

# Fulfilling the Promise of Equity in Value-Based Care: A Focus on Communications and Use in Health Technology Assessment

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# ACKNOWLEDGEMENTS

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# Introduction

Decision-making in healthcare is a complex process that involves researching the benefits, risks, and costs of specific healthcare interventions. This evidence is then weighed alongside other considerations to make informed decisions.<sup>1</sup> When decision-makers—such as health plans, employers, and patients—decide whether to pay for or use a healthcare intervention, many factors are taken into account. Health technology assessment (HTA) is a tool that helps organize and analyze evidence and information about access, affordability, and delivery of healthcare interventions.

HTA is defined as the analysis of clinical and economic value of a particular healthcare intervention, considering factors like cost, safety, and efficacy. It is used by employers, payers, manufacturers, and policymakers to determine what treatments are available to patients and at what cost. In the United States, HTA methods have traditionally not included the fair distribution of resources, a component of health equity. Effective decision-making must ensure that the people involved, the data and methods applied, and the approach to applying evidence all consider equity. This focus on equity is essential as decision-makers use HTA findings to guide their choices.

HTA is a standard practice in healthcare decision-making in the United Kingdom, European Union (EU), Canada, and many other regions. However, its use has been limited in the United States. Recent policy developments, such as the [Medicare Drug Price Negotiation Program](#) and changes to drug evaluation procedures in the EU, present opportunities for HTA to contribute to value-based care. However, this potential will remain untapped without an equity-centered approach to HTA. In other words, **there is [No Value Without Equity](#)**.

Given the high stakes of these policy changes, and of healthcare decision-making overall, transparency and commitment to equitable processes are essential throughout the full spectrum of HTA use, from scoping and design to communication and integration of research findings into decision-making.



## Plain Language Report Summary

Decision-making in healthcare involves complex processes, including assessing the benefits, risks, and costs of healthcare interventions. Health technology assessment (HTA) is a tool that helps organize and analyze this information to inform decisions about these interventions. Traditionally, HTA has not focused on fair distribution of resources, which is essential for health equity. In addition, communication of HTA findings has not been done in a way that is easy for patients and other stakeholders to understand. Involving patients is necessary for advancing equity in HTA.

To address this, the Center for Innovation & Value Research (formerly Innovation and Value Initiative) has identified four foundational changes necessary for communicating HTA research to patients and other stakeholders effectively:

1. **Transparent Communication:** Ensure open, clear communication throughout all stages of HTA. This involves sharing information in a timely, accessible manner and creating opportunities for dialogue with stakeholders, especially patients and caregivers.
2. **Understandable and Usable Information:** Use plain language to communicate HTA findings so that patients and decision-makers can easily understand and use the information. This includes organizing information clearly and avoiding technical jargon.
3. **Addressing Health Impacts on Different Groups:** Clearly discuss what is known and unknown about how healthcare interventions impact different patient groups. This includes acknowledging limitations and uncertainties in the findings and considering the diverse needs of patients.
4. **Inclusive Decision-Making:** Integrate HTA into a holistic, inclusive decision-making process. This means involving patients and caregivers as full partners and considering their preferences and perspectives in healthcare decisions.

By making these changes, HTA can better serve all patient populations, ensuring equitable access to innovative treatments and improving overall healthcare outcomes.

## Driving Change through Equity-Centered Communications and Use

The goal of health technology assessment (HTA) is to guide decisions about the use, access, and reimbursement of health technologies, such as medications, treatments, and devices. Clear communication of HTA research findings with decision-makers, patients, and other stakeholders is crucial but often overlooked.

HTA researchers need to understand what decision-makers—like payers, employers, and other purchasers—and patients need to know about a healthcare intervention’s potential benefits, risks, and costs. They must also consider how the intervention is used in the real world, particularly how it fits into the lives of patients and caregivers.

Patients and caregivers should be informed about how coverage decisions for healthcare interventions might affect them. They should also have the opportunities to share their insights or raise concerns. Decision-makers need to understand what aspects of value HTA can and cannot assess for a particular intervention, including who benefits and who bears the opportunity costs.

Clear and open communication throughout all stages of HTA research is essential for improving access and coverage decisions. Our aim is to create



**Opportunity cost** refers to what you give up when you make a decision. It involves weighing the benefits of the chosen option against the benefits of the next best option. It is important to think about, so you can decide what is most important.

a healthcare system that not only values innovation, but also ensures everyone has a fair chance to benefit from its health treatments and interventions.

## Advancing Equity through HTA

The [Center for Innovation & Value Research's](#) (the Center, formerly Innovation and Value Initiative) [Health Equity Initiative](#) has been working to identify and advance action in how HTA accounts for health equity. In partnership with a Health Equity Initiative Steering Committee, and through dialogue with over 40 stakeholders representing patients and caregivers, researchers,

**HTA advances equity** when it reduces health disparities by aligning access and affordability of healthcare interventions with differing needs and values of diverse patient populations, especially those who are most marginalized.

policymakers, clinicians, industry, payers and purchasers, the Center has developed a framework for centering equity in HTA (Appendix 1). This framework includes four essential domains of HTA practice where fundamental shifts are necessary to ensure that HTA advances equity:

**Power, People, and Processes; Data and Inputs; Methods; and Communications and Use.** In [\*Fulfilling the Promise of Equity in Value-Based Care: A Focus on Power, People, and Processes in Health Technology Assessment\*](#),

the Center explored the first domain of its Health Equity Framework to identify actions that stakeholders can take to address power structures, which may include addressing implicit bias and co-design of HTA studies with patients and caregivers. In [\*Fulfilling the Promise of Equity in Value-Based Care: A Focus on Data and Methods in Health Technology Assessment\*](#), the Center focused on the opportunities to identify patient and healthcare data and the methods for analyzing this evidence in a way that makes equity a priority throughout HTA conduct.

In this document—the final report in a series of three publications highlighting each domain in greater detail—the Center explores the **Communications and Use** domain. This report discusses opportunities and imperatives for using equity-centered HTA in healthcare decision-making and ensuring transparent, clear communication throughout that process.

By “communication,” the Center means how researchers and experts explain both the process and findings of HTA, and by “use,” how purchasers and payers use HTA findings to make decisions about access to healthcare services and treatments.

Throughout this report, the Center argues that the HTA process, findings, and resulting decisions should include people with lived experience—patients and caregivers— as full partners.

To help readers identify future efforts, the Center has outlined action steps for stakeholders involved in shaping HTA through various mechanisms, including funding, research, publication, and implementation. These actions are based on insights from stakeholder engagement. With a focus on accountability and lasting practice change, we address six key stakeholder roles: **Researchers, Patients and Caregivers, Professional Association Leaders, Journal Editors, Research Sponsors, and Payers and Purchasers.**

Detailed descriptions of each stakeholder role can be found in the Appendix. To facilitate action, this document is organized into two main sections. “Foundational Changes” focus on necessary actions to implement the Communications and Use domain. “Case Studies” offer real-world examples of these steps in practice. Additionally, we provide links to Action Guides, which outline steps for achieving these foundational changes for each of the six key stakeholder roles.



# Foundational Changes in HTA Communications and Use

Ensuring equity in HTA requires clear, open, and ongoing communication throughout all stages of HTA, including its use in decision-making.

For each of the foundational changes identified in Figure 1, we present a set of practice changes and accountability actions.

**Practice changes** highlight ways that researchers, patients, and caregivers can engage in open, two-way dialogue to ensure that the process and implications of HTA are clear. Practice changes represent both near-term and long-term shifts in norms for HTA communication and use. **Accountability actions** are near-term actions, possible over the next 1-2 years, that professional association leaders, journal editors, research sponsors, and payers and purchasers can take to incentivize the practice changes.

We also share two case studies highlighting some of these changes in practice.

**Figure 1. Foundational Changes in HTA Communications and Use**

Equity in HTA **Communications and Use** means that:



There is transparent communication throughout HTA conduct, reporting, and use.



Patients and decision-makers can understand and use HTA findings.



HTA practitioners discuss what is known and unknown about how health technology impacts different groups of patients.



HTA is part of a holistic and inclusive process for making healthcare decisions.

