U.S Department of Health and Human Services AGENCY EQUITY ACTION PLAN

2023 Update pursuant to Executive Order 14091 on "Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government"

HHS Equity Action Plan Leads:

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Message from the Agency Head

At the U.S. Department of Health and Human Services (HHS), we strive every day to advance the health and well-being of the American people. Our work – from critical social services to breakthrough scientific discoveries – impacts millions of families across the country. HHS is committed to making sure that our positive impact is reaching and helping everyone.

Last year, I launched a policy-focused *Secretary's Challenge on Equity*, to inspire our dedicated workforce to be innovative in uncovering opportunities to support a robust wellness system for all. What we collectively learned from that Challenge is that we have more work to do, such as identifying and correcting gaps in our data standards to address equity, communicating more effectively with diverse audiences, and strengthening our role in facilitating an inclusive health and human services workforce. HHS is actively advancing these efforts and making the question of whether our reach is for everyone's benefit a central part of how we continuously improve our services.

I am proud to share our equity action plan for the upcoming year. Our areas of focus are: keeping children safely at home with their families, enabling access to quality health care, strengthening behavioral health and maternal health, and diversifying clinical research. These areas were selected intentionally because they have been raised by communities, health care practitioners, and partners as areas where we can be most impactful in supporting all people and families to thrive.

I look forward to sharing our regular progress over the coming year and demonstrating HHS's continued commitment and support to equity and better outcomes for all.

Xavier Becerra

Advancing Equity Through Agency Mission

The mission of HHS is to enhance the health and well-being of all Americans, by providing for effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services. For those services and science to be effective and for us to realize our goal of shifting from an illness care system to a wellness care system, we need to acknowledge and incorporate equity considerations into what we do so that we can influence social drivers and ensure that differential circumstances do not lead to differential outcomes. Our vision is that all people, including underserved populations, have optimal opportunities for healthy and thriving lives with the support of HHS policies and approaches that are structurally designed and implemented to reach, facilitate, and advance health and well-being for all.



Executive Summary of Equity Action Plan

HHS has selected five areas of focus for our 2023 equity action plan. These actions are a selection of HHS's work to advance equity. They correspond with <u>HHS 2022-2026 strategic plan</u> and key Biden-Harris Administration priorities for HHS. The plan also sits in parallel to specific efforts related to equity within HHS's family of agencies, such as the <u>National Institute of Health's strategic plan for diversity, equity, inclusion, and accessibility</u>, the Administration for Children and Families' <u>equity in action</u> commitments, the Centers for Disease Control and Prevention's <u>CORE commitment to equity</u> and the Centers for Medicare and Medicaid Services' <u>framework for equity</u>. As such, this plan should be considered a portion, but not the total, of our efforts to ensure that all people can enjoy optimal health and well-being.

The five areas of this plan represent important opportunities for several HHS agencies to work together to collectively advance equity in support of public health, medical care, human services, and well-being. They include:

- **Preventing Child Welfare System Involvement:** We understand that families in poverty and those in Tribal and other communities are impacted by the child welfare system more than others, in some cases largely because they lack sufficient access to economic resources and community networks. Our efforts will be directed at connecting families in need to supports that enable them to stay together and preventing discriminatory and other practices that make it difficult for children, youth, and families to heal when child welfare is involved.
- **Promoting Accessible and Welcoming Health Care:** A lack of health insurance coverage and social and geographic barriers to care mean that not everyone is receiving health care that meets their needs within their communities. Our actions will promote access to comprehensive insurance coverage and quality care designed to meet the diverse needs of Americans so everyone can benefit from preventive care and effective treatments.
- Improving Maternal Health Outcomes: Too many women, particularly racial and ethnic minority populations, and those in rural areas, are losing their lives or health during pregnancy or after giving birth. Our actions will address gaps in insurance coverage and the birthing care infrastructure to ensure better maternal health outcomes.
- Meeting Behavioral Health Needs: The impact of the COVID-19 pandemic increased mental health and substance use challenges for all populations, but disproportionately exacerbated the already existing behavioral health disparities among underserved racial, ethnic, and sexual minority populations. The rising rates of suicide, depression, anxiety, and substance misuse among youth and adults are impacted by a decreasing workforce, limited resources, underinsurance, and lack of culturally competent care. Our actions will improve access to behavioral health care coverage and ensure that prevention and treatment are accessible and meet the needs of all populations.
- Advancing Clinical Innovation: To increase our understanding of what treatments are most effective for which populations, we need to increase the diversity of our research and clinical trials to inform that science. Our actions will engage a more diverse set of populations in informing our efforts and participating in clinical research so that we can innovate to improve health and well-being outcomes.

We have identified these action areas through visits to communities, listening sessions and roundtables with people impacted by these issues, grantee and research community discussions, Tribal



consultations, formal written invitations for comment, and more. HHS will continue to engage the public on these action areas, our progress, and next steps throughout the year and beyond.

Equity Progress Update and Accomplishments

2022 Equity Action Plan Update and Accomplishments. Our initial <u>2022 equity action plan</u> focused on five areas: civil rights protections and language access, acquisitions, grants, capacity building and maternal mortality. HHS remains committed to continuing progress in these areas. Select accomplishments include:

Civil Rights Protections and Language Access:

- Published draft rules on language access in all health programs and activities funded by the Department. On August 4, 2022, the Office for Civil Rights (OCR) published a Notice of Proposed Rulemaking (NPRM), proposing comprehensive updates revisions to the Department's regulations implementing Section 1557, the nondiscrimination provision of the Affordable Care Act. <u>See proposed rule</u>. The proposed rule restores and strengthens civil rights protections for patients and consumers in certain federally funded health programs and affirms protections against discrimination on the basis of race, color, national origin, sex, including sexual orientation and gender identity, age, and disability.
- Created a comprehensive structure for implementing HHS's action plan and practices for language access. The Department relaunched the HHS Language Access Steering Committee (LASC), which is comprised of representatives from every HHS agency. The LASC will facilitate the sharing of effective practices and procedures for enhancing language access.
- Ensured state compliance with language access and effective communication obligations during and after public health emergencies. On April 5, 2023, OCR dispatched a letter to state health officials reminding states of their language access and effective communication obligations under federal civil rights laws to ensure that individuals and families continue to have access to Medicaid and Children's Health Insurance Program (CHIP) coverage upon the expiration of the Families First Coronavirus Response Act continuous enrollment condition.

