



Health Equity Initiative
IVI  INNOVATION AND
VALUE INITIATIVE

NO VALUE WITHOUT EQUITY

Transforming Practice and
Accountability for Equity in Health
Technology Assessment

March 2023

Innovations in HTA to Advance Equity

The health technology assessment (HTA) field acknowledges that status quo methods and processes often fail to assess and account for health equity^{2,3,4}. Efforts to integrate equity into HTA practice have thus far been exploratory, yielding recommendations, frameworks, and checklists, but inconsistent adoption^{5,6,7}. A common limitation cited by practitioners of HTA to account for this lack of focus on equity relates to the quality, representativeness, and availability of data⁸. While inclusion and representativeness in research is garnering significant attention, we are only seeing the beginnings of fundamental changes to improve such inputs.

Among Innovation and Value Initiative's (IVI) core principles is a commitment that HTA account for and uphold equity⁹. Building on a series of webinars in 2020-2021, IVI initiated a multi-stakeholder-driven process to explore necessary changes to HTA practice¹⁰. IVI's [Health Equity Initiative](#) aims to identify actionable changes to HTA processes, methods, and communication that acknowledge and resolve existing health disparities in research and healthcare decision-making¹¹. By incorporating representative leadership, methods, and data, HTA can evolve to uphold health equity and prevent further perpetuation of disparities.

After publishing early findings from key informant interviews¹², IVI hosted two roundtable dialogues to identify and prioritize action steps. Primary findings from these conversations include:

- **Fundamental change to the conduct of HTA is necessary to advance health equity.** Incremental or small adjustments “around the edges” will not reduce existing disparities or prevent further inequities in healthcare access or outcomes for patients. This means truly centering HTA on patients’ values and preferences in order to achieve better outcomes for patients, their families, and the broader healthcare system.
- **Stakeholders in positions of power must be accountable for leading change. Further, there is collective responsibility for allyship that includes, and responds to, the perspectives of patients and caregivers.** Funders and payers with financial resources control the prioritization and activation of research. Government payers, regulators, and foundations set expectations for the quality and execution of research, as well as for its use in decision-making¹³. Professional societies and scientific journals set parameters for research quality and influence the pace of change for new methods and the emergence of new research actors, including patients and patient communities. Leaders and implementers within these institutions have an opportunity – and a responsibility – to hold HTA practitioners, researchers, and implementers accountable for integrating equity into all aspects of HTA.
- **All actors must meaningfully engage patients and caregivers in HTA from the start.** New approaches for patient and caregiver engagement are needed when conducting HTA, to meaningfully include these partners in co-creating the questions being asked and designing value assessments that center patients’ lived experiences, goals, unmet needs, and patient-important impacts.

“Health technology assessment advances health equity¹ when it reduces health disparities by aligning access and affordability of healthcare technologies and services with the differing needs and values of diverse patient populations, especially those who are most marginalized.”

IVI's multi-year Health Equity Initiative is guided with the partnership of a cross-sector steering committee. The committee established the definition above to guide the work of developing best practices and new methods to ensure health technology assessment advances health equity.

- **HTA practitioners can no longer wait for better data.** We must begin using the learning laboratory approach – the HTA field can use modeling to shine a light on where there is missing data, where there is a need for research investment, and lead from a platform of improving decision-making through better data.
- **Mixed methods approaches are necessary.** Qualitative and quantitative methods are necessary to guide the direction of HTA and inform the outcomes used to assess healthcare value. Qualitative methods can provide insight into experiences of different subpopulations, highlight impacts not measured in clinical research, and reflect patients' preferences.

IVI Health Equity Initiative

40 Stakeholders*

*Note: Some have two sectors.

