



**Health Equity Initiative**

**IVI**  INNOVATION AND  
VALUE INITIATIVE

# KEY INFORMANT INTERVIEWS

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**Summary**

**November 2022**



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## Introduction

During September and October 2022, Innovation and Value Initiative staff conducted a series of nine one-hour virtual interviews with “key informants” — individuals with lived experience, professional expertise, and skills in research, clinical delivery, policy, or data analysis. Individuals invited to participate were identified by the multi-stakeholder Steering Committee during both virtual meetings and via post-meeting referrals. In addition, IVI staff reviewed key papers, external equity initiatives, and presentations, and sought additional nominees from the IVI Board and Patient Advisory Council. This document summarizes key themes arising from the discussions. IVI has shared these findings with the Steering Committee and with interview participants. We intend to publish key learnings from this phase of work in November and will explore areas for process and methods action during one or more roundtable discussions. All quotes and comments are unattributed.

## What is VALUE?

Although we did not ask key informants to define value specifically, throughout the conversations they highlighted specific aspects of value as important or missing from value assessment discussions.

### Important Elements of Value

- Many key informants referred to **financial considerations** as implied in the meaning of value. But they varied in how they framed these considerations. Some spoke about costs to payers or employers, other focused on cost-benefit tradeoffs, and others on prices. Incentives for investors and manufacturers were implied in many of the comments around financial components of value. One informant called out needing to rethink the “winners and losers” in economic theory currently undergirding conversations about value in healthcare. Another informant reinforced the idea that we must be intentional to avoid the unintended consequence that is portrayed as zero-sum game of resource allocation.
- Several key informants also called out the importance of considering **quality** alongside or on a level playing field with costs. This begged the question of what constitutes quality. While we did not specifically explore definitions of quality, one informant emphasized equity as an essential element of quality (as underscored by the Institute of Medicine in its 2001 *Crossing the Quality Chasm* report) while another called out the inconsistency in definitions of quality as assessed by many different healthcare performance measures.
- One key informant highlighted **consumer choice** as an important element of value.
- Many informants highlighted the role and importance of **language and culture** to equity and value. A researcher noted that attitudes about inequity in health vary regionally in the U.S. and that researchers needed to add diversity of perspectives in framing and prioritizing research questions. Another informant noted that social and cultural values in the U.S. stratify people into classes with different educational, job and income opportunities based on race, sex, ethnicity and disability. Such stratification ignores multidimensional identities and factors of value. Another dimension raised by informants

addressed diversity of research workforce to ensure people with disabilities, cultural needs and communication preferences were included in equity-designed research.

### Missing Elements of Value

- Key informants repeatedly raised questions about differing perspectives on value, asking questions such as: **Whose view of value are we prioritizing and value to whom?** They called for the value assessment process to include broader perspectives on value beyond the payers, researchers, and economists who currently shape discussions and decisions around value and value assessment.
  - Key informants prioritized the **perspectives of people with lived experience** (also referred to as patients, consumers, or employees). One informant specifically called centering perspectives of underserved communities; another insisted that people must define value for themselves. Other informants emphasized needing diversity across a range of perspectives, with special focus on bringing together stakeholders who don't (currently) discuss value.
  - One key informant raised questions about **societal perspectives on value**, noting that regional and political differences often track with dramatically different notions of value. Another informant called out harm, such as denied treatment or technology, that specific communities experience when their lives are de-valued by healthcare. This makes any value-based discussion a risky undertaking for those within that community.
- Key informants repeatedly raised **time frame considerations** as missing from current definitions of value. They called out the need to consider longer time horizons, update value assessments over time, and examine not only *what* is important to patients, but also *when* specific factors are important to them. For example, one informant shared that what's valuable to newly diagnosed patients may be very different for those who have been living with a chronic disease for many years and have already tried several different therapies.
- Several key informants called out blind spots or gaps in current understandings of value. These included **focusing too narrowly on quantitative data** or measures; ignoring the **intersecting influences of race, income, and gender** on value; and prioritizing patient adherence and treatment efficacy over **other dimensions of value**.
- One key informant called out qualitative data and the **patient experience** as missing from definitions of value, noting that looking at cost-benefit only is inadequate. Current practice focuses outcomes but neglects upstream factors (societal perspective). Another called out the "aha!" moment for those paying for healthcare services when they recognize that many patients, particularly patients of color, **experience harm** from their interactions with the healthcare system. This diminishes the value of services or technology that the employers are offering. Several other informants called out the importance of acknowledging and preventing harm without tying it to definitions of value.
- Several informants highlighted missing elements of **value in the context of purpose**. For example,