Maternal Mortality:

- Awarded <u>Equity in Postpartum Care Challenge grants</u> to identify successful and promising approaches to improving postpartum care and equity in maternal health outcomes.
- The Centers for Medicare & Medicaid Services (CMS) has approved 42 states, DC and the Virgin Islands to provide 12 months of continuous postpartum coverage through Medicaid and CHIP (as of December 2023). An estimated 540,000 Americans annually are eligible for essential care for a full year after pregnancy. HHS secured this option for states permanently in the Consolidated Appropriations Act of 2023 and CMS will continue to work with states on continuous coverage.
- CMS established a <u>"Birthing Friendly" hospital designation</u> a publicly-reported, public-facing hospital designation on the quality and safety of maternity care (to be launched Fall 2023). CMS will award this designation to hospitals that report they participated in a national or statewide quality collaborative and implemented all recommended interventions.
- HHS established a National Maternal Mental Health Hotline on Mother's Day 2022, which provides 24/7, free, confidential emotional support, resources, and referrals before, during, and



after pregnancy in English and Spanish and offers interpreter services in more than 60 languages. During the first year, hotline counselors responded to nearly 12,000 calls and texts.

<u>Grants:</u>

- Established guidance for HHS programs to use plain language in funding opportunities. The Office of Grants is formally tracking and reporting readability statistics for all Notice of Funding Opportunities (NOFOs) and related public documents. These documents must be easy to read and understand to reach as many potentially qualified applicants as possible.
- Published an NPRM clarifying nondiscrimination on the basis of sex in certain HHS grants. HHS OCR and Assistant Secretary for Financial Resources published an NPRM which states that, in statutes administered by HHS that prohibit discrimination on the basis of sex, the Department interprets those provisions to prohibit discrimination on the basis of sexual orientation and gender identity. This NPRM further builds on HHS' efforts to ensure access to health and human services in furtherance of President Biden's Executive Orders on Preventing and Combating Discrimination on the Basis of Gender Identity and Sexual Orientation and Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals.

Acquisitions:

 Successfully launched the small business customer experience procurement forecasting tool and increased small business procurement opportunities. HHS established the Small Business Customer Experience (SBCX) system as the department-wide procurement forecasting tool for small businesses. It is designed to reduce barriers to entry for small businesses and increase competition. Use of this tool has generated over 5000 procurement opportunities for FY23, which is double from the previous year.

Capacity Building:

Provided practical and hands-on guidance to HHS offices on identifying actions to ensure
opportunity for all. To ensure all staff and offices understand how to assess for opportunities to
deliver our services equitably, HHS created learning opportunities and tools for internal use.
These include resources for engaging communities and people with lived experience and
requirements and opportunities to improve access for people with disabilities. Our assessment
tools helped HHS surpass our 2022-2023 <u>Agency Priority Goal on equity</u>. Many tools are
available publicly, including resources on conducting <u>equity assessments</u> and <u>equity in research
and analysis</u>.

Environmental Justice Scorecard (pursuant to section 223 of EO 14008): The President's Justice40 Initiative sets a goal that 40 percent of the overall benefits of certain federal investments should reach disadvantaged communities that are marginalized and overburdened by pollution and underinvestment. These federal investments address climate change, clean energy and energy efficiency, clean transit, affordable and sustainable housing, training and workforce development, remediation and reduction of legacy pollution, and the development of critical clean water and wastewater infrastructure.

The Phase One Environmental Justice Scorecard provides an update on initial progress made by HHS in implementing the Justice40 Initiative. Metrics and highlights in Fiscal Year 2022 include:

- **13** Justice40 covered program(s)
- 18 funding announcement(s) covered under the Justice40 Initiative
- \$4.7 billion in funding made available from Justice40 covered programs



See <u>HHS's progress on advancing environmental justice</u> to achieve health equity for communities across America.

Additional Efforts to Advance Equity: HHS continues to advance equity across the Department and partner with other federal agencies. Select accomplishments include:

- Guidance on Nondiscrimination in Telehealth for people with disabilities and limited English proficient persons: HHS and U.S. Department of Justice (DOJ) issued a joint guidance document on the protections in federal nondiscrimination laws, including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, Title VI of the Civil Rights Act of 1964, and Section 1557 of the Patient Protection and Affordable Care Act, regarding access to telehealth for people with disabilities and limited English proficient persons. This document reminded healthcare providers that while telehealth expands healthcare opportunities for individuals who would otherwise be unable to receive healthcare in person, it must be provided in a manner that is accessible to individuals with disabilities.
- LGBTQ+ Behavioral Health Equity Center of Excellence: The Center of Excellence on LGBTQ+ Behavioral Health Equity (CoE LGBTQ+ BHE) mission is to bring information and resources to the behavioral health field to enhance culturally responsive care and decrease disparities for this population and does so by providing training and technical assistance opportunities for behavioral health professionals.
- Established HBCU-Connect, a new initiative with Historically Black Colleges and Universities (HBCUs). The National Institute of Environmental Health Sciences, an Institute within NIH, developed the initiative to inspire the development of environmental health science leaders from diverse backgrounds. HBCU-Connect is a multifaceted effort to strengthen ties between the institute and faculty and students at academic institutions that are often underrepresented in the sciences.

Advancing Equity Through Key Legislation: HHS has key responsibilities in implementing the Inflation Reduction Act (IRA)'s provisions related to prescription drug costs. HHS is working to ensure that all eligible individuals, particularly seniors and people with disabilities, can feel the benefits of the IRA's health care cost-saving provisions and will be engaging with communities on IRA implementation. HHS along with the Departments of Labor and Treasury, is implementing the <u>No Surprises Act</u> provisions which reduce surprise medical billing. HHS is conducting outreach to ensure that all consumers are aware of their rights and protections under the Act, including making resources available in multiple languages to reach all communities.



HHS Strategies to Advance Equity in FY 2024

Strategy #1: Prevent neglect and improve care to help children thrive in their families and communities

Whole-of-Government Equity Objective(s): Health Equity, Civil Rights

Barriers to Equity:

- Families who are experiencing poverty are more likely to be reported to child protective services (CPS) for neglect compared to families with more resources. The strategy seeks to better resource families so that CPS intervention and foster care, which destabilizes families, is not necessary.
- Certain populations of children and families experience structural barriers to resources and services that meets their unique well-being needs – namely Black families, American Indian and Alaska Native (AI/AN) families, LGBTQI+ youth, children and parents with disabilities and parents with limited English proficiency.

Evidence Base to Support Strategy:

- Families with lower income and those in historically underserved communities are overrepresented in the population of people reported to CPS agencies for neglect.¹
- A significant body of research has documented the overrepresentation of certain groups, particularly Black, Hispanic/Latino, and American Indian/Alaska Native children and families, in the child welfare system relative to their representation in the general population.²
- Research shows that even modest increases in resources provided through several mechanisms such as earned income tax credits (EITC), Supplemental Nutrition Assistance Program (SNAP) or Temporary Assistance for Needy Families (TANF) benefits, can reduce CPS involvement and the incidence of neglect.^{3,4,5} Interventions that provide economic supports and concrete services have been shown to reduce child maltreatment reports and foster care entry.⁶
- LGBTQI+ youth are overrepresented in foster care, often due to family lack of acceptance, and experience more trauma, disruption in placements and extended stays in foster care than non-

https://doi.org/10.1377/hlthaff.2022.00743

⁶ Weiner, D.A., Anderson, C., & Thomas, K. (2021). System transformation to support child and family well-being: The central role of economic and concrete supports. Chicago, IL: Chapin Hall at the University of Chicago.