## Key Questions

- Is the process of engaging impacted patients in HTA clear from start to finish?
- Can patients and decision-makers understand what HTA findings mean for individual and population health?
- Do HTA findings answer questions about how healthcare interventions will impact specific groups of patients?





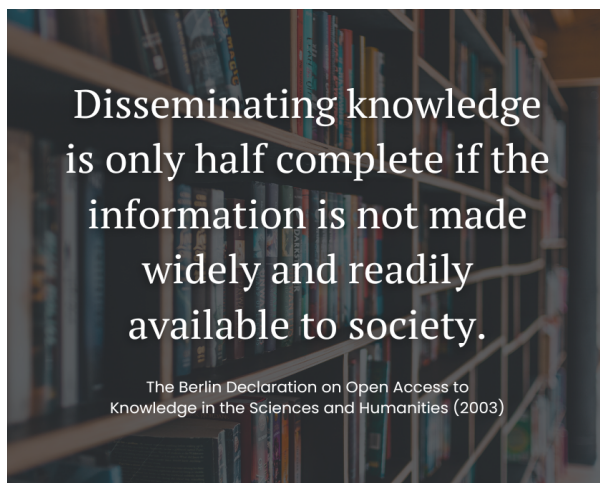
## There is Transparent Communication throughout HTA Conduct, Reporting, and Use

Equity-centered HTA must be communicated in a way that is open and clear (we refer to this as “transparency”). Transparency means that information is readily available, in a timely manner, in places and formats that everyone can access and use without restrictions. This ensures that all interested stakeholders have access to the available evidence about medical interventions and can understand what that evidence says about their potential benefits and costs. Transparency is also essential to create accountability. This is especially important for impacted populations – the communities of patients and caregivers whose health and access to treatment are likely to be affected by decisions informed by a particular HTA. Impacted populations need transparency about how researchers conduct HTA, what those analyses show, and how payers and purchasers are using HTA findings to inform decisions.

Transparency requires two-way communication, with ongoing dialogue throughout HTA conduct. This means proactively sharing information and creating opportunities for decision-makers and representatives of impacted populations to ask questions, raise concerns, and engage in dialogue from beginning to end.

Transparent, two-way communication, about HTA is especially important when:

- Scoping an assessment, framing questions, and choosing outcomes (including patient-centered outcomes) to include an analysis.
- Identifying existing health disparities (differences in health outcomes between small groups) and any necessary subgroup analyses (looking at treatment effects among smaller groups).
- Planning for data collection, especially when collecting information from patients and caregivers.
- Reporting preliminary results and sharing how they might affect decision-making.
- Sharing how feedback from external stakeholders will be used.



- Sharing any limitations in data or methods.
- Explaining how the HTA results will be used to make coverage decisions.

Partnering with patients and caregivers, especially people from diverse backgrounds and perspectives, throughout the HTA process is essential. It is vital that HTA practitioners be transparent about their own decisions in HTA design and conduct, especially how patient priorities and input influences those choices.

### Transparency When Reporting HTA Findings

Information about HTA findings must be transparent, actionable, and easily accessible to researchers, decision-makers, and impacted populations.

Within the research community, a key mechanism for transparency is [open access publishing](#), which makes journal articles, data, and other publications available to anyone at no cost. This means no requirement for a paid subscription, license fee, membership, or other purchase before readers can access the full content of a research article. Consistency in reporting is also important, especially [standards for systematically reporting engagement processes](#) (including patient and caregiver contributions and compensation), representativeness of



data, data and methods limitations, and the equity implications of HTA findings.

Outside the research community, it is vital to make HTA findings readily available to decision-makers such as payers and purchasers, and ultimately to patients. HTA practitioners must make the effort to share findings in the ways and places that these audiences prefer, and can use to inform their choices.<sup>2</sup> This requires sharing information beyond academic publications and scientific conferences. HTA practitioners must consider where, how, and in what language patients and payers already get health information and share information in a mix of formats such as video, audio, infographics, and text. Communicating through a variety of channels and partnering with representatives of key audiences (such as patient advocacy organizations) will help HTA practitioners share findings in ways that are relevant, clear, and easily accessible to the people ultimately impacted by an HTA.

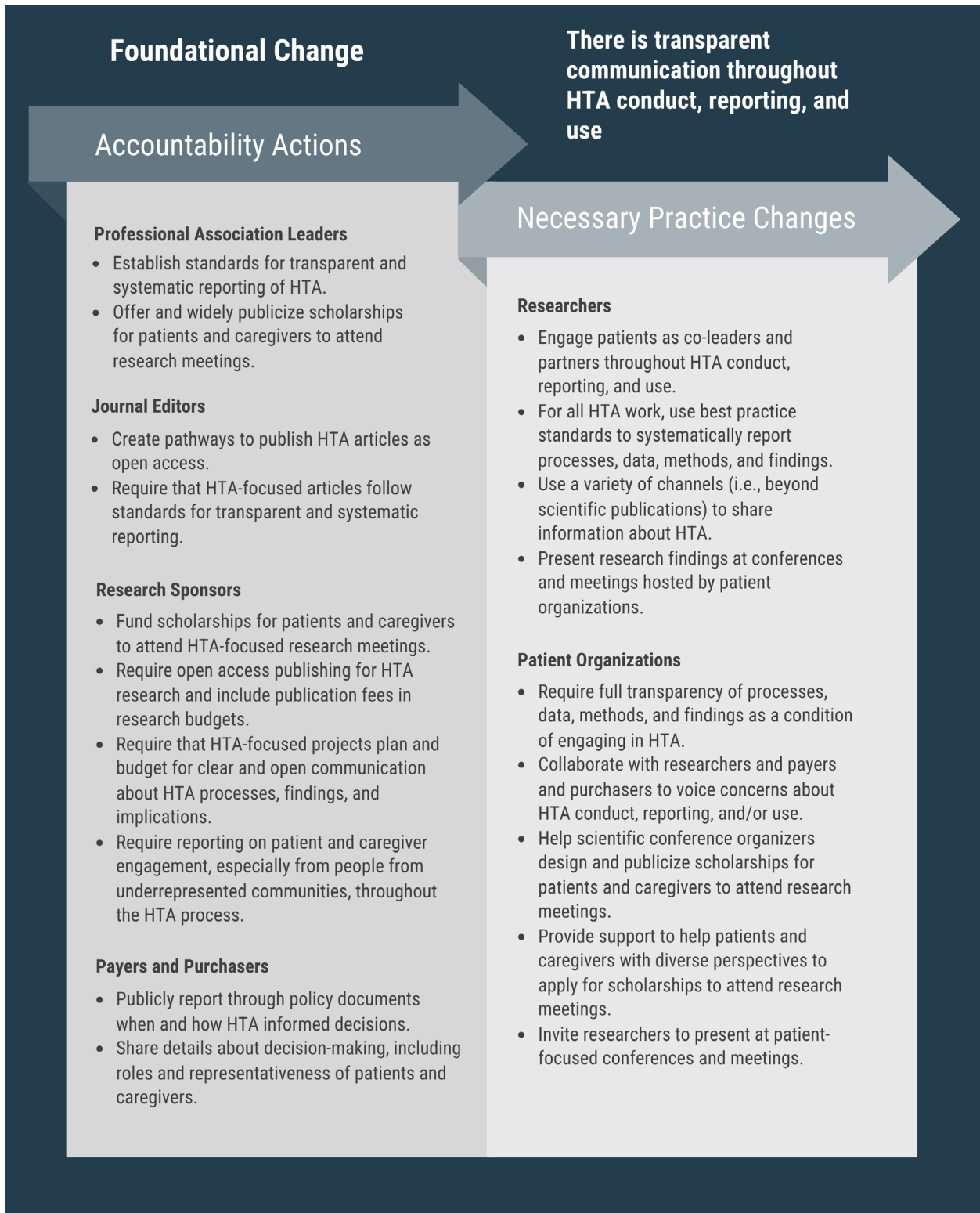
### Transparency About HTA Use

Finally, payers, purchasers, and others using HTA to inform decision-making must be transparent about that use. Currently, in the U.S. there is wide variation in how health plans use evidence, including clinical research, comparative effectiveness research, and HTA, to make decisions about healthcare intervention access and pricing. For example, one study found

little consistency in the evidence cited by 17 large commercial U.S. health plans to inform their specialty drug coverage policies.<sup>3</sup> This variation means it is especially important that decision-makers publicly report how they use HTA and other evidence to inform decisions, and engage impacted populations in that decision-making.