disability communities that may reject medical model framing of seeking to “cure” or “fix” disabilities are not well represented in the structural design of health technology assessment, which emphasizes cost-effectiveness of a treatment as opposed to accommodations for supporting quality of life and ability to “live the life they want.”

## What is Health Equity?

### A State of Health Equity

- Key informants described **health equity in terms of justice, fairness, access, and equal opportunities for health**. They spoke about equity in two dimensions: in health-related social conditions and in access to healthcare.
  - In describing **health-related social conditions**, informants focused on environmental, social, and political factors that drive differential rates of disease, disability and need for healthcare. They emphasized the importance of tying disparities in health outcomes to these upstream factors, and ultimately acknowledging and addressing root causes of health disparities.
  - In describing **access to healthcare**, informants focused on health literacy, availability of health services in patients’ preferred language, location of health services, and absence of barriers to health. One key informant described health inequity as denied access to quality of life.
- Across these definitions, key informants primarily focused on describing equity. In contrast, only two focused on **defining health**, emphasizing quality of life and a complete state of physical, mental, and social wellness. One informant called out needing to examine community-level impacts rather than focusing only on individual-level health. Another informant discussed notions of quality of life at length, recognizing controversy around how quality-of-life measures harm people with disabilities, particularly when used to deny treatment or assistive technology. This informant called for **broader understanding of what quality of life means** to people with very different life experiences.
- One key informant emphasized the **distinction between equity and equality**. Equality is focusing on providing the same thing for everyone. Equity is understanding differential experiences and outcomes for different groups of people, providing what they need in a tailored way.
- Two key informants emphasized **distinguishing** observed differences in treatment or outcomes based on **patient preferences** from **health disparities**. They highlighted this distinction as particularly important when shifting from a population-level focus (such as making recommendations for coverage, treatment, or reimbursement for a whole population) to individual decision-making at the point of care.

### Equitable Process

- Across nearly all the interviews, key informants consistently emphasized **equity in who does the work**

of value assessment. They called out the need for intentionally including diversity of thought in framing questions about value, diversity among value assessment practitioners, and transparency in who conducts value assessments, and the research that underpins such evaluations. As discussed below (see Key Questions to Guide Equity-Centered Practice), they raised many of these “who” questions throughout the interviews.

- One key informant noted the importance of **embedding equity throughout the value assessment process**. And across the interviews, key informants focused most consistently on what they look for as evidence that a process (be it value assessment, research, engagement, etc.) is equitable. They also raised questions about how to make value assessment equitable through simplification of the process and through intentional efforts to build trust. This may also point to the need for more public/private collaborations and funding streams.
- In describing equitable processes, informants focused on **equity in engagement, methods and data, and communication**, highlighting specific practices to integrate throughout the value assessment process (Table 1).

## Framework for Incorporating Equity in Value Assessment

During the Key Informant Interviews, we displayed on screen the working Framework or logic model (see Figure 1) that IVI developed in consultation with the Steering Committee. A series of questions (see Appendix 1) guided interviewees through the key dimensions outlined in the Framework and gathered input on how it could be further refined to reflect a pathway towards more equity-centered value assessment.

Overall, there was agreement that the framework captured the key domains that must be addressed to incorporate equity into value assessment. These discussions overall validated the working Framework.

