



# Action Guides

Readers can find all of the action steps from this report, organized by stakeholder role, within the brief, 2-page action guides linked below. These guides are meant to provide ideas on where to begin taking action to foster change in the practice of HTA. Each stakeholder guide includes links to best-in-class resources and tools to help readers create impact. These action guides will continue to grow and evolve over time as new actions and resources are identified by partners. Click below to download the guide that aligns with your role or explore the [full set of action guides](#).

**To fulfill the promise of value-based care, integrate equity throughout HTA by taking the actions highlighted in these guides.**



[Researchers](#)



[Patients and Caregivers](#)



[Professional Association  
Leaders](#)



[Journal Editors](#)



[Research Sponsors](#)



[Payers and Purchasers](#)

# Action Guide for RESEARCHERS



Researchers and the institutions where they work are critical to the equitable conduct of health technology assessment (HTA). They plan and carry out assessments, generate the evidence on which assessments are based, collect and analyze data, develop new methods, and publish findings. The actions below highlight opportunities for principal investigators, chief science officers, and other research leaders to partner with patients and caregivers in the conduct of HTA, prioritize representation, recognize patient and caregiver contributions, and diversify the HTA workforce.

## Researcher actions to center equity in HTA:

- Establish ongoing partnerships with patients and caregivers to inform all HTA research, from planning and scoping through analysis, synthesis, and application.
- Outline clear roles for co-creation, including how patient input is weighted with other expert input.
- Prioritize partnerships with patients and caregivers who are representative of people experiencing the condition of focus and of communities experiencing persistent health inequities.
- Build into project plans time for earning trust within marginalized communities. Maintain these relationships over time and across projects.
- Compensate and support patient and caregiver partners for all contributions to HTA.
- Establish institutional policies requiring compensation and recognition for patient and caregiver partners.
- Offer patient and caregiver partners opportunities for co-authorship, including support in learning publication processes.
- Include in publications impact of patient and caregiver partnership on objectives, inputs, data, analyses, and interpretation.
- To broaden recruiting efforts for faculty, staff, and students, build relationships with universities and academic programs that serve underrepresented communities (e.g., minority-serving institutions) and provide training in complementary fields (e.g., community-based participatory research).
- Hire and collaborate with individuals who bring experience living and working within a variety of communities, academic disciplines, and professions.
- Create opportunities within the HTA field that do not require a PhD or traditional academic pathways.



## Resource Spotlight: Tools for Researchers

- The [Patient-Centered Outcomes Research Institute](#) (PCORI) offers a wide range of resources, training, and tools to help research teams partner with patients, caregivers, and other stakeholders throughout the research process. While PCORI focuses on comparative effectiveness research, their guidance is applicable to a wide variety of research approaches, including HTA.
  - A good place to start in developing partnership skills is [Building Effective Multi-Stakeholder Research Teams](#), a two-part interactive learning module that focuses on engaging stakeholders as active members of a team and working together as an effective multi-stakeholder team.
  - PCORI's [Engagement Resources](#) web page provides a wealth of additional resources, including templates for developing an [engagement plan](#), [budgeting for engagement activities](#), and a [guide for engaging with research partners in data analysis](#).
- The National Health Council's [Fair Market Value Calculator](#) offers guidance on fair compensation for patients and caregivers based on their experience, time commitment, contributions, and other considerations. The tool is free for public use and includes an accompanying user guide, glossary, and principles for patient engagement compensation.
- The Equity Lab and the National Health Council created [Inclusive Workplaces](#), a guide with examples and considerations for building a representative workforce across the healthcare sector, including within life sciences companies.



# Action Guide for PATIENTS AND CAREGIVERS



Patients and caregivers, and especially the organizations that represent and advocate on their behalf, are essential partners in equity-centered health technology assessment (HTA) practice. Below, we focus especially on actions for patient organization leaders to help establish partnerships with other HTA stakeholders. Since each patient organization has its own leadership structure, we focus on actions for individuals playing a wide variety of leadership roles (e.g., CEO; program, policy, or advocacy lead; research directors; board members).