	13 Patients & Caregivers
	19 Researchers
	3 Government/Policymakers
	4 Clinicians
	6 Payer/Purchasers
	8 Industry

	12
	Steering Committee Members



10
Key Informant Interviews



2
Roundtables



30+
Hours of Dialogue



100+
Action Ideas

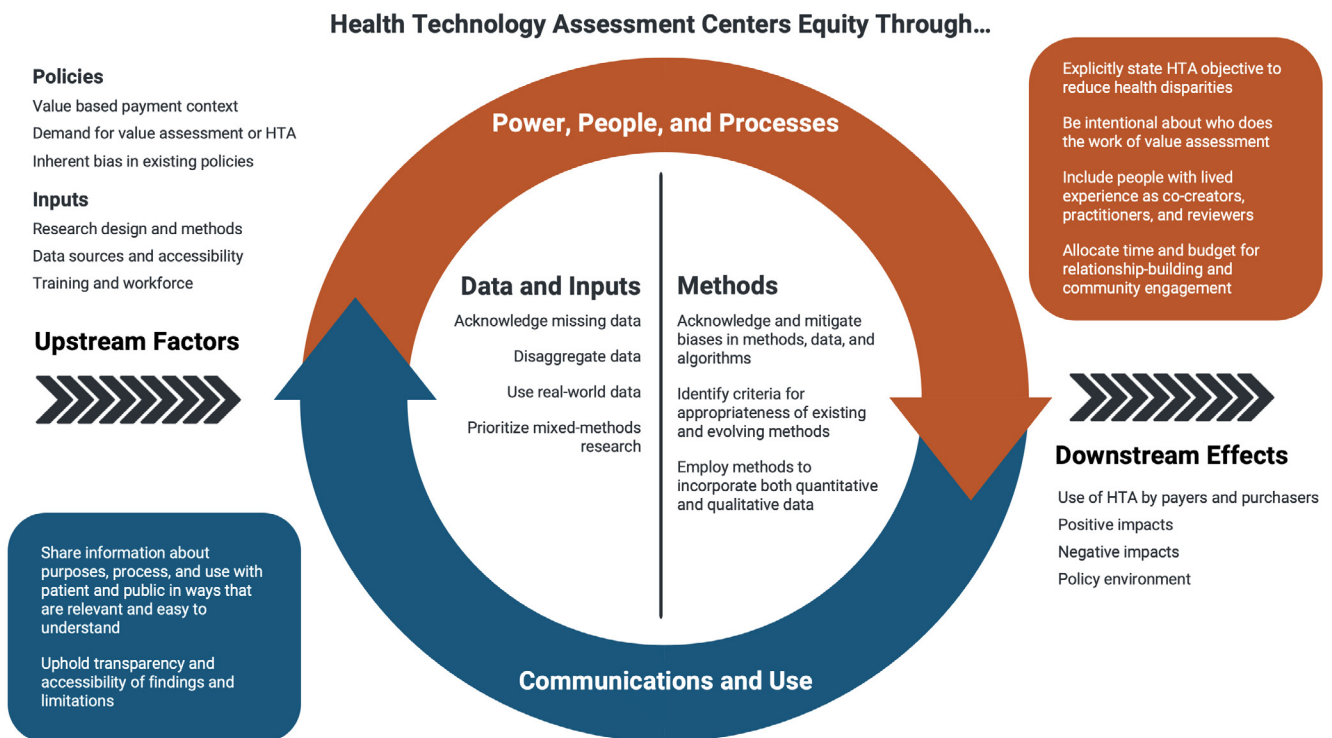
Ensuring that HTA advances health equity is a journey, rather than a destination. Like many entities prioritizing health equity, IVI believes it is vital to acknowledge incremental progress and learning, call out unanswered questions, and tackle complex challenges through collaboration¹⁴. This report documents our journey to date, and provides a vision for the next phase of collaborative effort. IVI will refine and release in-depth recommendations over the next several months, culminating in a capstone whitepaper and public dissemination later in 2023.

Framework

Based on the many hours of dialogue with patients, caregivers, and other stakeholders, IVI developed a framework (Figure 1) that guides our understanding of how HTA and health equity are connected through the ecosystem of research on value in healthcare. This framework highlights the interdependence of action by all stakeholders and clarifies where work must occur to fundamentally reorient HTA toward equity.