**Figure 2. Accountability Actions and Practice Changes for Transparent Communication Throughout HTA Conduct, Reporting, and Use**







## Patients, Decision-Makers, and Other Stakeholders Can Understand and Use HTA Findings

It is essential that HTA is communicated in ways that patients, decision-makers, and others can understand and use in decision-making. This requires using language that anyone can understand without the need for technical expertise. This way of communicating, known as plain language, is an essential skill for researchers, policy makers, and public health professionals. [Plain language](#) communication helps audiences find what they need, understand that information the first time they read or hear it, and use the information to meet their needs.

Plain language communication:

- Focuses on the most important information first.
- Organizes information to make it easy to follow, including using headings and bulleted lists. Uses visuals, such as tables, figures, or infographics, to help communicate information.
- Uses short sentences, written in active voice, and avoids unnecessary words.
- Uses familiar and concrete words while avoiding jargon (or technical terms). Whenever possible, it uses words with three syllables or fewer. When technical concepts are necessary to understand a message, plain language explains those terms or concepts in simple terms.

Use the simplest possible language. Above all, remember how it was before you, yourself, grasped whatever it is you're explaining.

Carl Sagan, *The Demon-Haunted World: Science as a Candle in the Dark* (1995)

A good rule of thumb for writing in plain language is write at a 9<sup>th</sup> - 11<sup>th</sup> grade reading level<sup>4</sup>. [Microsoft Word](#) and a variety of [other online tools](#) offer feedback on reading level for any text.

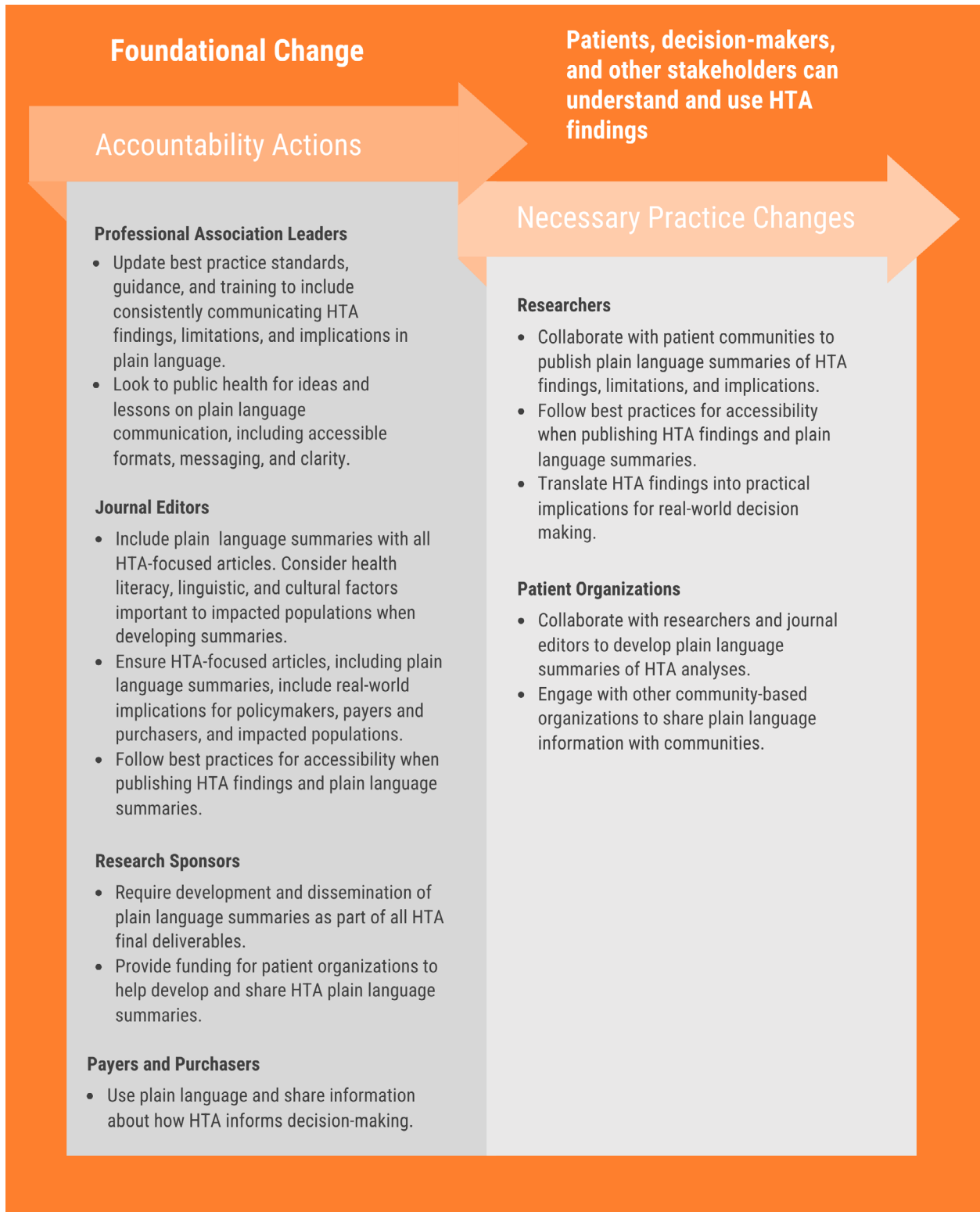


It is equally important to explain in plain language what HTA findings mean and how patients, decision-makers, and others can use the results. This includes explaining how HTA results can inform decisions about health plan design or care planning, and how HTA is one piece in overall healthcare decision-making. Sharing information in accessible formats is also important to ensure access for people with disabilities (including visual impairment or hearing impairment), and often makes information easier for everyone to access. Guidance on accessibility best practices is readily available (see for example [web accessibility](#), [document accessibility](#), and [video accessibility](#) guidance). Many software programs such as Microsoft Word, Adobe, and Zoom have embedded tools to aid in making content accessible.

Sometimes, making information easy to understand requires using multiple languages. Many services are available to prepare translations. Making content relevant also includes using examples and images that are relevant and meaningful to each audience.



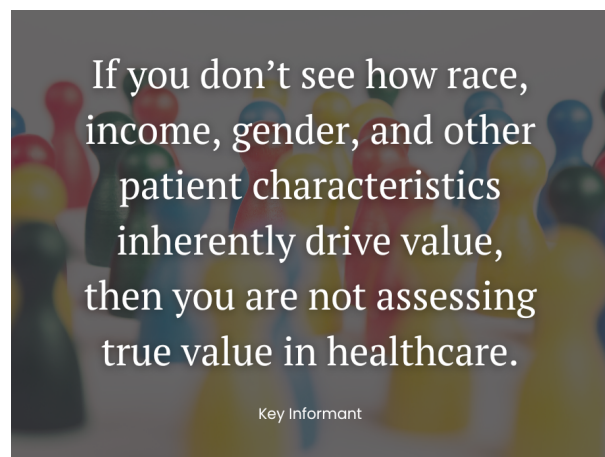
**Figure 3. Accountability Actions and Practice Changes So Patients, Decision-Makers, and Other Stakeholders Can Understand and Use HTA Findings**





## HTA Practitioners Discuss What is Known and Unknown About How Health Technology Impacts Different Groups of Patients

There is no average patient. The benefit or harm resulting from a healthcare intervention will vary across individuals. This variation depends on each person's unique attributes, circumstances, and needs. To provide a full picture of the value of an intervention, it is important to consider not only the potential impact for overall population health, but also impacts for different groups of patients.



A recent IVI report provides detailed discussion of [equity-centered data and methods](#) that HTA practitioners can use to examine differences in impacts for different patient groups. But conducting analyses is not enough. It is also important to clearly *communicate* about the differences in impacts of the intervention. Reports, summaries, and

journal articles reporting HTA analyses must include discussion of implications of the assessment for a range of patients and caregivers, with an emphasis on communities that have experienced the most persistent health inequities.