## **Patient organization leadership actions to center equity in HTA:**

- Raise awareness among patients and caregivers about how HTA informs payer and purchaser decision-making and help individuals find opportunities to partner with researchers conducting HTAs.
- Expand efforts to diversify the community of patients and caregivers who are available and prepared to partner in research and HTA. Emphasize representation of communities most impacted by health inequities.
- In expanding outreach to marginalized communities, collaborate with community-based organizations, equity-focused consulting firms, and minority-led organizations.
- Build into outreach plans time for earning trust within marginalized communities. Maintain these relationships over time and across initiatives.
- Partner with research institutions and professional associations to:
  - Build capacity among patient communities to participate in HTA.
  - Develop and provide training and learning communities for patients and caregivers regarding HTA terminology, processes, and participation.
  - Provide training and support on the peer-reviewed publication process for patient and caregiver partners.
  - Establish fair market rates for compensating patients and caregivers who partner in HTA.
- Set expectations for and help patients and caregivers negotiate compensation at fair market rates.
- Sponsor scholarships or fellowships that support patient advocates pursuing careers in HTA.



## Resource Spotlight: Tools for Patients and Caregivers

- Through the [PATIENTS Professors Academy](#), the University of Maryland School of Pharmacy provides free training to patients and caregivers to prepare them for engaging in patient-centered research, including HTA. The 5-week on-line program teaches a 10-step framework for continuous patient and stakeholder engagement to equip patients and caregivers to drive research within their communities.
- EveryLife Foundation for Rare Diseases led development of the [Guide to Patient Involvement in Rare Disease Therapy Development](#), a resource created BY the community and FOR the community to optimize rare disease product development efforts. The Guide focuses on including patient experience in therapy development for rare diseases, including demonstrating the value of therapies to patients with rare disease and their families.
- National Health Council partnered with patients and caregivers to co-create a guide, the [Patient-Centered Core Impact Sets \(PC-CIS\) Blueprint](#), to address inconsistencies between what health impacts are important to patients and what outcomes are typically collected in research or used in HTA. A PC-CIS is a standardized, patient-derived and patient-prioritized list of the most important impacts a disease and/or its treatments have on a patient's health and daily life, and that of their family and caregivers. Using PC-CIS in HTA will focus coverage and reimbursement decisions on what patients care about most.



# Action Guide for PROFESSIONAL ASSOCIATION LEADERS



Professional associations play an important role in health technology assessment (HTA) practice by establishing best practices, guidelines, and standards; providing training and mentorship; and ensuring high-quality, ethical HTA conduct (in HTA, this includes organizations such as [ISPOR](#), [ASHE](#), [AcademyHealth](#), [AdvaMed](#), [Medical Device Innovation Consortium](#), and [PhRMA](#)). These core functions represent accountability mechanisms to incentivize the practice changes necessary for equity-centered HTA. Leaders and membership within these associations have opportunities – and an imperative – to lead the way in making HTA a tool for advancing equity.

## Professional association leadership actions to center equity in HTA:

- Update HTA best practice standards, guidance, and training to emphasize partnerships and co-creation with patients and caregivers.
- Highlight through standards and training the importance of engaging patients and caregivers who are representative of communities likely impacted by an HTA, especially communities experiencing persistent health inequities.
- Share best practices on compensation for and co-authorship with patient and caregiver partners. Collaborate with patient organizations to establish fair market rates for compensation.
- Provide equity skills training to researchers conducting HTA.
- Design training in partnership with patient organizations; individuals who bring expertise in equity for different populations (e.g., by race/ethnicity, culture, disability status); and patients and caregivers representing marginalized communities.
- Transparently report demographic composition of membership, committees, and leadership positions.
- Provide additional mentorship and peer support for individuals entering the HTA field who identify as part of communities that experience persistent health inequities and/or are underrepresented in health research.
- Make the case for how a career in HTA offers opportunities for individuals from diverse backgrounds. Tailor for specific communities underrepresented in the HTA workforce.



## Resource Spotlight: Tools for Professional Association Leaders

- The Patient-Centered Outcomes Research Institute's (PCORI) [methodology standards associated with patient-centeredness](#), including engaging people representative of the population of interest.
- The [Equity and Inclusion Guiding Engagement Principles](#) developed by PCORI's Advisory Panel on Patient Engagement.
- In its [Consolidated Health Economic Evaluation Reporting Standards \(CHEERS\)](#) (updated 2022), the Professional Society for Health Economics and Outcomes Research (ISPOR) provides guidance on reporting the process and impact of patient and caregiver engagement in health economic analyses and research.
- AcademyHealth offers recommendations for [Diversity, Equity, and Inclusion in Health Services and Policy Research](#), including diversifying the workforce and integrating equity practices throughout publishing. These recommendations can serve as an example for similar efforts in health economics.



