

No Value Without Equity: Action Opportunities Emerging from the IVI Health Equity Initiative

January 2023

The [Innovation and Value Initiative's \(IVI\)](#) founding mission is to improve the science and the practice of health technology assessment to ensure it is equitable, represents multiple perspectives, and adapts to the ever-evolving knowledge derived from both clinical research and lived experience of patients and families. Through intentional engagement on the complex limitations of current methods and practice, IVI has demonstrated an impact and continues to spur practitioners to act with greater [transparency](#), to test flexibility in [methodological approaches](#), and to prioritize the complexity of diverse [patient perspectives](#). In addition to patient-centricity and transparency, a [hallmark principle](#) underpinning health technology assessment in the U.S. must be supporting health equity.

Introduction

Recent commentaries and research offer further evidence that there can be no meaningful discussion of value in health care without intentional focus on health equity. Across a wide range of organizations offering frameworks and recommendations (see "Resources/Further Reading" on page 5) to embed equity into our thinking and action, there are two common themes about needed change:

1. Power imbalances in design and decision-making must be intentionally addressed to give equal leadership to lived expertise from patients, families, and communities marginalized in research and care delivery; and
2. Data and research must reflect real-world diversity across multiple dimensions to be considered relevant and reliable for decision-making.

The Innovation and Value Initiative (IVI), as part of the [Health Equity Initiative \(HEI\)](#), recently conducted a series of key informant interviews with stakeholders that reinforced these themes and identified early learning opportunities applicable to the field of health economics research and health technology assessment¹. This research brief summarizes our work to date and reinforces our belief that without explicit attention to equity, health technology assessment risks reinforcing or exacerbating disparities in the U.S. healthcare system.

Background

Current methods used in health technology assessment in the U.S. generally evaluate clinical outcomes and cost considerations of interest to payer stakeholders. These methods are often deemed inadequate to evaluate and inform other dimensions of value, such as patient heterogeneity, economic impacts outside medical costs, disparate access to care or outcomes, and comprehensive impacts on quality of life.

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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.

Interview Participant

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While some aspects of patient-defined value are commonly included in health technology assessments as qualitative information alongside quantitative estimates, there is little agreement on what factors are most important to include, or on how to capture and measure perspectives from diverse communities of patients. Patient data sources are increasingly available, due to significant contributions

¹ Health technology assessment and value assessment have been used interchangeably, although HTA is more commonly used in ex-U.S. contexts. Both terms refer to the evaluation of cost, benefit, and risk to determine resource use in health care. IVI uses the term to reflect the evolution in the U.S. from a focus on pharmaceuticals to a broader effort to assess clinical, real-world impact and cost-effectiveness across therapeutic interventions and technologies.

of patient organizations, but do not yet reflect the full breadth of patients' experiences and have not been utilized effectively for health technology assessment to date.

Building on a 2021 public dialogue series addressing the importance of health equity and the insufficiencies in current methods and practice, IVI initiated a multi-year collaborative learning effort to explore how health technology assessment must account for and uphold equity. Through dialogue with patient communities, researchers, foundations, clinician leaders, and others, IVI invited a multi-stakeholder Steering Committee to collaborate in this process. Leaders were invited based on expertise in health equity (e.g., demonstrated through publication, presentation, or professional action), lived experience, and representation of perspectives both closely tied to VA/health technology assessment (HTA) and to broader health care delivery and policy contexts. Contributors represent both existing members and non-members of IVI to ensure wide-ranging opinion and diversity across multiple dimensions, including disability, gender, age, race, language, health condition, and geographic location.

Shared Leadership Yields a Common Vision

The IVI Health Equity Initiative Steering Committee established early on the importance of clarifying the definition of health equity and its intersection with the unique focus on health technology assessment. Based on collaborative dialogue in group and individual discussions, as well as consideration of definitions used by other organizations, the Committee formed the following definition of the initiative's focus on equity:

Health technology assessment advances health equity 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.

The initiative seeks to further refine the specific parameters of how health technology assessment advances health equity through a series of key informant interviews, subsequent roundtable discussions, and a capstone consensus meeting (in Spring 2023) to define promising practices and opportunities for change.