IVI developed this framework in partnership with our [Health Equity Initiative Steering Committee](#) to identify key domains necessary to center equity in HTA. This helped concentrate consensus-building roundtable discussions about action steps to change status quo processes, methods, communications, and use of HTA that both reflects and upholds equity in decision-making. The framework, and the action recommendations emerging from this work, uphold IVI's core principles of: **patient-centricity, transparency, and equity.**

Figure 1. Health Equity Initiative Value Framework



Notes: External (“upstream” and “downstream”) factors all outside of the HTA field and represent forces that can influence both inertia and transformative action. Such factors include HTA inputs (data availability and quality), fiscal constraints, research funding and publication requirements, and healthcare policy.

Health Equity Initiative Framework Domains

Power, People, and Processes: This domain is foundational to ensuring equity in health technology assessment (HTA). Rebalancing power emphasizes the importance of patient and lived-experience perspectives and leadership in the conduct of such research. To ensure that HTA accounts for underrepresented populations, and spotlights resource gaps, practitioners in the field must shift their mindset and their processes. Establishing, documenting, and reporting the impact of patient engagement¹⁵ is an example of early action for continuous improvement, transparency, and trust.

Data, Inputs, and Infrastructure: While upstream factors, including infrastructure (interoperability, data accessibility, data sharing), have impact on HTA, this domain acknowledges the prioritization and selection of data sources to inform models and cost-effectiveness analyses that are primary outputs of HTA. There are many related initiatives¹⁶, which will improve the quality and type of data available to researchers. More work is needed, focusing on identifying representative sources of data, developing and using real-world evidence, and transparency about both data limitations and potential for selection bias as essential elements in the analyses.





Methods: While debates about modification and exploration of novel methods are ongoing (and have recently increased), the methods used in HTA model development and analyses have been slow to change¹⁷. Of note, papers published over a decade ago regarding health equity in HTA focused on many of these same process, transparency and methodological factors, but have yielded little change in practice¹⁸. This domain speaks to both immediate practices and tools that should be prioritized to elevate equity considerations in HTA, as well as longer-term areas for investment and collaboration through all organizations acting in this research field.

Communications and Use: Equally important is how the results and limitations of HTA are communicated to both impacted communities (i.e., patients and caregivers), as well as decision-makers (e.g., payers, purchasers, and clinicians). Transparency and inclusion are key principles that must be guideposts for action. Essential actions for HTA practitioners and researchers (that contribute inputs to HTA) include full process transparency, consistent inclusion and delineation of data sources, subgroup analysis or explanation as to why such analysis is omitted, plain language communication about potential implications for both represented and underrepresented subgroups, and identification of research and data gaps that must be prioritized to improve future assessments.

Accountability for Equity in HTA

Building on the IVI HTA Equity Framework, key informants and roundtable discussants articulated necessary action steps and roles for specific actors sharing responsibility for change. The overarching call for a culture of accountability was a consistent theme of discussions among all stakeholders. Table 1 depicts high-priority action steps for stakeholders. This blueprint offers a reference point for further discussion within and among stakeholder groups. In the following pages, we address each of the four domains with a focus on emerging actions.