# Action Guide for JOURNAL EDITORS



Peer-reviewed scientific journals are a crucial vehicle for disseminating health technology assessment (HTA) research, methods, and results, as well as the evidence that informs HTA. By exercising editorial oversight and discretion, establishing authorship guidelines, and facilitating the peer review process, journal editors ensure that rigorously conducted HTA and patient-centered or comparative effectiveness research is available for use. They also set expectations for what gets published, what details are included in those publications, and how contributors are recognized. When enacted by editors-in-chief, associate editors, and editorial board members of HTA-focused journals, the actions below can help to incentivize researchers to partner with patients and caregivers throughout HTA conduct, ensure that these partnerships are representative and fairly recognized, and diversify the HTA workforce.

## Journal editor actions to center equity in HTA:

- Require within HTA-related journals a description of whether – and if so, how – authors collaborated with patients and caregivers.
- As part of review processes, ask for details about how well patient and caregiver partners represent the population experiencing the condition of focus and communities experiencing persistent health inequities.
- Require disclosure within HTA-related journal articles whether patient and caregiver partners were compensated and offered opportunities for co-authorship.
- Encourage patient and caregiver partner co-authorship by:
  - Updating guidelines for authors to describe how patient and caregiver partners can meet co-authorship criteria.
  - Giving more weight in peer review to submissions that include authors with lived experience.
- Invite and publish commentary on implications of HTA findings, methods, or frameworks written by patients and caregivers from diverse backgrounds and individuals with expertise in equity for different populations (e.g., by race/ethnicity, culture, disability status). Emphasize implications for marginalized communities.
- Transparently report demographic composition of editors and reviewers.
- Collect self-reported demographic data from authors. Publicly report diversity of contributors.



## Resource Spotlight: Guidance for Journal Editors

- The [British Medical Journal](#) requires that authors document if and how they involved patients and the public in research conduct within a [designated section](#) of all research articles. The journal's policy is based on [Guidance for Reporting Involvement of Patients and the Public](#) (GRIPP2) in study aims, methods, results, discussion, and reflections.
  - ISPOR's 2022 [Consolidated Health Economic Evaluation Reporting Standards](#) (CHEERS) provides guidance on reporting **patient and caregiver engagement** in health economic analyses and research.
- The peer-reviewed journal, [Progress in Community Health Partnerships: Research, Education, and Action](#), provides an additional example of author guidance and editorial review criteria that emphasize academic-community partnerships in both the conduct and publication of research
- *Health Affairs* launched a [strategy for its equity program](#) emphasizing that in scholarly publishing “equity begins with authors, reviewers, and editors.” The journal also created a [Health Equity Advisory Committee](#) and [captures the demographic characteristics](#) of authors and reviewers.
- The Workgroup of European Cancer Patient Advocacy Networks (WECAN) offers an open-access training course, [Patients in Publications](#), for patient advocates who want to learn how to publish their own research or collaborate as a co-author.



# Action Guide for RESEARCH SPONSORS



Through their financial support, organizations sponsoring patient-centered outcomes research, comparative effectiveness research, health economics and outcomes research, and related research make health technology assessment (HTA) possible. Directors, program officers, and other decision-makers within these entities (e.g., government, foundations, life science companies) set priorities, establish review criteria and processes, and provide oversight. The actions below highlight opportunities for research sponsors to act as stewards for equity-centered HTA by prioritizing patient and caregiver partnership throughout HTA conduct, ensuring that these partnerships are representative and fairly recognized, and supporting efforts to diversify the HTA workforce.

