrant residents.

## References

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# Context: Santa Clara County's African/African Ancestry community

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## Community history

The deep roots of the African/African Ancestry community to Santa Clara County and more specifically, downtown San Jose, are underrepresented in the historical record because of a lack of preservation of related documents and an overall failure to document important events. As a result, historical information of national and international importance has been overlooked or missed and the overall archival record of San Jose's history is incomplete. Nonetheless, as the concept of health and place is examined in this report, it is important to highlight the direct connection of more than 200 years of African/African Ancestry heritage and multilingual links to the original founders of Santa Clara County.

When San Jose was established as a city in Santa Clara County in 1777, nine families were involved in its first settlement. Some of the settlers were Mulattos, known today as bi-racial, Black, or African American. In 1855, the census of the first Convention of the Colored People of California noted that 175 Blacks lived in Santa Clara County with real estate worth \$75,000. Most of them were engaged in agriculture; very few were employed as menial laborers. They were sober, industrious and plain-dealing people.

Dating back to the early 1860s, the downtown San Jose neighborhood has been the center of Black religious life in San Jose. Its Black churches date back to 1864, when the First African Methodist Episcopal Zion Church was founded shortly after the proclamation ending slavery in the United States was signed. During this period, (Black) parishioners met in each other's homes until they became more firmly established. The church membership grew along with the growth of the Black population in San Jose as the end of the Civil War saw the greatest migration of Blacks to the western United States. Black churches in San Jose are important markers for the settlement patterns of the county's African/African Ancestry population.

San Jose's Black history is also directly tied to expanding educational opportunities which were of monumental importance for California's early Black population. For example, the site of the AME church was also the site of the first high school for black students, the Phoenixonian Institute, which opened in 1861. Most pastors at that time also doubled as educators. As the site of the California's only high school for Black youth, Santa Clara County and particularly the City of San Jose was a magnet for talented youth and their families.

By the 1890s, the downtown San Jose community supported three Black churches. With the founding of Antioch Baptist church in 1893, the black community in downtown San Jose was now large enough to support three churches, though the Black community represented less than 1% of the total county population.

The Garden City Women's Club founded in San Jose in 1908 was vital to the Black community's health and social well-being. The club's mission was to organize Black women for the purpose of promoting education, public welfare, moral values, civics, and fine arts. The Garden City Women's Club members also began the San Jose chapter of the NAACP (National Association for the Advancement of Colored People), which is a vital element of the community to this day. This group focused on providing a myriad of community services that included but were not limited to providing educational scholarships and helping the homeless.

African/African Ancestry community members began to integrate into other parts of Santa Clara County in the late 1950s. Stories of discrimination and racially spurred events against Blacks are told anecdotally by many residents who were among the first to integrate the many cities that were predominately lived in by White residents. Black residents of Santa Clara County were active in the civil rights movement that was sweeping the country. Some were involved with the Black Panthers movement and activities, others made their way to

the Southern United States to participate in marches and demonstrations, and still others followed the teachings of Malcom X.

In 1968, Tommie Smith and John Carlos, two San Jose State University African American student athletes earned gold and silver medals at the Mexico City Summer Olympics. During the award ceremony, both athletes raised a black-gloved fist as an act of protest against the racism, discrimination and segregation happening at home in the United States. This act, known as the 1968 Olympic Black Power Salute, is regarded as one of the most overtly political statements in the history of the modern Olympic Games. The irony is that the first African American church in San Jose, was initially located where San Jose State University is today. In 2005, San Jose State University honored former students Smith and Carlos with a 22-foot high statue of their protest placed in the center of the campus.

In the 1970s, large influxes of African immigrants arrived from various parts of the world, mainly from the African continent. African immigrants and refugees were and still are dispersed throughout the county. African immigrants settled in the county for various reasons: some were fleeing war, while others came to take advantage of educational opportunities; many have made Santa Clara County their permanent home. The county now hosts several community centers and support organizations that provide services and social engagement for African immigrants who settled in Santa Clara County.

The downtown area of San Jose has historically been the hub for development of enterprise that contributes to the success of the Black community in Santa Clara County. The early African American settlers came with an express purpose of impacting and spreading human rights and dignity for residents. There is an unbroken strand tying the abolitionist movement from the highly significant first Underground Railroad rescue in the state to the efforts of today's community service and religious organizations. An understanding of Santa Clara County's historical narrative and its interconnectedness to health and place can serve as important tool for improving conditions and the lives of its African/African Ancestry community.

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## **Community strengths and assets**

Despite many challenges and threats to health and well-being, the African/African Ancestry community in Santa Clara County demonstrates significant strengths and assets. Community based institutions, support networks, people taking care of one another, and a strong sense of resiliency all serve as protective factors and promote community well-being and self-reliance. In community conversations and key informant interviews with African/African Ancestry community members, participants highlighted the importance of local community institutions, a broad commitment to community well-being, and the ability to draw strength from prior struggles.

These assets are particularly important given the extensive literature demonstrating the relationship between community assets and health and well-being.<sup>12</sup> Perhaps more importantly, these assets offer a critical starting point for addressing health inequities and improving community health.

## **Indigenous institutions**

In the face of discriminatory experiences, the county's African/African Ancestry community has developed institutions to support health and well-being of community members. Described as "pillars in the community," faith based and spiritual institutions have been a consistent source of support, as well as a resource for information about health and healthcare. Many local churches, mosques, and other places of worship with congregations that are largely comprised of African/African Ancestry community members, for example, offer services such as tutoring, computer skills training, counseling, parenting classes, job training, health education, and health screenings. Many of these places of worship also provide referrals to other needed services. During sermons or other gatherings, there are often health announcements or discussions about policies that could help the community such as access to health insurance through the Affordable Care Act.

Several community members, especially recent immigrants, reported turning to churches and mosques for help and guidance during challenging times. They cited religion as helping them endure stressful circumstances such as unemployment, poverty, and discrimination and to "not give up." One participant who had recently been released from custody stated, "I'm blessed that the spiritual part of me addresses the physical and lets me know there are people that are worse off. Worrying and things like that will make you sicker. Anger and other things especially when you get older have a huge effect on things like your heart" (Reentry community conversation participant). Another participant stated that "not having a relationship with God is an illness for me. When I didn't have it I was sick, mentally and physically... For me, it's [about] having a higher power" (Reentry community conversation participant).

*"A lot of families find strength not just from within, but from their communities, churches, social groups, and institutions. In many ways, the groups and organizations that support families are very important to the longevity and livelihood of the people in our communities."*

(Community activist key informant)

## **Community support networks**

In addition to drawing on local places of worship as key institutions to support community health and well-being, the county's African/African Ancestry community has built a number of critical community-based organizations oriented towards meeting otherwise unmet needs of the African/African Ancestry community members, including Ujima Adult and Family Services Inc., the African American Community Service Agency (AACSA), the Ethiopian Community Service Center, Joyner Payne Youth Service Agency, and the Black Leadership Kitchen Cabinet (BLKC). For example, the non-profit Ethiopian Community Service Center provides referrals to health services, offers free clinics, and holds seminars. The center relies on word of mouth among Ethiopian immigrant networks to spread awareness and build community trust.

*"A strong point is that we all stick together. We have a center and if we offer a free clinic, word can really spread between Ethiopian services, mosques, etc. There's a strong network of Ethiopian doctors and nurses that work in SCC. With new immigrants, it comes down to trust. They have heard so many stories and don't want to get taken advantage of or put in a bad situation. So when they hear about resources from someone in their community, they are more likely to trust that."*

(Ethiopian community advocate key informant)

The African American Community Service Agency (AACSA), founded in 1978, is one of the only African American cultural centers in the Silicon Valley. AACSA provides educational, cultural, social and recreational programs, services and activities in order to perpetuate and strengthen African American identity, culture, values, traditions, knowledge and family life. Services are open to everyone, regardless of race, religion, age or disability. The Joyner Payne Youth Service Agency was created to serve African/African Ancestry youth and their families, empowering the community to utilize appropriate resources, to provide employment opportunities and anti-violence programs to inner-city youth, and to educate their families on health and welfare services so that these youth will be inspired to make a positive impact in their communities.

*“There is a big hole in service delivery since a lot of agencies aren’t dealing with Black kids at all. Our kids don’t gravitate toward those services or act interested. Two edged sword. People weren’t soliciting the kids and they [African/African Ancestry youth] weren’t looking. They would get a bare minimum of services and the juvenile justice system passed our kids by. Recently, people are jumping on the bandwagon; the larger dominating agencies are recognizing that they need to address the needs of all kids. Reason they are doing is that we got involved - we showed them.”*

(Youth advocate key informant)

The Black Leadership Kitchen Cabinet (BLKC) was created in 2005 by concerned community leaders as a means to address the broader social concerns that are currently impacting the African/African Ancestry community. The BLKC is a collective group of over 50 local organizations and community members. The group convenes monthly to discuss current and ongoing needs of the community and to discuss ways to ensure that these needs are addressed. As a whole, these organizations are able to collaborate together to make progress that would be difficult for individual agencies to achieve alone. In turn, they have developed a very powerful voice and their meetings are regularly attended by representatives from the Board of Supervisors, Mayor’s office, school superintendents, county administrators, and police departments.

*“We are a force to be reckoned with; that is a major asset for our community.”*

(Educator key informant)

*“It starts with unity. When people are able to unify, it strengthens their voice and strengthens their outcomes.”*

(Youth advocate key informant)

Ujima Adult and Family Services, Inc. started in 1994. It strives to improve the lives of youth and adults by providing Afro-centric behavioral health and support services to the African/African Ancestry community. Services are provided to African/African Ancestry youth involved in the juvenile justice and social services systems. This commitment to building African/African Ancestry institutions to address unmet needs within the community continues to be an important motivator among the African/African Ancestry community members in the county, with the BLKC and other community leaders currently working together to try to build an African/African American community health clinic in the county.

*“One of the issues facing this community is that there is no healthcare facility center targeting our community. That is a huge void. Japanese, Chinese, Korean, Latino... they all have clinics that specifically target their ethnic communities. [We] need one specific to [the] African American community. That*



*disparity is huge when understanding why healthcare problems are what they are in the Black community; there is no place people can go where they trust. These people look like me, where I can talk about my problems, where my confidence won't be violated, where these people care about me. That is a missing institution; that void is the key thing we are working on. Hopefully within the next two years we will have clinic up and running."*

(Community activist key informant)

**Community members taking care of each other**

Many African/African Ancestry community members reported helping each other during challenging times, a factor that promotes community self-reliance. Following adverse events, including those as extreme as hate crimes, community members reported coming together and developing a strong shared voice that is channeled toward advocacy efforts. Many residents described this process as extremely supportive, empowering, and energizing. As shown in the table below, 8 in 10 (80%) African/African Ancestry community members report receiving a high level of social and emotional support.

**Percentage of adults reporting that they always or usually get the social and emotional support that they need by race/ethnicity**

Race/ethnicity	Social and emotional support %
African American	80
Asian/Pacific Islander	66
Latino	76
Non-Hispanic White	84
Santa Clara County	76

Source: Santa Clara County Public Health Department, 2013-14 Behavioral Risk Factor Survey

*"African people don't like to see other Africans be homeless. They will put them in their living room. It is difficult to find homeless Africans because someone will take them in. If it's a Nigerian, and I'm from Cameroon, I'll [still] take them in."*

(Health professional key informant)

*"Regardless of how the Black community runs, when someone is down, we do the best of our ability to help. [You] don't see community leaving someone behind or leaving them on streets unless you can't help that person."*

(Young adults community conversation participant)

Family support was also described as an important community asset. Several young adult community conversation participants discussed how much they appreciated the strong role that their parents played in their life and how hard their parents worked to give them a better life. They also discussed how much they learned from their parents about morality and that they looked up to their parents and listened to what they told them.

*"I had a strong Black father growing up who led me in the right direction but a lot of my friends did not have fathers in their lives. My dad was their dad sometimes. Part of the reason I am in college is because of my dad."*

(Young adults community conversation participant)

*"We can feed into our children's positive attitudes to make them feel like they are somebody [by saying] I love you. You can do it. I'm here for you. I know what world is like out there but you are above that."*

(Elders community conversation participant)

*"I think there's a strong sense of wanting our kids to do better and trying to prepare our kids overall. Parents advocate for their kids on multiple levels and it's huge. Being an advocate for our children in the school system [is critical to] making sure they're getting what they need. I always tell families, regardless of their background, if something is not right, you can advocate for your kids in the medical system too."*

(Health professional key informant)

## Resiliency

African/African Ancestry community members draw upon a history of struggle and perseverance as a source of inspiration and resiliency. This resiliency serves as a protective factor and as a resource. For example, African/African Ancestry youth report a high degree of community assets relative to other racial/ethnic groups in the county (See table below).

### Percentage of middle and high school students reporting positive assets by race/ethnicity

Race/ethnicity	Family support %	Equality and social justice %	Cultural competence %	Caring neighborhood %	Religious community %	Self-esteem %
<b>African American</b>	67	62	55	37	59	58
<b>Asian</b>	63	63	52	32	47	39
<b>Latino</b>	67	62	43	32	47	42
<b>Non-Hispanic White</b>	77	57	50	45	35	54

Notes: Family support is defined as having family life that provides high levels of love and support. Equality and social justice is defined as youth placing high value on efforts to promote equality and reduce hunger and poverty. Cultural competence is defined as youth having knowledge of and comfort with people of different cultural/racial/ethnic backgrounds. Caring neighborhood is defined as youth having experiences with caring neighbors. Religious community is defined as youth spending one or more hours per week engaged in activities in a religious institution. Self-esteem is defined as youth reporting high self-esteem.

Source: Search Institute Survey Services, Project Cornerstone, Developmental Assets Survey Reports, 2010

*"As a race, we are a very strong people. Looking at our past, we come from strong generations. Even if families are dysfunctional, they are still strong in a way. That is what makes us resilient. My mom is very strong, I get it from her. I tell myself 'I'm not going to let that faze me' and move on to the next point in my life. Resilience comes from seeing it in other people in our family and in history. It feels like it is built in."*

(Young adults community conversation participant)

*"If you take away skin color or what I look like, you take away my struggle and history. I feel like what I went through in my life being this color made me who I am today. It made me a strong person."*

(Young adults community conversation participant)

Persistence was described as a factor that contributes to the resiliency among the African/African Ancestry community members. This tenacity was emphasized as a strategy that the community has used to overcome discrimination and other negative forces. Residents felt like this strength empowered them to never give up, bring community members together, beat the odds, demonstrate capacity, and educate policymakers and the media on ways to reduce discrimination. Immigrants reported feeling particularly resilient because of the challenges they had to overcome to immigrate to the United States.

*"We have no control over what another person does, but we have control over ourselves. It is not what you are called; it is what you answer to. You know who you are, don't buy into someone's negative behavior. You are better than responding to someone's negative behavior."*

(Elders community conversation participant)

Finally, many participants cited pride in their culture and heritage as a tremendous source of resilience and strength.

*"I love the color of my skin and where I am and would not change for the world. Being Black is a beautiful thing. We've got beat, dancing, laughing, music, and football."*

(Young adults community conversation participant)

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## Community health overview

Santa Clara County is home to a vibrant African/African Ancestry community. This chapter will present an overview of the demographics and health status of this population. Overall, the community has made tremendous strides towards better health despite continued evidence of disparities in health outcomes.

### Demographics and community overview

The proportion of Santa Clara County residents who are of African/African Ancestry has been declining since 1990 (See table below). In 2012, 49,013 or 3% of the county's 1,837,504 residents identified themselves as African American. Seventeen percent (17%) of the African/African Ancestry community are foreign-born and primarily emigrated from Africa.<sup>1</sup>

More than three-quarters (78%) of the African/African Ancestry community has completed at least some college coursework or attained a higher education degree. Despite relatively high educational attainment among the African/African Ancestry community members, the median income for African/African Ancestry households is \$65,347, which is lower than the median household income for Asian households (\$105,088), White<sup>f</sup> households (\$100,480), and the county overall (\$91,425), but higher than Latino households (\$55,220). Nearly 1 in 6 (16%) African/African Ancestry community members live below 100% of the Federal Poverty Level,<sup>g</sup> a higher percentage than White residents (6%), Asian residents (9%), and the county overall (11%), but lower than Latino residents (19%).

### Population estimates for African American residents and total county population, 1980-2012

	1980	1990	2000	2010	2012
<b>African American</b>	43,716	56,211	47,182	46,428	49,013
<b>Santa Clara County</b>	1,295,071	1,497,577	1,682,585	1,781,642	1,837,504

Note: African American category represents both Hispanic and non-Hispanic African Americans.

Source: U.S. Census Bureau, Census 1980-2010; U.S. Census Bureau, 2012 American Community Survey 1-Year Estimates

### Educational attainment by race/ethnicity

Race/ethnicity	Less than high school %	High school graduate %	Some college or Associate's degree %	Bachelor's degree or higher %
<b>African American</b>	8	14	43	35
<b>Asian</b>	12	10	17	61
<b>Latino</b>	36	24	27	14
<b>Non-Hispanic White</b>	4	13	28	55
<b>Santa Clara County</b>	14	15	24	47

Notes: Percentages may not add to 100% due to rounding. Educational attainment is reported for adults ages 25 or older. Asian category does not include Latinos.

Source: U.S. Census Bureau, 2012 American Community Survey 1-Year Estimates

<sup>f</sup> Data on White residents and households represent Non-Hispanic residents and households. In the report, they will be referred to as "White."

<sup>g</sup> In 2012, 100% Federal Poverty Level for a family of 4 was \$ 23,050.

## Annual household income by race/ethnicity

Income	African American %	Asian %	Latino %	Non-Hispanic White %	Santa Clara County %
\$0-\$24,999	19	13	20	12	14
\$25,000-\$49,999	19	10	26	14	15
\$50,000-\$74,999	21	11	16	13	13
\$75,000+	41	66	37	62	58
<b>Median household income</b>	\$65,347	\$105,088	\$55,220	\$100,480	\$91,425

Source: U.S. Census Bureau, 2012 American Community Survey 1-Year Estimates

## Health indicators

Although disparities between the health status of African/African Ancestry community and other racial/ethnic groups in the county have decreased in recent years, disparities continue to exist. Key health indicators and disparities are discussed in greater detail in the following section.

### Life expectancy

*African/African Ancestry residents have the lowest life expectancy in the county.*

Life expectancy at birth of African/African Ancestry community members in the county has risen over the past decade, yet it remains lower than that of members of all other racial/ethnic groups in the county (see table below). In 2012, the life expectancy for African/African Ancestry community members was 78.9, lower than the life expectancy for Asian/Pacific Islander residents (88.0), Latino residents (84.3), White residents (82.1), and the county overall (83.8). In particular, African/African Ancestry males have the shortest life expectancy in the county of 77.1 years. The age-adjusted death rate among African/African Ancestry community members declined from 938 deaths per 100,000 residents in 2000 to 759 deaths per 100,000 residents in 2012. However, the African/African Ancestry age-adjusted death rate is higher than the age-adjusted death rate for Asian/Pacific Islander residents (378), Latino residents (508), White residents (605), and the county overall (527).

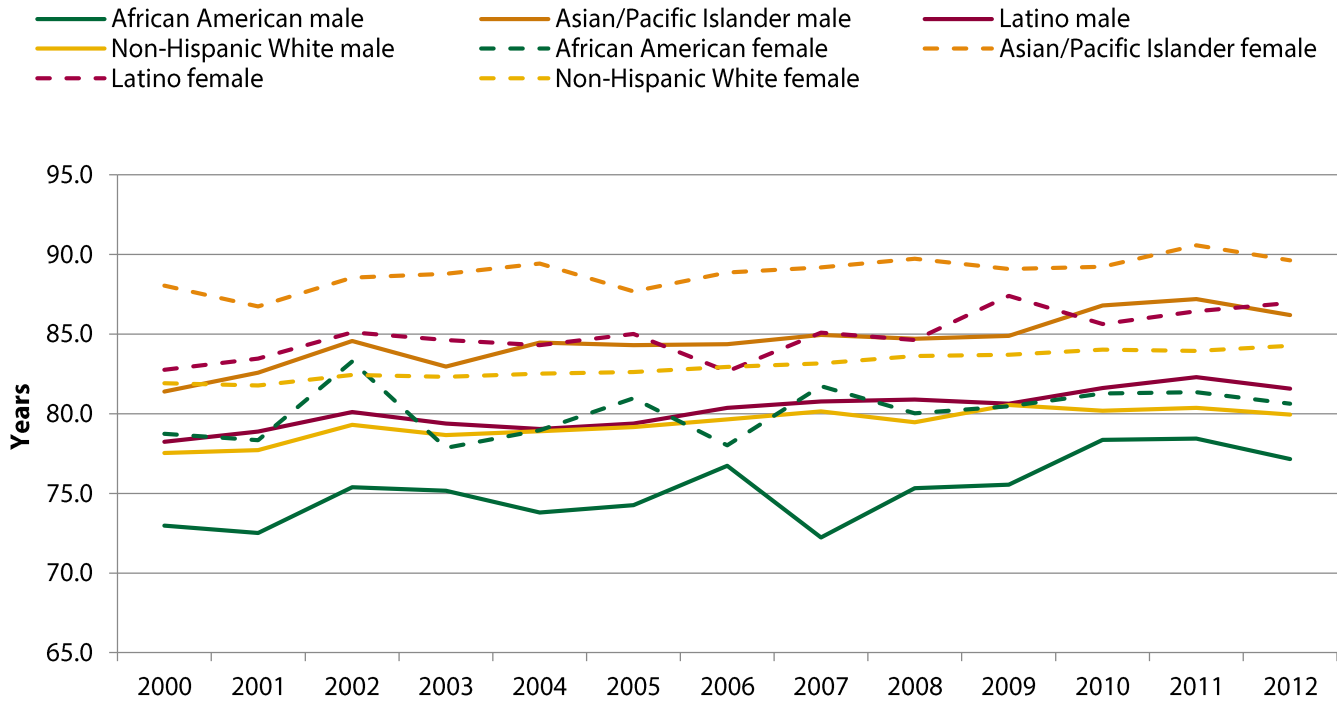
## Life expectancy at birth by race/ethnicity, 2000-2012

Race/ethnicity	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>African American</b>	75.9	75.4	79.2	76.1	76.3	77.3	77.0	76.3	77.6	77.9	79.7	79.8	78.9
<b>Asian/Pacific Islander</b>	84.5	84.7	86.7	85.8	87.0	86.1	86.6	87.2	87.3	87.1	88.1	89.0	88.0
<b>Latino</b>	80.6	81.3	82.8	82.1	81.8	82.3	82.1	82.9	82.7	84.1	83.7	84.4	84.3
<b>Non-Hispanic White</b>	79.8	79.8	81.0	80.6	80.8	81.0	81.1	81.7	81.6	82.2	82.1	82.2	82.1
<b>Santa Clara County</b>	80.7	81.0	82.2	81.6	82.1	82.0	82.2	82.8	82.8	83.5	83.8	83.9	83.8

Note: African American and Asian categories do not include Latinos.