It is equally important to acknowledge uncertainty in findings by clearly stating what an assessment does and does not show. This must include discussing how:

- Limitations in HTA processes, data, and methods could introduce bias in results,
- Findings are (or are not) applicable to diverse populations, or
- Not looking at differences across patients may hide big differences in findings.

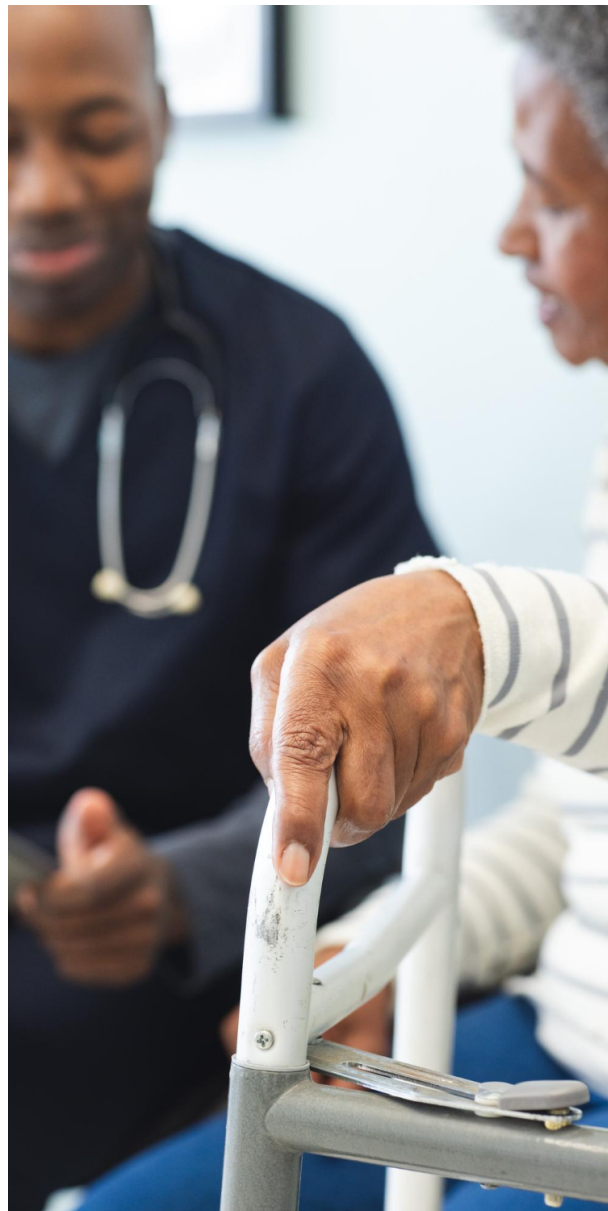
HTA practitioners must also acknowledge uncertainty in HTA results and what that uncertainty could mean for decision-making. This is especially important when an HTA includes (or does not include) subgroup analyses. Information about how an intervention could benefit or harm different groups of patients is important for informing equitable (or fair) distribution of healthcare resources. When data on different patient populations is

not available, HTA practitioners must acknowledge the increased uncertainty in their findings. Clearly identifying and discussing these trade-offs is essential to ensure that decision-makers can take this uncertainty into account when making decisions impacting reimbursement, insurance design, and policy.

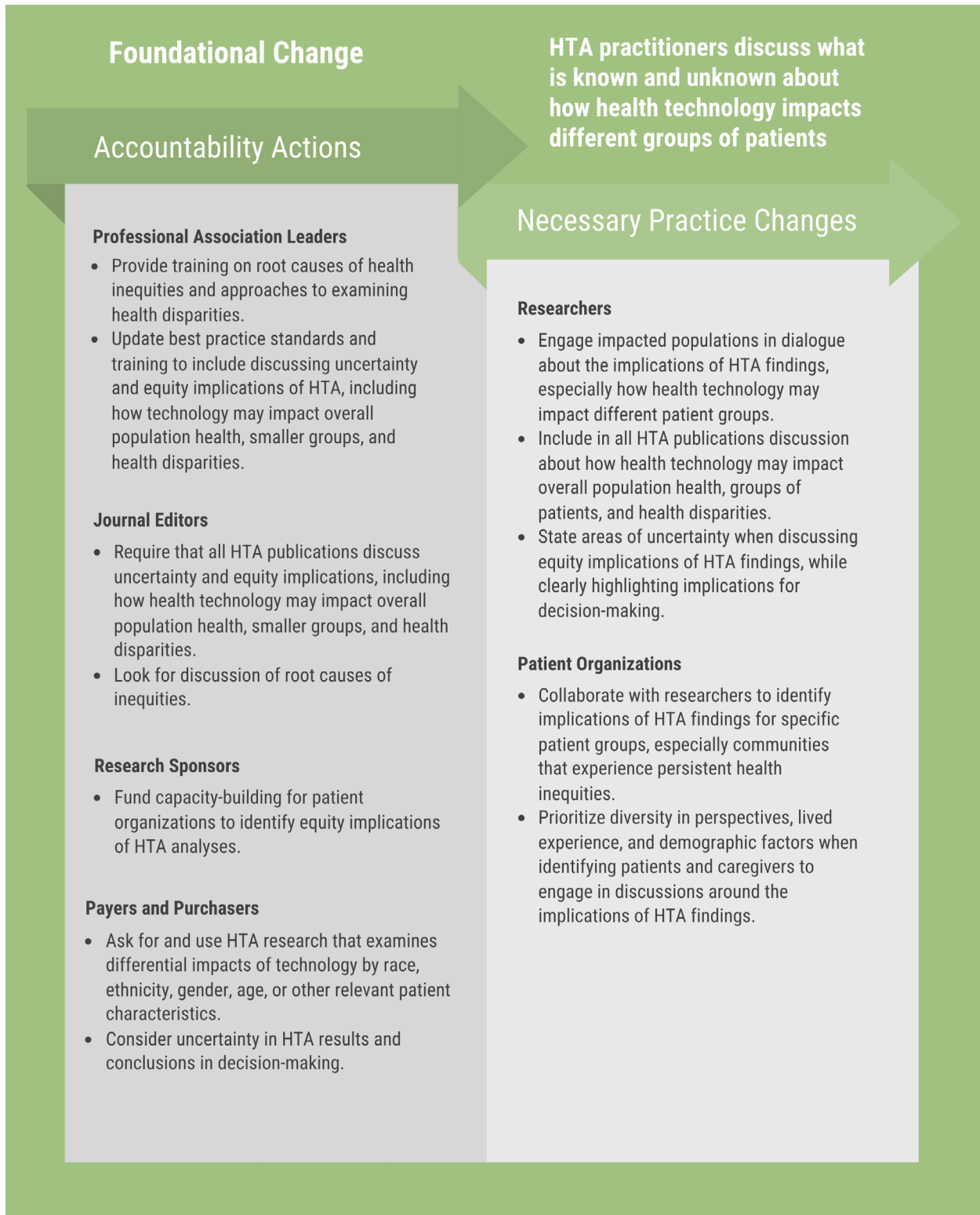
To understand and explore equity implications of an HTA analysis, it is important to engage in dialogue with patients and caregivers. Patient insights are essential to understand the realities of accessing, paying for, and using healthcare interventions. In addition, patient feedback offers contextual factors and unique life circumstances that shape those realities. To gain a full picture, it is important to partner with individuals who bring a wide range of perspectives and lived experiences. For an in-depth discussion of partnering with patients and caregivers, see the Center report on [Power, People, and Processes in HTA](#).

Finally, when communicating about different groups of patients, it is essential to use [inclusive and respectful language](#). Best practices include [using person-first language](#) (e.g., a person with asthma, people living with mobility disabilities, people with limited access to mental healthcare), [avoiding stigmatizing or blaming language](#) (e.g., *people who smoke* instead of *smokers*; *people experiencing homelessness* rather than *the homeless*), and [recognizing diversity within and across communities](#). It is especially

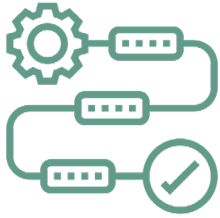
important to [ground discussion of health disparities in the root causes of inequities](#), recognizing that factors such as race, ethnicity, sexual orientation, age, and gender identity are not themselves risk factors for poor health, but rather proxies for the systematic oppression, racism, and social disadvantage frequently experienced by individuals with these characteristics.