Key Informant Interviews

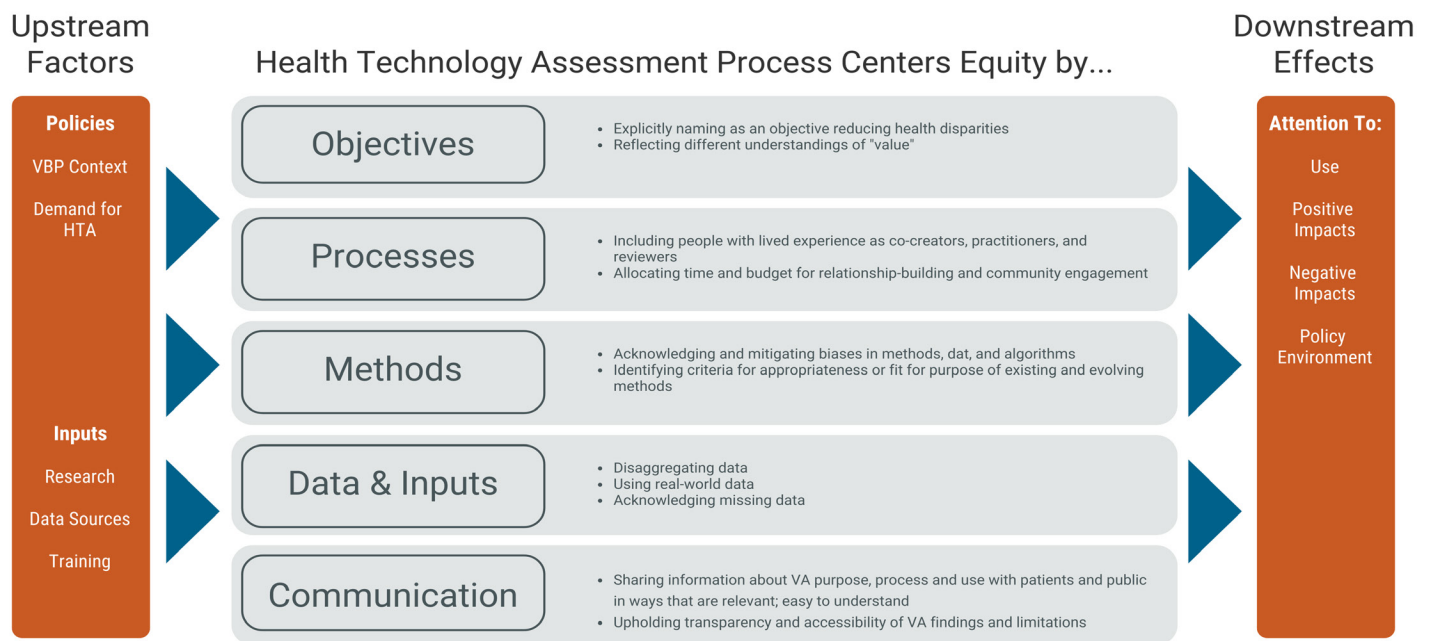
In September and November 2022, IVI conducted a series of ten interviews with key informants representing a cross-section of health care stakeholders (see Appendix 1). Key informants were identified through a process that included review and publications and presentations, recommendations from members of the IVI Foundation Board and Patient Advisory Council, Equity Initiative Steering Committee recommendations, and referrals from those invited but unable to participate. Invitees were reviewed for balance of sector perspectives, areas of expertise, diversity, and opportunity to explore linkages with equity initiatives in other organizations, with emphasis on ensuring representation of all stakeholder sectors in the key informant interviews.

The one-hour discussions were preceded by sharing of a pre-read document and interview guide co-developed with the Equity Initiative Steering Committee. Interviews were conducted virtually with recording for transcription accuracy. The key informant interviews explored views on value, health equity, and important elements of equity-centered health technology assessment practice (i.e., framework domains) (see Figure 1 for original framework, see Appendix 2 for Interview Discussion Guide). To identify common themes and expected characteristics, questions also explored which criteria key informants used to evaluate whether research or data appropriately accounts for equity concerns.