Source: Santa Clara County, 2000-2012 Death Statistical Master File; State of California, Department of Finance, Race/Ethnic Population with Age and Sex Detail, 2000-2010; State of California, Department of Finance, State and County Population Projection, 2010-2060

## Life expectancy at birth by gender and race/ethnicity, 2000-2012



Note: African American and Asian categories do not include Latinos.

Source: Santa Clara County, 2000-2012 Death Statistical Master File; State of California, Department of Finance, Race/Ethnic Population with Age and Sex Detail, 2000-2010; State of California, Department of Finance, State and County Population Projection, 2010-2060

## Age-adjusted death rates per 100,000 residents in Santa Clara County by race/ethnicity, 2000-2012

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>African American</b>	938	963	755	890	885	833	874	883	796	797	682	699	759
<b>Asian/ Pacific Islander</b>	490	493	429	448	417	438	427	412	402	410	376	358	378
<b>Latino</b>	660	642	557	603	607	587	597	563	568	522	530	510	508
<b>Non-Hispanic White</b>	728	721	668	687	664	665	664	628	631	596	602	603	605
<b>Santa Clara County</b>	673	663	605	628	600	605	604	574	568	539	529	524	527

Note: African American and Asian/Pacific Islander categories do not include Latinos.

Source: Santa Clara County Public Health Department, 2000-2012 Death Statistical Master File; State of California, Department of Finance, Race/Ethnic Population with Age and Sex Detail, 2000-2010; State of California, Department of Finance, State and County Population Projection, 2010-2060



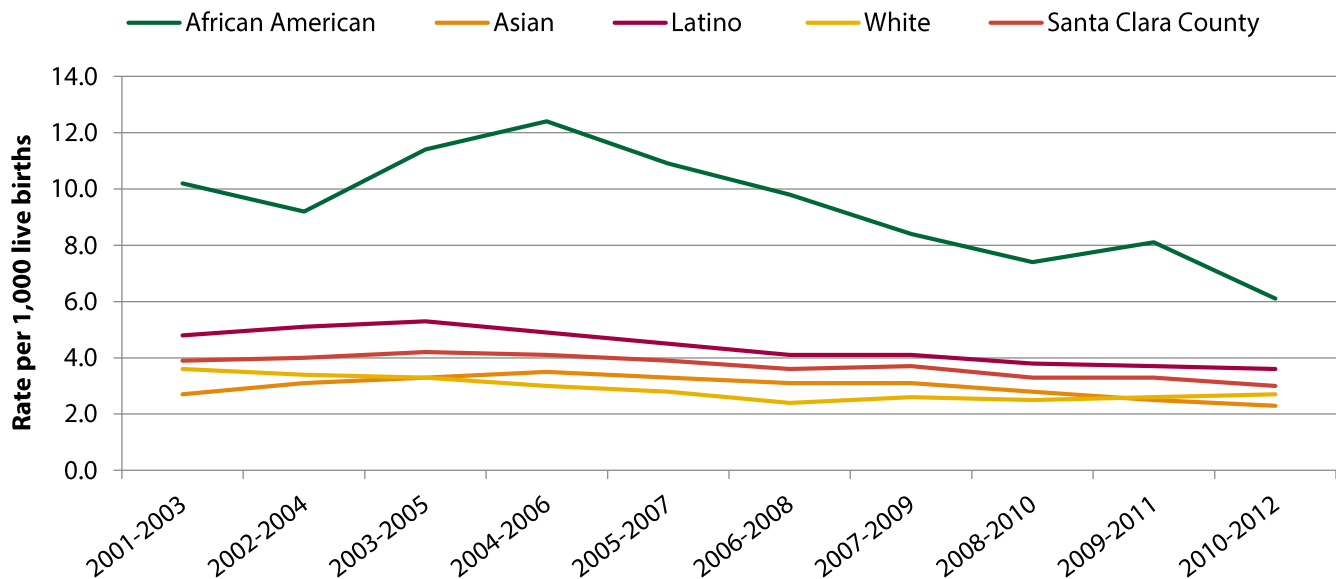
## Maternal and infant health

*African/African Ancestry residents have the highest infant mortality rate in the county.*

Health outcomes for African/African Ancestry mothers and infants have improved steadily over the past several decades. Nonetheless, notable disparities persist relative to all other racial/ethnic groups in the county. The tables below demonstrate that African/African Ancestry mothers and infants face worse outcomes than other racial/ethnic groups in terms of virtually all key indicators, including infant mortality rate and the percentage of preterm births and low birth weight babies.<sup>2</sup> Though upward socioeconomic mobility has been found to significantly contribute to positive birth outcomes to infants born to White women, the same trend has not been shown for infants born to women of African/African Ancestry.<sup>3</sup> For example, African/African Ancestry mothers have similar birth outcomes, including low birth weight babies and preterm births, regardless of their socioeconomic status. White mothers with higher socioeconomic status have better birth outcomes than those with lower socioeconomic status.<sup>4</sup>

The infant mortality rate among African/African ancestry infants is 6.1 deaths per 1,000 live births, a rate twice as high as the infant mortality rate in the county overall (3.0 deaths per 1,000 live births). The African/African Ancestry infant mortality rate is higher than the infant mortality rate among Asian infants (2.3), White infants (2.7), and Latino infants (3.6).

### Infant mortality rates per 1,000 live births, 3 year moving average, by race/ethnicity, 2001-2012



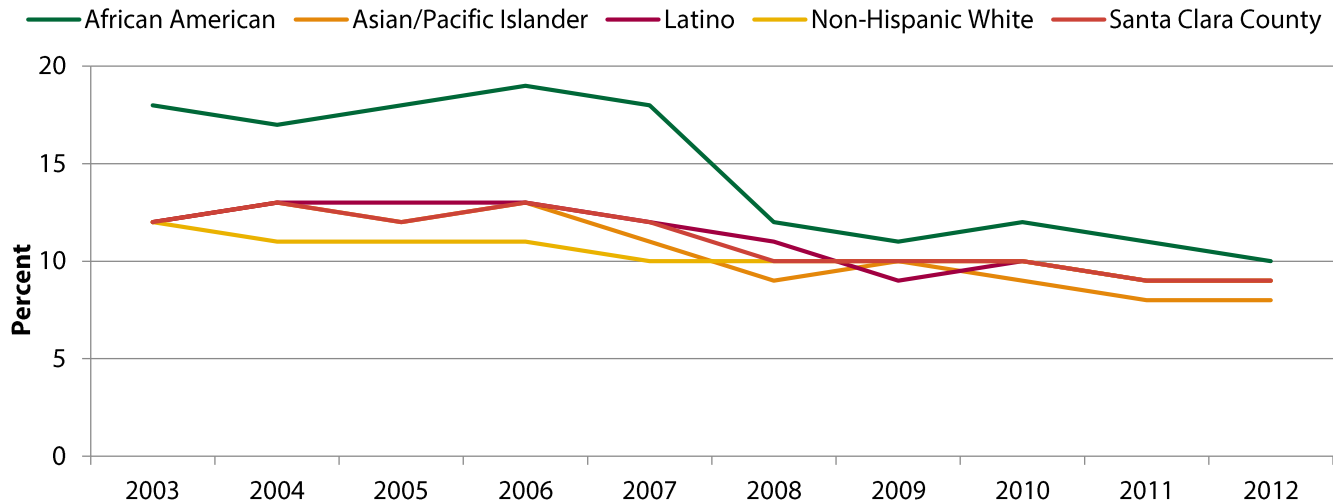
Source: California Department of Public Health, Vital Statistics Query System, 2001-2012

Approximately 1 in 10 (10%) African/African ancestry births are preterm, a percentage that is higher than for Asian/Pacific Islanders (8%), Latinos (9%), Whites (9%), and the county overall (9%). Similarly, almost 1 in 10 (9%) African/African Ancestry births are low birth weight, a higher percentage than among Asian/Pacific Islanders (8%), Latinos (6%), Whites (6%), and the county overall (7%).

Although higher infant mortality rates are clearly the most disturbing of these outcomes, it is important to note that preterm births and low birth weight are both associated with persistent disparities across the life span, including poor health outcomes and developmental delays. Research suggests that social disadvantage,

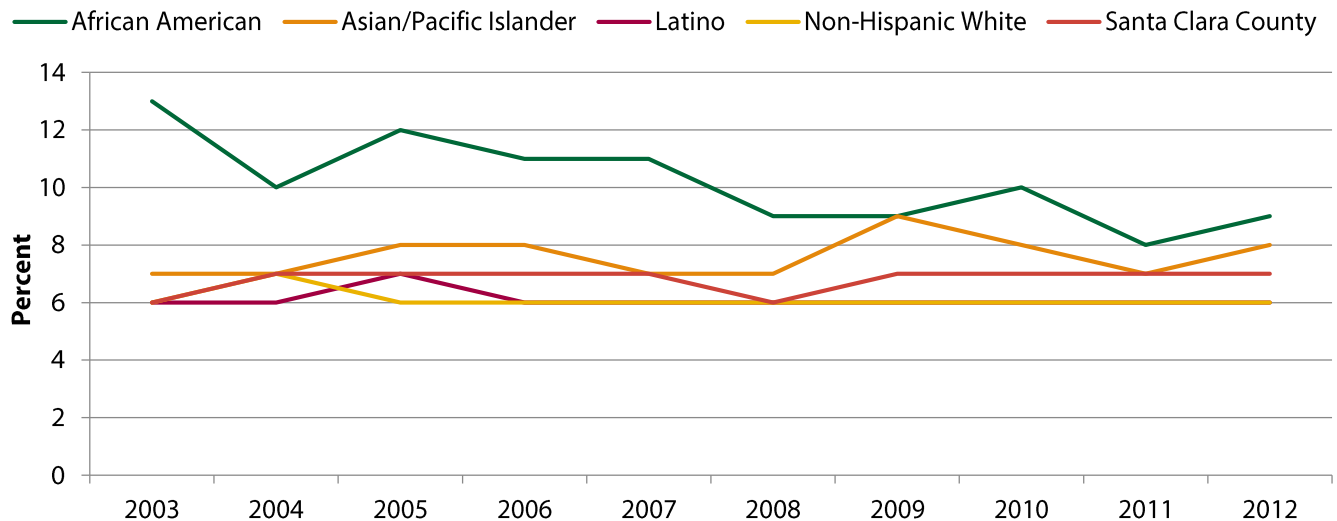
economic hardship, and constant vigilance such as defending oneself against racism and discrimination create stress among African/African Ancestry women of diverse socioeconomic levels, contributing to adverse birth outcomes.<sup>3</sup>

### Percentage of preterm births (<37 weeks gestation) by race/ethnicity, 2003-2012



Source: Santa Clara County Public Health Department, 2003-2012 Birth Database

### Percentage of low birth weight (<2500 g) by race/ethnicity, 2003-2012



Source: Santa Clara County Public Health Department, 2003-2012 Birth Database

## Cancer

*One in 4 deaths among African/African Ancestry residents is due to cancer.*

The following tables present the age-adjusted cancer incidence rate and age-adjusted cancer mortality rate by gender and race/ethnicity in Santa Clara County. The cancer incidence rate measures the rate at which new cancer cases are diagnosed in the county and the mortality rate measures the death rate due to cancer in the

county. African/African Ancestry community members have a higher overall cancer incidence rate (458 cases per 100,000 people) than Asian/Pacific Islander residents (308), Latino residents (391), and the county overall (430), but lower than White residents (497). African/African Ancestry community members have a higher cancer incidence rate for several types of cancers than all other racial/ethnic groups and the county overall.

African/African Ancestry community members have a higher cancer mortality rate (248 deaths per 100,000 people) than Asian/Pacific Islander residents (141), Latino residents (161), White residents (213), and the county overall (185), despite a lower cancer incidence rate than Whites.

Additionally, African/African Ancestry community members receive less preventive and routine healthcare services, and thus are more likely to be diagnosed at later stages of cancer. Cancer stage at the point of diagnosis is highly predictive of survival, indicating a contributing factor to cancer survival disparities in the African/African Ancestry community.<sup>5</sup>

### Age-adjusted cancer incidence rate per 100,000 individuals by cancer site, race/ethnicity, and gender, 2002-2011

	African American	Asian/Pacific Islander	Latino	Non-Hispanic White	Santa Clara County
<b>All Sites</b>					
Men	556	345	467	563	494
Women	378	284	341	450	385
All	458	308	391	497	430
<b>Breast</b>					
Women	108	88	100	150	124
<b>Colon&amp;Rectum</b>					
Men	64	43	50	47	47
Women	50	33	33	41	38
All	55	38	40	44	42
<b>Lung</b>					
Men	64	48	41	56	52
Women	52	26	26	48	39
All	57	35	32	51	45
<b>Prostate</b>					
Men	217	90	143	178	154

Notes: Data are for individuals ages 15 and older.

Source: Great Bay Area Cancer Registry, 2002-2011

**Age-adjusted cancer death rate per 100,000 adults by cancer site, race/ethnicity, and gender, 2008-2012**

	African American	Asian/Pacific Islander	Latino	Non-Hispanic White	Santa Clara County
<b>All Sites</b>					
Men	272	169	200	243	216
Women	236	120	133	193	163
All	248	141	161	213	185
<b>Breast</b>					
Women	35	15	18	32	25
<b>Colon and Rectum</b>					
Men	36	17	20	19	19
Women	31	11	13	17	15
All	32	14	16	18	17
<b>Lung</b>					
Men	52	42	33	54	47
Women	58	22	13	43	33
All	56	31	21	48	39
<b>Prostate</b>					
Men	47	11	17	27	22

Source: Santa Clara County Public Health Department, 2008-2012 Death Database; State of California, Department of Finance, State and County Population Projection, 2010-2060. Sacramento, California, January 31, 2013

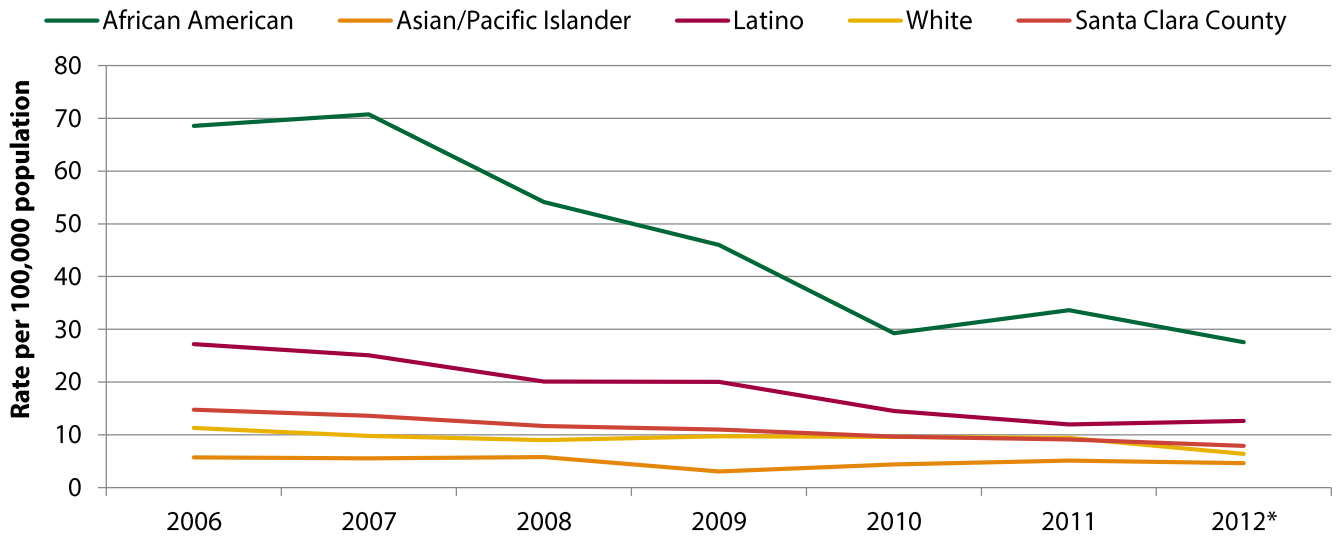
**HIV/AIDS**

*African/African Ancestry community has the highest burden of HIV/AIDS in the county.*

While rates of newly reported HIV infections among African/African Ancestry community members have declined from 70.8 per 100,000 people in 2006 to 27.5 per 100,000 people in 2012, African/African Ancestry community members are disproportionately affected by the HIV/AIDS epidemic and have a higher rate of new HIV infection (27.5 cases per 100,000 people) than Asian/Pacific Islanders (4.6), Latinos (12.6), Whites (6.4), and the county overall (7.9). Despite representing only 3% of the county population, African/African Ancestry community members comprised 12% of the HIV/AIDS case load in the county in 2012.<sup>6</sup>

This disparity is even more concerning given the relatively lower AIDS survival rates among African/African Ancestry community members compared with other racial/ethnic groups (see figures below). These findings have implications for how HIV prevention and treatment related resources should be allocated and suggest a need for a greater focus on the African/African Ancestry community.

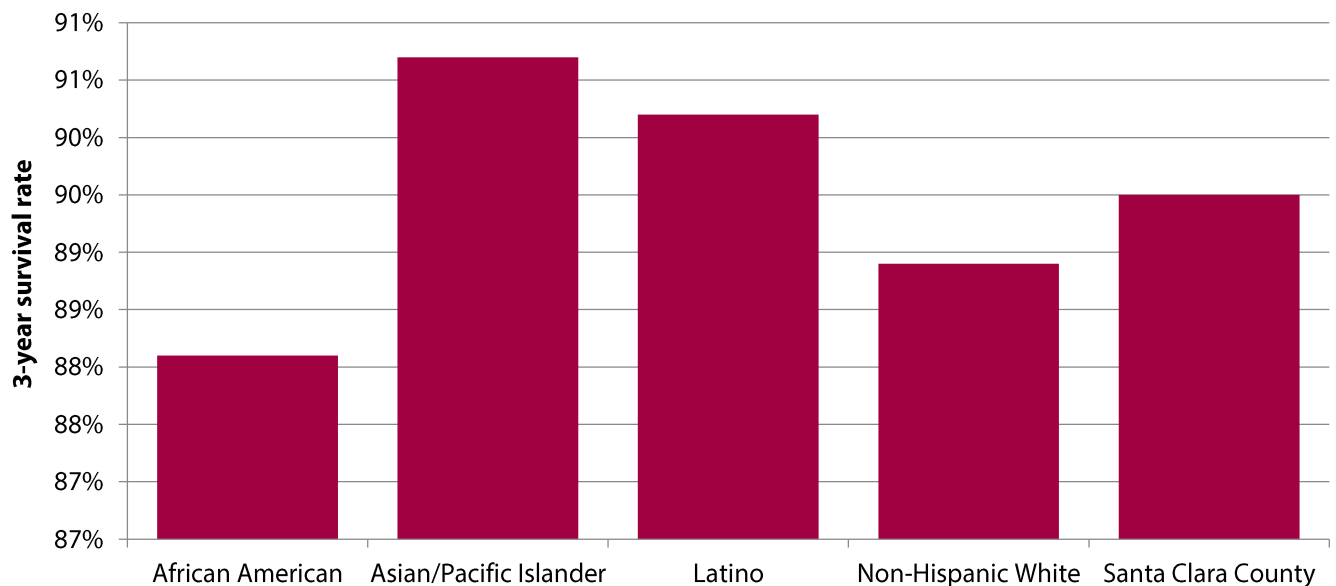
## Rates of newly reported HIV infections among adults and adolescents by race/ethnicity, 2006-2012



Note: Data includes people infected with HIV regardless of disease stage. The rates in 2012 are likely to be underestimated due to report delay.

Source: Santa Clara County Public Health Department, Enhanced HIV/AIDS Reporting System (eHARS) data as of December 31, 2012; State of California, Department of Finance, Race/Ethnic Population with Age and Sex Detail, 2000–2010. Sacramento, California, September 2012; State of California, Department of Finance, State of California, Department of Finance, State and County Population Projection, 2010-2060. Sacramento, CA, January 31, 2013

## 3-year survival rate of AIDS patients by race/ethnicity, 2000-2009



Source: Santa Clara County Public Health Department, Enhanced HIV/AIDS Reporting System (eHARS), data as of December 31, 2012

## Emergency department visit and hospitalization rate

*African/African Ancestry residents have the highest emergency department visit rate in the county.*

Research suggests that patients with access to primary health care services are less likely to go to the emergency department for routine care.<sup>7</sup> People with Medicaid or those without insurance are more likely to rely on the emergency department services for their ambulatory care compared to people with insurance. High rates of emergency department utilization and hospitalization may indicate a lack of access and/or a lack of culturally competent access to care or poorly managed chronic health conditions in the primary healthcare settings. Improving access to primary care services reduces emergency department utilization, which in turn creates a more efficient and affordable healthcare system. Receiving primary care and preventive services can help keep medical conditions from escalating and becoming more extensive and expensive.

The age-adjusted emergency department visit rate was higher among African/African Ancestry community members (49,065 per 100,000 people) than Asian/Pacific Islanders (10,431), Latinos (33,606), Whites (25,232), and the county overall (23,812). The age-adjusted hospitalization rate was also higher among African/African Ancestry community members (11,893 per 100,000 people) than Asian/Pacific Islanders (6,273), Latinos (9,194), Whites (8,962), and the county overall (8,372). This may suggest that African/African Ancestry individuals are less likely to access primary health care services than are other racial/ethnic groups and, consequently, more likely to rely on emergency care.

### **Emergency department visit and hospitalization rates by race/ethnicity**

<b>Race/ethnicity</b>	<b>Age-adjusted ED visit rate per 100,000 people</b>	<b>Age-adjusted hospitalization rate per 100,000 people</b>
<b>African American</b>	49,065	11,893
<b>Asian/Pacific Islander</b>	10,431	6,273
<b>Latino</b>	33,606	9,194
<b>Non-Hispanic White</b>	25,232	8,962
<b>Santa Clara County</b>	23,812	8,372

Source: Office of Statewide Health Planning and Development, 2011 Patient Discharge Data

## Health behaviors

*A higher percentage of African/African Ancestry adults reported ever being diagnosed with high blood pressure than other racial/ethnic groups and the county overall.*

Engaging in positive health behaviors is an important part of maintaining a healthy lifestyle and preventing or delaying some chronic diseases. Healthy eating and engaging in physical activity contribute to overall health and well-being. Thirteen percent (13%) of African/African Ancestry adults ate 3 or more servings of vegetables the previous day and 23% at 2 or more servings of fruits the previous day. Vegetable consumption among African American adults was lower than all other racial/ethnic groups and the county overall. Fruit consumption among African American adults was lower than among White adults (33%) and the county overall (27%), and the same as Asian/Pacific Islander and Latino adults.

A third (33%) of African/African Ancestry adults ate fast food at least weekly in the past 30 days. This percentage was lower than among Latino adults (47%), White adults (38%), and the county overall (38%), but equivalent to fast food consumption among Asian/Pacific Islander adults (33%). A lower percentage (34%) of



African/African Ancestry adults drank 1 or more sodas weekly in the past 30 days than Latino adults (59%) and the county overall (36%), but higher than among Asian/Pacific Islander adults (32%) and White adults (27%).

