IVI INNOVATION AND VALUE INITIATIVE

Fulfilling the Promise of Equity in Value-Based Care: A Focus on Power, People, and Processes in Health Technology Assessment

September 2023

ACKNOWLEDGEMENTS

Suggested Citation:
Bright J., Ridley M., Schultz E. (September 2023). "Fulfilling the Promise of Equity in Value-Based Care: A Focus on Power, People, and Processes in Health Technology Assessment." Produced by the Innovation and Value Initiative, Alexandria, VA.

CONTENTS

Introduction

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 of 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, integrate equity throughout HTA by taking the actions outlined in this report.**

How can HTA be considered reliable and valid if it is not representative?

– Key Informant
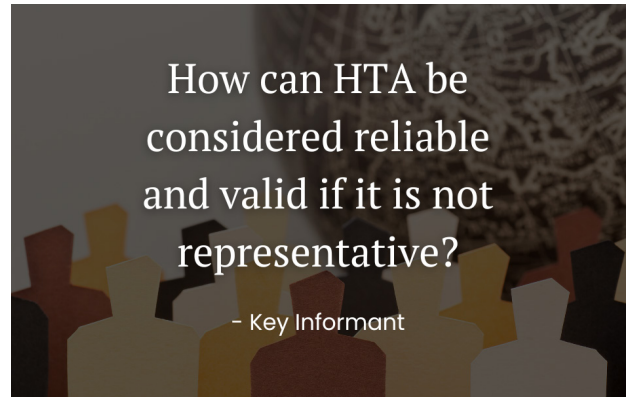
Integrating Equity throughout HTA Practice

The Innovation and Value Initiative's (IVI) 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 the Health Equity Initiative Steering Committee, and through dialogue with over 40 stakeholders representing patients and caregivers, researchers, policymakers, clinicians, payers and purchasers, and industry, IVI developed a framework for centering equity in HTA (Figure 1).

IVI'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:

Figure 1. Health Equity Initiative Value Framework

Policies
Value based payment context
Demand for value assessment or HTA
Inherent bias in existing policies

Inputs
Research design and methods
Data sources and accessibility
Training and workforce

Upstream Factors

Power, People, and Processes

Explicitly state HTA objective to reduce health disparities

Be intentional about who does the work of value assessment

Include people with lived experience as co-creators, practitioners, and reviewers

Allocate time and budget for relationship-building and community engagement

Data and Inputs
Acknowledge missing data
Disaggregate data
Use real-world data
Prioritize mixed-methods research

Methods
Acknowledge and mitigate biases in methods, data, and algorithms
Identify criteria for appropriateness of existing and evolving methods
Employ methods to incorporate both quantitative and qualitative data

Downstream Effects
Use of HTA by payers and purchasers
Positive impacts
Negative impacts
Policy environment

Share information about purposes, process, and use with patient and public in ways that are relevant and easy to understand

Uphold transparency and accessibility of findings and limitations

Communications and Use

- **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:** This domain focuses on prioritizing equity when selecting data sources to inform the models and cost-effectiveness analyses that are the primary outputs of HTA. Key strategies for equitable data use include 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 in 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.

In prior publications, including the 'No Value Without Equity' synthesis report, IVI explored these domains and identified action steps necessary to center equity in HTA. To understand the intersections of health equity and HTA, IVI's Health Equity Initiative has engaged patients and other stakeholders thorugh a series of key informant interviews, two roundtable discussions, and through public discourse during the 2023 4th Annual IVI Methods Summit. IVI deeply appreciates the contributions of our patient and stakeholder partners and steering committee in the development of this initiative.

Driving Change through Power, People, and Processes

In this document – the first of a series of publications highlighting each domain in greater detail – IVI delves into the *Power, People, and Processes* domain to discuss opportunities and imperatives for key players in HTA practice and use. To help readers identify steps they can take today, we have identified action steps for stakeholders who shape HTA through many different mechanisms. With an eye toward accountability and lasting practice change, we focus on six key stakeholder roles: **Researchers, Patients and Caregivers, Professional Association Leaders, Journal Editors, Research Sponsors, and Payers and Purchasers**. See the Appendix for detailed descriptions of each stakeholder role.

