



Access, Affordability and Quality:
A Patient-Focused Blueprint for Real Health Equity
February 1, 2022



Health Equity Initiative

2021 Policy Recommendations

The National Health Council (NHC) historically has engaged in health equity advocacy through much of the work that we do with our members. The national dialogue on equity that emerged in 2020 strengthened our resolve to focus on a more coordinated, mission-focused approach to our health equity work.

Our collective work over the past 18 months confirmed where equity gaps exist in the health sector. Through engagement with leaders in the health and other sectors, we found consensus on defining the problem and areas of prioritization, reflected in the recommendations of this report. In reading this report, several critical issues are carried through each section. This design is purposeful as each area may stand alone apart from the full report.

Our Process

In 2020 we undertook a dialogue with our Board of Directors, members, and national thought leaders to identify those equity-related policy areas that were most significant to people with chronic diseases and disabilities, partnering with NHC member the National Minority Quality Forum. The result of that initial dialogue was a [consensus statement](#) signed by 58 CEOs of national patient groups committing to work together on four priority areas:

- Advocate for equitable access to affordable and comprehensive health insurance coverage;
- Promote an inclusive, equitable, accessible, and high-quality care delivery system;
- Partner with organizations that have a track record in addressing social determinants of health to reduce health disparities; and
- Collaborate with the biomedical and health-services research and the health economics ecosystem to support equity in development and valuation of new and innovative treatments and services.

Our guiding principle has been that:

Our current health system came of age when racial segregation and many other forms of discrimination based on such things as gender identity and sexual orientation, disability, and other factors were sanctioned by custom and law. Widely practiced discrimination bred structured health disparities for racial groups and other populations whom the society decided to disadvantage. The U.S. health care system has dismantled the outward manifestation of segregated care so that race is no longer the explicit discriminator. However, the legacy system continues to bolster discriminatory practices and has replaced the language of segregation with new discriminators. These discriminators, such as location, personal income, and employment and insurance status, disproportionately impact the historically disadvantaged. The net result is that structured health disparities remain.

In 2021, we once again gathered thought leaders in discussion for each of the four priority areas, resulting in the four sets of policy recommendations included in this report. Each discussion identified some core principles as well as specific policy recommendations, both short-term and more complex but critical issues.

Each area of policy recommendations demand comprehensive attention from policy makers. We can no longer address issues of health equity in a piecemeal manner. It is time for a complete transformation of the health care system to promote unbiased structures and processes to advance equitable access to quality health care for all.



Health Equity Initiative

Equitable Access to Affordable and Comprehensive Health Insurance Coverage Policy Recommendations

Background

On Tuesday, July 27, 2021, the National Health Council (NHC) hosted a Roundtable on advocating for equitable access to affordable and comprehensive health insurance coverage. This Roundtable is a follow-up to the NHC and the National Minority Quality Forum (NMQF) [consensus statement](#), signed by 58 Chief Executive Officers in the NHC's volunteer health agency membership.



A group of diverse thought leaders from across the health ecosystem had a robust discussion on issues that permeate our health care system regarding access to health insurance coverage. The agenda of the Roundtable focused on specific areas of policy that affect equity in access to insurance coverage, including:

- Quality of Coverage, including underinsurance and access to medication;
- Outreach & Enrollment, including making plans understandable and navigation of the process for enrollment;
- Medicaid, including the program as a target for state budget cuts and inequities between states due to the optional status of some Medicaid services; and
- Community Specific Issues, including immigration bans on coverage for five years and LGBTQ health care coverage.

The Roundtable participants began by identifying some fundamental principles that should guide all coverage policies to ensure equity. The principles are:

- The number of uninsured people must be reduced;
- Reforms are needed to ensure high-quality, comprehensive insurance coverage and to ensure accountability of insurance coverage;
- Recognize and actively address both implicit and explicit bias in the health care system; and
- It must be easier for individuals to access care and understand their coverage through simplifications to the system without undermining a sustainable business model.

