

IMPROVING REPRESENTATION

in Clinical Trials and Research

Building Research Equity For Women and Underepresented Groups

REPORT CONCLUSIONS

The United States has long made substantial investments in clinical research with the goal of improving the health and wellbeing of our nation. There is no doubt that these investments have contributed significantly to treating and preventing disease and extending human life. **Nevertheless, large swaths of the U.S. population, and those that often face the greatest health challenges, are less able to benefit from these discoveries because they are not adequately represented in clinical research studies.**

In 2020, the National Academies of Sciences, Engineering, and Medicine was tasked by Congress to undertake a study “*examining and quantifying the long-term medical and economic impacts of the inclusion of women and racial and ethnic minority population subgroups in biomedical research and subsequent translational work*”.

Five overarching conclusions, based on a comprehensive analysis of the research, were identified by the report committee.

01 Improving Representation IS URGENT

Despite greater diversity in the United States today, deep disparities in health are persistent, pervasive, and costly.

Failing to reach these growing communities will only prove more costly over time and prevent meaningful reductions in disparities in chronic diseases.

02 Improving Representation REQUIRES INVESTMENT

In order to better address health disparities, our workforce should look more like our nation. Building trust with local communities cannot be episodic or transactional and pursued only to meet the goals of specific studies; it requires sustained presence, commitment, and investment.

03 Improving Representation REQUIRES TRANSPARENCY & ACCOUNTABILITY

Transparency and accountability throughout the entire research enterprise must be present at all points in the research lifecycle – from the questions being addressed, to ensuring the populations most affected by the health problems are engaged in the design of the study, to recruitment and retention of study participants, to analysis and reporting of results.

04 Improving Representation IS THE RESPONSIBILITY OF EVERYONE INVOLVED

The clinical research landscape involves multiple stakeholders— participants, communities, investigators, IRBs, industry sponsors, institutions, funders, regulators, journals, and policy-makers. The responsibility (and cost) will be borne to some extent by all stakeholders in the larger research ecosystem, acting in consort to improve representation.

05 CREATING A MORE EQUITABLE FUTURE ENTAILS A PARADIGM SHIFT

The clinical research field must embrace a paradigm shift that moves the balance of power from institutions and puts at the center the priorities, interests, and voices of the community.

An ideal clinical trial and research enterprise pursues justice in the science of inclusion through scalable frameworks, expects transparency and accountability, invests more in people, institutions and communities to drive equity, and invests in the science of community engagement and empowerment.

READ THE FULL REPORT

www.nationalacademies.org/improve-representation

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2022. *Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underepresented Groups*. Washington, DC: The National Academies Press.

Copyright 2022 by the National Academy of Sciences. All rights reserved.

*The National
Academies of*

SCIENCES
ENGINEERING
MEDICINE