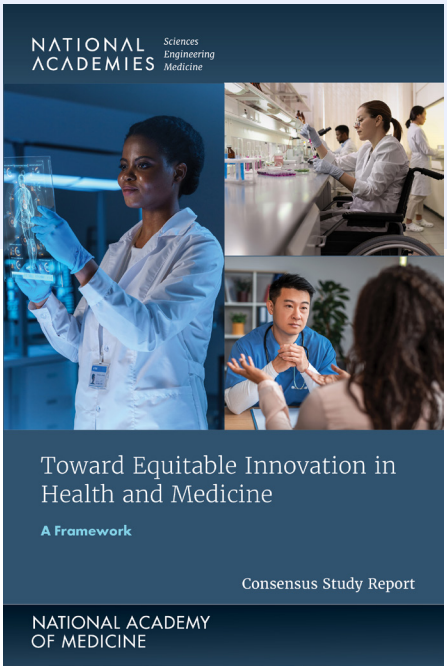
Toward Equitable Innovation in Health and Medicine



A Framework

OVERVIEW

Innovation in health and medicine has the potential to positively impact both individuals and society as a whole. Yet, questions remain around who has the opportunity to benefit from emerging technologies and who may be left behind. The COVID-19 pandemic revealed stark underlying inequities in health care and technology in the United States and globally. As game-changing innovations in gene editing, regenerative medicine, artificial intelligence, and other areas find their way into daily life, it is vital to proactively consider how we can fairly distribute the benefits and risks associated with the development and deployment of these technologies.

Therefore, a coalition of philanthropic and for-profit organizations sponsored a consensus study of the National Academies of Sciences, Engineering, and Medicine and the National Academy of Medicine (NAM) to provide guidance on managing the risks, benefits, and ethical and societal implications of new technologies in health and medicine. The study built on the work of the NAM's Committee on Emerging Science, Technology, and Innovation in Health and Medicine, which was established in early 2020 to explore societal, ethical, legal, and other implications of technologies contributing to the NAM's vision of "a healthy future for everyone."

In 2022, the National Academies appointed a 19-member ad hoc committee with expertise in technology development and assessment from the lenses of emerging science; public health, philosophy, and social sciences; economics; innovation policies; regulatory oversight;

the rights and needs of historically marginalized or underrepresented communities; and other domains. The report *Toward Equitable Innovation in Health and Medicine: A Framework* offers a governance framework for supporting an equitable innovation ecosystem along with recommendations for actions to translate this framework into practice.

EQUITY IN INNOVATION

Equity reflects a combination of equality, justice, and fairness. The report's case for taking equity seriously in health innovation stems from the assertion that inequities around race, gender, sexuality, disability status, geography, and other circumstances are ethically unacceptable, economically debilitating, and scientifically diminishing.

The implications of health technologies extend beyond individual concerns to encompass collective societal values and needs. Accordingly, the committee chose to focus on eight dimensions of equity in the context of health technology development:

- *Topical equity*—An innovation portfolio should include topics of relevance to diverse communities, including populations that have traditionally experienced injustices.
- *Innovator equity*—Innovators should reflect diverse populations to tap a broad scope of imagination and creativity.
- *Input equity*—Development and implementation processes should include teams with diverse representation to make products relevant to a wide community of users, demonstrate respect for affected communities, and enhance accountability.
- *Evaluation equity*—New technologies should be evaluated in diverse or representative populations to reduce errors in assessing benefits and harms and broaden eventual applications.
- *Deployment equity*—Technologies should be accessible to and benefit a diverse population, including traditionally underserved or marginalized groups.
- *Value capture equity*—The value created from new technologies should be captured and distributed fairly.
- *Contextual equity*—New technologies should not perpetuate past injustices and should address or correct past injustices where possible.
- *Attention equity*—Organizations and innovators should attend to equity concerns, including by actively seeking and mitigating inequities in how technologies are deployed.