Policy Recommendations

NHC members identified two categories of policy priorities. The first category includes policy recommendations that can be achieved in the short term, including those that have been proposed in Congress or by the Administration. The NHC will raise the profile of health equity efforts throughout the health ecosystem. The second set of recommendations includes issues that are more complex and need Congressional and regulatory action, and private-sector partnerships to achieve.



Short-Term Priorities

- Increase support for patients navigating the health insurance system at the time of enrollment and after they have coverage.
- Expand Medicaid in states that have not done so and/or create a federal fallback for those in the Medicaid coverage gap.
- Extend postpartum coverage extensions in Medicaid.

More Complex but Critical Issues

- Explore policies to address administrative burden for enrollment for those who are eligible but remain uninsured.
- Develop innovative payment models for high-cost therapies.
- Establish policies that would simplify coverage, i.e., standard or no cost-sharing, standard formularies.
- Improve data and data sharing to be comprehensive and consistent including data on things such as sexual orientation, gender identity, race/ethnicity, disability status, language, veteran status, and social needs (potentially through improved and better utilized medical billing Z codes that document SDOH data such as housing status, food insecurity, transportation access, etc.). It is important this be done in a way that protects patients' privacy and rights.
- Share this data across sectors outside of health while still respecting patients' privacy and rights (social services, corrections, transportation, etc.).
- Explore management processes through an equity lens.



Health Equity Initiative

Access to Care Policy Recommendations

Background

On Friday, October 22, 2021, the National Health Council (NHC) hosted a Roundtable on advocating for equitable access to care. This Roundtable is a deliverable of the NHC's and the National Minority Quality Forum's (NMQF) consensus statement, signed by 58 Chief Executive Officers in the NHC's volunteer health agency members.



A group of diverse thought leaders from across the health ecosystem had a robust discussion on issues that permeate our health care system

regarding access to care. The agenda of the Roundtable focused on specific areas of policy that affect equity in the delivery of health care, including:

- Workforce;
- Health Delivery System Infrastructure;
- Health Literacy and Communications/Navigation;
- Non-Discrimination Enforcement; and
- Standards of Care and Diagnoses.

The Roundtable participants began by identifying some fundamental principles that should guide all policies related to care delivery to ensure equity. The principles are:

- Eliminating disparities in the care delivery system will require action to address multiple barriers, such as:
 - economic access,
 - comprehensive coverage,
 - geographic access, and
 - being able to navigate the system and available options;
- Patients deserve access to culturally and linguistically appropriate care that is safe, respectful, and free from discrimination;
- Patients deserve to know how to get care, who is caring for them, and how their care is being administered;
- Access to care must not be dependent on patients' ability to physically get to the site of care. While providers must be more prevalent in underserved areas, barriers still

exist for people with disabilities and chronic conditions in accessing settings of care even when they are in their neighborhood; and

- Addressing equity in access to care will produce better care for everyone, regardless of economic status, race, gender identity, or sex.

Policy Recommendations

NHC members identified two categories of policy priorities. The first category includes policy recommendations that can be achieved in the short term, including those that have been proposed in Congress or by the Administration. The NHC seeks to raise the profile of these efforts throughout the health ecosystem. The second set of recommendations includes issues that are more complex and need Congressional and regulatory action, and private-sector partnerships to achieve. These will require greater levels of research, policy development, and socialization.

Short-Term Priorities

- Increase investment in the federal safety net health care programs such as Community Health Centers and the National Health Service Corps.
- Clarify, strengthen, and enforce existing federal non-discrimination laws.
- Educate patients on their legal rights and build support for medical-legal partnerships such as the [National Center for Medical-Legal Partnerships](#).
- Increase access to telehealth to assure more people can access health services. In 2020, the NHC joined with 34 national patient organizations to endorse a set of [telehealth principles](#). The primary focus of any policy should be supporting providers and patients working together to decide what type of visit is most appropriate for them.
 - Any expansion of telehealth services must be designed to reduce health disparities and must not perpetuate them.