Engaging in regular physical activity is also important for overall health and well-being. More than 8 in 10 (84%) African/African ancestry adults reported any physical activity or exercise in the past month, a higher percentage than Asian/Pacific Islander adults (83%), Latino adults (72%), and the county overall (82%), but lower than White adults (87%).

**Percentage of adults reporting select health behaviors by race/ethnicity**

Race/ethnicity	Ate 3 or more servings of vegetables the previous day %	Ate 2 or more servings of fruit the previous day %	Ate fast food at least weekly in the past 30 days %	Drank 1 or more sodas with sugar weekly in the past 30 days %	Any physical activity or exercise in the past month %
<b>African American</b>	13	23	33	34	84
<b>Asian/ Pacific Islander</b>	18	23	33	32	83
<b>Latino</b>	17	23	47	59	72
<b>Non-Hispanic White</b>	21	33	38	27	87
<b>Santa Clara County</b>	19	27	38	36	82

Source: Santa Clara County Public Health Department, 2013-14 Behavioral Risk Factor Survey

Among African American adults, more than a quarter (26%) are obese, almost 1 in 10 (10%) were ever diagnosed with diabetes, approximately 1 in 5 (19%) were ever diagnosed with asthma, 4 in 10 (40%) were ever diagnosed with high blood pressure (hypertension), and approximately 3 in 10 (31%) were ever diagnosed with high blood cholesterol. These percentages are higher among African/African Ancestry adults than among most racial/ethnic groups and the county overall.

## Percentage of adults reporting select chronic health conditions by race/ethnicity

Race/ethnicity	Obese %	Ever diagnosed with asthma %	Ever diagnosed with high blood pressure %	Ever diagnosed with high blood cholesterol %	Ever diagnosed with diabetes %
African American	26	19	40	31	10
Asian/ Pacific Islander	8	11	19	31	6
Latino	33	15	27	25	11
Non-Hispanic White	23	16	33	38	8
Santa Clara County	20	14	27	32	8

Source: Santa Clara County Public Health Department, 2013-14 Behavioral Risk Factor Survey

### **Significance of mixed methods approach**

This report is intended to help explore some of the reasons behind the health disparities presented in this chapter. Quantitative data is one way of analyzing data that presents health outcomes as numbers and numeric categories in order to compare across various population subgroups or time. This quantification helps with answering questions about the health status of a population, and disparities that exist between various groups. However, it does not provide reasons for these disparities. Mixed methods techniques, combining quantitative and qualitative research, helps provide a richer and deeper understanding of health outcomes than would otherwise be possible with quantitative data alone. This health assessment used a mixed methods approach, drawing upon both quantitative and qualitative data sources. Qualitative data findings are presented in the next chapter.

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# Qualitative findings

## Cultural (in)competence

### *Introduction*

Research indicates that individuals who are racial minorities experience professional mistreatment within the healthcare context in various ways, including interpersonal communication, perceptions of bias, stereotyping, and cultural incompetency.<sup>1</sup> Cultural incompetence may be experienced in various ways, including ineffective relations with an individual based on language, thoughts, communications, actions, customs, beliefs, values, and certain racial, ethnic, religious, or social groups. Cultural incompetence in these areas may manifest in behaviors, attitudes, and policies that undermine effective professional treatment in cross-cultural situations.<sup>2</sup> The absence of cultural competence contributes to the disparities in healthcare. When healthcare providers fail to respect and respond to health beliefs, practices, and cultural and linguistic needs of African/African Ancestry individuals, this undermines the quality of healthcare that individuals receive, and in turn undermines their health outcomes.<sup>3</sup>

African/African Ancestry community members in Santa Clara County experience extensive professional mistreatment and a lack of cultural competence in the healthcare delivery system and other systems pertaining to health and well-being. Such experiences have a negative impact on the interactions between African/African Ancestry people and the healthcare delivery system, as well as on the African/African Ancestry community's overall access to quality healthcare. Overall, health services in the county are not well oriented to serve the African/African Ancestry community and do not acknowledge the cultural norms, needs, and experiences of its community members.

Certain subpopulations of the African/African Ancestry community, including LGBT community members and African immigrants, expressed particular concerns regarding cultural competence and professional mistreatment. For example, LGBT community members discussed during the community conversations about the need for services that are culturally competent for people who are both of African/African Ancestry and LGBT. African immigrants also reported during the community conversations about experiencing professional mistreatment in the form of discrimination for being foreign-born, which can negatively impact access to healthcare services and success in navigating service systems. During community conversations, participants identified the need for more African/African Ancestry health providers who could understand and relate to their health needs.

### Key findings:

- Provider mistreatment and a lack of cultural competence are common experiences across all African/African Ancestry groups and across a wide array of services pertaining to health and well-being.
- Healthcare services are not well oriented to serve people who are of African/African Ancestry, and do not acknowledge their cultural norms, needs, and experiences.
- These issues are especially acute for certain groups within the African/African Ancestry community, including African immigrants and LGBT community members.
- Community members pointed out the absence of African/African Ancestry health providers as a critical issue that exacerbates cultural incompetence and reduces the community's overall health and well-being.

## **Cultural incompetence and professional mistreatment**

African/African Ancestry community members reported professional mistreatment and a lack of cultural competence across a wide range of services, including healthcare contexts such as hospitals and clinics, as well as social services such as child welfare. African/African Ancestry community members expressed frustration that the health and well-being services available to them in Santa Clara County are not well oriented to acknowledge their cultural norms, needs, and experiences. As an Ethiopian community member noted in a community conversation, “There is not a specific system for Africans or African Americans. Everything is very vanilla, which makes it cookie cutter. They do not address specific issues for a community, given diseases and mental health, skin diseases from where you came from, tuberculosis... By vanilla I mean, general treatment, not race related, no specific things for African communities” (Ethiopian community conversation participant).

A number of participants pointed out that the health providers’ cultural incompetence compromises the quality of healthcare that African/African Ancestry community members receive in the county. In addition to the idea that the healthcare system seems to promote the “notion that one hat fits all” (Health professional key informant), providers are often unaware of health needs and concerns of African/African Ancestry community members.

One woman described the inadequate care that her infant son received from a physician who was not well-versed in common health issues among African/African Ancestry children and contrasted this with the care her son now gets from an African/African Ancestry doctor. “I switched my son from Valley Medical; they told me my child looked jaundiced, because he was light skinned... I switched to a different doctor, who I have seen since I was a child, an African American doctor... He said ‘I see this more often with Black children than maybe with different children’. Because he was more culturally sensitive, he understood and he helped with the childhood asthma, help me get the eczema under control, instead of giving me the water based lotions I was getting before that were not doing anything but breaking him out more” (New moms community conversation participant).

For many African/African Ancestry community members, a major part of provider mistreatment and cultural incompetence centers on frequent experiences of being negatively stereotyped by their service providers, and mistreated based on their race. Some participants expressed concern about the way that many African/African Ancestry community members present themselves, feeding into negative stereotypes. Others emphasized experiences of negative stereotyping around cultural and socioeconomic factors such as gender or income level.

*“People are frustrated. The impression is that people that come to the county emergency room don’t have insurance, they have nowhere to go, no income.”*

(West African community conversation participant)

*“Men of African Ancestry across the board are always seen as absent fathers, not in the home. European men, Asian men, when you think of them you don’t necessarily think that, but for African Ancestry men the perception of being absent is perpetuated, and so the fathers continue to not have access to the services to be part of their children’s lives.”*

(Social worker key informant)

For African/African Ancestry women, these negative stereotypes became especially pervasive when they are pregnant or mothering young children. Women participating in a program for new and expecting mothers spoke at length about the stereotypes that they confront in seeking healthcare and the resulting impact on the treatment they receive. “Since I am 25 and having my third child, [the doctor] seemed like she thought I was a welfare queen. We got into an argument about me asking for information that I had a right as a patient to have. I think because of my race, I didn’t get the information. Even when I knew enough to ask, I got push back from her and the obstetrics department” (New moms community conversation participant).

A woman who participated in the West African community conversation relayed similar experiences of stereotyping pertaining to social disadvantage and economic hardship. “Even if you have insurance and go to a county hospital some [doctors] assume you are on welfare. If you have a baby, assuming you are low income, they give you the Depo shot to prevent you from coming back and don’t tell you the negative side effects like it dries your milk if you planned to breast feed or give you a choice; the perception is that you are low income, on Medi-Cal, poor, and not knowledgeable. You cannot make a decision if that is what you want or not” (West African community conversation participant).

The experiences of these women are especially noteworthy in light of the widespread and persistent maternal and infant health disparities experienced by African/African Ancestry women and children relative to other racial/ethnic groups (as discussed in the Community Health Overview chapter). Research shows that the impact of stress induced by racism contributes to African American women’s adverse birth outcomes and that experiences such as those discussed above have been shown to create stress and increase the likelihood of poor birth outcomes. Such adverse outcomes are powerful predictors not only of infant mortality and health, development and disability during childhood, but also have health implications over the lifetime.<sup>4</sup> The experiences of cultural incompetence or professional mistreatment described here also relate to community members’ concerns about being treated unfairly due to membership in a group that has historically suffered discrimination. Research supports such concerns as a source of chronic stress.<sup>5</sup>

### Percentage of Santa Clara County residents by English speaking ability

	Speaks a language other than English at home %	Speaks English less than "very well" %
<b>African American</b>	17	6
<b>Santa Clara County</b>	51	22

Note: African American category does not include Latinos.

Source: U.S. Census Bureau, 2010-2012 American Community Survey 3-Year Estimates

### ***Diversity of the African/African Ancestry community***

#### Immigrants

Santa Clara County’s African/African Ancestry community is very diverse, and is comprised of people from all over the world. Seventeen percent (17%) of African/African Ancestry community members in the county are foreign-born, in contrast to 7% of African/African Ancestry community members in the State of California and 9% in the United States.<sup>6</sup> Although community members celebrate this diversity, many people also pointed to this diversity as the site of much cultural incompetence and professional mistreatment.

African immigrants experience unique challenges in accessing quality healthcare services. In addition to experiencing a general lack of cultural competence and provider mistreatment, African immigrants face an

additional layer of cultural incompetence tied to language differences, health professionals' lack of knowledge about particular health issues that African immigrants are more likely to experience. A number of community members pointed out language as a particularly common source of mistreatment and cultural incompetence. As a new mom participating in a maternal infant health program explained, "Our accent, when they hear it, they try to dismiss you, try to act like you don't know the system. ... You think we are one of them, a part of them but ... as soon as you talk and they hear you, they understand what you're saying but treat you like you don't know what you are talking about. It's really frustrating to feel discriminated against because you're identified as a foreigner" (New moms community conversation participant).

Other African immigrant community members spoke of challenges faced by immigrants with limited English language proficiency, pointing out that most healthcare settings do not have adequate translation services for African languages and providers often fail to make sure that patients with limited English proficiency get the information and care that they need. "The community does not speak English very well. They are going to make assumptions for you and not provide what is appropriate within your rights. We're at a major disadvantage, and the Ethiopian community does not know how to use the system to get many different options" (Ethiopian community conversation participant).

### Percentage of Santa Clara County residents who are foreign-born

	African American %	Santa Clara County %
<b>Foreign-born</b>	17	37
<b>Region of birth among foreign-born</b>		
<b>Europe</b>	3	8
<b>Asia</b>	3	63
<b>Africa</b>	78	2
<b>Oceania</b>	0	1
<b>Latin America</b>	15	26
<b>North America</b>	1	2

Source: U.S. Census Bureau, 2012 American Community Survey 1-Year Estimates

*"We need culturally sensitive material that contains [information relevant] to West Africans, instead of giving literature that is for everyone. [They need to] know the audience and bring the proper materials.*

(West African community conversation participant)

*In terms of African refugees who come for services, there are inherent cultural differences, even in the way we provide services. For example, the way we do sex education—the delivery, the approach, and the words we use."*

(Health professional key informant)

*"They told me my child looked jaundiced, because he was light skinned. ... I switched to a different doctor, who I have seen since I was a child, an African American doctor. ... Because he was more culturally sensitive, he understood and he helped."*



(New moms community conversation participant)

*"I don't know if cultural competence is the answer because I don't believe you can ever be truly culturally competent, but having a cultural sensitivity, approaching the client/participant with the 'you probably know better than I do, so tell me what you think, tell me about you. I know what I know about this, but I don't know anything about you. I think that would build confidence... I've definitely heard horror stories. Or in my own experience, when doctors have a condescending pretentious tone in their demeanor. People sense that they're being talked down to sure. That's not going to build confidence."*

(Health professional key informant)

### African/African Ancestry LGBT community members

LGBT community conversation participants discussed the need for services that are culturally competent for African/African Ancestry LGBT community members. Overall, there are few services available in Santa Clara County that cater to the needs of the LGBT community, particularly for lesbians, transgender individuals, and LGBT youth and young adults. Of the services available, few if any are culturally relevant for members of the African/African Ancestry community. As a result, many African/African Ancestry LGBT participants noted that they seek services outside Santa Clara County, in places such as San Francisco and Oakland.

Like other African/African Ancestry community members, LGBT members expressed frustration about health providers' "one size fits all approach," (LGBT community conversation participant) and their apparent lack of knowledge about the health issues that affect them. Community conversation participants documented that their healthcare providers were not well versed in the health risks and needs of LGBT population, particularly for lesbians and transgender individuals, and expressed the feeling that it was their responsibility to educate their providers about their needs as African/African Ancestry LGBT community members.

*"As a lesbian, I want to know what I am at risk for, and the nurses and gynecologists are not super-confident in sexual health for women and the trans communities. Accessing healthcare can be problematic for some people. But once you get your access will you find someone who is culturally competent?... Cultural competency and education are really big issues."*

(LGBT community conversation participant)

*"There are quite a few unique challenges [that African American LGBT people in Santa Clara County face]. One is the sense of distrust in the community itself and the lack of commitment by county service providers to the community, and the one size fits all approach."*

(HIV educator key informant)

### **Underrepresentation in the health professions**

These issues of cultural incompetence are exacerbated by the extremely small number of African/African Ancestry health professionals in Santa Clara County. This underrepresentation often means that African/African Ancestry community members struggle to find healthcare providers who are aware of and sensitive to their needs, concerns, and experiences. The lack of African/African Ancestry providers is an issue across various domains of the healthcare delivery system in the county, resulting in the widespread sentiment

that the African/African Ancestry community is not receiving adequate services. Research suggests that the absence of racial concordance (or sameness) in patient-physician relationships negatively impacts patients' perceived quality of health care, as well as the likelihood of utilizing needed services.<sup>7</sup>

One key informant spoke at length about her efforts to seek adequate and culturally competent mental healthcare. The White provider to whom she was initially referred to did not know how to read culturally specific social and emotional cues, and downplayed her need for mental health services. Not until she insisted on getting a referral to an African/African Ancestry psychologist, did the participant get the care she needed. "I asked for a psychologist of color. I thought I could relate better. Instead they gave me a white man. I explained to him no one in my family admitted to going to a psychiatrist, I've never been to one. I've been taught that I am a strong Black woman, that's how I was raised, that I just have to be strong. You deal with your problems head on and keep moving... I told him you can't go by what you see, you see a calm exterior but inside I am troubled. I told you everything happening with me – I'm not sleeping, I'm not eating. He said, "I think you are fine, you look fine." He couldn't identify and he didn't even try.... I went back to administration, saying, there has to be a Black psychiatrist somewhere in this whole system, then they referred me to a Black woman and it was great after that. When I initially asked, they insisted on the white guy, he didn't even try to understand my culture, he didn't make an attempt" (African/African Ancestry health expert key informant).

Given the limited number of African/African Ancestry health providers in the county, many community conversation participants expressed uncertainty about how to find providers who looked like them and understood their culture, values, and needs. In a field with so few professionals who look like them and share their culture, many participants expressed doubt that providers would know how to relate to them and provide services they needed. "When I went to Kaiser in San Jose I looked around and there was nobody else that was Black. If I don't see a lot of Black people around here so I'm going to assume that you don't know how to deal with Black people" (College students community conversation participant).

Some community members expressed the desire for clinics and community centers specifically tailored to serve the African/African Ancestry community. Often, remarks to this effect related to a desire for someone to care about the health of not just one individual of African/African Ancestry, but the entire community. "Japanese, Chinese, Korean, Latino, they all have clinics that specifically target their ethnic communities. We need one specific to the African American community ... There is no place people can go where they can trust [their providers]. [We want to be able to say], 'these people look like me, I can talk about my problems, my confidence won't be violated; these people care about me'" (Community activist key informant).

Another aspect of underrepresentation in the service delivery system is the resulting lack of choice. Both providers and service recipients noted the desire for greater choice about their providers, including whether or not to have a provider of African/African Ancestry. Like many other issues pertaining to cultural competence and representation, participants linked the problem of underrepresentation to institutionalized racism.<sup>h8</sup> Many participants related their experiences of institutionalized racism in the context of the healthcare system. "We need to tear down systemic structural racism that exists. It even exists as an employee of the system; I live it all the time. If it is stemming down from the top, it's felt by the employees, it reaches the public. Like that scripture that says if the head is sick then the rest of the body is sick. Because we don't have people that look like us to treat us, we don't have people who understand us or even trying to understand us" (African/African Ancestry health expert key informant).

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<sup>h</sup> Institutionalized racism is differential access to the goods, services and opportunities of society by race.

*“To find a doctor who looks like you and has a vested interest in your people as a whole is very difficult if not impossible. That alone is very discouraging, and you’re put at a disadvantage.”*

(South Bay Black Firefighters representative key informant)

*“I have never seen a Black doctor at Valley Medical. They may have some, but I have never seen them.”*

(Reentry community conversation participant)

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## Racism and discrimination

### Introduction

African/African Ancestry community in Santa Clara County experiences extensive racism and discrimination that has both direct and indirect effects on community members' health and well-being. For instance, racism and discrimination are a pervasive source of stress and anxiety that directly impacts the mental health of African/African Ancestry community members. In addition, the stress and anxiety that stem from living in a racist society have dire implications for the physical health of African/African Ancestry community members, as noted by community members and well-documented in public health research. For example, research suggests that women of African/African Ancestry between the ages of 49 and 55 are biologically older than their White counterparts, due to stress.<sup>1</sup> Moreover, differential access to resources and opportunities that can accumulate over one's lifetime and across generations negatively affect health outcomes for the African/African Ancestry community.<sup>234</sup> The persistence of racism and discrimination, in combination with the historical accumulation of disadvantage, has created a structural and institutional context in which African/African Ancestry community members are overrepresented in a series of institutions associated with poor outcomes such as the criminal justice system, foster care, and special education.

### Key findings

- The stress of racism has negative psychological and physiological health implications.
- The institutions within which participants most frequently reported experiencing racism and discrimination were schools and the healthcare delivery system, including hospitals and emergency services and social services.
- Community members noted that the prevalence of racist stereotypes about African/African Ancestry community members interferes with access to quality healthcare services and ultimately undermines the community's health and well-being.

### Psychological implications

Racism and discrimination pose major barriers to good mental health for the African/African Ancestry community members in the county. Racism and discrimination were reported to be the cause of mental health issues by participants in one-fourth of all discussions that were held as part of this health assessment. Anger, anxiety, stress, lower self-esteem, preoccupation, and hyper vigilance were among the numerous psychological symptoms cited by the participants. Many community members felt that they have had to overcompensate to avoid discrimination, which creates additional stress.

*"African Ancestry folks try to deal with that negativity in a way that is controlled without reacting to it to not put more stress on themselves. But then it is a constant distraction – always wondering if people are looking at you funny as if you are about to rob them. It puts pressure on individuals to not lead a full, relaxed life. You're not good enough."*

(Mental health professional key informant)

*"Discrimination and racism; they impact you a lot. When I was going over to vote [in San Jose] with my friend, a police officer saw us and told us we looked exactly like some perpetrator he was looking for. I don't think he stopped us for that. He stopped us because he was going off a stereotype. We had just come*

*from a voting station and we were wearing the stickers. Because he was a police officer, it made me feel unsafe. Because of that, I stress out sometimes about the authority that is supposed to be governing around the area I live in and go to school. Should I even trust these people that are supposed to be protecting me? When you encounter situations like that, it lowers your self-esteem as a person."*

(College students community conversation participant)

In terms of subgroups, African/African Ancestry community members with serious mental illnesses that we spoke to described experiences with "double discrimination" (Mental health consumers community conversation participant) that further compromise their health and well-being. Many felt that society applies biases to people of color as well as those with psychological disorders, which poses added burdens to those who are in both categories. Racism and discrimination also profoundly influences the mental and behavioral health of immigrant population. This group faces unique challenges in navigating their way through a new country and often felt that "they are not treated with respect or kindness, as they should be" (West African community conversation participant).

Relative to the county overall, as depicted in the table below, a higher percentage of African/African Ancestry community members reported thinking about their race constantly (15%) or daily (13%) or experiencing emotional and/or physical symptoms as a result of how they were treated based on their race (11%) than most other racial/ethnic groups and the county overall. Indicators of stress and/or depression may be impacted by experiences of racism and discrimination. Previous research has demonstrated a relationship between racism and depression and anxiety.<sup>5</sup>

### Percentage of adults who think about race and experienced symptoms due to racism and discrimination by race/ethnicity

Race/ethnicity	Thinks about their own race constantly %	Thinks about their own race daily %	Emotional or physical symptoms in the past 30 days %
African American	15	13	11
Asian/Pacific Islander	17	7	7
Latino	30	11	12
Non-Hispanic White	--	6	6
Santa Clara County	13	8	8

Notes: Percentages for non-Hispanic Whites for "thinks about own race constantly" not reportable due to insufficient sample size and/or a relative standard error greater than 30%. Thinks about own race daily includes respondents who think about their own race once a day or once an hour. Emotional symptoms defined as adults who felt emotionally upset, for example angry, sad or frustrated, as a result of how they were treated based on their race; physical symptoms defined as adults who experienced any physical symptoms, for example, a headache, an upset stomach, tensing of their muscles, or a pounding heart, as a result of how they were treated based on their race.

Source: Santa Clara County Public Health Department, 2013-14 Behavioral Risk Factor Survey

## Percentage of adults reporting select symptoms of stress and/or depression by race/ethnicity

Race/ethnicity	Felt worried, tense, or anxious at least once in the past 30 days %	Frequent mental distress %	Depression %
African American	57	11	11
Asian/Pacific Islander	51	7	6
Latino	61	11	10
Non-Hispanic White	64	10	24
Santa Clara County	59	9	14

Notes: Frequent mental distress is defined as 14 or more days in the past 30 days where mental health was not good. Depression indicator is defined as a doctor, nurse, or other health professional ever having told the person that he/she has a depressive disorder, including depression, major depression, dysthymia, or minor depression.