**Figure 4. Accountability Actions and Practice Changes for HTA Practitioners to Discuss What is Known and Unknown About How Health Technology Impacts Different Groups of Patients**







## HTA is Part of a Holistic and Inclusive Process for Making Healthcare Decisions

Equitable healthcare decision-making requires a holistic view of healthcare interventions. In the U.S., HTA frameworks have typically evaluated interventions by assessing how well a treatment works in clinical trials (clinical efficacy), the benefits of a treatment relative to its costs (cost-effectiveness), and potential costs and savings for payers and health systems (budget impact). This approach can sideline important aspects such as patient preferences, social drivers of health, and the broader impact on communities and society. For HTA to become a tool for advancing equity, the scope of HTA and its use in healthcare decision-making must evolve to include mixed approaches that look at cost-effectiveness and what is important to patients and caregivers, especially those whose ideas are often missed.

Integrating the perspectives of patients and caregivers within HTA provides a more comprehensive assessment of healthcare interventions. In particular, it is essential to include [patient preferences](#) and other outcomes that matter to patients, such as [patient-centered economic impacts](#). Ultimately, ensuring that HTA reflects what matters most to patients and caregivers requires collaborating with them throughout the HTA process. The two prior reports from the Center discuss [partnership](#) and [data](#)

**Health inequities** are long-standing patterns of health disparities due to unjust differences in social, economic, environmental, and healthcare resources.

[and methods](#) to support equity-centered HTA.

However, while HTA can inform healthcare decisions, it is not a decision-making process on its own. To reach its full potential for supporting equity-centered, value-based care, HTA must be just one part of a holistic and inclusive process for making decisions. This requires transparency, clear communication, and above all, meaningful inclusion of patients and caregivers. They must be full participants in decision-making, with the same access to information, level of representation, and authority as other experts. It is also essential that patients and caregivers included in healthcare decision-making bring a wide range of perspectives and represent the populations that will be impacted by those decisions. This means prioritizing representation of patients who are at highest risk for the condition of focus or who experience health disparities.

Frameworks such as Accountability for Reasonableness<sup>5,6</sup> and EVIDEM<sup>7</sup> offer guidance on healthcare decision-making, but in practice may not adequately integrate patients and caregivers. Structured processes such as the Delphi Method and multi-criteria decision analysis (MCDA) offer approaches for integrating evidence with stakeholder expertise, including patients' and caregivers' lived experience. Ultimately, patients and caregivers must be recognized as decision-makers and integrated into these processes. [Forthcoming Federal rules](#) requiring greater beneficiary engagement within Medicaid member advisory groups will increase the need for, and opportunities to test out, inclusive decision-making processes that integrate lived expertise.

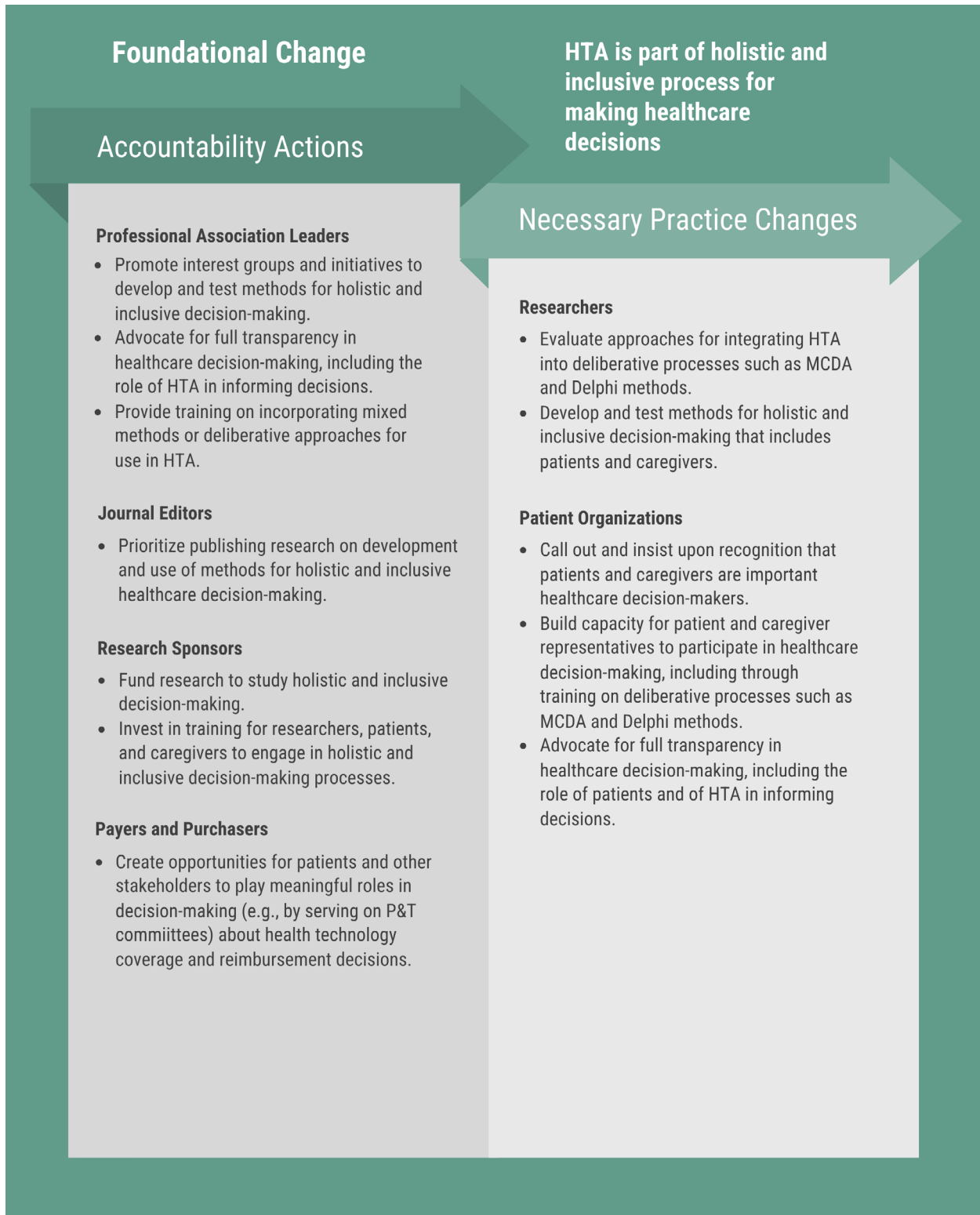
The EU and other regions outside the U.S. offer examples of including patients and caregivers in healthcare decision-making, including integrating patient and society perspectives into HTA. The EU recently adopted [new HTA regulations](#) that integrate patient consultation and public comment into multiple aspects of HTA conduct and healthcare decision-making. The regulations recognize lived experience of a condition as essential expertise on par with clinical and technical expertise. Accordingly, the regulations require that patients with lived experience be included in an HTA stakeholder network. The [PREFER Expert Network](#) brings together pharmaceutical companies, academic institutions, and

government agencies that conduct HTA with patients from across Europe to integrate patient preference studies into research and decision-making.

By broadening the criteria for assessing healthcare interventions and integrating equity-centered HTA into a holistic and inclusive decision-making process, decision-makers can ensure that healthcare policies and interventions are not only efficient and effective, but also equitable and responsive to the needs of all patients, especially communities experiencing the most persistent health inequities.



**Figure 5. Accountability Actions and Practice Changes for HTA Being Part of a Holistic and Inclusive Process for Making Healthcare Decisions**



# Case Studies

The case studies in this section highlight foundational changes in practice. Though the approaches and contexts differ for each case, together these examples show how small steps can add up to big changes that prioritize equity in communicating and using HTA.