To help readers begin taking action, this document is organized into two main sections. **Foundational Changes** focus on steps necessary to put the *Power, People, and Processes* domain into practice. **Case studies** offer real-world examples of these steps in practice. We also include links to **Action Guides** with steps and resources customized for each of six key stakeholder roles.

> Equity is not a method or procedure, it's a way of thinking and acting.
>
> – Key Informant
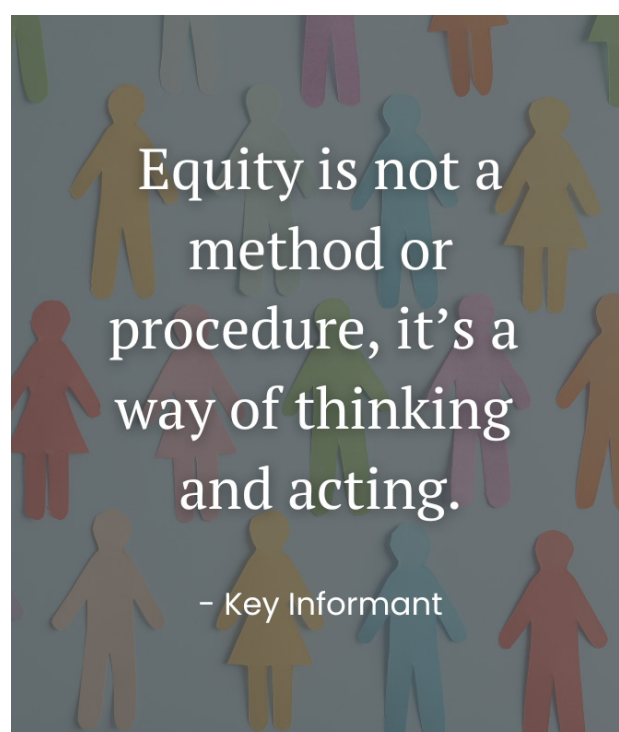
Foundational Changes in HTA Power, People, and Processes

Ensuring equity in HTA requires that practitioners in the field shift how they work, and who they work with, in defining and assessing the value of health technologies. Equity in HTA Power, People, and Processes means that:

Patients and caregivers are partners in co-leading and co-creating HTA

HTA prioritizes representation from marginalized communities

Patient and caregiver contributions are recognized

HTA workforce includes and sustains diverse individuals

For each of these foundational changes, we present a set of practice changes and accountability actions.

Practice changes highlight ways that researchers, patients, and caregivers must work differently – and together – to build lasting partnerships. Practice changes represent long term shifts in practice that must take place over many years.

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 must take to incentivize the longer-term practice changes.

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

Key Questions

Who is doing the work of health technology assessment?

How are diverse perspectives and experiences integrated throughout health technology assessment practice?

Patients and Caregivers are Partners in Co-leading and Co-creating HTA

Co-creation means equal partnership among researchers, patients and caregivers, and other stakeholders throughout all stages of HTA planning, analysis, dissemination, and use. Co-creation exceeds and builds upon eliciting patient and caregiver perspectives through interviews, focus groups, or surveys. In co-creation, researchers, patients and caregiver partners, and other stakeholders engage in ongoing dialogue to share ideas, co-design research questions, iteratively adapt methods and approaches, and together shape the conduct of HTA.

Co-leadership means researchers, research sponsors, and payers and purchasers share power and decision-making with patient or caregiver partners who take on formal leadership roles such as co-investigator, co-lead, or membership on a governance board. There is no one model for co-creation or co-leadership. Patient and caregiver partners may work alongside other members of a team, serve on a steering committee or advisory board (with decision-making authority), act as advisors or consultants, or serve as subject matter experts.

Patient and caregiver communities are leading the way in calling for co-creation and co-leadership throughout the healthcare sector. IVI has responded to this call by consistently integrating patient leadership and empowerment throughout all of its stakeholder convening efforts and continues to follow the example of patient and caregiver community leaders. IVI has been privileged to partner with organizations such as the [National Health Council](#), [EveryLife Foundation for Rare Diseases](#), [Arthritis Foundation](#), [Sick Cells](#), [National Patient Advocate Foundation](#), [National Minority Quality Forum](#), and other IVI member organizations on convenings and research projects that demonstrate the impact of patient and caregiver engagement in HTA.

Figure 2 outlines practice changes and accountability actions necessary for patients and caregivers to meaningfully partner in co-creating and co-leading HTA.