At the same time, several of the discussions underscored the need for fundamental redesign of health technology and value assessment in order to actually incorporate health equity. The conclusion that there is no value without equity emphasized critical shifts in thinking and action, including:

- A wider “lens” is required to focus on equity, beginning with upstream factors all the way through the outputs and use of value assessment.
- Patients’ lived experience must be visible for there to be trust.
- There must be an examination of the “Why?” – Why is value assessment being conducted? Why is value assessment being applied for this purpose? Why are the people conducting the value assessment involved? These questions will help us understand: Who stands to benefit from conducting the value assessment?
- Power structures and power dynamics between the value assessment entity and patient communities must be intentionally addressed and biases explicitly acknowledged and mitigated.

In the sections that follow, we discuss key informants' views on each of the domains within the working Framework (as presented to them during the interviews). We also include an initial summary (see Table 1) of equity-centered practices that will guide further phases of IVI's Equity Initiative foster open dialogue with all stakeholders in health technology assessment.

### Objectives: Importance of Addressing Bias in Value Assessment

A bullet point included under the Objectives domain of "explicitly naming as an objective reducing health disparities" resonated with a number of informants. Intentionality and being deliberate were shared as important from the outset. Discussion from many of the key informants centered on the lack of trust among many patients and stakeholders in the healthcare system and in the enterprise of health technology assessment itself.

**There Is No Value Without Equity:** Equity must be a fundamental driver of value assessment. A first step is reframing notions of scientific rigor to require equity, as one key informant asked, "Is work reliable and valid if it is not representative?"

**Patient Lived Experience:** Healthcare, at its core, is a complex delivery of preventive services, treatments for acute conditions, and ongoing care for complex, chronic conditions in people throughout their lifespan. Feedback from a range of stakeholders focused on the clear lack of patient and family lived experience in existing value assessment approaches. Movement toward more equitable value assessment will require the inclusion of patients, families, and caregivers in defining research questions addressed through value assessment and throughout the assessment process.

**Intentionality Is Required to Account for Social Determinants of Health, Unmet Health-Related Social Needs, and Health Disparities in Value Assessment:** Key informants emphasized linking disparities in health outcomes and upstream factors that drive these disparities (i.e., social drivers of health), especially the environmental, social, and political conditions that create differential unmet needs among marginalized populations. They called for value assessment to acknowledge root causes by incorporating qualitative information and communities' unique social, political, and historical contexts.

One key informant noted: "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."

**Mitigating Bias:** A number of key informants raised the need to mitigate biases built into value assessment methods, data, and algorithms, particularly in the context of the increasing use of Artificial Intelligence (AI) in healthcare.

### Processes: It All Begins with Patient, Caregiver, and Family Engagement

Most key informants highlighted the Processes domain as essential, emphasizing that equitable processes must be present for value assessment to advance health equity. For some, the Processes domain was more important than the Objectives or Methods domains.

**Equity is Essential from Beginning to End:** Informants emphasized integrating equity throughout the value assessment process, from defining objectives and key questions through choice of data, application of methods, and interpretation and communication of findings. They also highlighted the need for equity-centered approaches upstream of value assessment (for example, in generating evidence through research) and downstream in how value assessment is used to guide decision-making and policy.

**Engagement is Central to Rebalancing Power and Process:** Most key informants focused in on patient engagement, caregiver engagement, and other stakeholder engagement as the most important aspect of value assessment processes. Interviewees expressed that good engagement practices that intentionally embed equity throughout the value assessment process are necessary. One informant also touched on the importance of making value assessment more accessible to patients, payers, providers, and other stakeholders.

**Who is Engaged is Important:** While key informants indicated that engagement is essential, more important is WHO is engaged in the process. Some of the informants discussed the responsibility of those leading the value assessment process to convene and build consensus among stakeholders, most importantly people who bring lived experience and represent marginalized communities. Informants acknowledged that engagement is resource-intensive, long-term work. One informant noted, “the most important thing is that you don’t start something and it goes away when funding ends. People see too much of that.”

**Engagement Must Begin Upstream:** Designing for engagement and diversity from the start of any study or value assessment process is paramount. Key informants emphasized that this cannot be an activity that comes at the end of the process. Patient engagement provides necessary context to center value assessment on the outcomes that matter to patients and the real-world tradeoffs they face in their care. Key informants also emphasized defining with patients what value means to them.