The two case studies that follow include:

- PCOR Translation Center
- EveryLife Foundation for Rare Diseases Economic Burden Research Dissemination



## Case Study: Patient-Centered Outcomes Research (PCOR) Translation Center

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit organization and one of the largest funders for patient-centered comparative effectiveness research (CER) in the United States. PCORI emphasizes empowering patients and giving them the evidence they need to make informed decisions. Based on [authorizing legislation](#), PCORI is required to publish findings in a timely manner while ensuring results are both easy to understand and scientifically accurate. To help meet this requirement, PCORI created the [PCOR Translation Center](#) in 2016 to support their work in translating detailed scientific reports from all its funded CER studies into user-friendly, plain language summaries.

### Strategies for Centering Equity in HTA

This example illustrates how HTA practitioners can present complex research findings in a format that is understandable and usable for the lay public. The PCOR Translation Center has developed and follows a rigorous, standardized process for translating research results into brief plain language abstracts for public release and research summaries for ongoing studies. Some best practices have emerged that can be applied to translating any complex healthcare research, including health technology assessments, such as:

- **Develop summaries tailored to your audience.** PCORI develops two plain language summaries for each research report – one geared for healthcare professionals, and one for the public. Detailed scientific reports are also available.
- **Use a question-and-answer format with concise section headings.** PCORI uses general headings which can apply to all content areas – project rationale, methods, results, limitations, and how the research will inform decisions (see callout box).
- **Convene and engage with multiple stakeholders to advise the translation process.** PCORI engaged patients, caregivers, clinicians, and experts in health communication, health literacy, and evidence review in developing a standardized template for the research abstracts. Each research abstract is reviewed by 4-6 patients and caregivers with relevant lived experience.

#### *Headings Used in Plain Language Summaries*

- What was the research about?
- What were the results?
- Who was in the study?
- What did the research team do?
- What were the limits of the study?
- How can people use the results?



- **Engage plain language experts to support translation of complex topics.** It can be difficult to break down technical concepts into language that can be understood at a 6<sup>th</sup> - 8<sup>th</sup> grade reading level. Work with writers skilled in plain language approaches to scientific writing.
- **Adapt the plain language summary for other populations.** For example, each PCORI summary is also translated into Spanish. In addition, PCORI provides an audio recording file of the English summary, available for download.

PCORI has produced over 480 research results abstracts since the start of the Translation Center covering a broad range of research topics. Several examples include a comparison of two [different diabetes drugs](#), a comparison of treatments for reducing fatigue among patients with [multiple sclerosis](#), and a [comparison of blood pressure treatments](#) in different racial and ethnic groups.

## Lessons Learned

PCORI identified several areas of learning from this initiative that specifically highlights essential priorities in translating complex topic areas, including:

- Support consistency across summaries. Make sure the translation process is applicable to all types of studies, regardless of the topic.
- Prioritize content that is most important to patients first. Plain language summaries are short and concise, often adhering to a set word limit. Prioritize content such as the results and participant demographics.
- Balance plain language and precision when developing plain language summaries. Use and define technical terms as needed that are often used by providers.
- Consider an average reading level between 6<sup>th</sup> - 8<sup>th</sup> grade.

PCORI research results abstracts include a breakdown of the research participants by age, race, and ethnicity as well as by gender. This transparency of who is included in the research study begins with transparency requirements incorporated in the research funding announcements. User testing of the research abstract template underscored that this information is a priority for patients when understanding how research findings may (or may not) be important to their health journey. With nearly a decade of experience preparing plain language research summaries, PCORI offers [important lessons](#) and best practices for making research findings transparent, accessible, and easy to understand.

# Case Study: Equity-Centered Communication Highlights the Economic Impact of Rare Disease

The EveryLife Foundation for Rare Diseases collaborated with patients, caregivers, and researchers to conduct a series of studies assessing the economic impact of rare disease in the United States. The patient advocacy organization shared findings in multiple formats to meet the needs of different audiences and consistently explains what findings mean for patients, caregivers, policymakers, and other stakeholders. This focus on clear and transparent communication provides an example of how to make the findings and implications of economic analyses easy for different audiences to access, understand, and use.

## Strategies for Centering Equity in HTA Communication

After completing a study in 2021 on the [economic burden of rare diseases](#) in the U.S., EveryLife Foundation provided a [two-page infographic](#) written in plain language, a detailed summary document, a [peer-reviewed journal article](#), and videos explaining the [significance of the study](#) and [implications of the findings for policymakers](#). Each of these materials is tailored for a specific audience, including patients and caregivers, payers, researchers, and policymakers. To ensure full transparency, the organization published the research article open access, so that anyone can read the detailed scientific information without needing a journal subscription or incurring a publication fee.

More recently, the organization completed a study on the cost of delayed diagnosis in rare diseases. It shared results through a [website highlighting key findings](#), an [infographic](#), and a [detailed summary document](#). Across the organization's website, an embedded "translate" button allows users to instantly translate content into any one of over 100 languages. EveryLife Foundation also provides technology-enabled Spanish translation during some of its live events.

Key elements of how EveryLife Foundation communicates study results include:

- **Use a standardized format.** EveryLife Foundation organizes web content into three main sections: *About the Study*, *What We Found*, and *What Can You Do*. This helps readers quickly jump to the content that is most meaningful to them.
- **State the main findings in simple sentences.** Explaining the significance of those findings using measures of impact anyone can understand, such as dollars spent, years lost, or hospital stays avoided.
- **Include examples to illustrate key concepts.** In the reports, examples for concepts like direct medical costs, indirect costs, and non-medical healthcare costs were included.

- **Offers resources for more detailed information.** Linking out to more detailed information allows readers to access more information based on their needs or interest.

## Lessons Learned

In reflecting on how clear and transparent communication has strengthened its work, EveryLife Foundation's leadership highlighted several lessons learned:

- **Build in multiple rounds of review with patients, caregivers, and intended audiences.** When developing infographics, the organization developed first drafts with an advisory board committee of patients, economists, and healthcare advisors. They then engaged additional groups of patients and caregivers in several more rounds of review to ensure a diverse range of perspectives. Some of the most important feedback came late in that review process, leading to crucial adjustments before finalizing materials.
- **Be fully transparent about limitations and welcome feedback to improve data and encourage use.** When reviewing a near-final report, a caregiver raised a concern that the analysis did not reflect her family's experience. The team conducted new analyses to address that feedback, ultimately improving the strength of the work. Openly sharing limitations in its analyses also helped EveryLife Foundation shine a light on data gaps preventing similar analyses for a wider range of rare diseases. Other rare disease organizations are using that learning to address some of those data gaps, ultimately strengthening their advocacy work.
- **To guide communication, stay focused on the ultimate goal.** For EveryLife Foundation's analyses, that goal is advocating for the rare disease community. With that in mind, they focus communication not only on clearly explaining what findings mean, but also how other patient organizations can use the findings to advocate for policies that will improve outcomes for patients with rare disease and their families. Connecting communication to use improves impact.

This focus on clear and transparent communication has helped EveryLife Foundation and other rare disease organizations highlight the impact of rare disease, building momentum for policy change. Discussion about the public health impact of rare disease has completely shifted in the U.S. That shift is a result of having data about economic impacts of rare disease, and equipping patients, caregivers, and advocates to clearly communicate what those data mean in their own lives and communities.

# 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 action 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](#).



[Researchers](#)



[Patients and Caregivers](#)



[Professional Association Leaders](#)



[Journal Editors](#)



[Research Sponsors](#)



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# Making Progress Toward Equity in HTA Communications and Use

Accountability is an essential part of the change process. The Center and other stakeholders can gauge progress in centering equity in HTA within the Communications and Use domain by monitoring signs of near-term progress. By progress, we mean interim steps toward larger changes that make HTA communication transparent, easy to

understand, and focused on the impact of healthcare interventions for different groups of patients. We focus on these signals rather than formal metrics recognizing the early stage of equity integration into HTA.

