



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/>.