¹ Child Welfare Information Gateway. (2023). Separating poverty from neglect in child welfare. U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. https://www.childwelfare.gov/pubs/bulletins-povertyneglect

² Child Welfare Information Gateway. (2021). Child welfare practice to address racial disproportionality and disparity. U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. https://www.childwelfare.gov/pubs/issue-briefs/racial-disproportionality/

³ Johnson-Motoyama M, Ginther DK, Oslund P, Jorgenson L, Chung Y, Phillips R, Beer OWJ, Davis S, Sattler PL. Association Between State Supplemental Nutrition Assistance Program Policies, Child Protective Services Involvement, and Foster Care in the US, 2004-2016. JAMA Netw Open. 2022 Jul 1;5(7):e2221509. doi: 10.1001/jamanetworkopen.2022.21509. PMID: 35816315; PMCID: PMC9280401.

 ⁴ Puls, H.T., Hall, M., Anderst, J.D., Gurley, T., Perrin, J., Chung, P.J. (2021). State Spending on Public Benefit Programs and Child Maltreatment. *Pediatrics*, 148 (5): e2021050685. 10.1542/peds.2021-050685
 ⁵ Johnson-Motoyama M and Ginther DK. (2022). Associations Between State TANF Policies, Child Protective Services Involvement, And Foster Care Placement, Health Affairs. 41:12, 1744-1753.

LGBTQI+ youth.⁷ Child welfare agencies who actively identify and ensure access to foster homes that provide stable, supportive, and safe families for LGBTQ+ youth can nurture positive outcomes for such youth.⁸

• HHS civil rights cases show a continuing trend of discrimination in complaints against child welfare agencies brought by or on behalf of children and/or parents with disabilities, including those with substance use disorders.

Actions to Achieve Equity: To address these barriers, HHS will:

- Increase evidence-based prevention programs, services and supports to children and families leveraging the Family First Prevention Services Act to enable more children to be supported in their own homes.
- Provide increased guidance to regulated agencies and enforce nondiscrimination provisions to better educate agencies of their responsibilities and available resources to facilitate intact family support and reunification for all families.
- Intensify technical assistance efforts and issuance of policy guidance to states on ways to disentangle poverty from states' considerations of child neglect to reduce unnecessary CPS interventions and trauma allowing more children to stay safely within their own families and communities.
- Provide policy options and practice expectations for child welfare agencies on how they can ensure the most appropriate, stable, family-like and caring placements for children, including appropriate placements for LGBTQI+ youth and kinship care, to protect their well-being in foster care and expedite return to their families when feasible/appropriate.

Proposed Metrics (Outputs and Outcomes):

Near- to Medium-Term

- Increased number of states and Tribes with Title IV-E prevention plans with culturally relevant interventions to reduce disparities in foster care for children
- Increased proportion of federal spending on Title IV-E Prevention Activities relative to Title IV-E foster care
- Increased voluntary adoption by state child welfare agencies of practices to protect families and children from discrimination

Longer-Term

- Increased rate at which children who have a child-specific prevention plan enter out of home care within 24 months of their prevention plan start date
- Reduced proportion of children who are removed from their home with associated factors of neglect and housing instability
- Increased placement stability for children in foster care
- Increased proportion of exits from foster care to reunification with family and discharge to relatives

⁸ Child Welfare Information Gateway. (2021). Supporting LGBTQ+ youth: A guide for foster parents. U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. https://www.childwelfare.gov/pubs/LGBTQyouth/



⁷ Baams, Wilson, & Russell, 2019; Matarese et al., 2021; Sandfort, 2020; Huggins et al., 2019; Conron & Wilson, 2019; Wilson & Kastanis, 2015

Public Participation and Community Engagement:

- The Administration for Children and Families (ACF) <u>hosted nine cross-sector summits</u> in 2022 to build knowledge among partners about the economic mobility challenges facing their communities. All regions engaged their state leaderships in promoting intentional engagement of parents and others with lived experience to inform their policies and practices.
- ACF and states will continue partnering to engage communities ongoingly about child welfare through the <u>Child and Family Service Reviews</u>. This process ensures meeting federal child welfare requirements, determining what is happening to children and families as they are engaged in child welfare services, and assists states in enhancing their capacity to help children and families achieve positive outcomes. Through these reviews, states and ACF engage impacted communities including youth, parents, foster parents, Tribes, courts and child welfare workers to review data on performance and identify strengths and areas needing improvement within their agencies and programs.



Strategy #2: Promote Accessible and Welcoming Health Services for All

Whole-of-Government Equity Objective(s): Health Equity, Civil Rights

Barriers to Equity:

- Certain populations continue to face barriers to quality, affordable health services, including those with low-incomes, rural communities, households with a primary language other than English, immigrants, Tribes/Native Americans, racial and/or ethnic minority communities, LGBTQI+ populations, and persons with disabilities.
- Certain populations experience biased treatment and care.
- The health care workforce needed to provide care in underserved areas needs additional supports to facilitate improved health care access and quality for populations that historically face barriers to care.
- There continues to be an unequal distribution of physicians coupled with a physician shortage, especially for certain specialties including primary care, dental health, and mental health practitioners.

Evidence Base to Support Strategy:

- Lack of health insurance coverage continues to be a large barrier to accessing health care services, and unequal distribution of coverage contributes to health disparities.^{9,10,11} Studies show that having health insurance is associated with improved access to health services and better health monitoring.^{12,13,14}
- Social, economic, cultural, and geographic barriers continue to affect access to care, especially for rural and Tribal communities, Native Americans, racial and ethnic minority, and low-income populations.^{15,16}

¹¹ Tolbert J., Drake P., Damico, A. (2022). Key Facts about the Uninsured Population. *Kaiser Family Foundation*. <u>https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-</u>

population/#:~:text=One%20in%20five%20uninsured%20adults,health%20conditions%20and%20chronic%20disea ses.

¹⁶ Douthit, N., Kiv, S., Dwolatzky, T., & Biswas, S. (2015). Exposing some important barriers to health care access in the rural USA. *Public Health*, *129*(6), 611–620. doi: <u>10.1016/j.puhe.2015.04.001</u>



⁹ Institute of Medicine (U.S.) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care* (B. D. Smedley, A. Y. Stith, & A. R. Nelson, Eds.). National Academies Press.

¹⁰ Call, K. T., McAlpine, D. D., Garcia, C. M., Shippee, N., Beebe, T., Adeniyi, T. C., & Shippee, T. (2014). Barriers to care in an ethnically diverse publicly insured population: Is health care reform enough? *Medical Care, 52*(8), 720–727.