Figure 2. Accountability Actions and Practice Changes for Patient and Caregiver Partnership in HTA

Foundational Change

Accountability Actions

Patients and caregivers are partners in co-leading and co-creating HTA

Necessary Practice Changes

Professional Association Leaders

- Update HTA best practice standards, guidance, and training to emphasize partnerships and co-creation with patients and caregivers.
- To guide standards adoption, design training in partnership with patient organizations.

Journal Editors

- Require within HTA-related journal articles a description of whether – and if so, how – authors collaborated with patients and caregivers.
- Prioritize publishing articles with patient and caregiver co-authors.

Research Sponsors

- 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 that HTA reports include details of partnerships with patients and caregivers, including their roles and contributions.
- Fund patient organizations to develop and provide training and learning communities that prepare patients and caregivers for engaging in HTA work.

Payers and Purchasers

- Assess patient and caregiver engagement as part of evaluating appropriateness of an HTA for decision-making.
- Prioritize using HTAs where patients and caregivers partnered through HTA processes.

Researchers

- 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.

Patient Organizations

- 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.
- Develop and provide training and learning communities for patients and caregivers regarding HTA terminology, processes, and participation.

HTA Practice Prioritizes Representation from Marginalized Communities

When forming partnerships with patients and caregivers, it is important for researchers, research sponsors, and payers and purchasers to **prioritize representation** from individuals who bring lived experience within communities that experience the most persistent health inequities. This helps guard against inadvertently reinforcing or exacerbating existing health inequities. There is no formula for assuring representation. One place to start is to consider the following:

- Which communities of patients and caregivers are likely to be impacted by decisions based on the HTA?
- How do these impacted communities differ in health needs, social context, and life experiences?

- Who is un-represented or under-represented within traditional data sources?
- Where are the gaps in representation? Whose perspectives are missing?
- Where are there opportunities to connect with patients and caregivers from within these communities?

Figure 3 outlines practice changes and accountability actions necessary for prioritizing representation within HTA partnerships.

Figure 3. Accountability Actions and Practice Changes for Prioritizing Representation in HTA Partnerships

Foundational Change

Accountability Actions

HTA practice prioritizes representation from marginalized communities

Necessary Practice Changes

Professional Association Leaders

- Update HTA best practice standards, guidance, and training to emphasize the importance of engaging patients and caregivers who are representative of communities likely impacted by an HTA, especially communities experiencing persistent health inequities.
- Provide equity skills training to researchers conducting HTA. Design training in partnership with individuals who bring expertise in equity for different populations (e.g., by race/ethnicity, culture, disability status) and with patients and caregivers representing marginalized communities.

Journal Editors

- 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.
- 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.

Research Sponsors

- Require that HTA reports include details of partnerships with patients and caregivers, including how well partners represent marginalized communities.

Payers and Purchasers

- Consider adequacy of representation for marginalized communities, including their role in HTA conduct, when evaluating appropriateness of an HTA for decision-making.
- Prioritize using HTAs where marginalized communities were represented as patient and caregiver partners throughout HTA conduct.

Researchers

- Establish ongoing partnerships with patients and caregivers who are representative of people experiencing the condition of focus and of communities experiencing persistent health disparities.
- Build into project plans time for earning trust within marginalized communities. Maintain these relationships over time and across projects.