## Signs that the HTA field is making progress toward equity-centered HTA communications and use include:



**There is transparent communication throughout HTA conduct, reporting, and use.**

- Increase in the number of HTA-focused publications that are publicly available at no cost.
- Journals create pathways for patient organizations and public payers to access HTA-related articles at no cost.
- Increase in the number of patient organizations contributing public comments, data, recommendations, or other information during HTA conduct.
- Increase in the number of scholarships to help patients and caregivers attend research meetings.





**Patients and decision-makers can understand and use HTA findings.**

- Increase in the number of journals that require plain language summaries accompanying HTA-focused articles.
- Increase in the number of HTA-focused publications, including journal articles, that include a plain language summary.
- Increase in the number of U.S. HTA-focused publications, including plain language summaries, available in languages other than English.



**HTA practitioners discuss what is known and unknown about how health technology impacts different groups of patients.**

- Increase in the number of HTA publications that include discussion of how policy choices based on findings could impact health disparities (i.e., reduce, maintain, or widen gaps).
- Increase in the number and diversity (demographic and cultural) of patients who engage with HTA practitioners to discuss equity implications of findings.
- Within HTAs examining differential impacts for different groups of patients, findings are grounded in theory and evidence linking health disparities with root causes, including systemic racism and other forms of oppression.



**HTA is part of a holistic and inclusive process for making healthcare decisions.**

- Increase in the number of published research articles focused on development and use of holistic and inclusive healthcare decision-making methods.
- Increase in the number of U.S. payers and purchasers that share information about how they use HTA in decision-making about coverage, pricing, or health plan design.
- Increase in the number of U.S.-based examples of patients and other stakeholders playing meaningful roles in decision-making about health technology coverage and reimbursement decisions.

In keeping with its mission to advance the science, practice, and use of patient-centered HTA, the Center calls on its peer institutions to join in a commitment to equity-centered HTA practice. This report, and the Center's ongoing Health Equity Initiative, represent initial steps toward fulfilling this commitment.

**The Center commits to:**

- Sharing openly information about the process of patient, caregiver, and other stakeholder engagement as part of any research.
- Publishing research findings through open access in scientific and other peer-reviewed journals.
- Developing plain language summaries of its research articles and making these freely available.
- Following best practices for accessibility in all its communications.
- Translating materials into languages other than English to support broader patient engagement in HTA.
- Partnering with payers and purchasers to ensure that HTA research projects are aligned with decision-makers' information needs.
- Devoting resources to clear, transparent, and consistent communication through the Center's research projects.
- Convening researchers, patients and caregivers, payers and purchasers, and other stakeholders to explore and model holistic and inclusive deliberative processes.
- Offering scholarships for patients and caregivers to attend in-person meetings hosted by the Center.

# Appendix 1: Health Equity Initiative Value Framework

Value-based care promises to deliver better healthcare experiences, better population health outcomes, and lower healthcare costs by directing resources toward the most effective treatments.

A decade of experience implementing value-based care makes clear: there is no value without equity. The increasing focus on equity in [policymaking](#) and [system transformation efforts](#) reflects this learning. Institutions and decision-makers across the healthcare sector have committed to ensuring that everyone has a fair and just opportunity to be as healthy as possible.

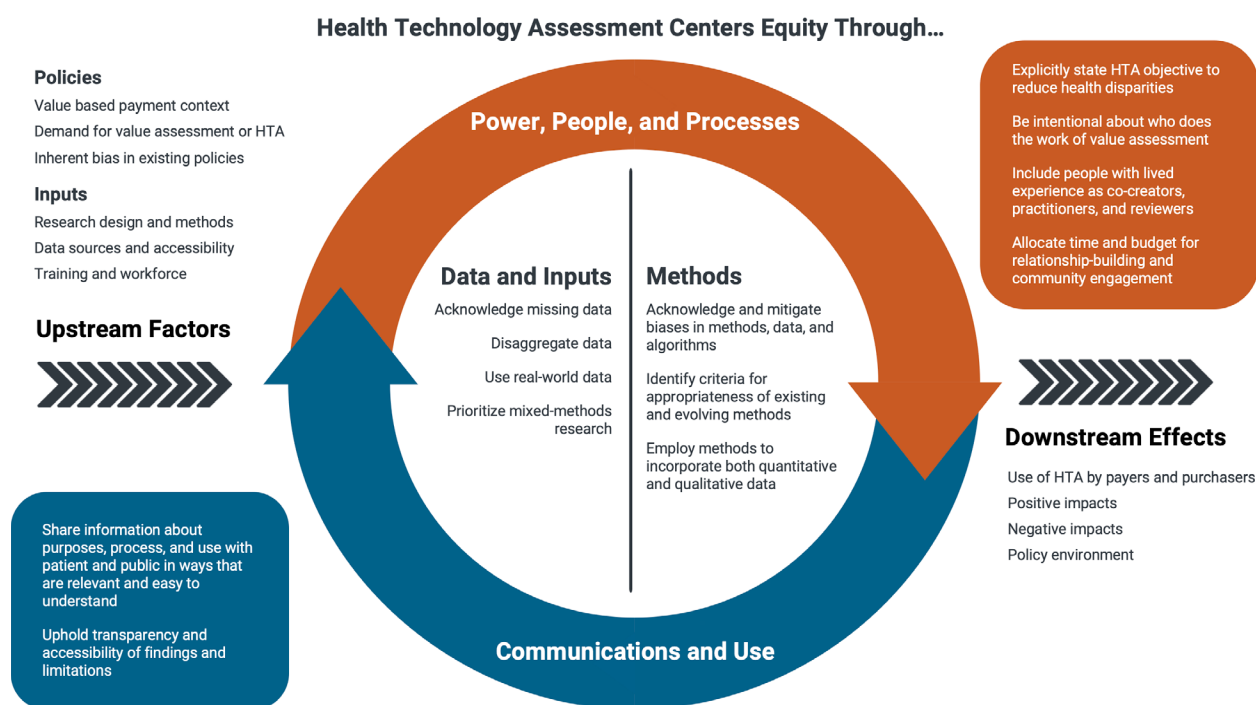
**Health technology assessment (HTA), too, must commit to and integrate equity.** HTA advances equity when it reduces health disparities by aligning access and affordability to healthcare technologies and services with differing needs and values of diverse patient populations, especially those who are most marginalized.

Researchers, patients and caregivers, professional association leaders, journal editors, research sponsors, and payers and purchasers must act now – and act together – to ensure that HTA practice is grounded in equity. **To fulfill the promise of value-based care, stakeholders must integrate equity throughout HTA by taking the actions outlined in this report.**

## Integrating Equity throughout HTA Practice

[The Center for Innovation & Value Research's](#) (the Center, formerly Innovation and Value Initiative) [Health Equity Initiative](#) aims to identify actionable changes to HTA processes, methods, and communication that acknowledge and contribute to progress in addressing existing health disparities through more informed healthcare decision-making. In partnership with a [Health Equity Initiative Steering Committee](#), and through dialogue with over 40 stakeholders representing patients and caregivers, researchers, policymakers, clinicians, industry, payers, and purchasers, the Center has developed a framework for centering equity in HTA (Figure A1).

**Figure A1. Health Equity Initiative Value Framework**



The Center’s framework for centering equity in HTA includes four essential domains of HTA practice where fundamental shifts are necessary to ensure that HTA advances equity:

- **Power, People, and Processes:** This domain is foundational to rebalancing power throughout HTA processes, with an emphasis on grounding HTA in lived experience through co-creation and leadership by patients, caregivers, and community members, particularly those from marginalized communities.
- **Data and Inputs:** The domain focuses on prioritizing equity when selecting data sources to inform the models and cost-effectiveness analyses that are primary outputs of HTA. Key strategies for equitable data use include using representative data, developing and using real-world evidence, and transparently acknowledging data limitations and biases.
- **Methods:** This domain speaks to immediate practices and tools necessary to integrate equity considerations into HTA, as well as longer-term areas for investment and collaboration among all organizations acting in this research field.
- **Communications and Use:** This domain focuses on full process transparency in the design and assumptions of HTA models, how the results and limitations of HTA are communicated to both impacted communities (i.e., patients and caregivers), and decision-makers (e.g., payers, purchasers, and clinicians), and clarity about the impact of those limitations on the use of HTA for decision-making.