IVI staff mapped key informant input using online whiteboards to identify common themes, key perspectives and feedback on the working equity framework. The mapping was then used to summarize themes, which were shared during a Steering Committee discussion for feedback and clarification. A summary narrative was also shared with all key informant participants to ensure transparency, shared learning, and ongoing feedback with the overall initiative.

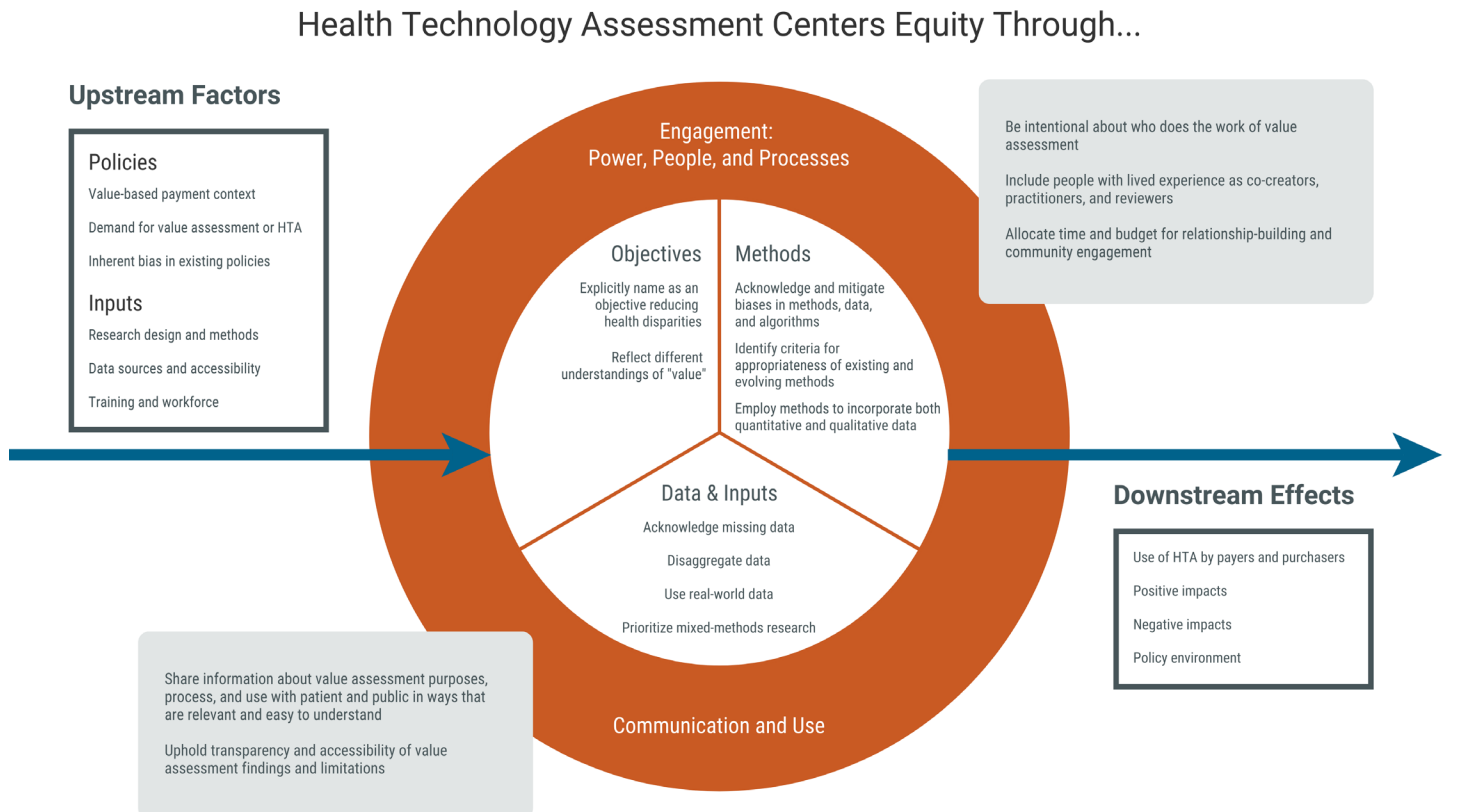
In Figure 1, we acknowledge the presence and impact that upstream factors such as policy trends (e.g., value-based reimbursement and external demand from payers for the conduct of HTA) and factors related to traditional inputs (e.g., research design, data sources, and methods training) have on how equity is viewed and incorporated into HTA. We also acknowledge the downstream impacts that equity-