Table 1. Blueprint: Accountability for Equity in HTA

		DOMAINS			
		 Power, People, Processes HTA is co-created with patient experts, whose contributions are documented and compensated	 Data, Inputs, and Infrastructure HTA uses representative, quantitative and qualitative data that reflects outcomes and impacts relevant to patients and caregivers	 Methods HTA uses mixed methods to identify relevant data; researchers employ existing equity-focused methods and test emerging methods	 Communications and Use Transparent, plain language communication of HTA findings, including equity impact and subgroup analyses, and identification of data gaps
STAKEHOLDER OPPORTUNITIES	HTA Assessors/ Researchers	Prioritize early and consistent partnership with diverse patient communities to define HTA objectives, research strategies, data availability, and implications for health disparities. Establish consistent checklists for data and methods choices and document the impact of patient partnership on analysis. Communicate limitations, data uncertainty, and study findings in plain language.			
	Life Science Companies	Prioritize early and consistent partnership with diverse patient communities to define HTA objectives, research strategies, data development, and methods used. Support post-market research to define impacts of an intervention on subpopulations.			
	Payers/ Purchasers	Require HTA developers to disclose patient engagement strategy informing an HTA and impact on choice of objectives, metrics, data used and methods of analysis. Require subgroup population analyses and clear delineation of gaps in data that have implications for decision-making that affect the unrepresented and underrepresented groups. Invest in patient community with capacity to partner with HTA researchers.			
	Policymakers	Set expectation that study leadership, data used, methods chosen, and communication strategies reflect patient populations affected by HTA. Require transparency related to data and methods limitations, and report on research priorities to support future equity-focused analysis.			
	Publishers & Professional Societies	Create review criteria related to equity in HTA, including clear documentation of engagement with patients and patient communities, use of equity-focused methods, equity impact analysis, and delineation of data gaps, methods limitations, and uncertainty. Require open access in HTA publications. Set reporting and other standards guiding professional practice. Host dialogue, training and professional scientific exchange to test processes and methods to improve equity in HTA.			
	Patient Communities	Collaborate across disease communities to identify common data elements fit for HTA purpose and to develop centralized resources for use in engagement with assessors and researchers. Identify representative leaders that can partner with HTA bodies. Emphasize accountability for action by other actors to uphold equity in HTA. Evaluate HTA activities against equity framework outlined in IVI Equity Initiative.			
	Research Funders	Increase investment for research teams that represent communities most affected by disparities, researchers that elevate and compensate patient co-research relationships, and projects that identify and address data gaps to promote understanding of need and impact on marginalized communities. Set expectations for HTA research transparency, communication and dissemination that are understandable to multiple audiences. Support patient researchers and capacity building for patient communities to expand technical ability to engage in HTA, and patient-led efforts to build data inputs fit for purpose for HTA.			



Power, People, and Processes

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

- Key Informant

KEY QUESTIONS

Who is doing the HTA work?

What is the impact of lived experiences expertise on HTA processes?

Envisioned Change: Development and conduct of HTA emphasizes power-sharing and co-leadership between researchers, decision-makers, and patient/family/caregiver communities impacted by such research. Research questions are defined collaboratively and modeling and analyses reflect insights and context from people with lived experience, to ensure research questions, inputs, methods, and analyses are relevant for real-world implementation. Processes, analytic methods and limitations of such work are fully transparent. HTA drives prioritization of research and data investments that help all actors understand differences based on heterogeneity, as well as disparities in access and use of resources.



Changes Needed to Achieve Equity in HTA*

- Engage patients, caregivers, and their communities BEFORE research begins. Focus on establishing TRUST and ALLYSHIP partnership first.
- Include people with lived experience as co-creators, practitioners, and reviewers.
- Report demographic composition of committees (i.e., leadership, reviewers, etc.) transparently.
- Fairly compensate patient, caregiver, and community research partners for their contributions.
- Require equity skills and training for HEOR researchers¹⁹.
- Provide capacity and training on HTA processes and engagement for patients and patient organizations.
- Define value based on what is most important to those affected – consider most marginalized groups. Engage those affected directly to understand how they define value²⁰.
- Document patient, caregiver, and community research partner contributions on HTA and their role throughout the HTA process²¹.

*As reported by Roundtable participants

First Steps for Stakeholder Action

Expanding on the roundtable recommendations, here are some examples of action steps stakeholders can take to advance health equity in HTA.

When HTA Centers Equity, Researchers²²:

- Co-develop research questions, objectives, and analysis plan from the outset with individuals and organizations who bring lived experience
- Compensate and support co-researchers and participants who bring lived experience
- Engage those affected, especially the most marginalized groups, to define elements of value.
- Document patient, caregiver, and community research partner contributions to HTA and their role throughout the HTA process²³.