Patient Organizations

- 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.
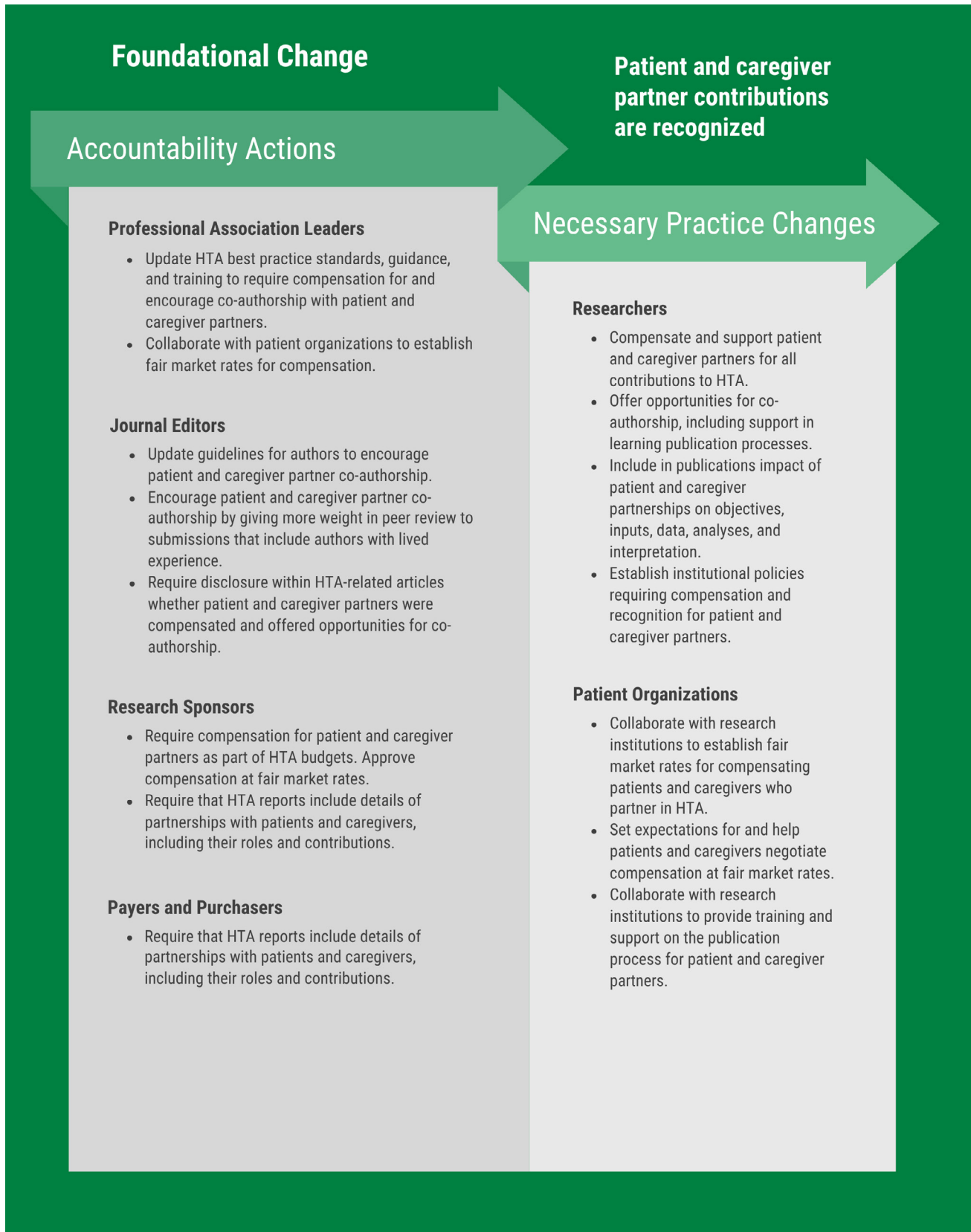
Patient and Caregiver Partner Contributions are Recognized

The lived experience that patients and caregivers bring to HTA is invaluable and must be recognized through **fair compensation and acknowledgment**. While financial support is not the only form of compensation, it is an important part of recognizing partners' contributions and leveling the playing field among members of a team. Financial compensation is particularly important to lower barriers to partnership for individuals who experience marginalization. Compensation can take many forms (e.g., honoraria, fixed price or hourly contracts, employment) and must be tailored to each individual's situation (i.e., considering benefits eligibility, childcare or transportation costs, travel expenses, and costs associated with technology access and use). Recognition also extends beyond financial compensation to publicly acknowledge patient and caregiver partners' contributions within publications and presentations, including documenting the impact of these contributions and offering opportunities for co-authorship.

Figure 4 outlines practice changes and accountability actions necessary for recognizing patient and caregiver contributions.

Figure 4. Accountability Actions and Practice Changes for Recognizing Patient and Caregiver Partner Contributions

Foundational Change

Accountability Actions

Patient and caregiver partner contributions are recognized

Necessary Practice Changes

Professional Association Leaders

- Update HTA best practice standards, guidance, and training to require compensation for and encourage co-authorship with patient and caregiver partners.
- Collaborate with patient organizations to establish fair market rates for compensation.