Source: Santa Clara County Public Health Department, 2013-14 Behavioral Risk Factor Survey

### Physiological implications

In addition to the psychological effects of racism and discrimination, physical health consequences are experienced by many African/African Ancestry community members. Manifestations cited include high blood pressure (hypertension), heart disease, diabetes, and other illnesses that are associated with chronic stress, many of which have disproportionately higher prevalence rates in the African/African Ancestry community members (see secondary data tables for details). These findings are consistent with literature related to the “weathering hypothesis” that suggests that early health deterioration, disease, or aging can be a consequence of the cumulative impact of repeated exposure to the stresses that are associated with racism and discrimination.<sup>678</sup>

*“[Racism] has a great deal of impact on stress. Unfortunately, we as a people still live in a society that’s very discriminatory based upon color. You would hope that the days when MLK said that we would be judged on our character would have come into fruition. But it’s still a reality that we as a people are judged predominantly based on what we look like, in other words, that we happen to be Black. So there are stereotypes that still follow us that have been in place for years and years, for tens and hundreds of years in some case. Racism is a great stressor for our people. And it’s incorporated into our very structure, not only in our mindset but also in our physicality. That’s a precursor, I believe, why so many African Americans have high blood pressure, why they’re under such a great load of stress, and finding themselves in the judicial system so often because of stress.”*

(South Bay Black Firefighters representative key informant)

*“Stress is probably one of the biggest contributors to health [problems]. We have pressure that none of the other races understand or identify. It is from inception when we are born; we always have to compete and prove ourselves. The guard is always up as a result of pressure, and [it causes] chemicals to release in our bodies. It happens from the time when we are kids, when we recognize when it matters what other people think about us. When they start going to school, they see people are being ranked and categorized and it*



*causes them to watch what they say, it has an adverse effect on our body. Heart disease comes, and also psychological problems because you are trying to keep it under control.”*

(Pastors community conversation participant)

*“Think about the things that are related to discrimination for being of African American and some of those issues have manifested themselves in a lot of depression, anxiety, substance use, and other stress related illnesses such as heart disease, diabetes, etc. Things that get exacerbated by the stress people are under living in a society that doesn’t respect African Americans on the same level as other individuals in the community.”*

(Mental health professional key informant)

### ***Discrimination in healthcare settings***

Participants identified the healthcare delivery system (e.g. emergency services and hospitals) as a common area of racism and discrimination, which ultimately poses barrier to health and well-being. Of the 156 mentions of racism and discrimination as a barrier during the community conversations and key informant interviews, 28 were situated within the context of healthcare. Community members reported numerous experiences in which they were mistreated in the healthcare settings based on stereotypes. These encounters included experiences such as negative perceptions of African/African Ancestry community members, poor service, low expectations, skepticism, poor assumptions, unfair judgment, and misinformation. These experiences of racial discrimination contribute to overall mistrust of the healthcare system. Other studies have reported similar findings of lower expectations and levels of trust for healthcare among African Americans than among Caucasians.<sup>9</sup>

*“I had a terrible experience with a gynecologist based on his stereotypical view of Black patients. I have witnessed and sat in report where providers identify only the Black race with sicknesses and not other races. I put that together and can understand the fear and mistrust.”*

(Black Infant Health Advisory Board community conversation participant)

*“Many of them [healthcare providers] think when you go in that you are not going to pay and their perception of you is unspoken. Just like when you walk down the street and a lady grabs her purse.”*

(Reentry community conversation participant)

The consequences of discrimination can be severe and affect service delivery, perpetuating negative health outcomes. Research shows that African/African Ancestry community members receive lower quality healthcare and experience worse outcomes from chronic illnesses.<sup>10</sup>

*“If folks see an African American resident come into a room, they may be judged negatively in terms of behavior. Because they are judged that way, they end up not receiving services they really need. It’s based on misperception.”*

(Mental health professional key informant)

*"[I] took Grandma to urgent care and was there for 7 hours. Others of different colors arrived after and were seen before. I reported it to a staff member and he said he would look into it but never came back. Our color caused a racial thing."*

(West African community conversation participant)

### ***Discrimination in educational settings***

Participants identified the school system (K-12 primary and secondary schools, community colleges, and universities) as another common locus of racism and discrimination. Of the 156 mentions of racism and discrimination as a barrier during the community conversations and key informant interviews, 22 were situated within the context of school. African/African Ancestry students reported that they have been treated differently, felt that others wished they were not there or wanted to get rid of them, and experienced a sense of helplessness at school not knowing what to do about the situation. Both youth and college-aged young adults noted that the relatively small numbers of African/African Ancestry teachers leads to a lack of support for African/African Ancestry students when dealing with these concerns, posing an added challenge. Parents also shared similar sentiments.

*"[The] education system doesn't do anything to help these kids. In situations where [a student is] in trouble academically or has behavioral or truancy problems, they are not treated equally. They are treated like they already failed, with no chance of moving ahead. They end up dropping out of school, and from there if you don't have a job you have to do something criminal to support yourself. Schools reinforce negative behavior by putting [students] in situations where they don't think they can succeed."*

(Youth advocate key informant)

*"It makes students uncomfortable to come to class, or distant from the teacher if teacher is not looking out for your interest. Teacher is not trying to help them because they don't care about them. Makes you feel isolated. I did not feel safe, I lost hope. Emotionally, you are angry, you don't care, which makes you lose faith and that affects your health. You get stressed."*

(Young adults community conversation participant)

*"I have seen teachers put kids in the back of the class, wondering why. Some teachers have a tendency to pass by you and not speak. You could at least smile. If we work together on same campus and you don't speak to me, how are you treating my child in the classroom? You don't see me. Any ill treatment can affect you mentally and physically."*

(Elders community conversation participant)

*"A while back when I was in college, there were big issues about racism and color among the deans, teachers, and students. We had one Ethiopian classmate; she got stressed out in laboratory, they did not want to practice with us because we are Black."*

(Ethiopian community conversation participant)

As another form of discrimination, participants reported that there is an overrepresentation of African/African Ancestry youth who have been placed into special education classes. The additional concern is that these classes and associated services are often not offered in a culturally appropriate manner.

**Percentage of middle and high school students who experienced bullying in the past 12 months by race/ethnicity**

Race/ethnicity	Physically bullied on school property in the past 12 months %	Psychologically bullied on school property in the past 12 months %	Bullied online by other students in the past 12 months %	Bullying combined (physical, psychological, and/or cyber) in the past 12 months %
African American	31	45	22	55
Asian/Pacific Islander	26	42	21	52
Latino	31	45	20	56
Non-Hispanic White	25	43	20	53
Santa Clara County	28	44	21	54

Source: California Healthy Kids Survey, 2009-2010

*“What happens for the folks in schools, they are challenged by African American youth, particularly African American males, and they seem to designate them as special ed., as needing to be in those classes and getting those services. If a child is in special ed., we need to make sure African American parents understand what that means and make sure students are getting all the services they’re entitled to—counseling, sometimes even special placements with a specific type of school that addresses what that student needs directly. That is usually not the case.”*

(Educator key informant)

Bullying is a major issue faced by many African/African Ancestry youth and has severe and even potentially fatal mental health consequences. A higher percentage of African/African Ancestry middle and high school students experienced physical bullying (31%), psychological bullying (45%), and cyber bullying (22%) than most other racial/ethnic groups and the county overall. Similar percentages of Latino middle and high school students experienced physical, psychological, and cyber bullying. Almost a third (30%) of African/African Ancestry middle and high school students felt so sad or hopeless for 2 weeks or more that they stopped doing usual activities in the past 12 months, a higher percentage than most other racial/ethnic groups and the county overall. A higher percentage (22%) of African/African Ancestry middle and high school students seriously considered attempting suicide in the past 12 months than other racial/ethnic groups and the county overall. During community conversations, parents felt that these concerns were not being adequately addressed by school administrators.

**Percentage of middle and high school students who felt so sad or hopeless for 2 weeks or more that stopped doing usual activities in the past 12 months by race/ethnicity**

Race/ethnicity	Felt so sad or hopeless for 2 weeks or more that stopped doing usual activities in the past 12 months %
African American	30
Asian/Pacific Islander	26
Latino	31
Non-Hispanic White	24
Santa Clara County	28

Source: California Healthy Kids Survey, 2009-2010

**Percentage of middle and high school students who seriously considered attempting suicide in the past 12 months by race/ethnicity**

Race/ethnicity	Seriously considered suicide %
African American	22
Asian/Pacific Islander	17
Latino	17
Non-Hispanic White	15
Santa Clara County	17

Source: California Healthy Kids Survey, 2009-2010

***Institutionalized racism<sup>i</sup>***

African/African Ancestry community members experience racism in many forms, all with consequences. Research suggests that institutionalized racism can have a profound impact on health and may exacerbate health disparities.<sup>11</sup> Institutionalized racism appears in many places throughout the county such as the government, workplace, media, and criminal justice system. A higher percentage (10%) of African/African Ancestry adults reported being treated worse than people of other races in social settings such as work or when seeking healthcare than other racial/ethnic groups and the county overall.

<sup>i</sup> Dr. Camara Phyllis Jones describes 3 levels of racism: institutionalized, personally mediated and internalized racism in "Levels of Racism: A Theoretic Framework and a Gardener's Tale." Jones defines Institutionalized racism as the "differential access to the goods, services and opportunities of society by race," structural in nature, and "often evident as inaction in the face of need." Examples of institutionalized racism include disparities in access to education, housing, employment, healthcare, and sources of power such as voting rights and representation in government.<sup>11</sup>

## Percentage of adults experiencing racism and discrimination by race/ethnicity

Race/ethnicity	Treated worse than people of other races at work or when seeking healthcare %
African American	10*
Asian/Pacific Islander	6
Latino	11
Non-Hispanic White	4
Santa Clara County	6

Note: \*Percentage for African Americans may be unstable due to insufficient sample size and/or a relative standard error greater than 30%.

Source: Santa Clara County Public Health Department, 2013-14 Behavioral Risk Factor Survey

Participants cited the limited number of African/African Ancestry members in positions of power as negatively affecting their own and other people’s perceptions about the community. Unfavorable media portrayals were discussed as further contributing to stereotypes as well as influencing how community members, especially youth and young adults, view themselves. Furthermore, community members noted that there are relatively fewer images in the media of African/African Ancestry community members doing well or engaged in healthy behaviors as compared to other racial/ethnic groups. These applications of racism perpetuate misconceptions that African/African Ancestry community members are incapable or incompetent and can also lead to mistreatment of the community.

*“[In the] justice system, the bench is made up of races other than Black... just one on the Supreme Court. We don’t see our race with everyone else’s. [We] don’t see enough minorities in general.”*

(Young adults community conversation participant)

*“[The] media...don’t show us Black people in situations where people are doctors or lawyers, they just show murders and violence. They portray us differently than they portray white folks; on the news it is constantly about African American residents that were robbed or shot somebody.”*

(Young adults community conversation Participant)

*“There are still people out there in this world that have a fear of Black people and that’s their biggest fear. In that they are not equal or they can’t have what I have. That’s a big piece as to why our children are suffering. There’s still a lot of racism and that plays into how you are treated and the overall demeanor. All of these things play a part with why our children are facing more health issues.”*

(Health professional key informant)

As another demonstration of institutionalized racism and discrimination, social workers who were interviewed for this health assessment described ways that the child welfare system has a tendency to break up African/African Ancestry families. They also noted that there are a disproportionate number of African/African Ancestry youth in foster care and that the services offered are often discriminatory and not culturally appropriate.

*“First, the social worker will often send them to other agency service providers outside of the community. I had a case of an African Ancestry family who needed parenting services. The social worker referred them to a Pacific Islander resource center, not to Ujima or an African Ancestry oriented resource center. That is the tip of the iceberg as to how things play out in social services. Families come to an agency, why not give them the choice of what type of social worker they want to work with – Black, female, or not. They don’t get that choice. There is something wrong with the model. Also, men of African Ancestry across the board are always seen as absent fathers, not in the home. European men, Asian men... when you think of them you don’t necessarily think that, but for African Ancestry men the perception of being absent is perpetuated, and so the fathers continue to not have access to the services to be part of their children’s lives. They don’t have the opportunity to have a whole relationship with the children.”*

(Social worker key informant)

*“Overall, when it comes to our community’s relationship with government, agencies have a [bad] track record. If you want services, you don’t get them. Like in child welfare, our families don’t gravitate towards it. Like during slavery when our families were ripped apart, go here, go there, because it benefitted slave master’s needs financially. Slave women, back then the White women would not want them around, and the children became innocent bystanders in that process. Historically, these services were once denied to us. Child welfare came out back in the late 1800s, when children were being put to work, disconnected from their families. Child welfare was created as agency to look out for orphan white kids. Children of African Ancestry, we protected ourselves like during the sharecropper system. The system now is being used for -what it says as is child welfare-our families are being ripped apart. It takes us much longer to be reunified, if at all, with our children.”*

(Social worker key informant)

Overrepresentation of African/African Ancestry community members in the criminal justice system has lasting negative effects on those individuals as well as the greater community. In particular, participants noted that African/African Ancestry youth are often unduly labeled as troublemakers, leading to their disproportionate participation in the juvenile justice system. Moreover, mental health issues stemming from experiences with racism and discrimination are a major concern for individuals involved with the criminal justice system, and in many cases may be contributing factors to their initial and/or continued involvement.

Reentry from the criminal justice system back into society was also described as a particularly challenging time. Incarcerated African/African Ancestry community members frequently encountered stigma, racism, and discrimination when trying to find jobs, housing, and services. These experiences make the transition back into the society even more challenging. Lack of culturally competent services, another example of institutionalized racism, was also cited as a barrier to reentry.

*“Many folks who are working in criminal justice system, particularly the police officers, are not used to working with African American youth. There is a tendency to over involve our young people with any kind of behavior that puts them at risk. In one neighborhood, things may be handled in a way that doesn’t involve the youth being put into criminal justice system. Often times, the African American youth are over identified and therefore getting arrested and going to jail more often than in other neighborhoods. Part of*



*the problem is those folks who are policemen. Disproportionately our kids are arrested for things that other kids are not arrested for in other communities.”*

(Educator key informant)

*“The way that the criminal justice system is set up, it doesn’t help Black and minority kids. The mentoring systems are relatively weak; when they come out of the justice system, they go back in and don’t have skills they need to adjust to life. [There are] not enough agencies outside of criminal justice system to monitor and help these kids adjust. [The] probation department itself is a joke. There’s a big difference in philosophies among probation officers. Some think punishment only, others try to help by mentoring kids to get back on the right path – [there is] no consistency.”*

(Youth advocate key informant)

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## **(Mis)information and avoidance**

### ***Introduction***

Many African/African Ancestry community members reported challenges in obtaining accurate information about health, healthcare services, and the broader healthcare delivery system as key issues impacting their ability to manage their health and to access needed healthcare. Participants linked limited knowledge and information about health and health issues within the African/African Ancestry community to negative health outcomes. Many participants also reported a lack of information about available services for health and well-being, with individuals frequently relying on word of mouth to obtain information about these services. This barrier was particularly relevant for African immigrants, compounding other barriers to successful navigation of the healthcare system, including language barriers and unfamiliarity with the American systems of care.

Many participants reported that a lack of easily accessible and, accurate information about health and the healthcare system fuels widespread mistrust of the healthcare system. Moreover, because the African/African Ancestry community has a long history of abuse at the hands of medical professionals, difficulty obtaining accurate information about health and healthcare compounds the existing mistrust that many African/African Ancestry community members already have for the healthcare system.<sup>1</sup> Participants reported that the combination of historical abuse and experiences of contemporary discrimination and misinformation lead many African/African Ancestry community members to avoid the healthcare system all together.

For African immigrants, cultural differences and a lack of familiarity with the American healthcare system can exacerbate mistrust of the system. As community conversation participants made clear, because of this mistrust, many African immigrants fail to disclose important health information to their healthcare providers, potentially compromising their health outcomes.

### **Key findings:**

- A lack of information or incorrect information about health and the healthcare delivery system is a primary obstacle to African/African Ancestry community members' ability to manage their health and access healthcare.
- Participants noted that the community would benefit from a greater understanding of the consumer's role in the healthcare system.
- The history of abuse at the hands of medical professionals, such as the Tuskegee experiment<sup>1</sup>, combined with a general lack of information and contemporary experiences of discrimination, lead many African/African Ancestry community members to avoid needed medical care.
- African immigrants experience additional challenges related to cultural differences and lack of familiarity with American healthcare system.

### ***Information and misinformation***

Research in public health and health communication reflects increasing recognition of the important role of culture as a factor associated with health and health behaviors, as well as a potential means of enhancing the

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<sup>1</sup> In 1932, the Public Health Service and the Tuskegee Institute began a study called the "Tuskegee Study of Untreated Syphilis in the Negro Male" to study the progression of untreated syphilis. Study participants were told that they were being treated for "bad blood" and given free medical exams, free meals, and burial insurance. They did not receive treatment for syphilis during the course of the 40-year study, even after penicillin was regularly used to treat the disease after 1947. In 1972, after an Associated Press story exposed the lack of informed consent in the study, a government advisory committee reviewed the study and ended it, classifying it as "ethically unjustified." (<http://www.cdc.gov/tuskegee/timeline.htm>)

effectiveness of health communication.<sup>2</sup> Health communication may be culturally targeted by source, message, and channel; the absence of such targeting has been shown to affect the communication of health information.<sup>2</sup>

### Lack of general health information

Lack of information about culturally relevant general health issues was identified as a primary barrier to healthcare access and managing health. Many participants noted the limited level of knowledge about health within the African/African Ancestry community and linked this dearth of knowledge to negative health outcomes. In particular, participants noted that a lack of knowledge about health profoundly impacts lifestyle choices in the context of home and family. “Lack of health education is a contributing factor. The ability of families to understand how they impact their families by the meals they prepare, by the clothes they wear, by where they sleep, what environment they live in. Drugs, alcohol, all those things are factors that impact health” (Political leader key informant).

Participants linked this issue to a need for more diverse and accessible locations for accessing health information that is relevant to the community. According to one health professional, a major challenge is the limited number of venues for obtaining such information. “Having multiple places where you can go to get health information. If you don’t have that, if you don’t know where to go, that’s a barrier” (Health professional key informant).

Another health professional noted that community members may lack information about the importance of having a primary care provider and using that provider as a resource for managing their health. “Make sure families know the importance of having a primary care provider, OB-GYN, pediatrician, et cetera, and use us as resources to navigate what they need and what is helpful to keep them healthy. It is shocking to me sometimes that people don’t realize everything that primary care providers have available for patients, and everything we monitor and take care of” (Health professional key informant).

### Lack of information about healthcare services and the healthcare delivery system

Lack of information about available healthcare services and the healthcare delivery system was identified as another primary obstacle to obtaining quality healthcare. This barrier includes issues such as information about what services are available, information about how to navigate the healthcare system, and the role community members play in their own healthcare.

Many participants noted a lack of awareness of what services are available and how or where to access them. This obstacle spans across most of the African/African Ancestry community, but is particularly evident among African immigrants. For example, many African immigrants expressed the need for education around what services are available within the county.

*“They need to have someone to educate the community of what is in Santa Clara County. We don’t know.”*

(West African community conversation participant)

Another African immigrant participant specified that information about the availability of subsidized health insurance for low income community members is not well known, and would be of great help to immigrants.

*“We need to teach our people, our culture. Their lack of knowing the system is a major issue. We need more access to resources. [We] need more education on the healthcare system. [We] need to find out what is out there.”*

(Ethiopian community conversation participant)

A lack of information about available services impacts a wide array of service domains and health concerns. This concern was raised by many African/African Ancestry stakeholders, including healthcare providers as well as consumers. Participants noted a lack of awareness surrounding service availability for various health and well-being needs, which places a burden on community members seeking resources required to maintain their health, negatively impacting healthcare access and health outcomes.

*“People need to know if services are available and then how feasible is it for them to get the service. Specifically in HIV, though it’s definitely impacting women and women of color, the access is minimal.”*

(Health professional key informant)

*“What is being done to educate families with disabled or autistic children or mental health [issues]? Do they know what is available to them? For known disabilities, there are more evident resources. But with autism, my kid falls through cracks with a less visible disability. You have to dig to find information. It is a burden. It is needed to be readily accessible.”*

(Ethiopian community conversation participant)

Lack of readily available information about healthcare services and the healthcare delivery system often means that community members rely on word of mouth to find needed and culturally relevant health care. As one provider noted, word of mouth, while effective, should be supplemented by information that comes directly from health providers and the healthcare system. “The services are definitely there. But one of the barriers is not knowing that they’re available for you. A lot of the services are there, and clients who come in largely come in by word of mouth; my mom, my cousin told me. My friend did this program and she really liked it so I came. It’s good that people are talking about it, but not so good that people don’t know about it. Having that visibility in terms of the healthcare services available for Black women. Putting a face and name to those services, a number, someone that someone can talk to” (Health professional key informant).

The need for adequate knowledge about how to navigate the healthcare system was identified as another major barrier by African/African Ancestry participants. Several participants emphasized the importance of knowledge about system navigation, and the need for advocacy and assistance. “Knowledge is a great equalizer. It’s great if you have personal knowledge on where to go or what to ask. Even if you don’t, take someone with you that knows what to ask or can advocate for you, negotiate so that you receive the correct type of care. It’s our responsibility to be as aware of a situation as we can be. If I don’t have the knowledge or expertise then let me seek out someone who can to come with me. If I act as a loner then I may enter that situation lost, unprepared, and come out scared and not receiving services needed because I didn’t understand what the doctor said. The end result is I suffer loss because I went in unprepared” (Black Infant Health Advisory Board community conversation participant).

Many participants also reported challenges with knowing how to relate to their healthcare providers, including knowing what questions to ask and knowing when to seek more information than is provided. In particular, participants identified the need to ask more questions when receiving healthcare services and

information: “The lack of education, just not knowing, believing that the doctor told me this, so he/she must be right. Not following up, not challenging the doctor to dig deeper, get more information. You’re talking about your own personal health, or that of your family. Deal with more than just the surface level response, inquire, what can I do? Are there other avenues where I can go? Can I get a second/third opinion? What mainstream outcomes are out there that maybe I can look at to address this issue?” (South Bay Black Firefighters representative key informant).

One participant expressed the desire for a pamphlet to educate African/African Ancestry community members about the role of consumers in obtaining healthcare. “Is it possible to create a pamphlet that details the role of consumers in receiving healthcare? Many people don’t know what those gaps are and this pamphlet would explain what to do when those gaps happen, what roles should be and what’s expected. If there are certain things we need people to do in order to get healthcare, what should we do?” (Black Infant Health Advisory Board community conversation participant).

*“Often times we go to the doctor and the doctor says something and we may not totally understand, but we have a tendency to take what they say at face value without digging any further or asking follow-up questions to see how it impacts our personal health.”*

(South Bay Black Firefighters representative key informant)

### Inaccurate information

Aside from the difficulty in obtaining information, community members were concerned about their experiences of receiving inaccurate information from health providers. Participants reported receiving incomplete or incorrect information about their health and healthcare options. African/African Ancestry women who were pregnant or who had young children reported receiving incomplete and inaccurate information from their healthcare providers, which in turn negatively impacted their ability to make choices about their health and the healthcare.