Figure 1. Visual Representation: Original Framework for Equitable Health Technology Assessment



Notes: VBP - Value-Based Purchasing; HTA - Health Technology Assessment

Figure 2. Revision of Framework, Accounting for Key Informant Insights



focused HTA can have, including use in medical, coverage and payment decision-making, impact on actual experience in care and both health and social outcomes, and influence on policy priorities. Fundamentally, this developing framework (see Figure 2) is intended to guide important redesign of health technology assessment methods and practice, so that it intentionally examines existing health disparities, and works to reduce their perpetuation in decision-making about value

Equity is Complex, and Critical to Value

Across all stakeholder representatives, broad agreement emerged about the intersection of equity and value. While interviewees emphasized different perspectives on solutions, all concurred that both the “Power, People, and Process,” and the “Data and Input” domains were high priority areas for action. Themes emphasized in the discussions include the following:

- **Equity must be considered in who does the work of health technology assessment** – In this context, lived experience is a priority, especially from communities that experience discrimination and health disparities. Language and cultural perspectives are also essential considerations, as is expertise in equitable processes and community engagement.
- **Transparency across all processes**, design, decision-making and communication of both limitations and findings is a non-negotiable characteristic of processes and actions that support equity
- **Equity is multi-dimensional** and includes fairness, justice, access, and equal opportunity to experience health and well-being. Therefore processes, data and methods must demonstrate the ability to represent these concepts within the analyses and application of HTA findings to decision-making.

“

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

Interview Participant

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- Inequities may arise from one or more factors, including race, health status, disability, health-related social conditions, language and culture, experience of care, and access issues. The intersectionality of these drivers must therefore influence all the domains of conducting health technology assessment. **Equity is both a driver and a result of action.**

Early Action Opportunities

We have consistently heard since the inception of this project that transparency and intentionality are characteristics of good practice to champion and integrate equity into all aspects of health technology assessment. This publication of our learning-in-progress is an effort to acknowledge that early and meaningful changes in each of the domains outlined above are both possible and essential to long-term, durable progress. Among the opportunities for early action are:

1. **Establish the benchmark that value cannot be measured without equity.** At all stages and across all domains of efforts to measure and pay for value, equity must be the lead driver. Clear commitment to this should be evident through decision-making, process design, transparency, data development and use, methods, and communication.
2. **Change who sets the health technology assessment agenda.** Including diverse patient and family communities in priority-setting processes, governance of health technology assessment, and design of research and methodologies to be used are achievable steps that advance processes and change power imbalances inherent in the current HTA efforts.
3. **Change health technology assessment processes.** Health technology assessors, researchers, and users of HTA must explore how to meaningfully change processes for learning from persons with lived experience, for co-design of research and methods, for shared prioritization and decision-making about investments needed in data collection, and for evaluating the use and impact of HTA on both access and health outcomes.
4. **Prioritize data sharing initiatives.** A growing trend toward data aggregation and data-sharing for more rapid-cycle learning is positive, but more work is



Equity demands that there be no more ad hoc workarounds and methods that adjust for equity at the end of a health technology assessment.

Interview Participant



needed to make such initiatives both transparent and more accessible to patient communities. Such initiatives remain siloed – for example within payer consortia or clinical research groups – and are often not connected to patient-designed resources of real-world data (e.g., registries or mixed-methods research). While HTA bodies are not usually builders of data sets, they must be champions for data-sharing and for improving data that reflect diverse experience of patients and caregivers.