When HTA Centers Equity, Patients and Patient Advocates²⁴:

- Set standards for research partnership that stipulate community engagement must happen first, before defining research question(s)
- Advocate for accountability with policymakers, funders, and regulators regarding inclusive processes, transparency, impact analysis, and data representativeness
- Collaborate with other organizations in disease space to identify key data and resources (e.g., patient diversity data, natural history, preferences, patient-reported outcomes) that are relevant to HTA research
- Expand efforts to diversity 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 disparities

When HTA Centers Equity, Funders and Payers²⁵:

- Make evidence of early engagement and partnership with patient and patient organizations at a community level a prerequisite for funding approval
- Set expectations for co-investigator and leadership roles for patient, family, and caregiver experts in HTA research
- Fund workforce capacity and training of researchers in equity and methods; increase equity in researchers receiving funding²⁶
- Require reports and analysis from HTA to include equity and patient engagement details and implications for findings



Data, Inputs, and Infrastructure

“Equity is not a method or procedure, it’s a way of thinking and acting.”

- Key Informant

KEY QUESTIONS

Is the data used representative of marginalized groups and populations most likely to be impacted by HTA?

Where is data generation needed and who is responsible for doing the work?

Envisioned Change: All data collection endeavors, from pre-clinical to implementation and outcomes assessment, engage representative patient communities to define impacts of importance based on their lived experience. Such end-to-end improvement will support more accurate subgroup analyses and contribute to clearer dialogue and consensus around common measures essential to include in HTA. Policies for linking and sharing data empower patients, caregivers, and patient communities to share and learn from research endeavors. Greater transparency in use of data for decision-making increases accountability of payers, purchasers, and others to those impacted by such decisions, namely, the clinicians and patients and caregivers.



Changes Needed to Achieve Equity in HTA*

- Start collecting patient data earlier (e.g., pre-clinical; natural history); collaborate with patients to define population(s) of importance at inception of HTA process, and select and build data sources fit for purpose for HTA
- Create common lexicon of race and ethnicity; standardize data reporting by race/ethnicity; collect granular level race/ethnicity data²⁷
- Develop resources needed to prioritize patient insight and data inputs (e.g., capacity-building grants, explicit budgets within research proposals)
- Define patient-reported economic measures: costs from patient perspectives, including direct non-medical and indirect costs
- Acknowledge data uncertainty and address gaps through real-world evidence and qualitative data development
- Expect HTA and models to define data limitations and identify research questions that should be prioritized to improve data quality, representativeness, and use for equity analysis
- Establish minimum expected standards for HTA researchers addressing data sources, types, and collaboration with patients and caregivers to define studies and data collection that must occur
- Use data appropriate to specific populations and decisions (e.g., Medicaid data, not just commercial or Medicare)
- Use ALL relevant data (e.g., claims, EHR, clinical/RCT, registry, quality and social care measures²⁸, etc.) and explicitly report data gaps

*As reported by Roundtable participants

First Steps for Stakeholder Action

Expanding on the roundtable recommendations, here are some examples of action steps stakeholders can take to advance health equity in HTA.

When HTA Centers Equity, Researchers:

- Commit resources and staff time to patient engagement and collection of data on preferences, outcomes and impacts important to them^{29, 30}
- Include full range of personal and economic impacts (not just healthcare-related) in HTA analyses^{31, 32}
- Include prominent reporting on data limitations (including un- and under-represented patient subgroups) and priority research questions with every HTA analysis
- Use data appropriate to specific populations of importance and specific decision contexts

When HTA Centers Equity, Patients and Patient Advocates:

- Identify patient subgroups that may not be represented in data, and prioritize efforts to expand representativeness of patient participants in research
- Advocate for clear reporting of data selection processes and limitations in HTA
- Advocate for prioritization of research that addresses data gaps and accessibility
- Explore development of common patient data format or repository for data that outlines history, heterogeneity, core impacts, measures, and existing resources (PFDD, registries, surveys, etc.)

When HTA Centers Equity, Funders and Payers:

- Support research on non-medical and indirect costs to patient family and caregiver communities as a critical input to HTA
- Establish public engagement processes to advise agencies on patient roles in early data collection, including involvement in early-phase research design, data collection methods, and ability to collect patient-relevant impacts earlier (e.g., CTTI-FDA initiative)³³
- Support/underwrite public-use data repositories and common formats for data collection with input and co-governance of patient, family, and caregiver communities
- Establish expectation that HTA and models define data limitations and identify gaps and research questions that should be prioritized to improve data quality, representativeness, and fit for purpose for equity in HTA
- Consider mechanisms for making Medicare and Medicaid data sets more usable and accessible for research purposes



Methods

*“How does society value equity?
How do we handle variation in
valuing equity?”*

- Key Informant

KEY QUESTIONS

Are mixed methods (qualitative and quantitative) being used in HTA? Why or why not?