¹² Baicker, K., Taubman, S. L., Allen, H. L., Bernstein, M., Gruber, J. H., Newhouse, J. P., ... & Finkelstein, A. N. (2013). The Oregon experiment — effects of Medicaid on clinical outcomes. *New England Journal of Medicine*, *368*(18), 1713–1722.

¹³ McWilliams, J. M., Zaslavsky, A. M., Meara, E., & Ayanian, J. Z. (2003). Impact of Medicare coverage on basic clinical services for previously uninsured adults. *JAMA*, *290*(6), 757–764.

¹⁴ Buchmueller, T. C., Grumbach, K., Kronick, R., & Kahn, J. G. (2005). Book review: The effect of health insurance on medical care utilization and implications for insurance expansion: A review of the literature. *Medical Care Research and Review*, *62*(1), 3–30.

¹⁵ Call, K. T., McAlpine, D. D., Garcia, C. M., Shippee, N., Beebe, T., Adeniyi, T. C., & Shippee, T. (2014). Barriers to care in an ethnically diverse publicly insured population: Is health care reform enough? *Medical Care, 52*(8), 720–727.

- According to Health Resources and Services Administration (HRSA) data, in areas where a health workforce shortage has been identified, the U.S. needs over 17,000 primary care practitioners, 12,000 dental health practitioners, and 8,200 mental health practitioners to address Americans' current health needs.¹⁷
- Evidence indicates that a workforce diverse in its experiences, supports enhanced access to care for underserved areas and populations, including with locating services in underserved communities, patient acceptance of preventive care, patient to clinician trust, clinician and patient communication, and provision of culturally relevant care. ^{18,19,20,21,22,23}
- Implicit racial/ethnic bias among health care professionals can lead to differences in the quality of health care services received by certain racial/ethnic populations and perpetuate existing health disparities.^{24,25}
- Women face individual-level barriers to accessing reproductive health care including lack of insurance, difficulty obtaining appointments or accessing a clinic, not having a regular physician, and fear of lack of confidentiality of services.^{26,27,28}

²⁸ Grindlay K, Grossman D. Prescription birth control access among US women at risk of unintended pregnancy. *J Womens Health (Larchmt)*. 2016;25(3):249-254. doi:<u>10.1089/jwh.2015.5312</u>



 ¹⁷ HRSA. (2023). *Health Workforce Shortage Areas*. <u>https://data.hrsa.gov/topics/health-workforce/shortage-areas</u>
 ¹⁸ Kington R, Tisnado D, Carlisle DM. Increasing racial and ethnic diversity among physicians: an intervention to address health disparities? In Smedley BD, Stith AY, Colburn L, Evans CH, (eds.). The Right Thing to Do, The Smart Thing to Do: Enhancing Diversity in the Health Professions. Washington, DC: National Academy Press, 2001.
 ¹⁹ Alsan, Marcella, Owen Garrick, and Grant Graziani. 2019. "Does Diversity Matter for Health? Experimental Evidence from Oakland." American Economic Review, 109 (12): 4071-4111.

DOI: 10.1257/aer.20181446

²⁰ Street R.L., O'Malley, K., Cooper, L., & Haidet, P. (2008). Understanding Concordance in Patient-Physician Relationships: Personal and Ethnic Dimensions of Shared Identity. *The Annals of Family Medicine*, 6 (3) 198-205; DOI: 10.1370/afm.821

²¹ Gonzalez H.M., Vega W.A., and Tarraf W. (2010). Health Care Quality Perceptions among Foreign-Born Latinos and the Importance of Speaking the Same Language. *The Journal of the American Board of Family Medicine*, 23 (6) 745-752; DOI: 10.3122/jabfm.2010.06.090264

²² Hoffman KM, Trawalter S, Axt JR, Oliver MN. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci*, 113:4296-4301.

²³ Goodfellow, Amelia; Ulloa, Jesus G. MD, MBA; Dowling, Patrick T. MD, MPH; Talamantes, Efrain MD, MBA, MSHPM; Chheda, Somil; Bone, Curtis MD, MHS; Moreno, Gerardo MD, MSHS. (2016) Predictors of Primary Care Physician Practice Location in Underserved Urban or Rural Areas in the United States: A Systematic Literature Review. Academic Medicine 91(9): p 1313-1321, DOI: 10.1097/ACM.00000000001203

²⁴ Burgess DJ, Fu SS, Van Ryn M. (2004). Why do providers contribute to disparities and what can be done about it? *J Gen Intern Med.*, 19(11):1154–1159.

²⁵ Hall WJ, Chapman MV, Lee KM, Merino YM, Thomas TW, Payne BK, Eng E, Day SH, Coyne-Beasley T. Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review. Am J Public Health. 2015 Dec;105(12): e60-76. doi: 10.2105/AJPH.2015.302903. Epub 2015 Oct 15. PMID: 26469668; PMCID: PMC4638275.

²⁶ Ralph LJ, Brindis CD. Access to reproductive healthcare for adolescents: establishing healthy behaviors at a critical juncture in the lifecourse. *Curr Opin Obstet Gynecol*. 2010;22(5):369-374. doi:10.1097/GCO.0b013e32833d9661

²⁷ Decker MJ, Atyam TV, Zárate CG, Bayer AM, Bautista C, Saphir M. Adolescents' perceived barriers to accessing sexual and reproductive health services in California: a cross-sectional survey. *BMC Health Serv Res*. 2021;21(1):1263. doi:10.1186/s12913-021-07278-3

- LGBTQI+ populations face challenges accessing health care services resulting in worse health outcomes due to stigma, discrimination, inequality in the workplace, and other barriers.²⁹ Additionally, changes in laws and policies have made it more difficult to access services, including gender affirming care, in certain parts of the country.³⁰
- American Indian and Alaska Native Tribal communities face historical challenges in accessing timely and quality health care services due to chronic underfunding and staffing for healthcare services, discrimination, poor infrastructure including limited cellular and broadband access, remote locations, and living in health-care deserts with long-standing structural and socioeconomic inequities among other barriers.³¹
- A variety of evidence shows that a diverse workforce supports access to care including with preventive care, patient to clinician trust, clinician and patient communication and culturally relevant care. ^{32,33,34,35,36}

Actions to Achieve Equity: To address these barriers, HHS will:

- Reduce bias in health care and research settings and increase access to quality, respectful, accessible, culturally relevant and linguistically appropriate care for underserved groups across the life course.
- Develop more culturally and linguistically inclusive practices and support nondiscrimination in health care services.
- Support a diverse health care, public health, and research workforce, especially in medically underserved and impoverished areas, health professional shortage areas and for providers who are most trusted by communities such as peer workers and those engaged in community-initiated care.

³⁶ Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proc Natl Acad Sci U S A 2016;113:4296-4301



²⁹ National Academies of Sciences, Engineering, and Medicine. 2020. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press. https://doi.org/10.17226/25877.