5. Acknowledge gaps in methods. HTA bodies need to collaborate more on the exploration and pilot testing of novel and mixed-method approaches to address equity – to specifically address subgroup analyses and uncertainty, for example. They also must consistently identify and acknowledge where current methods and tools traditional to the field are inadequate and even have discriminatory impacts. Limitations in methods must be clearly acknowledged as preventing decision-making about people who are not represented, for whatever reason. Moreover, methodological efforts to use “proxy” measures or estimates that have not been developed collaboratively with communities with lived experience must be identified as such, with resulting analyses de-emphasized as relevant to decision-making.

6. Explicitly communicate equity implications of HTA. In keeping with the overall theme of transparency and acknowledgment, HTA bodies must clearly communicate in all publications an analysis of the potential implications of an assessment on health equity. Better still, they should publish a joint analysis with affected communities that reflects on the

above issues of decision-making and data, methods limitations, and clear evaluation of what decisions, if any, can be informed by the HTA.

Future Research and Implications

IVI's Health Equity Initiative reinforces the organization's commitment to ally with all stakeholders seeking to improve how we define, measure, and represent equity in the discussion of value in the U.S. healthcare system. The early findings in this brief will guide our own research practice and inform the next phase of our work, in which we will convene roundtable dialogues with individuals across sectors to refine and prioritize areas for action. Through such intentional collaboration, IVI aims to accelerate learning and create practical processes and tools that ensure equity in value.

Resources/Further Reading:

- STAT News Commentary: [“Exploring Equity in Health Care Value”](#)
- IVI and Sick Cells White Paper: [“Finding Equity in Value: Racial and Health Equity Implications of U.S. HTA Processes”](#)
- American Journal of Managed Care Commentary: [“A Vision for Patient-Centered Core Impact Sets—A Unifying Approach to Patient Centricity”](#)
- PIPC White Paper: [“Aligning Health Technology Assessment with Efforts to Advance Health Equity”](#)
- Frameworks: [Racial Equity and Policy](#), [FasterCures Patient-Perspective Value Framework \(PPVF\)](#), [Asthma and Allergy Foundation of America](#)



Equity is about removing barriers and obstacles to having just opportunity for health. If you have not worked to understand the social, cultural and community drivers that affect people, then you are not assessing value.

Interview Participant



Essential Questions to Improve Equity in HTA (A Starter List)

- Who must be involved in prioritizing and designing HTA processes and structure?
- What expertise is needed on the team to ensure equity is a consistent driver of HTA work?
- How can processes and partnerships ensure data and methods are representative?
- What additional value elements, data and perspectives are needed to ensure HTA addresses equity?
- What data needs must be understood and invested in to ensure equity can be supported in HTA?
- What methods for engagement of lived experience will ensure relevance of HTA results?
- What are appropriate time horizons for HTA – both design of analysis, adjusting for care journeys, and reassessment based on evolving data?
- What criteria regarding power and processes, data, perspective, and methods must be met to demonstrate equity in HTA?

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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 value assessment in healthcare to make it more meaningful to those who receive, provide, and pay for care through collaboration among thought leaders in academia, patient organizations, payers, life science firms, providers, delivery systems, and other organizations.

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Appendix 1. List of Key Informants Interviewed

Key Informant Organization	Date of Interview	Stakeholder Perspective
Eberechukwu Onukwugha, PhD, MS (University of Maryland)	August 23, 2022	Research
Bayley A. Raiz, DBH, MBA, LCSW (CVS Health)	September 12, 2022	Payer, Clinician
Madhuri Jha, MPH, LCSW (Kennedy-Satcher Center for Mental Health Equity, Morehouse School of Medicine)	September 12, 2022	Research, Clinician
Brian Meissner, PharmD, PhD (AbbVie) Robyn Carson, MPH (AbbVie)	September 19, 2022	Life Science Industry, Research
Kenneth Mendez, MBA (Asthma and Allergy Foundation of America)	September 21, 2022	Patient Advocacy
Eboni Price-Haywood, MD, MPH, FACP (Ochsner Xavier Institute for Health Equity and Research)	September 26, 2022	Health System, Research, Clinician
Jessica Brooks Woods, MPM, PHR (Pittsburgh Business Group on Health)	October 7, 2022	Employer, Purchaser, Patient Advocacy
Megan Morris, PhD, MPH (University of Colorado Denver and Disability Equity Collaborative)	October 12, 2022	Patient Advocacy, Research, Clinician
Lisa Prosser, PhD, MS (University of Michigan)	October 12, 2022	Research
Alma McCormick (Messengers for Health)	November 30, 2022	Patient, Research