*“When the progesterone was first prescribed, I also knew they were doing a study on one type of progesterone that had not been approved by the FDA. I asked about it. . . . When I knew enough to ask, I got push back from her. Finally one of the pharmacists printed up the information. Others told me to Google it myself, some of them claimed they didn’t know about the study and that Medi-Cal was trying out the medicine, I found out because the pharmacist had a personal relationship with me and knew my health so she gave me information.”*

(New moms community conversation participant)

*“Even if you have insurance and go to a county hospital some assume you are on welfare. If you have a baby, assuming you are low income, they give you the Depo shot to prevent you from coming back and don’t tell you the negative side effects like it dries your milk if you planned to breast feed or give you a choice; the perception is that you are low income, on Medi-Cal, poor, and not knowledgeable. You cannot make a decision if that is what you want or not.”*

(West African community conversation participant)



## ***Trust and mistrust***

Participants pointed out that difficulties encountered while obtaining needed health information combined with experiences of receiving incomplete or inaccurate information, served to reinforce the African/African Ancestry community's preexisting mistrust of the medical profession and the healthcare system. This lack of trust compromises the willingness and ability of community members to access the services they need to manage their health. Additionally, patients with low trust in their providers may be less likely to comply with treatment, receive recommended screening tests, or develop quality relationships with their healthcare providers.<sup>3</sup>

### **Historical mistrust**

For African/African Ancestry community members, historical experiences of racism and discrimination are a major source of widespread mistrust towards the healthcare delivery system. Such issues of mistrust are widespread across many community members, and are well-established by research.<sup>3</sup> For example, research suggests that African/African Ancestry community members do not trust healthcare researchers for the fear of being used as 'guinea pigs' for medical research, and are less likely to trust healthcare researcher's explanations for their participation in studies.<sup>1</sup> Participants cited a number of historical circumstances in which African/African Ancestry community members were severely abused or mistreated within the context of the medical system and healthcare, linking these experiences to their lack of trust in the healthcare system. "What prevents women from getting healthcare? Mistrust. I don't know about fear, maybe some fear, but definitely mistrust. As a race we typically don't trust the medical system. For all the reasons above. We have a lot of history, Tuskegee Experiment, Henrietta Lacks, all those things that have affected us in the past" (African/African Ancestry health expert key informant).

*"We have a number of members that feel they aren't going to be treated as equitably as the white majority. They don't believe that they are going to give it all they have; [they remember] the experiments that have been done to our community."*

(Pastors community conversation participant)

Many participants related specific experiences of abuse or mistreatment in the medical system of themselves, their family members, or their friends. Participants linked these negative experiences to historical mistreatment, provider mistreatment, racism and stereotyping, and the difficulty of obtaining information from healthcare providers. All of these factors were repeatedly referenced in relation to a general sense of mistrust in the healthcare system. "A big [issue] people have shared with me, is the ability to trust their healthcare providers. There's a general sense of mistrust of healthcare providers, of other races especially. What I hear from my patients, they are relieved to have an African American person to talk to. I will listen, I won't judge them, I won't put a label that doesn't belong, I will actually care. ... In their experience, often times, they have not been listened to, they are not treated like everybody else, in a rude manner, disrespected manner, not being asked questions fully, a rushed interview. Things are omitted, it is rushed, things concluded before [the] interview [is] even over, and assumptions made based on race and appearance" (Health professional key informant).

*"I had a terrible experience with a gynecologist based on his stereotypical view of Black patients. I have witnessed and sat in on reports where providers identify only the Black race with sicknesses and not other races. I put that together and can understand the fear and mistrust."*



*“Again, the trust issue. People feel they are not treated with as much dignity or respect as they could be in the one to one exchange. I hear a lot. Lot of people’s problems are dismissed.”*

(Health professional key informant)

## Cultural mistrust

African/African Ancestry community members reported overall mistrust of medical care. Some participants reported that they have a fear of hospitals. Others reported that their cultural upbringing taught them to favor home care and holistic treatments, rather than seek medical care. “I know a lot of people don’t like doctors; they’d rather do all their treatments at home. They more do holistic healing. They don’t believe in taking pills or aspirin; they were raised that way. And if you’re raised that way you’re not going to go to the doctor. You just don’t. I think if people are not in pain or not feeling there is anything wrong, there is no reason to go to the doctor, especially because of the cost. You ask yourself ‘what am I going for?’” (College students community conversation participant).

*“Even now with Medi-Cal, if something is wrong, if I’m bleeding or something, I usually avoid hospitals. I don’t like hospitals. I have to be at threat of bleeding to death.”*

(Homeless men community conversation participant)

Many other African/African Ancestry participants expressed fear of receiving bad news if they seek medical care; one such participant related that some individuals prefer to rely on their faith than to seek a doctor’s assistance. “One of the ministers went to the doctor and they said he needed to repair his colon and he said he is going to trust the Lord because he doesn’t trust the medical profession. What is the fear of? Detecting what could be wrong. They don’t want to know. The guy I talked to said, ‘I just don’t feel comfortable’ when it was time for him to get his colon tested” (Pastors community conversation participant).

For African immigrants, cultural differences and a lack of familiarity with American healthcare systems exacerbate the issue of mistrust. This mistrust not only results in failure to seek health services when needed, but also contributes to how community members relate to their providers once they engage with the healthcare system. As noted by a West African community advocate, mistrust in the system compounds many existing challenges African immigrants face when navigating the healthcare system, including language barriers and a lack of familiarity with the American systems. “There is a lack of trust among immigrants to the system. It is very hard to navigate the system. And the language problem itself, they have some interpreters but they do not have explanation of language itself, they pay money for interpreters but they do not have the medical understanding of the people who need it.” (West African community advocate key informant).

In particular, many African immigrant participants related that immigrants often fail to disclose important information to their healthcare providers due to mistrust. African immigrants called for efforts to educate the community about the importance of sharing information with healthcare providers. “Due to distrust, we do not disclose information to the healthcare provider. We have to educate people to understand that telling all the facts to your provider is important, because that person needs an accurate picture. If you don’t give them everything, you hide your age but have a really bad heart – it won’t add up. There are a lot of those type of things that become complex.” (Ethiopian community conversation participant)

*“The community members usually think the doctor needs the minimum information about me and he can take care of it. But we definitely need to learn to give everything we know to the trusted healthcare provider, we don’t usually do that. ... It is the culture of the area that we come from. We have to teach our community how to use the system and optimize and maximize [it].”*

(Ethiopian community conversation participant)

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# Barriers to better health and well-being

## Introduction

African/African Ancestry community members in Santa Clara County experience unique challenges in accessing healthcare services. The barriers and hurdles they face accessing preventive and ongoing care can lead to negative consequences for community members, as well as for their families and the community as a whole. In particular, participants reported difficulty navigating the complexity of the healthcare delivery system, an issue that is exacerbated by the lack of services for and outreach to the African/African Ancestry community. These issues are especially acute for African immigrants, who face additional cultural and linguistic barriers. In general, the participants identified the need for more health providers to serve as community resources, educators, and liaisons to the African/African Ancestry community.

In addition to the challenges of navigating the healthcare delivery system, participants also noted that the high cost of healthcare limits their access to needed care. Although the high cost of care is a barrier to adequate healthcare for individuals from all racial/ethnic groups, the cost is especially prohibitive for the African/African Ancestry community, which has a lower median household income than most other racial/ethnic groups in the county (discussed in the Community health overview chapter). More than half (58%) of African/African Ancestry households spend 30% or more of their household income on rent, a higher percentage than Asian households (38%), White households (44%), and all county households (47%), but slightly lower than Latino households (60%).<sup>1</sup>

### Key findings:

- A lack of information and culturally-specific outreach regarding the complexities of navigating the healthcare system are primary barriers for the African/African Ancestry community, particularly among immigrants and older members of the community.
- Many participants identified cost as a major barrier to healthcare access.
- Access to insurance does not always equate to access to healthcare due to information barriers, lack of assistance, cultural insensitivity, and prohibitive costs.

## System navigation

Many African/African Ancestry community members pointed to challenges associated with navigating the healthcare system as a critical barrier to their ability to access quality healthcare. For many participants, the lack of readily available information about healthcare services and the healthcare delivery system (discussed in the previous chapter), exacerbates the difficulties of navigating the system. Moreover, several participants noted that healthcare providers rarely offer information that could facilitate better system navigation. As several participants noted, if people do not know about healthcare services or the healthcare system, no one will offer that information.

*“If you want something, you have to help yourself and you have to get it yourself.”*

(Young adults community conversation participant)

*“Unless you know how to play the system to get what you need, you need to navigate the system, and it’s not that easy. You need to know how it works. You may be qualified for services, [but] they are not going to tell you unless you know about it [and] ask about it.”*

(Young adults community conversation participant)

Community members pointed out that the unwillingness of healthcare providers to provide thorough information about health and healthcare is made worse by the community's limited knowledge about the healthcare system. One participant noted, "They don't know what questions to ask because physicians are in a hurry and they don't volunteer the information" (African/African Ancestry health expert key informant).

Thus, difficulty in obtaining information about healthcare from the system itself combined with a lack of knowledge around the healthcare delivery system within the community creates a critical barrier to healthcare.

*"There's a knowledge deficit and it creates lack of access."*

(Health professional key informant)

*"We need to teach our people, our culture, there's a lack of knowing the system is a major issue. We need more access to resources. [We] need more education on the healthcare system. [We] need to find out what is out there."*

(Ethiopian community conversation participant)

Moreover, these issues are made worse by the fact that neither health services nor outreach services are oriented toward African/African Ancestry community members, which increases the difficulty of navigation and access. Participants noted that the system itself does not provide avenues of support for African/African Ancestry community members, who may look to other support networks better suited to their culture if not their healthcare needs. "Services are not set up to attract Black people to participate appropriately. Black people who just need support, could use some help ... they seek out their clergy, seek out the church, that route for their support, their spiritual support along with mental health support. But they're not getting it through professional services that are offered simply because accessing these services is not made easy for them. Not easily accessible." (Mental health professional key informant)

Among the county's African/African Ancestry community, immigrants experience several additional hurdles to navigating the system. Language barriers, cultural differences, and a lack of appropriately trained interpreters leads to a lack of confidence in healthcare providers. "There is a lack of trust among immigrants of the system. It is very hard to navigate the system. And the language problem itself, they [health providers] have some interpreters but they do not have explanation of language itself; they pay money for interpreters but they do not have the medical understanding of the people who need it." (West African community advocate key informant)

The sheer number of locations and services adds to an overall sense of complexity. "For African immigrants in particular, a lot of it has to do with not having knowledge of the system and the cultural differences. Our systems are disjointed; in particular, for the Valley Health system, you may have to go to two or three places to get services you need so it is not a seamless system and a lot of times they don't know what questions to ask because they're not familiar with the whole system and so they are totally confused." (African/African Ancestry health expert key informant)

Recent immigrants already face the burden of learning many new services and systems simultaneously, including language, education, government, work, and community. Navigating the healthcare system adds an additional layer of complication. The fact that health providers and the healthcare system rarely take time to

ensure that patients fully understand their options, as several participants noted, has consequences for African immigrants who also face barriers related to language and unfamiliarity with the healthcare system. “The community does not speak English very well. They are going to make assumptions for you and not provide what is appropriate within your rights. We’re at a major disadvantage, and the Ethiopian community does not know how to use the system to get many different options” (Ethiopian community conversation participant).

## **Cost and access**

*“It’s about the bill.”*

(Elders community conversation participant)

In addition to identifying difficulties with system navigation as a barrier, community members also identified cost as a primary barrier to healthcare access. Some found that even with health insurance, the cost of obtaining needed care can be prohibitive. These costs do not only include the direct costs of healthcare coverage or insurance, but indirect and unplanned costs from lost work hours, treatments, medications, and co-pays. “I’m scared to call an ambulance, it costs too much. I got sick at school; they had to call an ambulance, then a little while later we got constant medical bills. We aren’t poor but we can’t afford that” (College students community conversation participant).

Some participants reported that financial hurdles came directly from the healthcare providers themselves, even with insurance coverage. “Doctors have you pay up front and have you go talk to your insurance yourself for the money back. They send you around in circles” (Elders community conversation participant).

For community members without health insurance, the consequences of the high cost of healthcare are particularly dire, leading many community members to rely on the emergency medical services or to avoid receiving healthcare all together. One participant spoke emotionally about a friend of hers who died after losing her job and, consequently, her health insurance. Unable to afford COBRA payments, the woman let her coverage lapse, with ultimately fatal consequences. “A friend was working, had insurance, but she got sick and could not work. Her insurance ended so she had to pay \$2000 with COBRA, she could not afford that, they could not assist her, then after a month [Medi-Cal] would have kicked in, but by then she died” (West African community conversation participant).

The cost of healthcare may not only be a barrier to accessing treatment services, but also for the prevention of long-term illness. “Illness to someone who has money isn’t the same as to someone that doesn’t have money. For example, diabetes may be a particular illness for us because we don’t have the finances to get treatment or even prevent it before it starts. This particular illness continues with us because we don’t have the financial stability to change it” (Pastors community conversation participant).

A culturally-sensitive outreach campaign targeting the African/African Ancestry community is important to educate community members about the long-term health benefits of preventive care. “[Immigrants] think healthcare is very expensive so they see going to the doctor as an extra cost or burden and can’t afford to go. If you are trying to make ends meet, healthcare is secondary. Financial restraints are really big. They go to the doctor when they hurt or are sick. They don’t see preventative care as necessary until something drastic happens and that will make them go. Any type of education for preventative care is missing” (East African community advocate key informant).

Because of the prohibitive costs, with and without insurance, some community members may only access healthcare during emergencies. Public employees responded that for some community members, emergency services are the primary or sole source of healthcare access. “For a lot of people, no matter what color, the healthcare system is out of reach. What I have experienced is that more people are using the 911 system as healthcare. We [the Fire Department] provide basic care if they’re not traumatic or acute. They know the only way to get free care is this way and they are okay with this. Some call every week or day. So they use the 911 system as their provider because they don’t have the money to spend on a physician” (Black Infant Health Advisory Board community conversation participant).

For several participants, preventive and routine healthcare costs prohibit regular access to these services. Some participants acknowledged that the high costs of healthcare create such a barrier that medical treatment may only be obtained through emergency services. “When I didn’t have Medi-Cal, I would not go to the doctor. I would have to call 911 if it got bad. I took meds over the counter or got a home remedy; I didn’t have coverage and couldn’t pay out of pocket for medication. When the hospital gave me a bill, I got sick just looking at it” (Elders community conversation participant).

### Percentage of individuals living in poverty by race/ethnicity, 2000-2012

Race/ethnicity	2000	2010	2012
<b>African American</b>	10	14	16
<b>Asian</b>	7	7	9
<b>Latino</b>	13	16	19
<b>Non-Hispanic White</b>	4	6	6
<b>Santa Clara County</b>	8	9	11

Note: Poverty is defined as living at or below 100% of the Federal Poverty Level (FPL).

Sources: U.S. Census Bureau, 2000 Census, 2010 American Community Survey 5-Year Estimates, 2012 American Community Survey, 1-Year Estimates

Older members of the African/African Ancestry community may experience more cost sensitivity than other members of the community. Healthcare and medications for older residents are typically expensive and their financial resources may be fixed and/or low. These issues are common for seniors across all racial/ethnic groups. In addition, the high costs of healthcare can be especially prohibitive for older community members who are dealing with end of life care. “When my grandmother first went to the end of life care it was \$3300 a month and when she needed extra care, if she hadn’t sold her home, she wouldn’t have gotten that care” (Pastors community conversation participant).

Regardless of access to additional resources to supplement healthcare costs, the additional financial stress of end of life care affects both the community members and their family. “My husband died about a year ago. I have real experience of what happens if you don’t have insurance. He had VA insurance and I had long [term] care insurance. All of the expenses that the care he used in facility was about \$6000 month. I am blessed to have had the insurance to cover it. If I hadn’t, we would have been destitute or he wouldn’t have been able to go to the facility... You never know what’s going to happen” (Elders community conversation participant).

Although the high cost of healthcare is an issue that affects all racial/ethnic groups, African/African Ancestry community members have a lower median household income (\$65,347) than the county overall (\$91,425) (please see the table in Community health overview for more information). A higher percentage (16%) of African/African Ancestry community members live in poverty than the county overall and most other



racial/ethnic groups in the county.<sup>2</sup> Financial difficulties can make the cost of obtaining healthcare particularly challenging as community members might have to choose between the basic necessities of life and healthcare services. As one participant noted, “Another issue is affordability to get right treatment, like higher class, middle class people do. [We] don’t get as much prevention and regular maintenance care because [it’s] unaffordable” (Homeless men community conversation participant).

Some participants acknowledged that they must put the cost of healthcare in a balance with the high cost of living. “[The] price of healthcare is very, very high. You have that dilemma. Do I buy food today or get my medicine?” (Political leader key informant).

## References

1. U.S. Census Bureau, 2012 American Community Survey 1-Year Estimates
  2. U.S. Census Bureau, 2012 American Community Survey 1-Year Estimates
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## Lack of support for the most vulnerable

### Introduction

The most vulnerable members within the African/African Ancestry community systematically have difficulty accessing sufficient high quality services in Santa Clara County. In particular, homeless people, people with disabilities, and both youth and adults who are or have been involved with the criminal justice system struggle to receive the services they need to support their health and well-being.

### Key findings:

- Homeless community members and those who have been involved with the criminal justice system do not get the services they need to support their health and well-being.
- The overrepresentation of African/African Ancestry community members within vulnerable groups exacerbates problems affecting the health and well-being of the whole community.

### Services for homeless people

Homeless people face specific health threats and corresponding needs related to lack of income and the state of homelessness. According to the 2013 Santa Clara County Homeless Point-In-Time Census and Survey, 22% of the homeless population in the county are African/African Ancestry, an increase from 17% in 2011.<sup>1</sup> Many homeless participants pointed out that the very fact of being homeless itself is an illness. For people who live on the streets, the basic components of well-being such as access to food and shelter and being able to maintain basic hygiene are often elusive.

*“You know speaking about myself, being homeless is an illness. Because it’s like I was saying your body don’t feel motivated or responsible when it comes to handling a situation. Being homeless that’s what a homeless person goes through, when their mind going every which way. And when you try to talk to them about a situation and they can’t come up with [a good response].”*

(Homeless men community conversation participant)

*“Health to me means getting a night’s sleep, being able to cleanse my body in the morning with a shower, putting on clean clothes. Um, and feeling like, feeling human you know. I feel inhuman when I’m denied those things. It takes a toll on me, my overall middle...mind or change when I’m denied the way that I normally live. So...I hate to think of being homeless. ...Being out there on the streets is really rough.”*

(Homeless men community conversation participant)

The logistics of being on the streets often prevents homeless community members from accessing health information and health services. One community advocate described the challenges of seeking services while living on the streets. “Homeless [people]—they don’t want to leave their stuff. It’s a barrier. It can get stolen, damaged, whatever. They’re not going to come in for care. You have to go to them” (Community activist key informant).

As African/African Ancestry homeless community members and those who work with them noted, the siloed nature of most health and social services also creates barriers for homeless people, many of whom have a multiplicity of needs. As a county public defender noted, “When I say support, there are a lot of times that

people need more than just the mental health treatment... a homeless person who has mental health issues, you can treat the mental health, but if you don't find some services that address the reasons why they are homeless – because its more than having mental health issues, then they are back in the same situation as before – they are on meds but homeless. We need system that addresses all their needs – housing food, all the basic needs, in addition to healthcare needs because they are all interrelated” (Public defender key informant).

Additional factors like recent incarceration, mental illness and drug use as well as the emotional toll of homelessness can impede a homeless individual's ability to access healthcare services, even those provided by public agencies for low or no-income populations. Considering these barriers to access, services that are not integrated or easily accessible by nature do not adequately meet the needs of the homeless people.

### ***Services for individuals involved with the justice system***

The general lack of services for vulnerable groups, especially a lack of holistic services, also impacts the well-being of community members who are or have been involved with the criminal justice system. As a youth advocate who started a community-based organization to work with juvenile-justice involved African/African Ancestry youth noted, “[There are] not enough agencies to directly affect the issues in the juvenile justice system. We need to create reentry programs for kids coming out of justice system and general programs for African American youth” (Youth advocate key informant).

As one mental health provider describes, the impact of stigma and other outcomes of youth incarceration last far longer than the reentry process. This early involvement with the criminal justice system hinders their ability to navigate and access societal and healthcare systems at a later time. Yet reentry services are not adequately designed to assist youth to transition from inside the juvenile justice system. “The group I'm most concerned with is youth in the criminal justice system. At a young age they get stigmatized by what happens in that system and many don't realize how troubling that is going to be. Once they get hooked into it, the end result is ... they don't understand how it will impact their ability to move in society, get the basics in their life and basic healthcare” (Mental health professional key informant).

*“The mentoring systems are relatively weak; when they come out of the justice system they go back in and don't have skills they need to adjust to life. [There are] not enough agencies outside of criminal justice system to monitor and help these kids adjust.”*

(Youth advocate key informant)

Adult members of the African/African Ancestry community who are or have been involved with the criminal justice system also lack adequate resources and services. Incarcerated community members face barriers to accessing healthcare inside the criminal justice system as well as after reentry. Many participants recalled their struggles to get seen by a healthcare provider for treatment once incarcerated.

*“[The] only reason they treat you is because of the law and many people die in prison. I knew someone who had chest pains and the CO [Correctional Officers] told him to go lay down and he died of a heart attack.”*

(Reentry community conversation participant)

*"I have witnessed people banging doors down to get care [in prison]. And these people are getting out and bringing all those sicknesses outside."*

(Reentry community conversation participant)

*"The only way to get medical attention is to fall to the ground, 'Man Down.' That's the only way to see the doctor. I used to do that all the time."*

(Reentry community conversation participant)

*"Then they charge you a co-pay if you do not have money on the books (\$5 every time you see the doctor) and they will hold you until they receive payment."*

(Reentry community conversation participant)

Those involved with the criminal justice system noted individuals' inability to access services and resources for a successful reentry, especially healthcare services. "One of the major issues is to access healthcare, specifically as it relates to mental health and physical health. A number of my clients are indigent and unemployed therefore they do not have access to health [insurance] or able to [get] insurance through their employer for healthcare related to treatment of physical illness or mental illness. I would say the number one issues is related to access to healthcare" (Public defender key informant).

This public defender noted that after being released from the criminal justice system, formerly incarcerated community members simply do not have access to preventive care through the healthcare system. "Number one is access to adequate care. Number two is sufficient follow up- I don't know if there are programs that monitor follow up with respect to their care. Follow up and/or subsequent care is number two, in terms that they may go to emergency room and get their issue dealt with but there is inadequate follow up and/or preventative care – is another issue that is common amongst these individuals. They typically are in crisis mode when they seek medical care or mental healthcare, and there is no preventative services out there for them that they are able to take advantage of" (Public defender key informant).

Community members who are involved with the criminal justice system often have a multiplicity of needs, which are often not addressed in a healthcare system that is better designed to address one issue at a time rather than addressing a series of compounding needs. As one of Santa Clara County's Public Defenders noted, many formerly incarcerated community members face co-occurring issues such as mental illness, substance use and homelessness, all of which pose additional challenges to their health and well-being.