³⁰ Dawson, L., Kates, J., Musumeci, MB. (2023). Youth Access to Gender Affirming Care: The Federal and State Policy Landscape. Kaiser Family Foundation. <u>https://www.kff.org/other/issue-brief/youth-access-to-gender-affirming-care-the-federal-and-state-policy-landscape/</u>

³¹Smith, M. (n.d.) Native Americans: A Crisis in Health Equity.

https://www.americanbar.org/groups/crsj/publications/human rights magazine home/the-state-of-healthcarein-the-united-states/native-american-crisis-in-health-equity/

³² Smedley BD, Stith AY, Colburn L, et al.; Institute of Medicine (US). The Right Thing to Do, The Smart Thing to Do: Enhancing Diversity in the Health Professions: Summary of the Symposium on Diversity in Health Professions in Honor of Herbert W.Nickens, M.D.. Washington (DC): National Academies Press (US); 2001. Increasing Racial and Ethnic Diversity Among Physicians: An Intervention to Address Health Disparities? Available from: https://www.ncbi.nlm.nih.gov/books/NBK223632/

 ³³ Alsan, Marcella, Owen Garrick, and Grant Graziani. 2019. "Does Diversity Matter for Health? Experimental Evidence from Oakland." American Economic Review, 109 (12): 4071-4111.DOI: 10.1257/aer.20181446
 ³⁴ Street RL Jr, O'Malley KJ, Cooper LA, Haidet P. Understanding concordance in patient-physician relationships: personal and ethnic dimensions of shared identity. Ann Fam Med. 2008 May-Jun;6(3):198-205. doi: 10.1370/afm.821. PMID: 18474881; PMCID: PMC2384992.

³⁵ González HM, Vega WA, Tarraf W. Health care quality perceptions among foreign-born Latinos and the importance of speaking the same language. J Am Board Fam Med. 2010 Nov-Dec;23(6):745-52. doi: 10.3122/jabfm.2010.06.090264. PMID: 21057070; PMCID: PMC2995948.

- Improve access and address barriers to care by engaging community health workers and trusted partners in rural communities, Tribal Communities, and other underserved communities
- Support continuity of coverage during Medicaid unwinding by working with states and external partners on renewals and connections to other forms of health coverage.
- Develop resources or programs to increase the number of culturally appropriate and informed health care materials and information available in-language for providers and partners.
- Advance social determinants of health (SDOH) research and adverse childhood experiences (ACEs) research to better identify and address structural barriers to healthcare access and influence positive outcomes .

Proposed Metrics (Outputs and Outcomes):

Near- to Medium-Term

- Changes in demographics of health care professionals including their service locations as well as the number of nurses and physicians who are members of, or have a history of service to, underrepresented minority communities
- Changes in and patterns of services accessed by patients including medical, dental, mental health, substance use disorder, vision, and enabling services
- Trends in demographic characteristics of total health center patients
- Trends related to health center patient income and insurance status
- Number and percentage of health center patients who are experiencing homelessness, are agricultural workers or dependents, served at a health center located in or immediately accessible to a public housing site
- Changes in health insurance and Medicaid coverage by state
- Changes in the development and use of culturally appropriate and informed health care resources for providers and partners

Longer-Term

- Improved health outcomes for underserved populations and communities
- Increased equity in access to affordable, high quality, culturally appropriate health care

Public Participation and Community Engagement:

- The HHS Office for Civil Rights (OCR) has been holding a series of convenings across the country on EO 14079 on *Securing Access to Reproductive Health and Other Healthcare Services* as part of OCR's continuing efforts to hold national and regional convenings with health care providers, civil rights organizations, patient advocates, and provider associations to raise awareness of Federal non-discrimination laws that protect individuals' access to appropriate reproductive health care.
- Subject matter experts are engaged in the development of HHS Office of Minority Health (OMH) Think Cultural Health e-learning programs, aimed at building knowledge and skills in providing culturally and linguistically appropriate services, to provide input on e-learning program curricula and content.
- OMH held listening sessions with subject matter experts and community representatives, on topics including community health worker sustainability and language access.



• The NIH UNITE Initiative for Ending Structural Racism hosted <u>14 listening sessions</u> with external stakeholders who work and serve in diverse settings related to biomedical or behavioral sciences. The insights shared provided valuable information on the full range of issues and challenges facing diverse talent and will help develop UNITE priorities and an action plan.



Strategy #3: Improve Maternal Health Outcomes for Rural, Racial and Ethnic Minority Communities

Whole-of-Government Equity Objective(s): Health Equity

Barriers to Equity:

- Maternal health outcomes vary by race, ethnicity, and rurality across the U.S. Key drivers of poor maternal health outcomes include lack of provider and service availability, lack of tailored interventions, cultural bias and relevant evidence on the safety and effectiveness of technological innovations, data lags, and inadequate preventive and supportive care.
- Social and environmental determinants of health such as income, housing, nutrition climaterelated exposures such as extreme heat and air pollution, underlie many of the risk factors that contribute to poor maternal health outcomes.

Evidence Base to Support Strategy:

- According to the CDC Pregnancy Mortality Surveillance System, women in rural areas are 60% more likely to die during the perinatal period than women in urban areas.³⁷
- Pregnancy related death rates are three times higher among Black individuals and two times higher among AI/AN individuals compared to White individuals.³⁸
- Although Hispanics/Latinos have lower rates of maternal mortality, they have higher levels of severe maternal morbidity than non-Hispanic White populations.³⁹
- Additionally, although data are limited, Native Hawaiian and Other Pacific Islander (NHOPI) populations also have higher rates of both maternal mortality and morbidity.⁴⁰
- According to the CDC- supported Maternal Mortality Review Committees data from 2017-2019, more than 80% of maternal deaths are preventable, meaning that a "reasonable change to patient, community, provider, facility or system factors" could have averted death.⁴¹
- Environmental exposures related to climate change have a disproportionate effect on pregnant women through influencing food and water security, civil conflicts, extreme weather events, and the spread of disease.⁴²

Actions to Achieve Equity: To address these barriers, HHS will:

⁴⁰ Maykin M, Tsai SP. Our Mothers Are Dying: The Current State of Maternal Mortality in Hawai'i and the United States. Hawaii J Health Soc Welf. 2020 Oct 1;79(10):302-305. PMID: 33047104; PMCID: PMC7547177.

⁴² Veenema RJ, Hoepner LA, Geer LA. Climate Change-Related Environmental Exposures and Perinatal and Maternal Health Outcomes in the U.S. Int J Environ Res Public Health. 2023 Jan 17;20(3):1662. doi: 10.3390/ijerph20031662. PMID: 36767030; PMCID: PMC9914610.