How does the inclusion or absence of subgroup analyses in HTA impact its use in real-world decisions? How does this impact marginalized and unrepresented populations?

Envisioned Change: HTA employs a range of methods that account for equity and allow comparison of how method choice influences HTA results. Analysts recognize the need for varied metrics and mixed methods for equitable decision-making, as no one measure (e.g., QALYs) can capture all relevant impacts. Multiple perspectives, including societal perspective, are included as core analyses in HTA modeling. Subpopulation analysis is a routine component of HTA, and limitations and implications for decision-making about resource allocation and access are transparently and consistently communicated to users of HTA as well as communities impacted (i.e., patients and caregivers). Scientific dialogue, publication, and professional development emphasize advancing methods for equity in HTA.



Changes Needed to Achieve Equity in HTA*

- Use existing equity checklists and other resources for HTA and continue to develop and refine them^{34,35}
- Use existing equity-related methods that are established and well-tested as tools to support rapid decision-making (e.g., equity impact analyses, QALY shortfall metrics); if not used, justify rationale^{36,37}
- Incorporate formal deliberative processes³⁸ (e.g., MCDA) that can explicitly include equity-related attributes
- Operationalize alternative analyses that can illuminate potential equity implications of health care interventions (e.g., distributional cost-effectiveness analysis (DCEA), extended cost-effectiveness analysis (ECEA), and equity weighting)
- Establish transparency standards for analyses of subgroup impacts and data to account for population and condition heterogeneity; absence of relevant subgroup analyses and/or data must be clearly documented and acknowledged in reporting
- Use data-driven approaches to uncover other patient characteristics relevant to observed differences in patient outcomes and access
- Incorporate perspectives beyond healthcare payers (including society) in HTA to reveal important equity-related aspects
- Provide training for researchers in patient engagement methods and plain language communication methods
- Explore and utilize qualitative and mixed methods approaches in assessments
- Acknowledge root causes by incorporating patients' and communities' unique social, political, and historical contexts³⁹

*As reported by Roundtable participants

First Steps for Stakeholder Action

Expanding on the roundtable recommendations, here are some examples of action steps stakeholders can take to advance health equity in HTA.

When HTA Centers Equity, Researchers:

- Explicitly report their use of and results from equity-related checklists for HTA
- Use existing equity-related methods, including formal deliberative methods, that can support equitable decision-making; and justify rationale if not used
- Identify subpopulations of relevance to assessment questions, using literature and input from patient and clinician communities; identify data gaps or other barriers to subpopulation analysis and implications or potential impacts of omission
- Include societal and other perspectives in HTA assessments, as quantitative analyses (when data are available) or as qualitative assessments of likely equity impacts from those perspectives; use of mixed methods promotes advancement of improvement measurement

When HTA Centers Equity, Patients and Patient Advocates:

- Expect and call for relevant subpopulation analyses in all reviews
- Identify patient characteristics relevant to differences in outcomes
- Work with stakeholders to point out limitations of data collection or assessment plans, and encourage plans to fill data gaps
- Call out where assessments are omitting important equity-relevant impacts outside of healthcare

When HTA Centers Equity, Funders and Payers:

- Seek clear identification of which equity-related methods are used and rationale for their absence
- Require that projects include subgroup analyses and/or discussion of how data gaps impact results
- Probe limitations posed by data gaps in applying HTA to real-world decision contexts
- Fund research into new methods to include disparity impacts and other equity considerations in HTA



Communications and Use

“If you don’t see how race, income, gender, and other patient characteristics inherently drive value, then you are not assessing true value in healthcare.”

- Key Informant

KEY QUESTIONS

Do findings and limitations identify data gaps and assumptions made as a result?