*"When they come into the system, they are able to get adequate care, or at least sufficient care, to get stabilized mental health wise, to get appropriate meds. Oftentimes after they get out of custody or on probation, there's no follow through or follow up; an inability to maintain or follow up on the course of treatment. Consequently, they go off meds, decompensate, a lot of times they self-medicate with street drugs. It becomes a vicious circle: They get arrested, in the system, get some treatment in jail, get stabilized, placed, get out, they start to feel good and don't need medication any more, and the cycle repeats. In terms of long term treatment, this is an issue for them, especially as it relates to mental health and long term and permanent services - collateral services. A lot of these individuals have mental health issues but don't have other stabilizing issues with respect to community – housing, employment, and access to social services. So I think it needs a combination not only mental health but also collateral like*

housing, employment, job situation and other services that will support their well-being and mental health and long term.”

(Public defender key informant)

### Percentage of residents who are unemployed by race/ethnicity, 2000-2012

Race/ethnicity	2000	2005	2006	2007	2008	2009	2010	2011	2012
African American	6	--	9	10	10	14	16	15	18
Asian	3	7	5	5	5	9	10	8	8
Latino	6	9	8	6	6	12	15	13	12
Non-Hispanic White	3	6	5	5	6	10	9	9	7
Santa Clara County	4	7	6	5	6	10	11	10	9

Note: Data not available for African Americans in 2005.

Source: U.S. Census Bureau, Census 2000; U.S. Census Bureau, 2005-2012 American Community Survey 1-Year Estimates

### ***Disproportionate impact on African/African Ancestry community***

The absence of adequate services for individuals who are homeless and/or have been involved with the criminal justice system disproportionately impacts the African/African Ancestry community as a whole because of the overrepresentation of community members within these groups. As previously discussed in the racism and discrimination chapter, historical and contemporary discrimination and institutionalized racism intersect to further compound these disadvantages.

The African/African Ancestry community faces both employment and income disparities that may be a contributing factor for homelessness. According to data from the U.S. Census Bureau, the percentage of unemployed African/African Ancestry community members ages 16 and older tripled from 6% in 2000 to 18% in 2012. In 2012, the percentage of unemployed African/African Ancestry community members was higher than all other racial/ethnic groups and the county overall.

African/African Ancestry community members are also overrepresented within the juvenile justice systems, both nationwide and in the county. Even though the African/African Ancestry community represents approximately 2% of the children and youth enrolled in K-12 education in Santa Clara County, they experience a disproportionately high felony arrest rate considering their small population size in the county.<sup>2</sup> In 2012, the felony arrest rate for violent offenses among African/African Ancestry children and youth ages 0-17 was 524 per 100,000 children and youth. The overall county felony arrest rate for violent offenses was 89 per 100,000 children and youth. Participants noted that stereotypes directly affect the way public sector employees work with African/African Ancestry children and youth, which in turn might be contributing to disproportionately high arrest rates.

*“Folks who are working in the criminal system, particularly the police officers, they are not used to not working with African American youth. There is a tendency to over-identify and over-involve our young*

*people with any kind of behavior that that puts them at risk. In one neighborhood, things may be handled in a way doesn't involve the youth put into criminal justice system, often times the African Americans, they are over identified and therefore more often than in other neighborhood getting arrested and going to jail. Part of the problem is those folks who are policemen and others. Disproportionately our kids are arrested for things that other kids are not arrested for in other communities."*

(Educator key informant)

### Rate of felony arrests for violent offenses among juveniles ages 0-17 by race/ethnicity

Race/ethnicity	Number	Rate per 100,000 children ages 0-17
African American	49	524
Latino	253	157
Non-Hispanic White	57	55
Santa Clara County	387	89

Note: Data not available for Asian/Pacific Islanders.

Source: State of California Department of Justice, Criminal Justice Statistics Center, 2012

Research suggests that the overrepresentation of African/African Ancestry children and youth within the juvenile justice system may result from the racism and discrimination experienced in schools. Even when controlling for other factors, African/African Ancestry children and youth are significantly more likely to be suspended and expelled from school than all other racial/ethnic groups, as well as more likely to be referred to the juvenile justice system for school-based infractions. Moreover, once suspended or expelled, these children and youth are also more likely to end up in the juvenile justice system.<sup>3</sup> This link has been well-documented and is labeled the "school-to-prison pipeline."<sup>4</sup>

Data on suspensions and expulsions in the county, in combination with the qualitative data collected as part of this health assessment, indicates a similar process in effect in the county. African/African Ancestry children and youth are disproportionately suspended or expelled as a form of discipline in the schools, comprising 7% of total suspensions and 6% of total expulsions in the county in the 2012-2013 school year, even though African/African Ancestry children and youth represent 2% of students enrolled in the public schools in the county.<sup>5</sup> An advocate who works with African/African Ancestry juvenile justice system involved youth in the county spoke about his experiences in these situations.

*"The education system doesn't do anything to help these kids. In situations where they're in trouble academically or have behavioral and truancy problems, they're not treated equally. They're treated like they already failed, and have no chance of moving ahead. They end up dropping out of school. From there if you don't have a job you have to do something criminal to support yourself. Schools reinforce negative behavior by putting them in situations where they don't think they can succeed."*

(Youth advocate key informant)



## Number of total suspensions and expulsions and percentage of violence and drug related suspensions and expulsions by race/ethnicity, 2012-2013

Race/ethnicity	Total suspensions	Violence and drug related suspensions %	Total expulsions	Violence and drug related expulsions %
<b>African American</b>	1,066	62	14	100
<b>Asian/Pacific Islander</b>	1,318	70	17	88
<b>Latino</b>	9,587	60	180	92
<b>Non-Hispanic White</b>	2,057	66	15	87
<b>Santa Clara County</b>	14,589	62	231	92

Source: California Department of Education, DataQuest, 2012-13

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## **(Dis)empowerment and power of choice**

### ***Introduction***

Many African/African Ancestry participants reported that a confluence of issues described earlier in the report contributes to an overall sense of a lack of personal choice in their experiences with the healthcare delivery system. In particular, participants reported a lack of choice in terms of choosing service providers, in part due to provider assignment by the system and in part due to underrepresentation of African/African Ancestry members in the healthcare professions. Many community members have healthcare providers who lack cultural competence and ability to understand and assist with their health and well-being needs, often depriving them of personal choice and agency.<sup>1</sup>

### **Key findings:**

- Many participants experience a lack of choice in healthcare providers and services.
- A lack of personal choice combined with cultural incompetence and mistreatment by healthcare providers contributes to a context in which African/African Ancestry community members do not feel empowered to advocate for their health and healthcare needs.
- Many participants noted the value of involving other trusted community members, especially ones with medical experience, to help them navigate and advocate for themselves within the healthcare system.

### ***Assigned services and providers***

Many participants reported often being assigned to service providers without the opportunity to choose for themselves. This lack of choice is influenced by the underrepresentation of African/African Ancestry members in healthcare professions. Often, this absence of choice resulted in community members receiving services from providers who lacked cultural competence and/or the knowledge to address the needs of African/African Ancestry patients, resulting in negative experiences with healthcare service delivery. One participant described her experience with seeking mental healthcare. Despite requesting a Black psychologist, she was referred to a White provider who affirmed her concerns by immediately misreading cultural cues regarding her emotional state.

*"I asked for a psychologist of color. I thought I could relate better. Instead they gave me a white man. I explained to him that no one in my family admitted to going to a psychiatrist, and I've never been to one. I've been taught that I am a strong Black woman, that's how I was raised, that I just have to be strong. You deal with your problems head on and keep moving. So after talking with that doctor, about the third visit of going through everything, he said, 'I don't see anything wrong with you, I'm looking at you, you look fine to me.' ... I went back to administration, saying, there has to be a Black psychiatrist somewhere in this whole system, then they referred me to a Black woman and it was great after that. When I initially asked, they insisted on the white guy, he didn't even try to understand my culture, he didn't make an attempt."*

(African/African Ancestry health expert key informant)

*“Families come to an agency, why not have the choice of what type of social worker they want to work with? ... They don’t get that choice.”*

(Social worker key informant)

Some participants reported a lack of information on how to find providers of African/African Ancestry. “I have never seen a Black doctor at Valley Medical. They may have some, but I have never seen them” (Reentry community conversation participant). Participants noted that the absence of African/African Ancestry providers reinforced the lack of choice in their healthcare experiences, and left them feeling discouraged and disadvantaged. “One of the great stumbling blocks for us as a people in Santa Clara County is that you really don’t know how to identify . . . Black doctors, so forth, areas you can go and talk with someone who looks like you who may have a vested interest in your health outcome, more so than just getting paid for your services. That information is hard to find. . . . So you’re in a system and you’re assigned to a doctor but to find a doctor who looks like you and has a vested interest in your people as a whole is very difficult if not impossible. That alone is very discouraging, and you’re put at a disadvantage” (South Bay Black Firefighters representative key informant).

Even when African/African Ancestry providers are available, a number of participants noted that African/African Ancestry patients are rarely directed toward them. An African/African Ancestry social worker discussed the frequency with which he sees African/African Ancestry families referred to services that are culturally inappropriate. “[T]he social worker will not direct appropriate services within their own community, because they think those services are inferior. They will often send them to other agency service providers outside the community. We had a case of an African Ancestry family who needed parenting services. The social worker referred them to a Pacific Islander resource center, not to Ujima or an African-oriented resource center” (Social worker key informant).

Additionally, echoing the experiences of other community members who received culturally incompetent services, he noted that upon being referred to African/African Ancestry providers or relevant services, African/African Ancestry families have more successful outcomes in the child welfare system: “Families from Africa immigrate to America, and they wind up with such a horrific experience in child welfare. When there is a change of workers, where that family is given an African social worker – things get better and they are able to unify the children. Why didn’t that happen when they had the other social worker? In those situations – who was the social worker they gave the family – it made a difference” (Social worker key informant).

## ***Self-advocacy***

The experience of being assigned to inappropriate care or struggling to find care that feels culturally appropriate is a critical factor that undermines the ability of African/African Ancestry community members to utilize health care services as well as advocate for themselves within the healthcare system.<sup>2</sup> Patients experience more participatory provider relationships including greater satisfaction and greater shared decision-making when the health care provider is ethnically concordant.<sup>345</sup> As a representative from the South Bay Black Firefighters Association noted, the experience of being assigned to a health provider who does not understand African/African Ancestry culture or health issues puts community members at a disadvantage when receiving healthcare and discourages them from accessing necessary care. This example and other circumstances discussed throughout this report may dissuade African/African Ancestry community members from advocating for their own health needs.

Issues of provider mistreatment and negative stereotyping also disempower African/African Ancestry community members, many of whom report being met with opposition from providers when trying to

advocate for themselves. As one participant explains, her physician resisted giving her information about healthcare options based on negative stereotypes about black mothers. “Since I am 25 and having my third child, she seemed like she thought I was a welfare queen. We got into an argument about asking for information that I had a right as a patient to have. I think because of my race, I didn’t get the information. When I knew enough to ask, I got push back from her... Finally one of the pharmacists printed up information. Others told me to Google it myself; some of them claimed they didn’t know about the study. ...” (New moms community conversation participant).

Another participant reported a similar experience, noting that provider opposition sometimes takes the form of misinformation or incomplete information sharing. This experience leaves African/African Ancestry community members without the information necessary to effectively advocate for themselves when receiving healthcare services. “Even if you have insurance and go to a county hospital some assume you are on welfare. If you have a baby, assuming you are low income, they give you the Depo shot to prevent you from coming back and don’t tell you the negative side effects, like it dries your milk if you planned to breast feed, or give you a choice. The perception is that you are low income, on Medi-Cal, poor, and not knowledgeable. You don’t cannot make a decision if that is what you want or not” (West African community conversation participant).

Consistent with the issues discussed in the (mis)information and avoidance chapter, these experiences intersect with other issues, including limited knowledge about health and the healthcare system within the African/African Ancestry community, to limit people’s ability to better advocate for their health and healthcare needs. As one participant noted, the feeling that healthcare providers do not have patients’ best interests at heart, in combination with a lack of understanding about healthcare issues facilitates a context in which community members do not feel empowered to ask important questions about their own health. “Often times we go to the doctor and the doctor says something and we may not totally understand, but we have a tendency to take what they say at face value without digging any further or asking follow-up questions to see how it impacts our personal health, and then discussing even further with others who may be able to enlighten us even further on what avenues are available to us” (South Bay Black Firefighters representative key informant).

*“Ignorance keeps people from seeking medical help. [It’s the] attitude of county of origin, certain ailments we live with- headache, runny nose, pains- our mothers lived with terrible pain and did not complain. Ignorance of not knowing what is major. Being treated a certain way keeps people for going, if someone goes there and says they have malaria, people will run away, put them in isolation.”*

(West African community conversation participant)

These concerns were noted by numerous participants, who pointed out that members of African/African Ancestry community lack the information to advocate for their own health and healthcare needs and the system is not set up to address these issues. “Also the lack of education, just not knowing, believing that the doctor told me this, so he or she must be right. Not following up, not challenging the doctor to dig deeper, get more information. You’re talking about your own personal health, or that of your family. Deal with more than just the surface level response, inquire, what can I do?” (South Bay Black Firefighters representative key informant).

Many participants, especially young adults, expressed a feeling that in seeking the information necessary to self-advocate, they had to work against the system. “Unless you know how to play the system to get what you need, you need to navigate the system, and it’s not that easy. You need to know how works. You may be

qualified for services, they are not going to tell you unless you know about it, ask about it” (Young adults community conversation participant).

*“If you want something you have to help yourself and you have to get it yourself.”*

(Young adults community conversation participant)

Many participants noted the value of involving other trusted individuals to help navigate and advocate for oneself within the healthcare system. In some cases, participants advocated for taking along a trusted family member or friend with more experience with the healthcare system. “Knowledge is a great equalizer. It’s great if you have personal knowledge on where to go or what to ask. Even if you don’t, take someone with you that knows what to ask or can advocate for you, negotiate so that you receive the correct type of care. It’s our responsibility to be as aware of a situation as we can be” (Black Infant Health Advisory Board community conversation participant).

*“I had a friend who went back and forth to Kaiser, [she was] sent home with meds for 2 weeks. I was able to tell her to go to the hospital to do XYZ, and then if they are not equipped to treat you tell them you need to go somewhere else. Then they treated her because she had education. ... Those of us who work in a hospital setting know what happens . . . if you don’t have insurance, they will treat you but the minimum and send you home.”*

(African/African Ancestry health expert key informant)

Medical professionals underscored these concerns and relayed their experiences serving as advocates for their family and friends within the healthcare system. Several providers expressed a desire for more advocates to help African/African Ancestry community members better navigate the healthcare system and advocate for their own needs. Many emphasized the importance of having trusted advisors within the healthcare delivery system. Issues of mistrust with the medical system are therefore an additional factor undermining the ability to self-advocate. “Some families don’t necessarily know the value of having your own primary care provider. Especially for teenagers, they see a doctor’s office for emergencies or if you’re sick. But there’s a value of having your own primary care provider who you meet with every one to two years, just to check in to see how things are going, address preventive health issues” (Health professional key informant).

*“Making sure families know the importance of having a primary care provider, OB-GYN, pediatrician, etc., and using us as resources to navigate what they need and what is helpful to keep them healthy. It is shocking to me sometimes that people don’t realize everything that primary care providers have available for patients, and everything we monitor and take care of.”*

(Health professional key informant)

*“If I don’t have the knowledge or expertise then let me seek out someone who can to come with me. If I act as a loner then I may enter that situation lost, unprepared, and come out scared and not receiving services needed because I didn’t understand what the doctor said. The end result is I suffer loss because I went in unprepared.”*

(Black Infant Health Advisory Board community conversation participant)

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# Strategies and recommendations

Throughout the course of this health assessment, one of the primary objectives of the steering committee and the larger stakeholder group has been the identification of strategies to address the disparities delineated in this report. The need to develop a plan of action has permeated all aspects of this health assessment, from the Stakeholder Forum in November 2013 to the steering committee meetings to the community conversations and key informant interviews to the June 2014 Health Summit. During community conversations and key informant interviews, community members were asked to reflect on identified issues or challenges, propose strategies for improvement, and recommend stakeholders, agencies, and organizations who should be involved in the implementation of these strategies. At the June 2014 Health Summit, attendees had the opportunity to review the health assessment findings and then discuss strategies to address each of these findings in small groups.

Through these processes, community members has had the opportunity to be part of the planning around next steps in order to ensure that the strategies and recommendations are truly community-driven. Moreover, in recognition of the multiplicity of actors and institutions whose actions impact the health and well-being of any community, these strategies and recommendations are intended to encompass a wide variety of organizations and individuals.

## Collaborative strategies

The strategies described here involve partnerships between local African/African Ancestry organizations as well as with public and private partners in Santa Clara County.

1. **Develop an online resource center.** One of the critical concerns that has emerged throughout this health assessment is the lack of culturally competent health and healthcare services, information, and outreach for African/African Ancestry community members in Santa Clara County. An online health resource center should be a key component of beginning to address these issues. An online resource center would provide information about health needs and concerns of interest to the African/African Ancestry community in a way that is culturally relevant and widely available. This online resource center could also provide a directory of African/African Ancestry health professionals in the county as well as a directory of individuals who have the *African/African Ancestry Skills and Knowledge Certification* (discussed in the next strategy).
2. **Require *African/African Ancestry Skills and Knowledge Certification* for all health and social service professionals working with African/African Ancestry community members.** The *Criteria for Afro-Centric Interviewers, Facilitators, and Scribes* used to recruit facilitators and scribes for this health assessment (and available in Appendix C), was based on an *African/African Ancestry Skills and Knowledge Certification* process that used to be available in Santa Clara County. The county should work with local African/African Ancestry community leaders to update this certification process and to require it for all health and social service providers who work with African/African Ancestry community members. The certification should also be available on a voluntary basis to individuals who are not required to become certified. The county should track the number of individuals who become certified and who are employed in each county agency or contracted service provider. The names of certified individuals and the organizations where they work should be available on the county website and on the African/African Ancestry resource center website.
3. **Train Afro-centric health coaches and employ them at public and private healthcare service locations.** Health coaching is an innovative but increasingly common way of improving patients'

experiences in healthcare settings by ensuring that they have a more thorough understanding of their own health as well as of the healthcare process, including the recommendations of their healthcare providers.<sup>1</sup> Health coaching can be performed by physicians, nurse practitioners/physician assistants, registered nurses (RNs), pharmacists, health educators, nutritionists, medical assistants, or community health workers/promotoras or champions (trained members) in the community.<sup>1</sup> The Santa Clara County Public Health Department and the Black Leadership Kitchen Cabinet (BLKC) should work to identify an existing health coaching curriculum and to revise it to incorporate an Afro-centric perspective that addresses issues of bias and privilege. The county should then work with the BLKC and other local African/African Ancestry organizations to recruit and train African/African Ancestry health coaches and to employ them at public and private healthcare service centers. As with the *African/African Ancestry Skills and Knowledge Certification*, the names and locations of African/African Ancestry health coaches should be available online, including on the county website and on the African/African Ancestry resource center website.

4. **Establish an African/African Ancestry Health Week.** Establishing an African/African Ancestry health week would provide an opportunity for government agencies, healthcare providers, community-based organizations, and African/African Ancestry health consumers to all come together to promote the health and well-being of the African/Ancestry community. All of these partners should come together to share information and resources, answer questions, promote services, and build relationships.
5. **Bring health resources into the community.** Throughout this health assessment, community members noted the difficulty of obtaining the information that they need about health and the healthcare system. In addition, this challenge is exacerbated by the limited number of African/African Ancestry health providers and agencies as well as by community members' distrust for health professionals and institutions. To address these issues, the county and local African/African Ancestry organizations should work together to establish health resource centers inside existing community organizations such as churches, mosques, and other places of worship. This would allow partners to leverage one of the African/African Ancestry community's strongest assets, the strength of indigenous institutions, to help overcome one of the most commonly noted barriers to improved health. Health coaches should be made available in these health resource centers to help community members.
6. **Initiate a community-driven messaging campaign.** Health professionals and community members who participated in this health assessment repeatedly pointed to a lack of outreach to the African/Ancestry community as an important factor limiting community members' knowledge about health and healthcare. In addition to the fact that there is little outreach to the African/African Ancestry community, a number of community members pointed to unfavorable media portrayal of African/African Ancestry community in health and healthcare related outreach materials. To combat both of these issues, the BLKC and other local African/African Ancestry organizations should collaborate with the county and African/African Ancestry health professionals to develop a messaging campaign that is directed towards the African/African Ancestry community using images, language, and media that are resonant for African/African Ancestry community members. This campaign should address both health and healthcare to address the limited availability of information on both of these issues.

7. **Develop and promote an Afro-centric definition of health. Use this definition as a measure of health and well-being among African/African Ancestry community members.** Health assessment participants pointed out that Afro-centric conceptions of health and well-being tend to be holistic, incorporating physical, mental, and spiritual health and well-being, in contrast to Euro-centric definitions which differentiate between physical and mental health and generally exclude spiritual health. Moreover, because metrics for health and well-being stem from Euro-centric institutions, these metrics tend to reinforce disconnected measures of health and well-being. In order to promote a more accurate definition of what health is for African/African Ancestry community members, local African/African Ancestry organizations should work together to establish Afro-centric definition of and to identify indicators for measuring health and well-being among the community members. The African/African Ancestry community should then work with public and private partners to disseminate this information and require collection of appropriate metrics for measurement.
8. **Implement health consumer satisfaction surveys at public and private healthcare settings.** In order to assess the healthcare satisfaction of African/African Ancestry community members in comparison to the healthcare satisfaction among members of other racial/ethnic groups, public and private healthcare settings, including hospitals and clinics, should create customer satisfaction surveys that explicitly ask about consumer's race/ethnicity and about the cultural relevance and competence of the services they receive. These data should be published annually and made available on the online African/African Ancestry resource center and other healthcare related websites.
9. **Establish an Afro-centric Health Clinic.** Establishing an Afro-centric Health Clinic with services that are tailored for African/African Ancestry community members in Santa Clara County would go a long way toward addressing many of the issues identified throughout this report, including the lack of culturally competent services, the difficulties of locating African/African Ancestry health providers, the limited availability of accurate and culturally relevant information, and the reliance on Euro-centric definition of health and well-being. This health clinic should strive to employ a predominantly African/African Ancestry staff, who are certified in the *African/African Ancestry Skills and Knowledge Certification* described above, and it should train and employ Afro-centric health coaches. This clinic should provide both physical and mental health services from an Afro-centric perspective to address patients' needs in a holistic way and to break down silos between physical and mental health services. In addition, this clinic should build on the existing infrastructure of African/African Ancestry organizations in the county.

## Individual strategies

In addition to identifying strategies at the organizational and institutional levels, community members identified a number of strategies that African/African Ancestry community members and families should take to improve their own health and well-being. These include:

1. **Take someone with you to healthcare appointments.** Community members noted that it can be difficult for healthcare consumers to advocate for themselves and easy for providers to dismiss their concerns when people attend healthcare appointments on their own. Many community members spoke of bringing family members or friends with them to appointments as a way to bolster their own confidence in self-advocacy and to make it more difficult for providers to overlook their concerns.