Journal Editors

- Update guidelines for authors to encourage patient and caregiver partner co-authorship.
- Encourage patient and caregiver partner co-authorship by giving more weight in peer review to submissions that include authors with lived experience.
- Require disclosure within HTA-related articles whether patient and caregiver partners were compensated and offered opportunities for co-authorship.

Research Sponsors

- Require compensation for patient and caregiver partners as part of HTA budgets. Approve compensation at fair market rates.
- Require that HTA reports include details of partnerships with patients and caregivers, including their roles and contributions.

Payers and Purchasers

- Require that HTA reports include details of partnerships with patients and caregivers, including their roles and contributions.

Researchers

- Compensate and support patient and caregiver partners for all contributions to HTA.
- Offer opportunities for co-authorship, including support in learning publication processes.
- Include in publications impact of patient and caregiver partnerships on objectives, inputs, data, analyses, and interpretation.
- Establish institutional policies requiring compensation and recognition for patient and caregiver partners.

Patient Organizations

- Collaborate with research institutions to 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.
- Collaborate with research institutions to provide training and support on the publication process for patient and caregiver partners.

The HTA Workforce Includes and Sustains Diverse Individuals

Representation and recognition in HTA cannot be limited only to patient and family engagement efforts. Equity must also be considered in who does the work of HTA. Put another way, integrating equity into the funding, conduct, and use of HTA requires equity in who receives – and awards – funding for HTA; in who conducts HTA and the research on which it is based; and in who uses HTA to inform decision-making. **Diversifying the HTA workforce** is essential to ensure that HTA practice and use reduces healthcare disparities and ultimately improves health outcomes for the most marginalized populations.

Key questions to explore as a starting place for diversifying the HTA workforce include :

- What expertise is needed on the team to ensure equity is a consistent driver of HTA work? Is that expertise adequately represented?
- Who frames the questions HTA seeks to answer? Whose values are reflected in how we assess the effectiveness and cost-effectiveness of health technologies?
- Who does the work? Who are the researchers and authors? How are those roles defined? How are individuals recruited? Who gets hired?

- Who is on the team? Who leads? Do they have experience in equity work?
- Who is at the table? Who is heard? Who decides?

In answering the above questions, it is essential to consider diversity and representation across intersecting dimensions of culture, language, race and ethnicity, professional training, gender, disability status, and geography. Diversifying the HTA workforce will require broadening notions of expertise to be inclusive of lived experience and a wider array of professional training and academic disciplines. It will also require creating inclusive workplaces within organizations conducting, funding, and using HTA. This means that these organizations must broaden opportunities to join the HTA workforce; hire, recognize, and support professionals who bring a diversity of backgrounds; and sustain these supports to create opportunities for career growth and leadership.

Figure 5 outlines practice changes and accountability actions necessary for diversifying the HTA workforce.

Figure 5. Accountability Actions and Practice Changes for Diversifying the HTA Workforce

Foundational Change

Accountability Actions

HTA workforce includes and sustains diverse individuals

Necessary Practice Changes

Professional Association Leaders

- Provide additional mentorship and peer support for individuals entering the HTA field who bring experience within communities that experience persistent health inequities and/or are underrepresented in health research.
- Transparently report demographic composition of membership, committees, and leadership positions.
- 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.

Journal Editors

- Transparently report demographic composition of editors and reviewers.
- Collect self-reported demographic data from authors. Publicly report diversity of contributors.

Research Sponsors

- Require prospective HTA teams to describe dimensions of diversity their team brings. Prioritize funding for teams that demonstrate diversity in perspectives, cultures, experiences, and expertise.
- Collect self-reported demographic data from researchers receiving funding for HTA work. Publicly report diversity of award recipients.
- Fund fellowships, leadership training, and mentorships for early- and mid-career HTA professionals who bring experience within communities that experience persistent health inequities and/or are underrepresented in health research.

Payers and Purchasers

- Invest in fellowships and other training initiatives to support underrepresented individuals in accessing opportunities in HEOR.

Researchers

- To broaden recruiting efforts for faculty, staff, and students, build relationships with universities and academic programs that serve underrepresented communities and provide training in complementary fields.
- 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.

Patient Organizations

- Partner with research institutions and professional associations to build capacity among patient communities to participate in HTA.
- Sponsor scholarships or fellowships that support patient advocates in pursuing careers in HTA.
- Build partnerships with patient communities that are underrepresented in research and/or that experience health disparities.