Do results analyze potential impact on disparities and on subgroups?

Envisioned Change: All HTAs include clear delineation of patient engagement plans and impact on the analysis, identification of inputs, methods and outputs related to equity analysis for the population and sub-populations. HTA also includes discussion of gaps in data, methods, and evidence on outcomes that may prohibit decision-making with support for equity. Such an Equity Analysis Plan is required by research funders and publishers and is considered a standard as part of professional health economics and outcomes research practice.



Changes Needed to Achieve Equity in HTA*

- Provide clear and ongoing information about data collection efforts to communities involved, including plain language communication about why data is being collected and how it will be used
- Communicate HTA reports and models transparently, in plain language, and with detail about objectives, processes, methods, and data⁴⁰
- Develop collaboration opportunities between health services researchers and implementation scientists
- Emphasize knowledge exchange focus for HTA and clarify what insights are most important for patients, clinicians, and payers
- Look to public health for ideas and lessons learned about plain language communication, including accessible formats and messaging; improve clarity of messaging, consistently communicate health technology impacts and for whom, and state areas of uncertainty
- Explicitly define timing and process for patient engagement in HTA , including impact such input contributed to objectives, methods, and data
- Include transparent documentation of subpopulation analyses, including inability to do such analysis and limitations of data
- Provide technical assistance to patient communities on how to participate in and interpret HTA and associated methods
- Describe groups within a condition that could be marginalized as a result of lack of representation in studies
- Define criteria or standards for communication throughout the process of conducting clinical trials (e.g., data collection purpose, procedures, analyses, etc.)

*As reported by Roundtable participants

First Steps for Stakeholder Action

Expanding on the roundtable recommendations, here are some examples of action steps stakeholders can take to advance health equity in HTA.

When HTA Centers Equity, Researchers:

- Publish plain language summaries in partnership with patient communities to share findings, limitations and implications; in developing summaries, consider health literacy, linguistic, cultural, and disability accessibility factors important to impacted communities
- Collaborate with patients, caregivers, and patient organization to co-publish the importance for patients, messages to payers and research funders regarding impacts on disparities, need for research and data, and implications of HTA
- Clearly define limitations of methods and data, including remaining areas of uncertainty and rationale for using or not using specific methods or analytical tools
- Describe groups within a condition that could be marginalized as a result of lack of representation in studies (e.g., women, people with disabilities, racial and ethnic communities)

When HTA Centers Equity, Patients and Patient Advocates:

- Require full transparency of information, process, data, and findings as condition of engagement in HTA deliberations
- Across patient communities, develop key questions as a benchmarking tool for HTA that all communities can use to evaluate HTA process and communication
- Refer HTA bodies to resources for effective patient engagement⁴¹
- Clearly define subgroup populations of importance to patient community to emphasize purpose in HTA

When HTA Centers Equity, Funders and Payers:

- Emphasize purpose of HTA as a tool to reduce disparities in access to and outcomes from health technology⁴²
- Require transparency, accessibility, and availability of processes, research design, data and dissemination (e.g., open access); require studies include action and investment to clearly and transparently communicate findings to patients and patient communities
- Require study deliverables to clearly outline priorities for further research investment, especially in data collection to improve equity
- Engage patient and patient communities in dialogue about HTA findings and implications for patient communities

IVI Health Equity Initiative: Where We Go From Here



Power, People, Processes

HTA is co-created with patient experts, whose contributions are documented and compensated



Data, Inputs, and Infrastructure

HTA uses representative, quantitative and qualitative data that reflects outcomes and impacts relevant to patients and caregivers



Methods

HTA uses mixed methods to identify relevant data; researchers employ existing equity-focused methods and test emerging methods



Communications and Use

Transparent, plain language communication of HTA findings, including equity impact and subgroup analyses, and identification of data gaps

IVI continues to engage stakeholders across the healthcare field to explore and implement changes necessary to achieve equity in the practice of HTA. As noted in this report, there are opportunities for action by every stakeholder. Our blueprint will guide our work with the steering committee and others in the coming months to outline specific action steps. In addition, IVI will define our own commitment to change, embedding these actions in our own engagement with patients and caregivers, model development, research, and communications. We remain committed to open and transparent communication of the learning emerging from the IVI Health Equity Initiative. Above all, we encourage your partnership and contribution to this crucial work.