Appendix 2. Key Informant Interview Guide

Interviewer's Introduction

Today, we appreciate you taking the time to speak with IVI about the issue of how value assessment should address and support health equity.

The purpose of these conversations is to elicit participants' perspectives on innovations in equity-centered value assessment methods and processes, domains on which IVI's Health Equity Initiative should focus, and practical considerations for equitable value assessment. Learning from these conversations will inform roundtable dialogues in late 2022 and a multi-stakeholder consensus meeting in 2023.

We'd like to record today's conversation for note taking purposes. We won't share that recording with anyone outside of the team and won't identify you in anything we share publicly from these interviews. Would it be ok with you if we record today's interview?

[Start recording if permission is granted.]

As a starting reference, we hope you've had time to review the project overview and framework explanation. The framework is a working draft reflecting our learning to date and will continue to evolve.

During the next 60 minutes, we would like to explore several questions with you relevant to health equity and the intersection with value, and specifically value assessment. We are interested in your work and views on these topics broadly, and welcome candor and your critical thinking to help shape our future phases of work. Above all, our intent is an interactive discussion with you. Before we get started, do you have any questions?

****Next Section is Background and Introduction Questions****

Background and Introduction Questions

In this section, listen for:

- Different views or understandings of health equity
- Different views or understandings of value or the practice of value assessment
- Tensions between individual and organizational/institutional views of equity or value
- What's not clear about IVI's initiative. Not important to clarify all details during interview, but is a sign of areas needing more clarity in future communications.

1. *Please tell us a bit about yourself and your role in your organization.*
2. *We shared with you some materials describing the purpose of this interview and how IVI views the intersection of health equity and value assessment. Before we get started, we wanted to make time for any questions or reactions to that.*

If pre-read material is not fresh in their minds, provide brief level-setting:

- Value assessment is one approach to health technology assessment, which is the evaluation of costs and benefits for health technologies to better inform decision-making about access, reimbursement and health care delivery, as well as other policy decisions that affect both health outcomes and resource utilization.
- Through discussion with the initiative's steering committee, we are starting this work by defining equity in value assessment as: *Value assessment advances health equity when it reduces health disparities by aligning access and affordability of healthcare technologies and services with the different needs and values of diverse patient populations, especially those who are most marginalized.*

****Next Section is Vision and Problem Statement Questions****

Vision and Problem Statement Questions

In this section, listen for:

- What aspects of equity do key informants raise as most important?
- How much do key informants focus on the process or methods of value assessment?
- How much do they focus on the outcomes or impact of value assessment?
- Where do key informants struggle to answer these questions – what are the aspects of value or equity they seem to need to wrestle with in fleshing out these statements?

For key informants with HTA/HEOR expertise, spend less time in this section and more on research action.

3. *Could you tell us a bit about how you or your organization focuses on value and/or equity? We're especially interested in any ways that your work brings those two threads together.*
4. *What are the problems related to equity that you and or your organization are trying to resolve? Please share what good looks like to you or your organization.*
 - *For example, we're interested to hear how you would flesh out this statement: Making equity a consistent focus on value assessment would require...*
 - *Why are these aspects of equity a priority for you and your organization?*

****Next Section is Framework Questions****

Input on Working Framework from IVI Health Equity Initiative Steering Committee

In this section, listen for:

- What elements of the framework seem to resonate most with key informants?
- Is there anything missing from the framework they would add? Anything they would remove?
- Where do they have questions or seem confused?
- What kinds of impacts or decisions do participants highlight as important upstream or downstream factors? Which of these are observable (e.g., data collection, statistical analyses, interpretation) and which are less transparent (e.g., study team composition, selection of research questions, choice of intervention and comparison groups, etc.)?