Case Studies

The case studies highlighted in this section illustrate 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 center equity throughout HTA practice and research.

You can find three case studies in the pages that follow:

- Recognizing the Importance of Developing Long-Term Relationships with the Community

- Engaging Patients to Understand Diversity of Treatment Preferences for Adults with Major Depressive Disorder
- Sick Cells Engages Patients to Co-Design Equity Centered Health Technology Assessment.

Case Study: Recognizing the Importance of Developing Long-Term Relationships with the Community

At the University of Texas at Austin College of Pharmacy, Dr. Leticia Moczygemba, in the Division of Health Outcomes, is working with the [Ending Community Homelessness Coalition](#) (ECHO) to study how a mobile health intervention impacts health outcomes for people experiencing homelessness in Austin.

Strategies for Centering Equity in HTA: The Interactive Care Coordination and Navigation (iCAN) program is a multicomponent mobile health intervention comprised of text messaging, case manager support, and preloaded apps connected to a health information exchange that relays biweekly reports about hospital or emergency department visits. The purpose is to improve care coordination and reduce preventable hospitalization and ED visits for people experiencing homelessness. To integrate equity throughout the research, the team:

- **Engaged a community advisory board.** The study was supported by a board with five case managers and five people who have experienced homelessness. The board informed the study approach and its focus on health outcomes. The team was able to convene the community advisory board quickly upon securing project funding because they had previously invested internal funding to form initial connections in the community.

- **Integrated the community into decision-making before, during, and after research.** Community partners were integral in finalizing iCAN, developing the recruitment protocol and inclusion criteria, developing interventions (including co-design of the apps on mobile devices), as well as informing health outcomes to be measured.

- **Shared back research findings continuously.** Some examples of iterative communication included providing phase one participants a brief description of outcomes from interviews, dedicating 20 minutes before focus group discussions to provide an overview of previous findings, and routine updates for the community advisory board presented by a case manager.

Lessons Learned: In reflecting how community engagement has strengthened this project, Dr. Moczygemba highlighted several lessons learned:

- **Ensure people see action from the feedback they provide.** It is important to listen to feedback through weekly meetings with community advisory boards, through all steps of the research process. If people don't feel heard, they are less likely to continue to attend meetings and contribute valuable feedback.

- **Educate and train your team and staff.** Members of all research teams should be adequately trained so that they feel comfortable being in the field and properly maintain relationships with the community. This can be accomplished through education, candid conversation with the team and staff, and through shadowing.

- **Establish protocols in the event emergencies occur in vulnerable groups.** Being in the field requires planning for safety of the research team and patients, including developing protocols in case of emergencies. In the case of this study, the team used established crisis protocols at each community site.

- **Utilize trainees to support community partnerships between studies.** The long-term community partnership must be maintained between grant-funded research studies. Involving graduate students to support community engagement can be a mutually beneficial situation for the trainee and the research practice as students gain experience and relationships can be maintained.

The iCAN program demonstrates approaches to building and maintaining longitudinal relationships with individuals representing marginalized communities, paving the way for more equitable and patient-centered programmatic work in the future.

Case Study: Engaging Patients to Understand Diversity of Treatment Preferences for Adults with Major Depressive Disorder

IVI collaborated with researchers at the [Patient-Driven Values in Healthcare Evaluation (PAVE) Center](#) of the University of Maryland and a diverse group of patients and patient advocates to explore patient-driven priorities for managing major depressive disorder (MDD). MDD , also called clinical depression, is a mood disorder that causes persistent feelings of sadness, low self-esteem, and loss of interest for an estimated 7-10% of U.S. adults. A key objective of the pilot project was to gather [treatment preference data](#) from a representative sample of adults with MDD, explore how those preferences vary among different patient communities, and integrate this information into health technology assessment (HTA).

Strategies for Centering Equity in HTA: To guide design and conduct of the project, the team convened a 20-member multi-stakeholder advisory group of patient advocates, researchers, payers, purchasers, health economists, and industry representatives. Five of these advisors represented patients through advocacy organizations and an additional two advisors brought experience working closely with underrepresented communities. In addition to this advisory group, the project team itself included a family caregiver with lived experience in mental health caregiving.