³⁷ CDC. (2023). Pregnancy Mortality Surveillance System. <u>https://www.cdc.gov/reproductivehealth/maternal-</u> mortality/pregnancy-mortality-surveillance-system.htm#urban-rural

³⁸ CDC. (2022). Infographic: Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. <u>https://www.cdc.gov/reproductivehealth/maternal-mortality/disparities-pregnancy-related-</u> <u>deaths/infographic.html</u>

³⁹ Howell EA, Egorova NN, Janevic T, Balbierz A, Zeitlin J, Hebert PL. Severe Maternal Morbidity Among Hispanic Women in New York City: Investigation of Health Disparities. Obstet Gynecol. 2017 Feb;129(2):285-294. doi: 10.1097/AOG.00000000001864. PMID: 28079772; PMCID: PMC5380443.

⁴¹ CDC. (2022). Pregnancy-Related Deaths: Data from Maternal Mortality Review Committees in 36 US States, 2017–2019. <u>https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/data-mmrc.html</u>

- Increase access and use of health care services by continuing to promote state implementation of 12- month postpartum coverage extension in Medicaid and CHIP to improve health insurance coverage for postpartum people, including the 40 percent of U.S. births covered by Medicaid and CHIP.
- Increase screening for maternal depression and substance use disorder (SUD) during the postpartum period to decrease maternal mortality.
- Address maternal/birthing care deserts and the maternity/birthing care safety net by strengthening birthing care infrastructure, including a focus on obstetrics (OB) readiness, especially in rural communities and Tribal communities.
- Build a competent and diverse workforce for maternal care pre- and post-birth, including midwives, doulas, promotoras and other non-OB (non-stigmatizing) community-based settings.
- Establish a task force focused on maternal mental health and perinatal mental health.
- Increase funding for economic development and social mobility for Tribal communities and families through grants and training and technical assistance.

Proposed Metrics (Outputs and Outcomes):

Near- to Medium-Term

- Changes in maternal mental health, mortality rates, and other health indicators
- Number of partnerships established in Tribal communities, rural communities, low-income and low-resourced communities, and other high need areas
- Changes in access to primary care across the perinatal spectrum
- Number of states and territories that extend Medicaid coverage for a full 12 months
- Changes in impact and number of people who benefit from expanded Medicaid postpartum care
- Changes in number of hospitals with "birthing friendly" hospital designation
- Changes in number of conversations with the National Maternal Mental Health Hotline counselors
- Changes in the number of health center obstetrician/gynecologist and certified nurse midwife full-time equivalents and the number of clinic (in-person) and virtual visits to those providers
- Changes in prenatal care provided directly to health center patients or by referral
- Changes in the percentage of mothers enrolled in home visiting prenatally (or within 30 days after delivery) who received a postpartum visit with a healthcare provider within 8 weeks of delivery
- Changes in the percent of primary caregivers enrolled in home visiting who are screened for depression within 3 months of enrollment or delivery

Longer-Term

- Improved maternal health outcomes for high-risk populations and communities
- Increased equity in access to affordable, high quality, culturally appropriate maternal health care

Public Participation and Community Engagement:

• CMS Center for Medicaid and CHIP Services seeks public comment annually regarding updates to the Medicaid and CHIP Maternity Core Set. The public comments resulted in the addition of Postpartum Depression Screening and Follow Up measure, as well as an Immunization in



Pregnancy Measure, to the Core Sets. These measures are used by CMS to measure and evaluate progress toward improvement of maternal and perinatal health in Medicaid and CHIP.

- CMS Center for Medicaid and CHIP Services (CMCS) engages, and consults states regularly as
 part of the Quality Improvement Technical Assistance work through the Maternal and Infant
 Health Initiative (MIHI). Group participants are encouraged to reach out to their beneficiaries to
 determine barriers to improving quality on metrics, such as attendance at postpartum care or
 infant well-child visits, transportation issues, or difficulty scheduling. These consultations help
 inform states of barriers encountered by beneficiaries.
- HHS OMH and CMS CMCS held a listening session to gather consumer feedback regarding using
 inclusive maternal language (especially as it relates to the word "maternal" and non-binary or
 gender conforming people). Participants included professionals with direct clinical, research, or
 system-level expertise on inclusive language or experience in providing affirming care for nonbinary and transgender patients. One key takeaway was that Inclusive language is important to
 make people feel cared for by their providers.
- NIH sponsored the Connecting the Community for Maternal Health Challenge to encourage and reward nonprofit community-based or advocacy organizations to develop research capabilities and infrastructure to pursue maternal health research projects. The challenge offered approximately \$3 million in prizes, distributed across multiple phases of the competition to organizations that successfully completed the objectives and requirements of each phase. Three webinars introduced the challenge sponsors at NIH, provided general guidance on proposal submission, and shared the opportunities that participation in this challenge provide. Ongoing webinars are providing guidance to participants in building and sustaining their research activities.



Strategy #4: Prioritize the Behavioral Health of Underserved Populations

Whole-of-Government Equity Objective(s): Health Equity

Barriers to Equity:

- Some populations are at higher risk of experiencing behavioral health challenges and some also face barriers to accessing mental and behavioral health care services, including racial and ethnic minorities, American Indian and Alaska Natives, rural populations, persons with disabilities, LGBTQI+ adults and youth, older adults, and other populations.
- There continues to be several workforce challenges among mental and behavioral healthcare providers, including shortages, geographic maldistribution, lack of diversity, and burnout.

Evidence Base to Support Strategy:

- Youth behavioral health has worsened. In the past decade, the percentage of students across every Tribal, racial and ethnic group feeling persistently sad or hopeless increased.⁴³ Female students, LGBTQI+ students, and students who had any same-sex partners were more likely than their peers to experience poor mental health and suicidal thoughts and behaviors.⁴⁴
- Behavioral health challenges are especially acute for the American Indian and Alaska Native population. The percentage of AI/AN persons aged 12 or older in 2021 with a past year substance use disorder (27.6%) was higher than among other racial or ethnic groups.⁴⁵
 Percentage of AI/AN persons aged 18 or older in 2021 with any mental illness (26.6%) was higher than among almost all other racial or ethnic groups.⁴⁶
- According to the 2021 National Survey on Drug Use and Health, the percentage of adults with any mental illness in the past year who received mental health services was lower among Asian (25.4%), Hispanic or Latino (36.1%), or Black or African American adults (39.4%) than among White (52.4%) adults.⁴⁷
- Adults with disabilities, compared with those without disabilities, experience more mental distress and are more likely to experience factors associated with a higher occurrence of mental disorders, including poverty and limited health care access.⁴⁸
- Preventing adverse childhood experiences is key to reducing behavioral health challenges.⁴⁹ As adverse child experiences and their social drivers are interdependent, comprehensive and

⁴⁹ Vital Signs: Estimated Proportion of Adult Health Problems Attributable to Adverse Childhood Experiences and Implications for Prevention — 25 States, 2015–2017



⁴³ CDC. (2023). Youth Risk Behavior Survey Data Summary & Trends Report.

https://www.cdc.gov/healthyyouth/data/yrbs/pdf/YRBS_Data-Summary-Trends_Report2023_508.pdf 44 CDC. (2023). Youth Risk Behavior Survey Data Summary & Trends Report.