“The only way to change the order, she thought, was not to do something differently, but to do a different thing.”

- Toni Morrison -

(Quoted by Roundtable Participant)

Acknowledgments

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Appendix A: List of Contributors and Phases of Work

Name	Organization	Sector	Phase
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Vakaramoko (Karam) Diaby, PhD	Otsuka	Life Sciences Industry; Research	Steering Committee; Roundtable Co-Chair
Judith Flores, MD, FAAP, CHCQM	National Hispanic Medical Association	Clinician; Research	Steering Committee
Nelly Ganesan, MPH	MorganHealth	Payers/Purchasers	Steering Committee
Pierluigi Mancini, PhD	Multicultural Development Institute	Clinician; Research	Steering Committee
Jacquelyn McRae, PharmD, MS	PhRMA	Life Sciences Industry; Research	Steering Committee
Eberechukwu (Ebere) Onukwugha, PhD, MS	University of Maryland	Research	Steering Committee; Key Informant; Roundtable Co-Chair
Lauren Powell, PhD, MPA	Takeda	Life Sciences Industry; Patients/Caregivers	Steering Committee
Jacob Quinton, MD, MSHS, MPH	Center for Medicare and Medicaid Innovation	Government	Steering Committee
Charlene Son Rigby, MBA	GlobalGenes	Research; Patients/Caregivers	Steering Committee; Roundtable Co-Chair
Bonnielin Swenor, PhD, MPH	Johns Hopkins University, Disability Health Research Center	Research; Patients/Caregivers	Steering Committee; Roundtable Co-Chair
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Lisa Prosser, PhD, MS	University of Michigan	Research	Key Informant
Bayley A. Raiz, DBH, MBA, LCSW	CVS Health	Payers/Purchasers; Clinician	Key Informant
Jessica Brooks Woods, MPM, PHR	Formerly Pittsburgh Business Group on Health	Payers/Purchasers; Patients/Caregivers	Key Informant

Name	Organization	Sector	Phase
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Rae Blaylark	Sickle Cell Foundation of MN	Patients/Caregivers	Roundtable
Nicole Boschi, PhD, MS	National Multiple Sclerosis Society	Patients/Caregivers	Roundtable
Julie Heverly	diaTribe Foundation; Time in Range Coalition	Patients/Caregivers	Roundtable
Meghan Khau, MHA	CMS Office of Minority Health	Government; Payers/Purchasers	Roundtable
Stacey Kowal, MS	Genentech	Life Sciences Industry; Research	Roundtable
Louise Lombard, MS	Agios	Research; Life Sciences Industry	Roundtable
Yasmeen Long, MA	FasterCures	Research	Roundtable
Greg Martin	PCORI	Research	Roundtable
Sabrena Mervin-Blake, MS	Clinical Trials Transformation Initiative (CTTI)	Research	Roundtable
Leticia Moczygamba, PharmD, PhD	University of Texas	Research	Roundtable
Daniel Nam, JD	Formerly Global Liver Institute	Patients/Caregivers	Roundtable
Kimberly Richardson, MA	Black Cancer Collaborative	Patients/Caregivers	Roundtable
Nancy Chiles Shaffer, PhD	CMS Office of Minority Health	Government; Payers/Purchasers	Roundtable
Claire Telford, PhD, MS	Pfizer (Formerly GlaxoSmithKline)	Life Sciences Industry	Roundtable
Andrea Thoumi, MPP, MSc	Duke Margolis Center for Health Policy	Research	Roundtable
Tracy Wang, PhD	PCORI	Research	Roundtable
John Watkins, PharmD, MPH	Premera BCBS	Payers/Purchasers	Roundtable

Endnotes

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About the Innovation and Value Initiative

IVI is a 501(c)(3) nonprofit research organization committed to advancing the science, practice, and use of patient-centered health technology assessment to support decisions that make healthcare more meaningful and equitable.



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