One of the advisory group's key contributions was guiding the team's approach to defining and recruiting a diverse survey sample, including devoting significant effort to ensure that populations experiencing disparities were overrepresented in the sample of 300 patients. Relying on published evidence alone to define a sample would miss patient communities underrepresented in research. To design a more representative sample, patient advisors drew on their own experiences to augment external data from the U.S. census data and national surveys. Together, advisors' experiences and this data helped them understand the distribution of people experiencing MDD and existing health disparities. The advisory group helped the team meet its goals for representativeness by guiding outreach efforts, including sharing the survey opportunity within their own communities.

An additional group of 20 patients with lived experience of MDD informed survey development through a series of in-depth interviews. These patients, who varied in age, education, income, insurance status, employment, and geographic region, shared their experiences with different depression treatments and how they thought about trade-offs among treatment options. The team used these patients' insights to develop a survey about treatment preferences, then worked with patients to review, test, and refine the survey. Advisory group members also suggested ways to make the survey more culturally responsive for patients.

The team completed the survey data collection in 2022 with a 45% response rate and diversity in age, race and ethnicity, gender, employment, and disease severity. The team is currently integrating treatment preferences measured through the survey into IVI's open-source value model on major depressive disorder. IVI and the PAVE team continue to engage patients by sharing back findings in plain language summaries and infographics on an ongoing basis.

Lessons Learned: In reflecting on how partnership with patients strengthened this project, the team highlighted several lessons learned:

- **Partner with patients and community leaders from the outset.** Their guidance is especially important to ensure that the goals of an HTA, and the outcomes assessed, align with community needs. This is particularly important to ensure HTA works to close health disparity gaps.

- **Plan from the beginning to allow extra time for building relationships and earning trust**, both with patient organizations and individuals who bring lived experience. This is especially important for communities that have traditionally been underrepresented in research.

- **Invest time in clear communication**. Being transparent is key to building trust and productive working relationships between researchers and patient communities. Sharing information back to communities helps maintain and deepen relationships over time.

Case Study: Sick Cells Engages Patients to Co-Design Equity-Centered Health Technology Assessment

As more treatments for sickle cell disease (SCD) become available, the need to measure the true value of treatments to patients becomes more important. Currently, there is insufficient data concerning what constitutes value to SCD patients and how to measure value in decision-making.

Strategies for Centering Equity in HTA: Sick Cells, a non-profit organization representing individuals and caregivers with lived experience, convened patients (sickle cell warriors), caregivers, clinicians, and other stakeholders to define outcomes that matter to patients but that are not typically measured in clinical research, and to begin to understand priorities among those factors for patients and caregivers. Sick Cells worked in collaboration with the University of Southern California Hematology Utilization Group Studies (USC HUGS) and the Comparative Health Outcomes, Policy, and Economics (CHOICE) Institute at the University of Washington School of Pharmacy to identify and assess core elements of value to be incorporated into SCD research measures for this six-month PCORI Engagement Award-funded (#EASCS-24293) project. The project utilized the Patient-Centered Core Impact Sets (PC-CIS) Blueprint to facilitate prioritization of patient outcomes.

An important part of integrating equity into HTA practice is ensuring that the way HTA models define value and measure outcomes reflects what is most important to patients, especially those from communities experiencing health disparities. To do this, Sick Cells:

- Empaneled a steering committee representing patients, caregivers, clinicians, researchers, and payers to guide the project. The steering committee acted as key project advisors and played an active role in creating agenda items, leading discussions, and advising on outputs.

- Convened a Community Advisory Board, a wider group of patients and caregivers with lived experience. In assembling the board, Sick Cells prioritized men and Latinx individuals living with SCD, who are underrepresented in research and advocacy around the disease. The board provided input on patient archetypes/priority subgroups, developed a prioritized list of disease impacts, weighed in on design and methods for the weighting and ranking exercise, and disseminated the key outputs of the project back to the SCD community.

- Prioritized and compensated a liaison role, led by an individual with lived experience, to facilitate the community advisory board and communicate between the board and the steering committee. This helped to activate and amplify community voices.

Lessons Learned: Sick Cells identified several areas of learning from this initiative that specifically highlights the need for action, including:

- **Multi-level structure to community involvement is important**, including both steering committee and patient-focused bodies, with a liaison role that has responsibility and empowerment to educate, identify gaps in methods and participation, and facilitate interaction.