https://www.cdc.gov/healthyyouth/data/yrbs/pdf/YRBS_Data-Summary-Trends_Report2023_508.pdf 45 SAMHSA. (2022). Key Substance Use and Mental Health Indicators in the United States: Results from the 2021 National Survey on Drug Use and Health.

https://www.samhsa.gov/data/sites/default/files/reports/rpt39443/2021NSDUHFFRRev010323.pdf

⁴⁶ SAMHSA. (2022). Key Substance Use and Mental Health Indicators in the United States: Results from the 2021 National Survey on Drug Use and Health.

https://www.samhsa.gov/data/sites/default/files/reports/rpt39443/2021NSDUHFFRRev010323.pdf

⁴⁷ SAMHSA. (2022). Highlights by Race/Ethnicity for the 2021 National Survey on Drug Use and Health. https://www.samhsa.gov/data/sites/default/files/2022-12/2021NSDUHFFRHighlightsRE123022.pdf

⁴⁸ Cree RA, Okoro CA, Zack MM, Carbone E. Frequent Mental Distress Among Adults, by Disability Status, Disability Type, and Selected Characteristics - United States, 2018. MMWR Morb Mortal Wkly Rep. 2020 Sep 11;69(36):1238-1243. doi: 10.15585/mmwr.mm6936a2. PMID: 32914770; PMCID: PMC7499832.

integrated approaches to support children and their families in their communities are essential. $^{\rm 50}$

Access to care continues to be an issue. In 2021 fewer than half of people with a mental illness were able to access timely care.⁵¹ Rural areas and economically disadvantaged cities have less behavioral health care providers serving the community,^{52, 53} and many behavioral health providers report burnout which can further challenge quality care.⁵⁴

Actions to Achieve Equity: To address these barriers, HHS will:

- Support the development of an inclusive behavioral health workforce that may deliver quality healthcare to diverse populations.
- Increase Behavioral Health Integration in clinical and non-clinical settings and continued investments in school-based health services to improve access for underserved communities, inclusive of emerging providers and trusted community facilitators.
- Focus on prevention and treatment for high-risk populations, including the mental health of children, including infants and toddlers, and youth.
- Expand suicide prevention and crisis work for high-risk populations and underserved communities to include culturally appropriate and in-language crisis services, as well as follow-up and evaluation after delivery of crisis care.
- Work with the Substance Abuse and Mental Health Services Administration's (SAMHSA) Centers of Excellence and relevant collaborators to address the behavioral health needs of specific underserved communities.
- Work with the Departments of Labor and the Treasury to publish rules implementing new Mental Health Parity and Addiction Equity Act (MHPAEA) requirements to ensure that private insurance and self-funded, non-governmental plans provide their enrollees with access to behavioral health care that is in parity with coverage of medical and surgical care
- Publish a report regarding the use of telehealth to address behavioral health service barriers and increase access to behavioral health care, as well as provide resources to facilitate broader use of telehealth for behavioral health care.

⁵⁴ Substance Abuse and Mental Health Services Administration (SAMHSA): Addressing Burnout in the Behavioral Health Workforce Through Organizational Strategies. SAMHSA Publication No. PEP22-06-02-005. Rockville, MD: National Mental Health and Substance Use Policy Laboratory. Substance Abuse and Mental Health Services Administration, 2022.



⁵⁰ ASPE. (2022). HHS Behavioral Roadmap for Behavioral Health Integration. <u>https://aspe.hhs.gov/sites/default/files/documents/4e2fff45d3f5706d35326b320ed842b3/roadmap-behavioral-</u> health-integration.pdf

⁵¹ SAMHSA. (2023). 2021 NSDUH Detailed Tables. <u>https://www.samhsa.gov/data/report/2021-nsduh-detailed-tables</u>

⁵² University of Michigan Behavioral Health Workforce Research Center. Estimating the Distribution of the U.S. Psychiatric Subspecialist Workforce. Ann Arbor, MI: UMSPH; 2018. <u>https://behavioralhealthworkforce.org/wp-content/uploads/2019/02/Y3-FA2-P2-Psych-Sub_Full-Report-FINAL2.19.2019.pdf</u>

⁵³ Mental Health Care Health Professional Shortage Areas (HPSAs). *Kaiser Family Foundation*. <u>https://www.kff.org/other/state-indicator/mental-health-care-health-professional-shortage-areas-hpsas/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D</u>

• Encourage states to implement an innovative service delivery system to facilitate successful reentry transitions for Medicaid-eligible individuals leaving prisons and jails and returning to the community.

Proposed Metrics (Outputs and Outcomes):

Near- to Medium-Term

- Changes in behavioral health outcomes for high-risk populations
- Changes in and patterns of services accessed by patients including medical, dental, mental health, substance use, vision, and enabling services
- Number of partnerships with non-clinical and school settings and assess utilization of resources
- Degree of behavioral health integration into primary care
- Number of trainings and technical assistance activities conducted by SAMHSA Centers of Excellence
- Utilization of the 988 Crisis Contact Centers available in English and Spanish text and chat

Longer-Term

- Improved mental and behavioral health outcomes for high-risk populations
- Increased equity in access to affordable, high quality, culturally appropriate behavioral health care
- Overall reductions in the economic and social barriers that contribute to poor mental or behavioral health outcomes

Public Participation and Community Engagement:

- SAMHSA and the White House Initiative on Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI) convened a <u>Summit on AANHPI Mental Health</u> in July 2023. Four key issues emerged: Anti-AANHPI Hate, Language Justice, Behavioral Health Workforce, and Engaging with 988. Partners in this meeting made commitments to these Action Plans. SAMHSA hosted a follow-up working meeting of AANHPI leaders from communities, advocates, practitioners, researchers, national organizations, foundations, technology companies, and federal partners to develop action plans on the four themes.
- SAMHSA sponsored a Behavioral Health Equity Challenge focused on innovative outreach and engagement strategies that connect communities to behavioral health services in underserved communities. From 426 entries, ten community -based organizations were selected as winners of the challenge in August 2023. These winners presented and documented the impact of their innovative strategies in mental health, substance use prevention, and substance use treatment across historically underserved communities. Recognition will be given to these winners through various presentations and showcases sponsored by SAMHSA.
- SAMHSA hosted a Policy Academy on Black Youth Suicide to develop a strategic plan to address high rates of suicide among Black youth. Teams from 8 states (GA, IN, KY, LA, MD, OH, OR, PA) convened to address their specific state's needs, work with experts in suicide prevention, and develop policy strategies to take back to their states. They will continue to receive technical assistance sponsored by SAMHSA and report back.
- Since 2022, Secretary Becerra and HHS leaders have been <u>traveling across the country</u> to hear directly from Americans about the mental health challenges they're facing and engage with local leaders to strengthen the mental health and crisis care system in our communities.