# Appendix 2: Stakeholder Roles

To identify action steps to integrate equity throughout HTA, we focused on six key stakeholder roles (below). We recognize that these stakeholder roles are not mutually exclusive, that roles differ by organization, and that we have not called out every role important to HTA. For example, payers often act as both sponsors and users of HTA-related research and policymakers are important in shaping the context of HTA conduct and use. Our goal in organizing around these six stakeholder roles is to highlight near-term action steps and opportunities for synergy as the actions of each stakeholder build on one another to catalyze fundamental changes in the practice of HTA.



## Researchers

Researchers and health economics and outcomes research (HEOR) professionals who conduct or produce HTA, regardless of institutional setting. This could include HTA practitioners working in academia; life sciences, pharmaceutical, device, or digital health industries; and other research institutions (e.g., [Institute for Clinical and Economic Review](#), [University of Washington CHOICE Institute](#), [The Center for Innovation & Value Research](#)). Lead researchers, such as principal investigators (PI), as well as others responsible for the oversight and conduct of HTA, and research institution leadership (e.g., directors, chief science officers) have important roles to play in shaping the conduct of HTA.



## Journal Editors

Editors-in-chief, associate editors, and editorial board members of peer-reviewed journals that frequently publish HTA findings, methods, or related research (e.g., [Value in Health](#), [PharmacoEconomics](#), [Journal of Managed Care and Specialty Pharmacy](#), [Journal of Comparative-Effectiveness Research](#)). Through editorial oversight and discretion, authorship guidelines, and facilitating the peer review process, journal editors play an important role in shaping what gets published about HTA, what details are included within those publications, and whose contributions are recognized through authorship.





## Patients and Caregivers

Individuals who receive healthcare services and their caregivers, especially individuals who bring lived or caregiving experience with health conditions, diagnoses, or treatments relevant to a particular HTA. This group also includes individuals working or volunteering within organizations that represent, support, or advocate for patients and caregivers (e.g., [National Health Council](#), [American Cancer Society](#)). While we group together patients, caregivers, and patient organizations for the purpose of this document, we recognize that caregiving is a distinct perspective from that of patients and that there is no universal patient or caregiver perspective. Patients, caregivers, and the organizations that seek to represent them are extremely diverse in experiences, values, preferences, and identities. We recognize that lived experience as patients and caregivers includes, and cannot be isolated from, intersecting cultural identities, socio-political context, and experiences of marginalization. Throughout this document, we refer to patients and caregivers as inclusive of both individuals bringing their own lived experience and organizations advocating on behalf of patients and caregivers. We also use the term 'patient' with the understanding that each patient is foremost a whole person and is not solely defined by their health condition(s).



## Payers and Purchasers

Decision-makers within employer purchasers and commercial and public payers who use findings from HTA to inform market launch planning, plan design, coverage, reimbursement, or other decisions about payment for healthcare treatment (e.g., chief medical officers and other C-suite leaders, medical or pharmacy directors, members of pharmacy and therapeutics committees, leaders within pharmacy benefit managers).



## Research Sponsors

Decision-makers within organizations sponsoring HTA-related work, whether supported through public or private grants, contracts, or other funding mechanisms. Specific research sponsor roles include directors, program officers, and leaders within entities that fund the conduct of patient-centered outcomes research, comparative effectiveness research, HTA, HEOR, or related research. Examples of sponsor organizations include the [National Institutes of Health](#), [Patient-Centered Outcomes Research Institute](#), philanthropies, and life science companies. We focus on the role of sponsors, rather than funders, recognizing that financial support for HTA comes from a variety of organizations and mechanisms, including those outside traditional research funders.



## Professional Association Leaders

Presidents, board and committee members, and other leaders of professional societies and trade associations focused on health economics and/or HTA practice. This includes membership organizations representing and providing oversight of professionals engaged in HTA, including health economists, researchers, and other HEOR professionals (e.g., [ISPOR -The Professional Society for Health Economics and Outcomes Research](#), [American Society of Health Economists](#), and [AcademyHealth](#)). This group also includes members of trade associations such as [Advanced Medical Technology Association](#), [Medical Device Innovation Consortium](#), and the [Pharmaceutical Research and Manufacturers of America](#) that establish best practices and principles related to HTA conduct and use. By establishing best practices, guidelines, standards, and training, leaders and members within professional associations play a key role in ensuring high-quality, ethical HTA conduct.

# Appendix 3: Glossary

Term	Definition
Cost-Effectiveness Analysis (CEA)	Form of economic analysis that compares the relative costs and outcomes, or effects, of different options. Cost-effectiveness analysis is the most commonly used HTA method to inform priorities for healthcare decision-making. Traditional CEA aims to inform decisions to improve overall health for a population based on the estimated impact of a particular healthcare technology for an average patient.
Comparative Effectiveness Research (CER)	Studies that compare the benefits and harms of two or more treatments, clinical strategies, or other healthcare technologies.
Effectiveness	The ability of an intervention (drug, device, treatment, test, pathway) to provide the desired outcomes in the relevant patient population.
Efficiency	A focus on how to use a limited set of resources.
Health Disparities	Health disparities are differences in health outcomes and status between population groups characterized by social, demographic, environmental, and geographic attributes. <sup>33</sup>
Health Economics and Outcomes Research (HEOR)	A term that includes both outcomes research studies encompassing real-world evidence of treatment patterns among patients, health outcomes, resource utilization, and economic evaluation of the costs associated with treatment. Multiple disciplines contribute to this type of research including clinical research, clinical outcomes assessment, epidemiology, health economics, policy research, and health services research.
Health Equity	There are many definitions of health equity. At its most basic, health equity is when everyone has the opportunity to be as healthy as possible. This means that everyone has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances. <sup>34</sup>
Health Inequities	Long-standing patterns of health disparities due to unjust differences in social, economic, environmental, and health care resources. <sup>35</sup>
Health Technology Assessment (HTA)	A method of systematically assessing the value of healthcare technology by using available evidence to model its expected benefits, risks, and costs.

Term	Definition
Impacted Population	Communities of patients and caregivers whose health and access to treatment are likely to be influenced by decisions based on a particular HTA.
Mixed Methods	Mixed methods strategically integrate or combine rigorous quantitative and qualitative research methods to draw on the strengths of each. <sup>36</sup>
Multi-Criteria Decision Analysis (MCDA)	A framework for supporting complex decision-making with multiple and often conflicting criteria that stakeholder groups and/or decision-makers value differently. Through the use of MCDA, priorities and preferences of patients, insured individuals, and experts can be integrated systematically and transparently into the decision-making process.
Patient Reported Outcomes (PRO)	A health outcome directly reported by the patient who experienced it. This is in contrast from clinical or other outcomes reported by physicians, nurses, or other individuals.
Perspective	Refers to the point of view adopted when deciding which types of costs, health, and economic benefits are to be included in an economic model (e.g., healthcare sector vs. societal).
Qualitative Data	Information in the form of text, words, stories, or descriptions. Examples of qualitative data include transcripts from interviews or text in news articles. Qualitative data is not numerical, though researchers can count themes or ideas occurring within qualitative data through qualitative research methods.
Quality Adjusted Life-Year (QALY)	The fraction of a perfectly healthy life-year that remains after accounting for the damaging effects of an illness or condition.
Quantitative Data	Information that can be counted or measured numerically. Examples include measuring distance in miles, cost in dollars, or time in hours.
Randomized Controlled Clinical Trials (RCT)	A type of research study that assigns some individuals (or other entities being studied) to different groups by chance. In medical research, typically one group receives an intervention, such as a medication or treatment, while the other group does not. This approach allows researchers to measure the effect of the intervention, while accounting for differences between individuals across the two groups. Randomized control trials are considered the “gold standard” for determining whether and how well a treatment works.

Term	Definition
Real-World Data and Evidence	Data about patients’ health status or delivery of health care that are routinely collected from a variety of sources. Sources may include electronic health records, insurance claims and billing data, product and disease registries, and data gathered through personal devices or health applications. Analyzing real-world data, such as through observational studies or pragmatic clinical trials, generates real-world evidence.
Social Determinants of Health (SDOH)	Conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels. <sup>37</sup>



## Endnotes

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