ALIGNING INNOVATION WITH EQUITY

The path from conception to the actual use of health technologies is complex. While particulars vary, a common thread is that parties spanning multiple sectors—funders, researchers, developers, regulators, users and affected communities, health care organizations, and others—make choices and take actions along the innovation life cycle. Decisions about funding and research investments, intellectual property, commercial investment and scale-up, performance evaluation, cost and insurance coverage, regulatory requirements, and postmarket assessments and responses all influence the trajectory of a technology as well as the ultimate distribution of its benefits and burdens.

The committee found that the U.S. ecosystem for emerging science, technology, and innovation in health and medicine is dynamic and diverse but does not currently prioritize alignment with equity. Working toward an equity-aligned innovation system will therefore require new processes that shift and diversify the traditional innovation life cycle. Figure 1 below identifies five imperatives to connect decision points along the cycle with the goal of advancing equitable innovation.

Through their choices and actions, all members of the innovation ecosystem have opportunities to enhance the alignment of technology development with equity considerations. Similarly, levers that can incentivize such actions exist at every phase of the innovation life cycle.

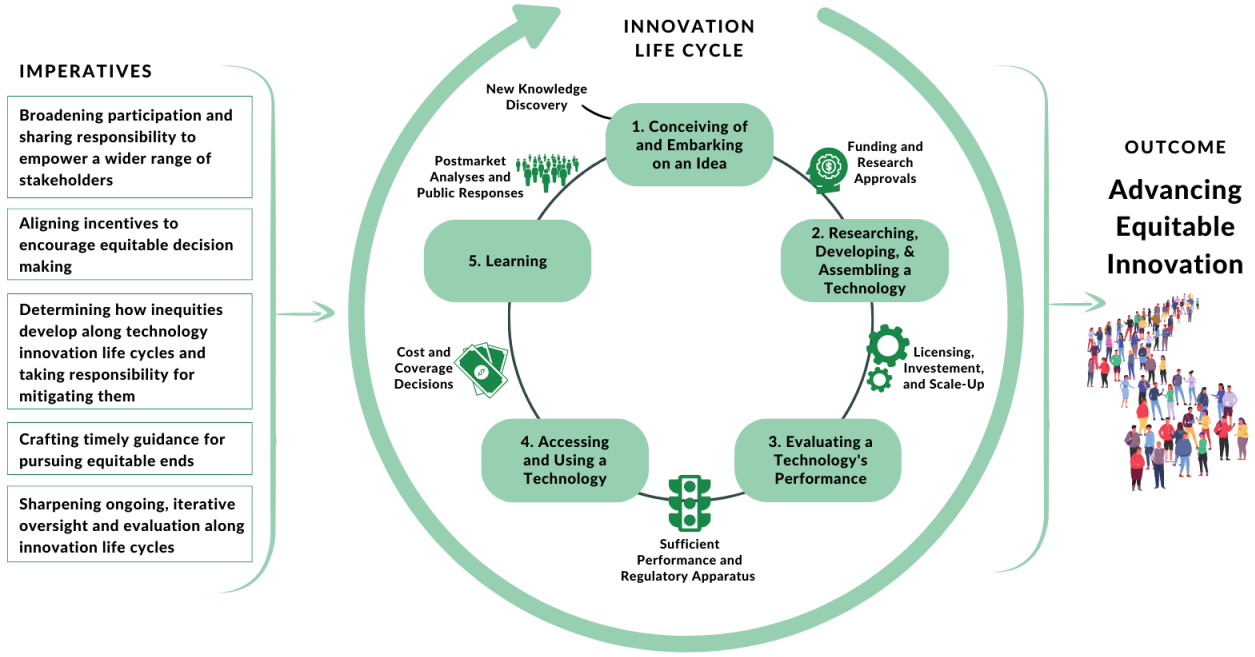


FIGURE 1 The governance framework for aligning emerging science, technology, and innovation in health and medicine with ethical principles, emphasizing alignment with equity.

The report concludes that a systems-level approach is needed to implement equity-promoting practices and oversight, incorporating steps such as using funding, priority setting, and other levers to advance equity; expanding and developing new metrics and equity-based models of technology assessment; and encouraging more robust engagement between innovators and the groups and communities that have been poorly served by the current innovation system.