IVI staff partner pulls up framework image, if needed.

Now we would like to hear your feedback on the working framework we shared describing domains of equitable value assessment (also in the pre-read materials). This framework reflects work to date and guidance from the initiative's steering committee. It will continue to evolve and we would like to hear your thoughts on how to refine it.

5. *Which of the framework domains are highest priority or most essential in health equity considerations in value assessment? If you had to pick a single most important domain, what would it be? Why?*
 - *Are there any domains missing that you feel are important to include in our working framework?*
 - *For the domain you feel is highest priority, are there any attributes (sub-bullets under the domain) missing, in need of further explanation or examples, or unnecessary? Why?*
6. *Are upstream issues as defined in the framework clear? Are we missing any other aspects that are essential factors in health equity, but which may be precursors or contributors to value assessment that advances health equity?*
7. *Are the downstream impacts of equitable value assessment clear? Are there additional aspects of the potential applications and impacts of value assessment that may affect equity or disparities?*

****Next Section is Research Action Questions****

Research Action Questions

In this section, listen for:

- What additional types or sources of data do key informants point to (e.g., SDOH data, patient-reported data, real-world data sources)? How or when might those data become available for value assessment (e.g., where in the pipeline)?
- What additional methods or practices do key informants point to? Do these come from within value assessment or other fields? What makes them promising?
- How optimistic are key informants about adopting equity-centered data, methods or practices into standard value assessment practice?

Next we would like to clarify some of the opportunities and challenges around equitable practice of value assessment.

Broad Questions (for all key informants):

8. *What methods or best practices do you look for as evidence that a project, research study, or analysis is equity-centered? Why?*
 - *What is required to ensure those methods or best practices are used widely and consistently?*
9. *What new data sources, methods or processes must be developed to ensure equitable practice of value assessment?*
10. *What can IVI learn from people doing this work in other fields? Where should we look, for examples to learn from?*
 - *Back Pocket: For example, we have looked at A Toolkit for Centering Racial Equity Throughout Data Integration for racial equity best practices when using algorithms and statistical tools, analyzing data, and reporting data or sharing findings.*
11. *What are the “bright spots” for making change happen (i.e., promising actions and/or attention to bring equity into the discussion of value? What makes your example(s) a solution or promising direction?*

Value Assessment-Specific Questions (for key informants with value assessment or health technology assessment expertise; prioritize about 15 minutes for this section):

12. *What new data sources, methods or processes must be developed to ensure equitable practice of value assessment? How will these help?*
 - *What can/should we do about the ongoing inadequacies of data to support decision-making?*
 - *What would you communicate to researchers in the value assessment field about the inadequacies of data? Are there immediate priorities that should get more attention and resources?*
13. *What aspects of value assessment require investment to support incorporating health equity considerations into value assessment practice? Which of these investments would you prioritize?*
14. *What feasibility issues arise for measuring and incorporating health equity in value assessment?*

****Next Section is Wrap-Up Questions****

Wrap-Up Questions

8. *What attributes do you look for in value assessment to evaluate how well it incorporates health equity?*

- *Why are these important?*
- *Adapt this question as needed to focus on value assessment, measurement, data, research, etc., depending on informant's expertise and conversation up to now.*

Before we wrap up, [Ellen/Melanie/Rick], any key question we missed?

Then ask informant:

- *Is there anything else we should have asked but did not?*
- *Who else would you recommend we connect with to help inform this initiative?*

Thank you for your participation in IVI's Health Equity Initiative and for your candor and insights today. We will share a brief summary of key takeaways from this phase of our work with you and look forward to your further input and questions.

About IVI

The Innovation and Value Initiative is a 501(c)(3) nonprofit research organization committed to advancing the science, practice, and use of value assessment in healthcare through collaboration among thought leaders in academia, patient organizations, payers, life science firms, providers, delivery systems and other organizations.

www.thevalueinitiative.org