More Complex but Critical Issues

- Increase the diversity of the health care workforce through:
 - Utilizing K-12 evidence-based pipeline programs and
 - Increasing the number of HBCU and minority-serving institution (MSI) Medical and Nursing Schools residency slots.
- Address ways that clinical assessment tools and diagnostics increase health disparities.
- Improve data and data sharing to be comprehensive and consistent including data on things such as sexual orientation, gender identity, race/ethnicity, disability status,



language, veteran status, and social needs (potentially through improved and better utilized medical billing Z codes that document SDOH data such as housing status, food insecurity, transportation access, etc.). It is important this be done in a way that protects patients' privacy and rights.

- Provide accurate health education to improve the population's health care literacy in culturally and linguistically appropriate ways.



Health Equity Initiative

Social Determinants of Health Policy Recommendations

Background

On September 21, 2021, the National Health Council (NHC) provided a response to the request for information from the newly formed [Congressional Caucus for Social Determinants of Health](#). [Social determinants of health \(SDOH\)](#) are conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. The caucus asked a series of questions about what is needed to ensure people have access to social supports.

Our response was informed by our health equity working group on SDOH as well as our Policy Action Team and Health Care Reform Action Team. The SDOH issues we identified that most greatly impact the health of people with chronic diseases and disabilities include:

- Being uninsured or underinsured;
- Economic and financial security;
- Access to affordable and accessible transportation options to access health care, social services, and the community;
- Food insecurity;
- Social isolation; and
- Affordable and accessible housing options.

The fundamental principle identified by our members is that **efforts to increase access to services that support SDOH must be inclusive of people with chronic diseases and disabilities**. For example, housing assistance efforts need to include accessible housing options and should be well connected to health services; increasing the accessibility and availability of public transportation; and addressing food insecurity recognizes the need for specialized diets, cultural preferences, and people's varying abilities to prepare meals.

Policy Recommendations

NHC members identified two categories of policy priorities. The first category includes policy recommendations that can be achieved in the short term, including those that have been proposed in Congress or by the Administration. The NHC seeks to raise the profile of health equity efforts throughout the health ecosystem. The



second set of recommendations includes issues that are more complex and need Congressional and regulatory action, and private-sector partnerships to achieve.

Short-Term Priorities

- Invest in professional, direct-care workforce, and family caregivers. One significant need is to invest in Medicaid home and community-based services (HCBS).
- Replicate and scale up successful, innovative transportation and other SDOH models at the Federal level to increase access to health care and social supports, including those solutions from areas both with and without public transit infrastructure.
- Increase access to affordable broadband services to support patient access to health resources and broaden economic opportunities and security.

More Complex but Critical Issues

- Provide adequate funding at the Federal, state, and local levels to support comprehensive, accessible social support systems that are available to anyone regardless of their economic situation or location including supporting creative models of addressing SDOH.
- Engage the full health ecosystem (including insurers, providers, and patient organizations) to address SDOH needs. Include resources, clarity of need, and best practices to better connect patients with the social service system.
- Establish a “no-wrong-door” approach to federal programs for patients that helps them seamlessly navigate health and social services. For example, when an individual enrolls in Medicaid they are assessed for eligibility for nutrition, housing, transportation, or other safety net programs and seamlessly linked to them.
- Improve data and data sharing to be comprehensive and consistent including data on things such as sexual orientation, gender identity, race/ethnicity, disability status, language, veteran status, and social needs (potentially through improved and better utilized medical billing Z codes that document SDOH data such as housing status, food insecurity, transportation access, etc.). It is important this be done in a way that protects patients’ privacy and rights.
 - Share this data across sectors outside of health while still respecting patients’ privacy and rights (social services, corrections, transportation, etc.).



Health Equity Initiative

Medical Innovation Policy Recommendations

Background

Throughout 2021, the National Health Council participated in and advised multiple efforts to address equity and access in medical innovation. This includes partnering with groups of researchers, patient organizations, and the biopharmaceutical industry. In addition, a special listening session was held at our Science of Patient Engagement Symposium in October to gather feedback. Our response was also informed by our health equity working group on medical innovation and by the years of NHC work on developing [best practices and tools](#) for patient engagement.