RECOMMENDATIONS FOR SUPPORTING AN EQUITABLE ECOSYSTEM FOR SCIENCE AND TECHNOLOGY INNOVATION IN HEALTH AND MEDICINE

Recommendation 1: Galvanize national leadership for aligning emerging science, technology, and innovation in health and medicine with principles of equity.

The White House Office of Science and Technology Policy (OSTP) should lead federal efforts to operationalize the governance framework and encourage federal, state, and local policy makers to drive equity-aligned innovation via relevant policy and oversight mechanisms.

Recommendation 2: Enhance a culture of innovation that incorporates equity as an ethical concept in technology development and integrates it into organizational practice.

Organizations that establish norms, conduct and oversee research and development, and generate intellectual property should take responsibility for incorporating ethical principles across the innovation enterprise through training, policies, and practices, including in decisions about research investments, study designs, and technology licensing and investment.

Recommendation 3: Incentivize the alignment of innovation with equitable benefit.

Specific governance levers can incentivize stakeholders to incorporate ethics and equity-focused assessments more fully into the innovation process and address misalignments that arise.

Recommendation 4: Empower diverse communities to participate in the innovation system.

To support the capacity of marginalized or underserved communities to substantively participate in the innovation system, best practices for engaging with these communities and incorporating policies and practices that facilitate, recognize, and value their contributions should be identified.

Recommendation 5: Invest in developing equity science for technology innovation.
The National Institutes of Health, National Science Foundation, and philanthropic organizations should support the development of additional equity science methods, metrics, and benchmarks for assessing the equity implications of technology innovation decisions.

Recommendation 6: Develop context-specific guidance on translating the governance framework for emerging science, technology, and innovation into practice.
Equity playbooks addressing different areas of science and technology innovation and different stakeholder communities and choice points in the innovation life cycle should be developed to provide concrete strategies for translating the governance framework into practice.

LOOKING TO THE FUTURE: AN ACTION AGENDA

OSTP can provide federal leadership by working with department and agency equity teams and convening a multistakeholder, cross-sectoral Equity in Biomedical Innovation Task Force to galvanize action.

Funders of emerging science, technology, and innovation can integrate equity considerations into the formulation, funding, and conduct of research in a variety of ways, such as mandating ethics and equity plans and training, enhancing the ability of underserved communities to participate in innovation, and supporting the development of equity science and metrics.

Researchers and organizations that conduct research and development can advance partnerships, policies, and standards that incorporate ethical and equity concerns; use best practices for codesigning research with affected communities; and include diverse perspectives on review panels and technology assessments.

The **U.S. Patent and Trademark Office, technology transfer and licensing offices, law firms, and venture capital and other investors** can help facilitate public benefit and equity through enhanced equity provisions in licensing and technology transfer practices, greater transparency in patent descriptions, and periodic portfolio analyses with attention to equity aims.

Communities, including those that are historically marginalized and underrepresented, can help support sustained, bidirectional engagement in innovation by identifying research priorities, participating in specific projects, and engaging with efforts to develop equity science more broadly.

Regulatory stakeholders can advance policies that recognize the importance of equity in evaluation criteria, by requiring testing strategies that reflect the full range of intended users and contexts, mechanisms for engaging with affected communities, and postmarket analyses to identify inequities that may arise after deployment.

Health care payers and delivery stakeholders can advance more equitable access to new technologies and more equitable health outcomes by including equity metrics in purchasing, use, and coverage decisions, as well as through postmarket studies and periodic portfolio analyses.

All stakeholders have a role in promoting a culture of equitable innovation and advancing context-specific strategies and governance mechanisms to facilitate an equitable innovation ecosystem.

Reorienting innovation to advance equity is a vital and challenging imperative for 21st-century science, medicine, and technology. The coordinated, cross-sectoral governance framework and recommendations in this report represent important steps toward achieving an innovation system that is more equitable, responsive to the needs of more people, and capable of recognizing and addressing inequities as they arise.

FOR MORE INFORMATION

This Consensus Study Report Highlights was prepared by National Academies' staff based on the Consensus Study Report *Toward Equitable Innovation in Health and Medicine: A Framework* (2023).

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