2. **Engage and advocate.** To ensure that the issues identified and strategies developed as a result of this health assessment continue to receive the attention they deserve from the various systems of care, African/African Ancestry community members must continue to advocate for their needs and those of the whole community. Community members must be present at meetings of the Board of Supervisors and other decision-making bodies so that when decisions are made and resources are allocated, the African/African Ancestry community is not overlooked.
3. **Teach children to own their health and their bodies.** African/African Ancestry parents and families must teach children about their bodies and health so that they can take care of their health and advocate for themselves in healthcare settings.
4. **Be a health ambassador.** African/African Ancestry community members can promote their own health and that of the community by becoming health ambassadors and helping others navigate the healthcare system. While health coaches and culturally competent health professionals are important, informal networks are a critical means by which the African/African Ancestry community spreads and receives information and knowledge (i.e. churches, mosques, other places of worship).

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## Conclusion

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This report is the first part of a more comprehensive study to document and understand the health disparities and inequities that exist in the African/African Ancestry community. This health assessment is intended to provide elected leaders, county agencies, and community organizations, advocates, and residents with information, inspiration, and ideas for improving the health and well-being of the African/African Ancestry community in Santa Clara County. With this goal, the report lays the framework for developing a call to action and solutions that will benefit the community and especially those who are underserved, underrepresented, and most in need of services to support and improve their health and well-being.





# Appendix A: Qualitative data collection protocols

## Community conversation questions

### 1. Health, wellness, illness

- a. When you think of health, wellness, and illness, what comes to mind? What does it mean to you?
- b. Prompts for facilitator:
  - i. How people manage health
  - ii. How people cope with stress
  - iii. Strengths/resiliency in our culture/community that helps you/us maintain good health and manage stress
  - iv. Discussion covers general health, mental health, violence, substance use, end of life care

### 2. Healthcare access

- a. In your experience, when you or Africans/African Americans you know in Santa Clara County need health care services, are they easy or difficult to get? What are some barriers, or challenges, to getting care when you need it? What helped, in terms of getting care when you need it?
- b. Have you, or other AAA that you know here, ever faced problems with healthcare related to health insurance? If so, what are some of the problems you have encountered?
- c. What are some of the problems you, or other AAA that you know here, have faced around getting high quality healthcare?
- d. Prompts for facilitator:
  - i. Life experience – worst and best experience when seeking health services

### 3. Healthcare delivery system

- a. Thinking about the health care delivery system as a whole, including doctors, dentists, specialty care, etc.; does the system offer care that is specific to your needs as an African/African American, and to African/African Americans you know here in Santa Clara County?
- b. In your experience, where is the healthcare system doing well in meeting your needs and the needs of others you know in our community? Where is it not doing well?
- c. Prompts for facilitator:
  - i. What prevents people from seeking medical help
  - ii. Cultural sensitive (Afro-centric) approach to health care

### 4. Chronic diseases

- a. Diabetes, high blood pressure, obesity and heart disease are common health problems. This is especially true for our community. What are some of the reasons for this? What contributes to this?
- b. Prompts for facilitator:
  - i. Physical activity
  - ii. Food
  - iii. Prevention
  - iv. Screening tests
  - v. Strengths/resiliency in our culture/community that contribute to avoiding, or managing, these conditions
- c. Given what all of us have said, what is the impact of these diseases on our community?

## **5. Discrimination and Racism**

- a. How does racism and discrimination impact your health, and the health of people you know in the African/African American community here in Santa Clara County?
- b. Prompts for facilitator:
  - i. Life experiences in various settings – work, school, healthcare, neighborhood, etc.
  - ii. How do you and others you know in our community here respond to discriminatory experiences?
  - iii. How do people cope with discrimination?
- c. How are you and other AAA you know here “resilient” in the face of discrimination, and what can we learn from this?
- d. What do you think can be done to reduce discrimination towards our community?

## **6. Additional questions**

- a. What are some of the ways to address the issues that were discussed today? What strengths in our community can we draw on?
- b. Are there any issues that affect you and our community here in Santa Clara County but were missing from our conversation?
- c. How and where do you and others in our community here get the health information you need?

## Key informant interview question sets

### Question set A: Community perspectives on healthcare

1. Please tell me a little bit about your work in Santa Clara County related to health and healthcare for people of African Ancestry? If it is not, please give us an insight/context into how your work relates/intersects with health and well-being for people of African Ancestry.
2. When you think of health, wellness, illness in the context of the African/African Ancestry communities, what priority issues come to mind?
  - a. How do they impact the quality of life in these communities? How do you think African Ancestry communities define these terms of health, wellness and illness?
  - b. For these priority issues, what is your sense of how severe they are in terms of impacting the quality of life for people of African Ancestry who live in your county?


Prompts for facilitator:

- i. How people manage health?
    - ii. How people cope with stress?
    - iii. Strengths/resiliency in our culture/community that helps you/us maintain good health and manage stress
    - iv. Discussion covers general health, mental health, violence, substance use, end of life care
2. From your experience, to what extent do African/African Ancestry residents of Santa Clara County have access to quality, culturally competent health care which meets their needs?
  - a. Are there providers who are knowledgeable about health issues for the African Ancestry community?
  - b. Can you give me specific examples of ways in which African/African Ancestry people lack access to health care in general or to quality health care?
  - c. When considering this lack of access to quality health care, are there issues that come to mind which are more specific to some groups within African/African Ancestry communities, e.g., women, older adults, youth, different ethnic or immigrant groups, etc.?
  - d. What are the health care needs that are unmet (e.g. access to wellness support, prevention, etc.)
  - e. Can you give me specific examples of quality, culturally competent care available for African/African Ancestry people in the county?
3. Discrimination is a serious issue that can have a negative effect on health and wellness. From your experience, how much and what types of discrimination do African/African Ancestry people experience around health care issues and in what contexts? Can you give specific examples?
  - a. By people acting in professional contexts?
  - b. By institutions?
  - c. Are there experiences that are more common among some groups within the African/African Ancestry community, e.g., older adults, youth, different ethnic or immigrant groups, etc.?

4. What barriers exist to obtaining quality, culturally competent health care in the African/African Ancestry community? To greater knowledge about African/African Ancestry population's needs among health care professionals?
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Fairness and discrimination?
  - d. Ability to communicate with limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?
5. Do you know of any programs, policies or practices that are currently underway in the county to improve health care access and quality, culturally competent care for African Ancestry residents?
  - a. Are there enough health professionals who are knowledgeable about health or other issues facing African/African Ancestry residents?
  - b. Are there other existing resources that could be utilized improve health access for African/African Ancestry residents?
  - c. Are African/African Ancestry residents aware of these resources? How do they find out about these services?
  - d. Are these programs working for African community?
6. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
7. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to improve health care and health care access for African/African Ancestry residents?
8. What solutions or strategies would you suggest public health stakeholders consider to improve wellness and disease prevention for African/African Ancestry residents?
9. What role can the community play in efforts to improve health care and access to health care for African/African Ancestry residents in Santa Clara County? To support or promote wellness? What role could you and your organization play?
10. Are there any other issues, trends or problems you see that you have not mentioned?
  - a. Regarding access or quality of health care?
  - b. Regarding health, disease prevention, and supports for wellness?
  - c. (prompt : any closing thoughts)

## Question set B: Mental health and substance use/abuse

1. Please tell me a little bit about your work in Santa Clara County related to addressing mental/behavioral health and substance abuse issues among people of African Ancestry? If it is not, please give us an insight/context into how your work relates/intersects with mental/behavioral health or substance abuse for people of African Ancestry in the county.
2. From your experience, what are the primary mental/behavioral health issues facing residents of African Ancestry?
  - a. To what extent is trauma an issue for people?
  - b. How do these issues compare to those experienced by the non-African/African Ancestry population?
  - c. What do you think contributes to each of these issues for the African/African Ancestry populations?
  - d. When considering mental/behavioral health, are there issues that come to mind which are more specific to some groups within African/African Ancestry communities, e.g., women, older adults, youth, different ethnic or immigrant groups, etc.?
3. What barriers exist to addressing these issues?
  - a. Do African/African Ancestry people have sufficient access to high quality, culturally competent mental health care?
  - b. Probe: are there policies, procedures, or other systemic issues in organizations or agencies that create barriers to addressing mental health issues?
4. What are the most serious substance use and abuse issues facing African Ancestry residents in Santa Clara County?
  - a. What do you think contributes to each of these issues?
  - b. How does substance use and abuse among African/African Ancestry residents contribute to other health or social problems?
  - c. When considering substance use and abuse, are there issues that come to mind which are more specific to some groups within African/African Ancestry communities, e.g., e.g., youth, those who are involved in the justice system, older adults, etc.?
  - d. To what extent is tobacco use an issue within the African/African Ancestry community?
    - i. What contributes to this?
    - ii. Is tobacco use more common among some groups within the African Ancestry community, e.g., older adults, youth, African immigrants, etc.?
5. What barriers exist to addressing these issues?
  - a. Probe: are there policies, procedures, or other systemic issues in organizations or agencies that create barriers to addressing substance use and abuse? Tobacco use and cessation?
6. What are the issues surrounding African/African Ancestry residents in receiving mental health or substance abuse services? What do you feel African/African Ancestry residents of Santa Clara County experience in terms of:

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- a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Fairness and discrimination?
  - d. Ability to communicate with limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?
7. Do you know of any programs, policies or practices that are currently underway in the County to address mental health and/or substance abuse issues and/or tobacco use and cessation among African/African Ancestry people in Santa Clara County? (probe: if so, please describe)
    - a. What is working well about these programs, policies or practices? What is not?
    - b. Are there enough mental health professionals or substance use/abuse counselors who are knowledgeable about issues in the African/African Ancestry Community? In the East or West African Communities?
    - c. Are there enough programs or places residents can go to address these issues? Is it easy to get?
    - d. Do you think African/African Ancestry residents or residents of African descent are aware of these resources? If so, how do they find out about these services? If not, how can people be encouraged to utilize these resources?
    - e. Are there other existing resources that could be utilized to address these issues?
  8. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
  9. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address mental health and/or substance abuse issues among people of African and African Ancestry in Santa Clara County?
  10. What role can the community play in efforts to improve mental health and reduce substance abuse among African/African Ancestry residents in Santa Clara County? What role could you and your organization play?

Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?



## Question set C: Elders/ chronic illness/ HIV/AIDS

1. Please tell me a little bit about your work in Santa Clara County related to the aged and/or persons with chronic health issues in the African Ancestry Community. If it is not, please give us an insight/context into how your work relates/intersects with these topics for people of African Ancestry in the county.
1. **Regarding Elderly:** From your experience, what are the biggest issues affecting the health of African/African Ancestry elderly in Santa Clara County? (First hear from them what they think the issues are, then probe with the following)
  - a. Are there issues that are more common among some groups within African ancestry communities, e.g., different ethnic or immigrant groups, men versus women, etc.?
  - b. To what extent are African/African Ancestry elderly affected by economic insecurity in Santa Clara County? Please describe. How are these issues impacting the health of African/African Ancestry elderly?
  - c. Can you speak to the issue of isolation among African/African Ancestry elderly? What do you think are the health impacts of this isolation?
  - d. How do African/African Ancestry family structures affect the health of the elderly, either in a positive or negative way?
2. **Regarding chronic disease:** From your experience, what are the biggest chronic health issues affecting people of African Ancestry in Santa Clara County? (First hear from them what they think any other issues are – such as high blood pressure, obesity, asthma-, then probe with the following)
  - a. What are the factors in African/African Ancestry communities which make these chronic illnesses prevalent?
    - i. What are the environmental factors, if any?
    - ii. In your experience, do African/African Ancestry residents have sufficient information regarding the prevention and treatment of chronic illness?
    - iii. Is chronic illness more of a concern among some groups within the African/African Ancestry community, e.g., older adults, youth, low income different ethnic or immigrant groups, etc.?
3. **Regarding HIV/AIDS:** From your experience, what are the issues faced by people of African Ancestry with HIV/AIDS in Santa Clara County? (First hear from them what they think any other issues are –then probe with the following)
  - a. Are there issues or experiences that are more common among some groups within African ancestry communities, e.g., youth, different ethnic or immigrant groups, homeless, low income etc.?
  - b. How do African/African Ancestry family structures affect the health and care of people with HIV/AIDS, either in a positive or negative way?
  - c. In your experience, do African/African Ancestry residents have sufficient information regarding the prevention and treatment of HIV/AIDS?
  - d. Can you speak to the issue of isolation among those with long term illness, particularly those with AIDS/HIV? What do you think are the health impacts of this isolation?


4. What are some of the barriers to addressing the needs of African/African Ancestry [elderly/chronic illness/people with HIV/AIDS] in Santa Clara County? (First hear from them about what they think the barriers are, then probe with the following :)
  - a. To what degree do African/African Ancestry elderly and/or chronically ill/people with HIV/AIDS feel confident that they will receive assistance with health and social services that are sensitive to their issues?
  - b. Probe: If they don't feel confident, are there any particular reasons for their lack of confidence?
5. What are the issues surrounding African/African Ancestry [elderly/chronically ill/people with HIV/AIDS] in receiving services? What do you feel African/African Ancestry residents of Santa Clara County experience in terms of:
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Fairness and discrimination?
  - d. Ability to communicate with limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?
6. **Regarding chronic disease:** In your experience, what are the issues with prevention or management of chronic illnesses among African/African Ancestry residents of Santa Clara County?
  - a. What are the barriers to prevention and management of chronic illnesses?
    - i. Regarding illnesses improved by lifestyle or environmental changes?
7. Do you know of any programs, policies or practices that are currently underway in the county to improve the health and wellbeing of [African/African Ancestry elderly residents/ people with chronic disease/people with HIV/AIDS]?
  - a. What's working? What's not working?
  - b. What are your thoughts on the need for or the availability of support programs aimed at improving the home care received by African/African Ancestry elderly residents or the chronically ill – such as training and technical assistance to service providers?
8. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
9. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to improve the health and wellbeing of African/African Ancestry [elderly residents/ people with chronic disease/people with HIV/AIDS]?
  - a. Are there other services or supports, in addition to physical health care, you would suggest public health stakeholders consider to improve the wellbeing of the [elderly/ chronically ill/people with HIV/AIDS].
10. What role could you and your organization play in efforts to improve the health African/African Ancestry [elderly residents/ people with chronic disease/people with HIV/AIDS]? What about other community organizations or groups in addition to public health stakeholders?

Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?

## Question set D: Women/ maternal and infant

1. Please tell me a little bit about your work in Santa Clara County related to women's health issues, particularly for African Americans and residents from African countries. If it is not, please give us an insight/context into how your work relates/intersects with the health and well-being for women of African Ancestry in the county.
2. From your experience, what are the primary health and health care issues facing African/African Ancestry women?
  - a. Are there issues or experiences that are more common among some groups within African ancestry communities, e.g., older women, younger women, different ethnic or immigrant groups, homeless, low income etc.?
    - i. Are there issues around access to women's health care in general?
    - ii. Regarding prenatal care and infant care?
    - iii. Regarding contraception and other reproduction-related services?
    - iv. Regarding breast cancer and other health challenges facing women specifically?
    - v. Are there health issues stemming domestic violence or other problems in the living environment (including homelessness)
    - vi. Are there issues surrounding education/information for African/African Ancestry women regarding their health care issues?
    - vii. Other?
    - viii. Can you give specific examples?
3. What barriers exist to addressing these issues? (First hear from them about what they think the barriers are, then probe with the following :)
  - a. To what degree do African/African Ancestry women feel confident that they will receive health and social services that are sensitive to their issues?


Probe: If they don't feel confident, are there any particular reasons for their lack of confidence
  - b. Are there experiences that are more common among some groups of females within the African/African Ancestry community, e.g., youth, older women, different ethnic or immigrant groups, etc.?
  - c. Are there situational or perception issues which prevent African/African Ancestry women from obtaining health care?
    - i. Is there fear or misunderstanding about addressing health issues?
    - ii. Is there fear or mistrust about health care practitioners/delivery?
4. What are the issues surrounding African/African Ancestry women's access to health and healthcare services? What do African/African Ancestry women in Santa Clara County experience in terms of:
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Fairness and discrimination?

- 
- d. Ability to communicate with limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?
  5. Do you know of any programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
    - a. Are there other existing resources that could be utilized address these issues?
    - b. What programs would you like to see to address the issues you identified?
  6. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
  7. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?
    - a. there other services or supports, in addition to physical health care, you would suggest public health stakeholders consider to improve the wellbeing of the women and mothers.
  8. What role can you and your organization play in addressing the issues you mentioned for African/African Ancestry women in Santa Clara County? What about other community organizations or groups in addition to public health stakeholders?

Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?

## Question set E: Youth/ young adults

1. Please tell me a little bit about your work in Santa Clara County related to youth and young adults in the African Ancestry Community. If it is not, please give us an insight/context into how your work relates/intersects with youth of African Ancestry in the county.
2. From your experience, what are the primary health issues facing African/African Ancestry youth, particularly in terms of health, mental health and/or general wellbeing? Can you give specific examples of any of these issues you identify?
  - a. Are there concerns that are more common for some groups within African ancestry communities, e.g., girls versus boys, different ethnic or immigrant groups, homeless, low income etc.?
  - b. Are there age ranges or school grades that are of particular concern (preschool, grade school, junior high, high school, 18-24 years)?
  - c. Are there specific issues surrounding:
    - i. Schools and education of African/African Ancestry youth?
    - ii. At-risk youth and the criminal justice system?
    - iii. Youth in the foster care system?
    - iv. Youth in immigrant families?
    - v. College-age youth?
  - d. Are there any other issues that come to mind? (Homelessness, lack of employment opportunities, etc.)
3. What barriers exist to addressing each of these issues?
  - a. Do African/African Ancestry youth have access to high quality culturally competent health care?
4. Do you know of any programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
  - a. What is working? What is not?
  - b. Are there other existing resources that could be utilized address these issues?
  - c. What programs would you like to see to address the issues you identified?
5. What are the issues surrounding African/African Ancestry youth in receiving health and healthcare services? What do African/African Ancestry youth of Santa Clara County experience in terms of:
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Fairness and discrimination?
  - d. Ability to communicate with limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?


- 
6. Do you have any comments about how formal or informal institutions could better assist with these issues and improve the health, mental health and wellbeing of African/African Ancestry youth?  
Institutions which have been mentioned in by stakeholders include:
    - a. Schools
    - b. Foster care system
    - c. Correctional institutions
    - d. Do others come to mind?
  7. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
  8. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?
    - a. Are there other services or supports, in addition to physical health care, you would suggest public health stakeholders consider to improve the wellbeing of youth?
    - b. What supports or other services could support African/African Ancestry families in raising youth?
  9. What role can you and your organization play in addressing the issues you mentioned for African/African Ancestry youth in Santa Clara County? What about other community organizations or groups in addition to public health stakeholders?

Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?



## Question set F: Family and domestic issues

1. Please tell me a little bit about your work in Santa Clara County related to families and/or domestic issues, particularly for African Americans and residents from African countries. If it is not, please give us an insight/context into how your work relates/intersects with this topic for people of African Ancestry in the county.
2. From your experience, what are the primary health issues facing families and households of African Ancestry - particularly in terms of physical health, mental health, and overall well-being?
  - a. Are there experiences that are more common among some groups within African ancestry communities, e.g., different ethnic or immigrant groups, or low income families, etc.?
  - b. Prompts:
    - i. Parenting and supports for parenting
    - ii. Foster care system
    - iii. Domestic violence
    - iv. Economic security
    - v. Education
    - vi. Are there other issues you would like to mention?
    - vii. Can you give specific examples of these issues?
3. What barriers exist to addressing each of these issues?
  - c. To what extent do African/African Ancestry families have access to high-quality, culturally competent health care? Mental health care?
  - d. To what extent do African/African Ancestry victims of domestic violence have access to high-quality, culturally competent health care and services? Mental health care?
  - e. To what extent do African/African Ancestry perpetrators of domestic violence have access to high-quality, culturally competent treatment and services? Mental health care?
4. Do you know of any programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
  - a. What is working? What is not?
  - b. Are there other existing resources that could be utilized to address these issues?
  - c. What programs would you like to see to address the issues you identified?
5. Are there any barriers with regard to the social services/programs that address with these issues, such as:
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Discrimination?
  - d. Ability to communicate with those of limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?




f. Other?

6. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
7. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?
8. What role can you and your organization play in addressing the issues you mentioned for African/African Ancestry families and related domestic issues in Santa Clara County? What about other community organizations or groups in addition to public health stakeholders?
9. Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?


## Question set G: Criminal justice

1. Please tell me a little bit about your work in Santa Clara County related to the criminal justice system, particularly involving African Americans and residents from African countries. If it is not, please give us an insight/context into how your work relates/intersects with this topic for people of African Ancestry in the county.
2. From your experience, what are the health issues facing those involved in the criminal justice system, in terms of physical health, mental health, and overall well-being?
  - a. Are there experiences or issues that are more common among some groups within African ancestry communities, e.g., women/girls versus men/boys, different ethnic or immigrant groups, homeless, low income etc.?
  - b. Are there particular issues related to:
    - i. Incarceration
    - ii. Re-entry into the community
    - iii. Youth and gang-related issues
    - iv. Violence prevention
    - v. Other?
3. Can you give specific examples of these issues?
4. What barriers exist to addressing each of these issues?
  - a. To what extent do African/African Ancestry people in the criminal justice system have access to high quality culturally competent health care? Mental/behavioral health care?
5. Do you know of any programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
  - a. What's working? What's not?
  - b. Are there other existing resources that could be utilized to address these issues?
  - c. What programs would you like to see to address the issues you identified?
6. What are the issues surrounding African/African Ancestry people in the criminal justice system in receiving health and healthcare services? What do people experience in terms of:
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. Fairness and discrimination?
  - d. Ability to communicate with limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?
7. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
8. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?

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9. What role can you and your organization play in addressing the issues you mentioned for African/African Ancestry residents involved in the criminal justice system in Santa Clara County? What about other community organizations or groups in addition to public health stakeholders?
  10. Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?

## Question set H: Social services access and delivery

1. What is your role/job/function in Santa Clara County? In your role, how do you serve African American and/or residents from African countries? What services do you and/or your organization provide?
  - a. If your role is not related to social services delivery, please give us an insight/context into how your perspective relates/intersects with social services access and delivery for people of African Ancestry in the county.
2. From your perspective, what are the primary issues affecting the physical health, mental health, and overall wellbeing of African/African American individuals in Santa Clara County?
  - a. Are there experiences or issues that are more common among some groups within African ancestry communities, e.g., men versus women, families, different ethnic or immigrant groups, homeless, etc.?
  - b. Prompts:
    - i. Health and health care
    - ii. Mental health or substance abuse
    - iii. Aid to families and households
    - iv. Foster care
    - v. Housing and shelter
    - vi. Other issues that are or could be addressed by social services?
    - vii. Can you give specific examples?
3. From your perspective, what issues are facing social service agencies in the delivery of services to African/African American residents in Santa Clara County? Particularly in terms of:
  - a. The quality and/or efficient delivery of these social services?
  - b. The ability of residents to be aware of, access and utilize available social services?
  - c. The amount or level of services provided for certain social services?
  - d. The coordination of related social services?
  - e. Meeting unmet needs?
  - f. Other?
  - g. Can you give specific examples?
4. What barriers exist to addressing each of these issues?
  - a. What are barriers to accessing high quality, culturally competent social services?
  - b. What barriers exist to improving service delivery?
5. Do you know of any programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
  - a. What do you think is working? What is not?
  - a. Are there other existing resources that could be utilized address these issues?