Strategy #5: Increase Clinical Research and Trial Diversity to Support Innovation

Whole-of-Government Equity Objective(s): Health Equity

Barriers to Equity:

- Racial and ethnic minority populations, AI/ANs, older adults, women, pregnant and lactating
 individuals, LGBTQI+ adults and youth, and persons with disabilities continue to be
 underrepresented in clinical trials, stifling health care innovation, and hindering the
 generalizability of effective treatments.
- Lack of diversity in clinical research has the potential to hinder innovation. Including populations that have been underrepresented in clinical trials and medical studies can help researchers better understand variation in the safety and effectiveness of interventions, identify new biological processes, and lead to new discoveries that can benefit other populations.⁵⁵
- Evidence from clinical studies help inform health recommendations, insurance coverage, and reimbursement of healthcare services. Without representation of specific groups in trials and studies, we may lack confidence about how new therapeutics will impact all populations. A lack of representation in clinical studies can impede access to effective medical interventions for underrepresented groups if they are not included to build the evidence base to begin with.⁵⁶
- Additional barriers contributing to underrepresentation of racial and ethnic minority patients' participation in clinical trials include mistrust or fear and stigma of participation, lack of comfort with the clinical trial process, lack of information about clinical trials, time and resource constraints associated with clinical trial participation, and lack of clinical trial awareness.⁵⁷

Evidence Base to Support Strategy:

• Currently, large swaths of the U.S. population, and those that often face the greatest health challenges, are less able to benefit from clinical research discoveries because they are not adequately represented in clinical research studies.⁵⁸

⁵⁸ National Academies of Sciences, Engineering, and Medicine. 2022. Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups. Washington, DC: The National Academies Press. <u>https://doi.org/10.17226/26479</u>.



⁵⁵ National Academies of Sciences, Engineering, and Medicine; Policy and Global Affairs; Committee on Women in Science, Engineering, and Medicine; Committee on Improving the Representation of Women and Underrepresented Minorities in Clinical Trials and Research; Bibbins-Domingo K, Helman A, editors. Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups. Washington (DC): National Academies Press (US); 2022 May 17. 2, Why Diverse Representation in Clinical Research Matters and the Current State of Representation within the Clinical Research Ecosystem. Available from: https://www.ncbi.nlm.nih.gov/books/NBK584396/

⁵⁶ National Academies of Sciences, Engineering, and Medicine; Policy and Global Affairs; Committee on Women in Science, Engineering, and Medicine; Committee on Improving the Representation of Women and Underrepresented Minorities in Clinical Trials and Research; Bibbins-Domingo K, Helman A, editors. Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups. Washington (DC): National Academies Press (US); 2022 May 17. 2, Why Diverse Representation in Clinical Research Matters and the Current State of Representation within the Clinical Research Ecosystem. Available from: https://www.ncbi.nlm.nih.gov/books/NBK584396/

⁵⁷ Clark, L.T., Watkins, L., Piña, I.L., Elmer, M., et al. (2019). Increasing Diversity in Clinical Trials: Overcoming Critical Barriers, Current Problems in Cardiology, 44, (5),

^{148-172, 0146-2806.&}lt;u>https://doi.org/10.1016/j.cpcardiol.2018.11.002</u>.

 Racial and ethnic minority populations and AI/ANs continue to be underrepresented in clinical trials and clinical research. Older adults, women, children, pregnant and lactating individuals, LGBTQI+ populations, and persons with disabilities remain underrepresented and may be impacted by enrollment criteria that limit their ability to participate in research.⁵⁹

Actions to Achieve Equity: To address these barriers, HHS will:

- Ensure people most affected by health challenges are represented in studies and clinical trials and medical products/device testing to better reflect the full spectrum of populations who are affected by the disease or condition for which a product/treatment is being developed, if approved.
- Engage communities throughout the entirety of the research process and study design to build trust and improve transparency and accountability.
- Engage Tribal communities throughout the research process to ensure honoring of tribal sovereignty, data sovereignty, and to engender trust, transparency, and accountability.
- Advance engagement with diverse communities to build trust and improve representation in clinical trials and studies by providing education, creating collaborative research opportunities, and hosting public meetings and webinars.
- Engage a more diverse set of populations in informing our efforts and participating in clinical research, respecting tribal sovereignty and data ownership, so that we can innovate to improve health and well-being outcomes.

Proposed Metrics (Outputs and Outcomes):

Near- to Medium-Term

- Trends in recruitment and report clinical trial demographics, including sex, age, race/ethnicity and sexual orientation and gender identity data, compared to populations affected by the disease or condition being studied
- Increase in the number of community group and research/medical center partnerships with those who have experience working with the populations impacted by the disease or condition being studied
- Increase in the number of clinical research studies with enrollment addresses of the populations affected by the disease or condition being studied
- Increase in the number of engagements with communities, including Tribal communities, throughout the research process to engender trust, transparency, and accountability
- Increase in the development and use of culturally and linguistically tailored materials and information, patient navigators, and community health workers

Longer-Term

- Enhanced patient understanding of the importance of clinical trials and the clinical trials process
- Increased diversity of clinical trial participants

⁵⁹ National Academies of Sciences, Engineering, and Medicine. 2022. Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups. Washington, DC: The National Academies Press. <u>https://doi.org/10.17226/26479</u>.



Public Participation and Community Engagement:

- The National Institute on Minority Health and Health Disparities (NIMHD), an Institute within NIH, hosted the Inclusive Participation in Clinical Research Workshop to improve inclusive participation and implementation of best practices in clinical research through discussion with interested groups, including community-based organizations, academic institutions, federal agencies, and pharmaceutical companies. Workshop participants learned about the multi-faceted approach necessary to improve inclusion in clinical research, methods utilized to overcome challenges, and lessons learned.
- The National Institute on Aging (NIA), an Institute within NIH, manages Alzheimer's & Dementia Outreach, Recruitment & Engagement Resources (<u>ADORE</u>), which offers a repository of resources to support the recruitment and retention of participants into clinical trials and studies on Alzheimer's disease and related dementias. This includes resources developed through community engagement and related to working with people living with Alzheimer's disease and related dementias.
- The National Institute of General Medical Sciences (NIGMS), an Institute within NIH, manages the Institutional Development Award (IDeA) program, which is a congressionally mandated program that builds research capacity in states that historically have had low levels of NIH funding. It supports competitive basic, clinical, and translational research, faculty development, and infrastructure improvements. Additionally, the IDeA Clinical and Translational Research Programs focus on community engagement by building hubs for recruitment and relationship development in communities in IDeA states.
- The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), an Institute within NIH, hosted a workshop: "Optimizing Clinical Trials in Chronic Disease," to discuss best practices for planning, preparing, and implementing clinical trials, including recruiting and retaining a representative study population. Workshop participants included patients, advocacy groups, pharmaceutical companies, federal agencies, and academic/medical centers. Takeaways included the importance of considering patient perspectives in planning and implementing trials, barriers to participation and methods to address barriers, and the role of sponsors in supporting efforts to create inclusive trials.