The medical innovation priorities identified that most greatly impact people with chronic diseases and disabilities include:

- Medical research must do a better job of “meeting people where they are” and engaging patients in their communities. This includes partnering with trusted voices in their communities to educate and engage diverse patients;
- Clinical trials need to be convenient and accessible for patients. Patients are appropriately compensated for participation;
- Diverse patients and caregivers need to be engaged as partners in clinical trial design and implementation. Their time, expertise, and contributions must be valued as reflected in the compensation for such. The patient community and partners have a responsibility to build capacity within their communities to ensure patients have the skills and knowledge to participate;
- Patient groups and other community-based organizations are critical partners in helping connect diverse populations with trials and building trust in science. Community partners need to be supported with resources and information to participate in these activities;
- Education about the value of trials and medical innovation needs to be readily available to patients, providers, and communities in understandable, clear, direct, and appropriate ways. This includes sharing information about trial outcomes with participants;
- There is a need to continue to diversify the research workforce; and
- Data collection is critical including:
 - Inclusion of all diverse and underrepresented populations;
 - Access, consistency, and interoperability of the data; and
 - Protection of privacy and security.



Providers are the most trusted advisors on clinical trials. They need clear, accessible information to help them connect patients to trials.

Policy Recommendations

NHC members identified two categories of policy priorities. The first category includes policy recommendations that can be achieved in the short term, including those that have been proposed in Congress or by the Administration. The NHC seeks to raise the profile of health equity efforts throughout the health ecosystem. The second set of recommendations includes issues that are more complex and need Congressional and regulatory action, and private-sector partnerships to achieve.



Short-Term Priorities

- Provide Federal guidance and tools to help increase diversity of clinical trials, including the use of decentralized trials where appropriate.
- Appropriately reimburse clinical trial participants for true costs of participation in research such as their time, travel, parking, lost time, childcare, and other factors that can affect participation. The NHC has created a [Fair Market Value Calculator](#) to determine fair compensation for patients and patient group representatives involved in patient-engagement activities. This tool can be widely utilized to help ensure patients are fairly supported.
- Improve data and data sharing to be comprehensive and consistent including data on things such as sexual orientation, gender identity, race/ethnicity, disability status, language, veteran status, and social needs (potentially through improved and better utilized medical billing Z codes that document SDOH data such as housing status, food insecurity, transportation access, etc.). It is important this be done in a way that protects patients' privacy and rights.

More Complex but Critical Issues

- Develop tools and resources for trial sponsors on designing clinical trials in the most inclusive way possible. This includes setting, site selection, targets, patient engagement activities, exclusion criteria, and other factors affecting diversity of participation. These efforts should include community-engaged and community-based participatory research.
- Encourage the research community to join together to create a long-term environment and infrastructure that supports an inclusive research workforce.
- Create guidance on appropriate demographic participation targets to support trial design that reflects disease state and protects patients' privacy.



About the Health Equity Initiative

The NHC hosted a series of Roundtables in 2021. The Roundtables are based on the issues identified in the Consensus Statement, which are:

- Advocate for equitable access to affordable and comprehensive health insurance coverage;
- Promote an inclusive, equitable, accessible, and high-quality care delivery system;
- Collaborate with the biomedical and health-services research and the health economics ecosystem to support equity in development and valuation of new and innovative treatments and services; and
- Partner with organizations that have a track record in addressing social determinants of health to reduce health disparities.

The NHC's Health Equity Task Force serves as advisors for our health equity initiatives by helping to ideate and prioritize the Roundtables, identify other member-facing resources, and advise the NHC on planning additional activities. Supporting the task force were four Roundtable work groups that each focused on one of the issues outlined in our consensus statement.

The NHC would like to thank the many partner organizations, both NHC members and non-members, who assisted in developing this report. We would particularly like to thank the nearly 75 national organizations representing patient groups, providers, civil rights groups, insurers, the biopharmaceutical industry, medical education, and other sectors that had direct involvement in developing these priorities.

The National Health Council is able to do this important work with the support of our funders. Please join us in thanking the following organizations for their support:



For more information, visit <https://nationalhealthcouncil.org/issue/health-equity/>.