- **Use creative methods for outreach** to expand inclusivity of patient voices – in this case identifying underrepresented communities – and using social media and community-focused communication methods to engage and elevate those voices.

- **Center lived experience** and the complexities of a disease across age, race and ethnicity, severity of condition, and caregiver status to understand the health journey and the varying health and economic impacts of SCD.

- **Utilizing mixed methods approaches** is important, and creating steps in the project to use structured research methods will engage research contributors who desire structured approaches, and create patient-focused results with greater usability in HTA.

- **Subgroup engagement and analysis** is important to addressing equity. Significant time was needed to improve representation from identified subgroups and that such outreach ideally would occur before the project launch. Budget more time at the front end of a project to engage underrepresented groups.

This work has had impact, such as influencing structural choices in HTA, including considering pain events occurring outside clinical settings, and including data on fatigue in economic modeling. Sick Cells is using this research to influence clinical research, define quality standards and measures, and converse with regulators and policymakers on how patient-prioritized impacts can drive improved data collection and evaluation of value.

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

Making Progress toward Equity in Health Technology Assessment

Accountability is an essential part of the change process. IVI and other stakeholders can gauge progress in centering equity in HTA within the Power, People, and Processes domain by monitoring signs of near-term progress. By progress, we mean interim steps toward larger changes that shift power in HTA conduct and use. We focus on these signals rather than formal metrics recognizing the early stage of equity integration in HTA

Signs that the HTA field is making progress toward integrating equity through shifts in the power structures, people engaged, and the processes of HTA include:

Patients and caregivers are partners in co-leading and co-creating HTA

❐ Increase in the ratio of patients and caregivers to other stakeholders included within governing bodies or advisory groups for research institutions conducting HTA

❐ Increase in number of HTA-focused, peer-reviewed articles that report on patient and caregiver engagement activities, including acknowledging the absence of engagement

❐ Evidence (e.g., through best practices or reports) of patients and caregivers co-creating HTA with research teams

HTA practice prioritizes representation from marginalized communities

❐ Increase in funding opportunities for patient and caregiver advocacy groups to partner with research institutions in HTA conduct, especially funding for groups led by and representing BIPOC, disability, and other underrepresented communities

❐ HTA practitioners consistently and transparently document processes for ensuring representation from marginalized communities

❐ Greater availability of capacity-building trainings and resources to support patient and caregiver participation in HTA

Patient and caregiver partner contributions are recognized

❐ All patients and caregivers engaged in HTA receive compensation in line with Fair Market Value standards

❐ Increase in patients and caregivers listed as co-authors on research presentations, peer-reviewed articles, and other dissemination of HTA-related research

❐ Greater availability of training for patients and caregivers on peer-reviewed publication process

HTA workforce includes and sustains diverse individuals

❐ Increase in number of HTA-focused journals that publicy report demographic composition of authors, editors, and/or reviewers

❐ Availability of fellowships that support diverse students or patient advocates in pursuing careers in HTA

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

IVI commits to:

- Define co-leadership roles with patient and caregiver partners.
- Apply CHEERS standards when reporting engagement efforts, including documenting contributions from patients and caregivers and how they shape an effort's conduct and impact.
- Conduct project-specific and annual evaluation of IVI processes related to stakeholder engagement, with a focus on equity and impact assessment.
- Prioritize diversity through stakeholder outreach for every IVI project and initiative. Collaborate and contract with experts who bring varying perspectives in life experience, geography, race and ethnicity, gender, and disability.
- Establish patient acknowledgment and fair compensation policies and apply these consistently across all activities, including research, webinars, meetings, and co-authorship opportunities.
- Expand opportunities for HTA careers through workforce development that prioritizes diversity. Hire and collaborate with individuals who bring experience living and working within a variety of communities, academic disciplines, and professions.
- Collaborate with a wide variety of organizations to demonstrate practical approaches to integrating equity throughout HTA.

We call on researchers, patients and caregivers, professional association leaders, journal editors, research sponsors, and payers and purchasers to join IVI in taking action now to ensure equity is a driving force in HTA.

Appendix: 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, Innovation and Value Initiative). 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, PharmaceoEcnomics, 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.

IVI INNOVATION AND VALUE INITIATIVE

info@thevalueinitiative.org
www.thevalueinitiative.org