## Research sponsor actions to center equity in HTA:

- Make evidence of partnership with patients and caregivers a prerequisite for funding approval. Encourage partnerships starting during proposal development and throughout HTA processes.
- Encourage co-investigator and leadership roles for patients and caregivers in HTA research.
- Require compensation for patient and caregiver partners as part of HTA budgets. Approve compensation at fair market rates.
- Require prospective HTA teams to describe dimensions of diversity within their team. Prioritize funding those teams bringing more diversity in perspectives, cultures, experiences, and expertise.
- Require reporting that include details of partnerships with patients and caregivers, including their roles and contributions and how well partners represent marginalized communities.
- Collect self-reported demographic data from researchers receiving funding for HTA work. Publicly report diversity of award recipients.
- Fund patient organizations to develop and provide training and learning communities that prepare patients and caregivers for engaging in HTA work.
- Fund fellowships, leadership training, and mentorship for early- and mid-career HTA professionals who identify as part of communities that experience persistent health inequities and/or are underrepresented in health research.



## Resource Spotlight: Guidance for Research Sponsors

- The Patient-Centered Outcomes Research Institute's (PCORI) [merit review criteria](#) include detailed guidance for assessing patient-centeredness and patient and stakeholder engagement within funding applications. PCORI has also established [methodology standards associated with patient-centeredness](#), including engaging people representative of the population of interest. These standards provide criteria against which to assess the rigor and representativeness of patient engagement in research.
- FasterCures provides an [Action Plan to Address Diversity across Clinical Trials and Biomedical Research](#) with recommendations for ways funders can improve representativeness within research while increasing workforce diversity.
- In its [Consolidated Health Economic Evaluation Reporting Standards](#) (CHEERS) (updated 2022), the Professional Society for Health Economics and Outcomes Research (ISPOR) provides guidance on reporting the process and impact of **patient and caregiver engagement** in health economic analyses and research. While this guidance does not yet address equity, by requiring researchers to follow this guidance, sponsors will create transparency around the role of patients and caregivers in HTA conduct; representativeness of those partners; and recognition of their contributions.



# Action Guide for PAYERS AND PURCHASERS



As the end-users of health technology assessment (HTA), payers and purchasers play a critical role in ensuring that how they act on assessments reduces health disparities and works toward more equitable health outcomes. In considering findings from an HTA as part of designing health plans, determining benefits, making formulary decisions, or setting reimbursement rates, payers and purchasers must consider how well the HTA integrates equity considerations. Questions for employer purchasers, and commercial and public payers to consider when assessing appropriateness of HTA findings for decision-making include:

- How did patients and caregivers contribute to the HTA process? To what extent did they shape the scope and research questions, analysis, interpretation, and reporting? To what extent did they have decision-making authority (e.g., co-leadership, approval of final report), and at what stages?
- How representative were patient and caregiver partners of communities that may be impacted by decisions based on these HTA findings? Which perspectives may be missing?
- How diverse is the team that conducted the HTA in terms of culture, language, race/ethnicity, professional training, gender, socioeconomic status, or geography? What expertise did the team bring in equity, community engagement, or lived experience within marginalized communities?

When taken by chief medical officers, medical or pharmacy directors, members of pharmacy and therapeutics (P&T) committees, and leaders within pharmacy benefit managers (PBMs), the actions below will base coverage decisions on equity-centered HTA.

## **Payer and purchaser actions to center equity in HTA:**

- Request that evidence submissions include details of partnerships with patients and caregivers, including their roles and contributions.
- Consider adequacy of representation for marginalized communities, including their role in HTA conduct, when evaluating appropriateness of an HTA for decision-making.
- Collect self-reported demographic data from members of the P&T committee reviewing HTA in decision-making. Publicly report diversity of committee membership.
- When evaluating appropriateness of an HTA for decision-making, assess patient and caregiver engagement as a criterion of evaluating appropriateness.
- Invest in fellowships and other training initiatives to help underrepresented individuals enter and succeed in health economics and outcomes research (HEOR) careers.



## Resource Spotlight: Guidance for Payers and Purchasers

- The Center for Health Care Strategies (CHCS) offers a [Checklist for Medicaid Decision-Makers](#) when developing payment and spending strategies to advance health equity. The guide includes eight key questions for state and other payers to consider, including what they pay for, who they contract with, and who is involved in decision-making.
- CHCS also provided recommendations to the California Department of Health Care Services on [designing a Medi-Cal Member Advisory Committee](#). Following this guidance will help public and commercial payers equitably engage marginalized communities in key decision-making.
- Proposed revisions to the [AMCP Format for Formulary Submissions: Guidance on Submission of Pre-Approval and Post-Approval Clinical and Economic Information and Evidence](#) includes information on representativeness in clinical trials that can also guide HTA practices.