- 
- b. What programs would you like to see to address the issues you identified?
6. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
  7. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?
  8. What role can you and your organization play in addressing the issues you mentioned for African/African Ancestry residents in Santa Clara County? What about other community organizations or groups in addition to public health stakeholders?
  9. Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?




## Question set I: Healthcare providers' perspective

(health care access, quality, health trends and issues)

1. Please tell me a little bit about your work in Santa Clara County related to providing health care, particularly for African/African Ancestry residents in the county. If it is not, please give us an insight/context into how your work relates/intersects with health care providers or health care services for people of African Ancestry in the county.


(We are looking for information regarding both African Americans and immigrants from African countries. Generally, I may use the term African/African Ancestry to be inclusive of those who have emigrated from African countries).
2. From your experience, what are the primary health issues facing African/African Ancestry residents in terms of physical health, mental health and overall well-being?
  - a. Are there health issues that are more common among some groups within African ancestry communities, e.g., men versus women, families, different ethnic or immigrant groups, homeless, etc.?
  - b. Prompts:
    - i. What social problems are affecting the health of your patients?
    - ii. What are the physical health and mental health problems facing your patients?
    - iii. What health care needs do you see that are not being met?
3. What barriers exist to addressing each of these issues?
4. From your experience what issues do you see regarding the delivery of health care services?
  - a. Availability of and access to services?
  - b. Quality of services and service delivery?
  - c. With regard to discrimination?
  - d. Communication issues with those of limited English proficiency?
  - e. Cultural differences, particularly for immigrant groups?
  - f. Other?
  - g. Can you give specific examples?
5. What barriers exist to addressing each of these issues?
6. Do you know of any programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
  - a. What is working? What is not?
  - b. Are there other existing resources that could be utilized address these issues?
  - c. What programs would you like to see to address the issues you identified?
7. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?

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8. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?
  9. What role can you and your organization, or related affiliations play in addressing the issues you mentioned for African/African Ancestry residents of Santa Clara County? What about other community organizations or groups in addition to public health stakeholders?
  10. Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?

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## Question set J: Residents of East and West African origin

1. Please tell me a little bit about your work in Santa Clara County specifically related to residents who have emigrated from African countries. If it is not, please give us an insight/context into how your work relates/intersects with residents from East or West Africa in the county.
  2. From your experience, what are the primary health issues facing African immigrant residents of Santa Clara County?
    - a. Health and illness? Are there specific health issues particular to African immigrant residents?
    - b. Mental health and how people deal with stress?
  3. This health assessment is trying to understand a range of issues affecting the health and well-being of people of African Ancestry in Santa Clara County, including African immigrants. As this particular interview is focused on residents from East and West Africa, I will mention the topics discussed in the other interviews and ask that you identify concerns or aspects of these topics that are particular to African immigrant residents. Where possible, give examples and specifics that apply to country of origin.
    - a. Health issues specific to certain groups within the community (youth, elderly, women, men?)
    - b. Chronic illness such as high blood pressure or obesity
    - c. Long term illness or disease, such as HIV/AIDs
    - d. Substance use and abuse, including tobacco
    - e. Homelessness
    - f. Involvement in the criminal justice system
    - g. Domestic violence
  4. What barriers exist to addressing each of these issues?
  5. From your experience what issues do you see regarding the delivery of health care services?
    - a. Availability of and access to services?
    - b. Quality of services and service delivery?
    - c. Lack of information or education about health care and available services?
    - d. Discrimination?
    - e. Communication issues with those of limited English proficiency?
    - f. Cultural differences that affect health care?
    - g. Do you see any other issues related to obtaining health care as a non-native resident?
    - h. Can you give specific examples?
  6. Do you know of any County programs, policies or practices that are currently underway in the county to address the issues you identified? (probe: if so, please describe)
    - a. What is working? What is not?
    - b. Are there other existing resources that could be utilized address these issues?
-

- 
- c. What programs would you like to see to address the issues you identified?
7. Are there community-based organizations or government agencies focused on your country of origin that also address the issues you identified?
  8. What strengths or assets do you think the African/Ancestry community has that helps people deal with these issues?
  9. What solutions or strategies would you suggest public health stakeholders (i.e., city planners, public works, Valley Health & Hospital, law enforcement; local businesses, SCCPHD, etc.) consider to address the issues you mentioned?
  10. What role can the community play in addressing you mentioned for African immigrant residents in Santa Clara County? What role could you and your organization play?
  11. Is there anything else that you would like to mention on this topic or in general regarding the health and healthcare for African/African Ancestry residents in the county?

## Appendix B: Stakeholder participation list

### Organizations represented by the stakeholders at November 2013 Stakeholder Forum and June 2014 Health Summit

African American Community Service Agency (AACSA)	San Jose State University, Department of African American Studies
African Immigrant Family Outreach	Santa Clara County Department of Family and Children Services (DFCS)
Alpha Kappa Alpha Sorority, Inc.	Santa Clara County Department of Mental Health
American Red Cross - Blue Tie Tag Program	Santa Clara County Department of Parks & Recreation
APRI / Antioch Baptist Church	Santa Clara County Public Defender's Office
Bellarmino College Prep	Santa Clara County Public Health Department Black Infant Health Program
Black Leadership Kitchen Cabinet (BLKC)	Santa Clara County Public Health Department PACE Clinic (HIV/AIDS)
Citizens League of Ethiopian America (CLEA)	Santa Clara County Social Services Agency (SSA)
Delta Sigma Theta Sorority	Santa Clara Valley Health and Hospital System
Ephesus S.D.A Community Church	SEIU - United Service Workers West
House of Sankofa	Silicon Valley African American Democratic Club
Icon Marketing & Media	Stanford Prevention Research Center
Joyner Payner Youth Service Agency	Sureway Ministries
Maranatha Christian Center	Tabia Theatre/ SJMAG
Minority Business Consortium	The Links
NCBW	Ujima Adult & Family Services Inc.
Office of Supervisor Cindy Chavez	Unity Care Group
Office of the Independent Police Auditor, San Jose Police Department	Urban & Regional Planning
Resource Development Associates (RDA)	We Start Gardens
San Jose City College	



## **Names of stakeholders present at November 2013 Stakeholder Forum and June 2014 Health Summit**

Adrian Steward, Akubundu Amazu-Lott, Al Farley, Alexis Fields, Alicia Okoh, Alma Burrell, Alonzo Fitz Sr., Amina Burrell, Anandi Sujeer, Andre Chapman, Andrew Reynolds, Angel Rollerson, Anyika Nkululeko, Ashanti Mitchell, Beatrice Thomas, Betty Duong, Beverly White, Brenda Newson, Charlene Alexander, Charles Jackson, Christina Youmbi, Clarissa Moore, Dan Peddycord, Dante, David Epps, Deane Wiley, Debra Hill-Houston, Derek Bryant, Dr. Marcus Hunter, Dr. Oscar Battle, Dr. Ruth Wilson, Edwin Patrick Jr., Elizabeth Birks, Ellen Rollins, Ethel Foronda, Gale Simmons, Genet Wodajo, Gregory Williams, Hannah Wikkeling, Hewitt Joyner, Irine Onciano, Jacquelyn Nash, James Charles, Josephine Nnakigozi, Judge LaDoris Cordell, Julie Shum, Kathleen Hooper, Khalid White, Laura Williams, Le Perez, Lily Moore, Linda Eskridge, Lori Medina, Mandeep Baath, Maria Rodriguez, Maritza Rodriguez, Mary Azah, Melody Hames, Michael Bradford, Mikaela Rabinowitz, Milan Balinton, Mohamed Ali, Nebi Alemu, Pamela Lowe, Pastor Colmon Burrell, Queen Ann Concord, Rachelle Chavez, Reginald Swilley, Rhonda McClinton-Brown, Richard Kos, Rocio Luna, Sanae Alexander, Sandra Dinley, Semert Haile, Shawny Williams, Shirley Parrish, Sonja Kos, Sonya Stamper, Sophia Harou, Steve Pinkston, Terry Pryor, Tony Alexander, Tracy Bowers, Tressa Williams, Viera Whye, Violeta Garcia, Walter Wilson, Wilbur Jackson, Workayehu Bezabih, and Yvonne Maxwell.

## Appendix C: Criteria for Afro-centric interviewers, facilitators, and scribes

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The following is a list of skills and knowledge required for those facilitating community conversations and those outreaching to the various African/African Ancestry groups to engage in community conversations or individual interviews for the demographic study.

- The ability to describe culture.
- An understanding of culture and the role it plays in how human beings organize themselves and interact/relate with each other and the earth.
- Ability to articulate historical understanding of African people in the U.S., the continent of Africa and throughout the Diaspora with specific knowledge of African experiences with health systems and medical experimentation.
- Ability to use various terminologies within an African American dialect and translate.
- Is comfortable/receptive (feels at home with African/African Ancestry people) and can culturally communicate ease, comfort and compassion.
- Ability to communicate the phenomena within the spoken and unspoken and capture that information.

### Interview Questions

1. Identify courses (college level or workshops/trainings) on Africans throughout the Diaspora history, art, music, social/economic, or current issues.
2. Identify volunteer work with members of the African/African Ancestry community.
3. Places of employment that served the African/African Ancestry communities. What were the cultural skills developed and duties and responsibilities?
4. Identify a psycho/social issue that the African/African Ancestry community identifies as critical and how does this issue impact the community from that cultural position.
5. What life experiences do you have that have developed you cultural knowledge and understanding of African/African Ancestry people?
6. What are the common threads that bind African people globally?



## Appendix D: Qualitative coding scheme

### Qualitative data analysis

The health assessment team took a grounded theory approach to qualitative data analysis. Grounded theory is a well-established method of data collection that combines inductive and deductive coding of data to ensure that participants' concerns drive findings while also allowing researchers to answer specific questions.<sup>1</sup> This involved a two-part coding process, whereby researchers do "open" coding, intended to allow themes to emerge from participants without being predetermined by the research questions, along with more "closed" coding process that seeks answers to specific questions. In the open/inductive coding, the researchers are primarily trying to answer the question: What did people say? By contrast, in closed/deductive coding, researchers are trying to answer the question: What do we know that we are looking for?

Using on this approach, the Public Health Department team developed the following six code "families":

- Issues: Health issues/ needs/ concerns
- Barriers: Barriers to better health and well-being/ causes of poor health and well-being
- Strengths: Community resiliency factors that facilitate better health and well-being
- Strategies: Strategies that people/ communities use to take care of their health and well-being and/ or potential strategies for the county/ stakeholders to employ in the future
- Institutions/ actors: the locus of any of the above
- Populations: subgroups affected

Analytic software 'ATLAS.ti' is used to for qualitative data analysis. Software's frequency and co-occurring codes functions are used to assess the frequency with which individual codes and code families occurred as well as the frequency with which codes and code families co-occurred. Findings were derived by using the co-occurring codes function between each family. For example, lack of information about health and healthcare was the primary barrier identified by community conversation participants for receiving high quality healthcare and schools were the most commonly identified locus of racist or discriminatory experiences.

### Coding scheme

Using ATLAS.ti qualitative research software, SCCPHD analyzed the qualitative data using a grounded theory approach that combines inductive and deductive coding. To do so, we used the following four-step process:

**Step 1:** All key informant interview and community conversation transcripts were read and coded thematically to identify concepts based on common themes across participants (open or substantive coding). Each transcription passage that received an initial substantive code was simultaneously coded to indicate any specific subpopulations that it references or to note that the passage refers to all of Santa Clara County's African/African Ancestry community members. For example, if a participant was speaking specifically about West Africans, the passage would receive a "West Africans" code in addition to any substantive or thematic code. The data analysts kept running lists of codes generated to facilitate consistent use of coding schemes across transcripts.

**Step 2:** Once a comprehensive list of initial codes was generated, the codes were organized into "families" or groupings of similar codes. For example, codes related to anxiety and codes related to depression were grouped into a family of mental health codes. Population codes were also grouped into families based on

commonalities across populations; for example, West African and East African codes were also grouped into a family code of African immigrants.

**Step 3:** Finally, because the primary goals of the health assessment were to 1) understand the health needs of African/African Ancestry community members in the county, and 2) develop recommendations for changes to meet these needs and facilitate health improvements, the coded passages codes also received a tertiary code that identified each as a health need or issue, a barrier to better health and well-being, a facilitator of better health and well-being (strength), or a potential strategy or resource that could improve health. These tertiary codes denoted each coded passage as one of the following:

1. Issues: Health issues/needs/concerns
2. Barriers: Barriers to better health and well-being/causes of poor health and well-being
3. Strengths: Community resiliency factors that facilitate better health and well-being
4. Strategies: Strategies that community and its members use to take care of their health and well-being and/or potential strategies to employ in the future
5. Institutions/actors: the locus of any of the above

Based on this scheme, if a participant discussed depression among West Africans, the passage would have five codes:

1. Initial substantive code, "depression;"
2. Initial population code, "West Africans;"
3. Substantive family code, "mental health;"
4. Population family code, "African Immigrants;" and
5. Tertiary type code, "health issue, need, or concern."

**Step 4:** We then used ATLAS.ti's frequency and co-occurring codes functions to assess the frequency with individual codes and code family occurred as well as the frequency with which codes and code families co-occurred. By running the co-occurring codes function between each family, we were able to derive the findings. For example, a lack of information about health and healthcare was the primary barrier participants identified to high quality healthcare.

**Inter-rater reliability:** One data analyst was responsible for coding all of the key informant interviews and one data analyst was responsible for coding all of the community conversations. After they had each coded 20% of their data (five key informant interviews and 3 community conversations), they then switched and coded the transcripts originally coded by the other analyst. They had an 88% inter-rater-reliability, indicating that they gave the same codes to the same passages almost 9 out of 10 times. The two analysts and the Public Health Department team then met to discuss the coding process and discuss the differently coded passages to increase the consistency of the coding schema.

## References

1. Charmaz K. Grounded Theory. The SAGE Encyclopedia of Social Science Research Methods. SAGE Publications; 2003.

## Appendix E: Quantitative data sources

The table below describes each data source and where to find more information if available. Additional detailed quantitative data tables can be accessed online by visiting [SCCPHD.org/statistics2](http://SCCPHD.org/statistics2) and clicking the “Reports” link. All materials will be listed under the report title. For more information, please contact Santa Clara County Public Health Department.

### Data Sources

Name of Data Source	Description	Additional Information
<b>Surveys</b>		
Santa Clara County Public Health Department, Behavioral Risk Factor Survey (BRFS)	Random-digit-dial surveys of adult residents of Santa Clara County on health and related risk behaviors conducted by the Santa Clara County Public Health Department every two to three years.	For information on the national version of the survey, please visit <a href="http://www.cdc.gov/brfss/">http://www.cdc.gov/brfss/</a>
California Healthy Kids Survey (CHKS)	In-person self-reported survey of fifth, seventh, ninth, and eleventh grade students in participating public schools in Santa Clara County on health and health risk behaviors. Conducted every other year.	<a href="http://chks.wested.org/">http://chks.wested.org/</a>
Project Cornerstone	In-person self-reported survey administered in Fall 2010 to over 38,000 students in more than 200 schools and 25 districts throughout Santa Clara County. The survey measures developmental asset levels, risk behaviors, and thriving (resilience) indicators.	<a href="http://www.projectcornerstone.org">http://www.projectcornerstone.org</a>
<b>Demographics</b>		
U.S. Census Bureau, U.S. Census	Demographic information on every household in the U.S. Conducted every 10 years.	<a href="http://www.census.gov/">http://www.census.gov/</a>
U.S. Census Bureau, American Community Survey 1-Year, and 3-Year Estimates	Social, economic and demographic information collected from approximately three million addresses in the U.S. each year.	<a href="http://www.census.gov/acs/">http://www.census.gov/acs/</a>
National Historic Geographic Information System, 1980, 1990	Provides aggregate census data and GIS-compatible boundary files for the U.S. between 1790 and 2010.	<a href="https://www.nhgis.org/">https://www.nhgis.org/</a>

<b>Vital Statistics</b>		
California Department of Health, Vital Statistics	Records of all births and deaths of Santa Clara County residents.	<a href="http://www.apps.cdph.ca.gov/vsq/default.asp">http://www.apps.cdph.ca.gov/vsq/default.asp</a>
Family Health Outcomes Project (FHOP)	Presents data as excel spreadsheet files that include rates and trends for key MCAH indicators. Data are available at the county and region level and include comparisons to statewide rates.	<a href="http://familymedicine.medschool.ucsf.edu/fhop/index.htm">http://familymedicine.medschool.ucsf.edu/fhop/index.htm</a>
CDC WISQARS	WISQARS (Web-based Injury Statistics Query and Reporting System) is an interactive database system that provides customized reports of injury-related data.	<a href="http://www.cdc.gov/injury/wisqars/index.html">http://www.cdc.gov/injury/wisqars/index.html</a>
<b>Health Surveillance Systems</b>		
Greater Bay Area Cancer Registry (GBACR)	The Greater Bay Area Cancer Registry gathers information on all cancers diagnosed and treated in a nine-county area (Alameda, Contra Costa, Marin, Monterey, San Benito, San Francisco, San Mateo, Santa Clara, and Santa Cruz counties). Data from Santa Clara County were utilized in this health assessment.	<a href="http://www.cpic.org/site/c.sk10L6MKJpE/b.5730971/k.47A8/ Greater_Bay_Area_Cancer_Registry.htm">http://www.cpic.org/site/c.sk10L6MKJpE/b.5730971/k.47A8/ Greater_Bay_Area_Cancer_Registry.htm</a>
Automated Vital Statistics System and California Reportable Disease Information Exchange system (CalREDIE)	Statewide surveillance systems that tracks reportable diseases using data from participating county healthcare providers and laboratories.	For statewide counts and rates on sexually transmitted diseases, tuberculosis, and HIV/AIDS, see <a href="http://www.cdph.ca.gov/data/statistics/Pages/default.aspx">http://www.cdph.ca.gov/data/statistics/Pages/default.aspx</a>
California Department of Public Health, Immunization Branch, Kindergarten Retrospective Survey	The Kindergarten Retrospective Survey provides estimates of immunization coverage among kindergarten students at various age checkpoints, based on a sample of California's kindergartens in concurrence with selective review. Conducted by local health departments.	<a href="http://www.cdph.ca.gov/programs/immunize/Pages/ImmunizationLevels.aspx">http://www.cdph.ca.gov/programs/immunize/Pages/ImmunizationLevels.aspx</a>
Santa Clara County Public Health Department, 2013 Tuberculosis Information Management System	Tuberculosis cases reported in Santa Clara County and data cleaned by the state.	

California HIV/AIDS Reporting System (HARS/EHARS)	Statewide surveillance system that tracks HIV/AIDS infection using data from participating county healthcare providers and laboratories.	<a href="http://www.cdph.ca.gov/data/statistics/pages/oahivaidstatistics.aspx">http://www.cdph.ca.gov/data/statistics/pages/oahivaidstatistics.aspx</a>
<b>K-12 Public School Assessment and Testing Systems</b>		
California Department of Education, Fitnessgram	Physical fitness testing conducted yearly in public schools at fifth, seventh, and ninth grades. Data from participating Santa Clara County schools were utilized in this health assessment.	<a href="http://www.fitnessgram.net/newstandards/#whatisbodcomp">http://www.fitnessgram.net/newstandards/#whatisbodcomp</a> .
California Department of Education, Educational Demographics Unit	Provides data and web-based query system (Data Quest) that provide information on various topics for students and schools in California.	<a href="http://www.cde.ca.gov/ds/sd/">http://www.cde.ca.gov/ds/sd/</a>
<b>Other Data Sources</b>		
Santa Clara County, Social Services Agency, Quarterly Statistical Data of Public Assistance Families in the County of Santa Clara	Statistical reports published quarterly by the Santa Clara County Social Services Agency on individuals and families who receive public assistance in the County of Santa Clara.	<a href="http://www.sccgov.org/sites/sa/Department%20of%20Employment%20-%20Benefit%20Services/Statistics/Pages/Statistics.aspx">http://www.sccgov.org/sites/sa/Department%20of%20Employment%20-%20Benefit%20Services/Statistics/Pages/Statistics.aspx</a>
Office of Statewide Health Planning and Development, Patient Discharge and Emergency Room Data (OSHDPD)	Data on inpatient discharges and emergency room services from California hospitals released annually.	<a href="http://www.oshpd.ca.gov/">http://www.oshpd.ca.gov/</a>
California Highway Patrol Statewide Integrated Traffic Reporting System (SWITRS)	Data on all reported fatal and injury collisions that occurred on California's state highways and all other roadways excluding private property.	<a href="http://www.chp.ca.gov/switrs/">http://www.chp.ca.gov/switrs/</a> <a href="http://tims.berkeley.edu/index.php">http://tims.berkeley.edu/index.php</a>
EpiCenter, California Injury Data Online	California data provided by a queryable online system of fatal and nonfatal injury data.	<a href="http://www.applications.dhs.ca.gov/epicdata/default.htm">http://www.applications.dhs.ca.gov/epicdata/default.htm</a>



California Department of Public Health, In-Hospital Breastfeeding Initiation Data, 2012	CDPH Maternal, Child and Adolescent Health Program analyze and publish breastfeeding rates by hospital, county and the State of California. The data is collected by the Newborn Screening Program from all non-military hospitals providing maternity services in the State.	<a href="http://www.cdph.ca.gov/data/statistics/Pages/InHospitalBreastfeedingInitiationData.aspx">http://www.cdph.ca.gov/data/statistics/Pages/InHospitalBreastfeedingInitiationData.aspx</a>
State of California Department of Justice, Criminal Justice Statistics Center, 2012	Criminal Justice Profiles publish interactive crime statistics tables from various databases managed by Criminal Justice Statistics Center, including adult probation, arrests, domestic violence related calls, etc. Data are available at county or county agency level.	<a href="http://oag.ca.gov/">http://oag.ca.gov/</a>
University of California, Berkeley, Center for Social Sciences Research, California Child Welfare Indicators Project, 2012	The California Child Welfare Indicators Project (CCWIP) is a collaborative venture between the University of California at Berkeley (UCB) and the California Department of Social Services (CDSS). The project provides policymakers, child welfare workers, researchers, and the public with direct access to customizable information on California's entire child welfare system, including child maltreatment.	<a href="http://cssr.berkeley.edu/ucb_childwelfare/">http://cssr.berkeley.edu/ucb_childwelfare/</a>









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