**Fair Compensation and Support are Essential:** One informant noted that “not paying patients to share their lived experience is extortionist,” emphasizing the importance of investment in fair compensation to patient contributors to research and health technology assessment. This theme also arose in the context of research funding, where those making funding decisions should emphasize inclusion and compensation of patient, family and caregiver partners in research design and execution. Finally, informants emphasized the importance of investing in accessibility, knowledge building and other support to ensure “equal footing” for the voice and contributions of lived experience.

## Methods

**Mixed Methods are Required:** Equity cannot be incorporated into value assessment without integrating both quantitative and qualitative data and methods (for example, sole dependence on randomized controlled trials [RCTs] must be addressed/undone).

**Real-World Data Allows for Insight:** Pairing real-world evidence (RWE) with evidence from RCTs will inform *how* to ensure clinical trials, comparative effectiveness research, and other evidence better represents the population of patients affected by a health condition or health technology in the real-world.



**Explore and Adapt Methods:** Equity in health technology assessment will force the field to adapt and test new methods that quantify patient preferences, that explore how to balance population-level preferences with individual preferences, and that account for wide variation at both levels accounting for multiple dimensions of diversity and the intersections thereof.

## Data

**Lack of Standardization of SDOH Data is a Problem:** Incentives are currently lacking in research, healthcare delivery, and in value assessment for consistently collecting standardized data on social needs. On the other hand, some marginalized communities raise concerns about ways such data could be used to deny them services, treatments, or technology on the basis of cost or perceived lack of benefit. Researchers and value assessment practitioners must weigh benefits, harms, and feasibility considerations in collecting and using data.

**Collection and Use of Qualitative Data on Patient Lived Experience is Essential:** Collection of qualitative data on patients' lived experience must be systematically incorporated into the research and healthcare value ecosystem. Several informants cautioned about "over privileging" randomized-controlled data over other evidence sources. Rather, many called for commitment to broader definition of data for value – including wider representation in clinical data, and incorporation of real-world data sources and patient perspectives. Another informant also called out the need to use the substantial quantitative and qualitative data already collected, emphasizing calls for wider data sharing over status quo proprietary silos. One informant shared that new methods of analysis in a holistic way will be required. They shared that the view from their patient community was that "we don't pick stories apart." Respecting patients meant retaining the rich complexity of the story in the data.

## Communication

**Need for Knowledge Exchange:** The importance of communicating information in ways that users can easily understand came up in discussion both in the context of making value assessment more accessible to patients and other stakeholders through use of plain language, as well as the need for research translation when communicating with policymakers.

**Equity-Centered Communication as a Skill:** One informant raised the issue that training in equity-centered communication is important for the field of value assessment practitioners.

**Need for Greater Transparency:** Many key informants highlighted the importance of transparently communicating the objectives, processes, methods, and data used as part of value assessment. Informants also highlighted the need to communicate about the impact of data (quality, type and even gaps) on decisions and recommendations. The latter point emphasized that transparency about decisions to include or omit data, and its effect on the resulting analysis is vital to ensuring equity in the use of health technology assessment for decision-making.

**Table 1: Emerging Ideas To Improve Equity in Value Assessment**

Value Assessment Processes	Equity-Centered Practices	Questions Driving Action
Engagement and Leadership	<ul style="list-style-type: none"> <li>• Design for engagement and diversity from beginning to end</li> <li>• Co-create value assessment with people who bring lived experience <i>and</i> are representative of marginalized populations</li> <li>• Allocate budget for relationship-building and compensation of patient partners</li> <li>• Work with communities on their priorities first before asking for their time</li> <li>• Form long-term relationships with communities whose voices have been missing from value assessment</li> <li>• Invest to build partners' capacity to engage in the value assessment process, especially discussing tradeoffs</li> <li>• Invest upstream in community-based research to generate community-centered evidence</li> <li>• Consider representativeness across dimensions in research team, data collection personnel and stakeholder engagement</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Whose view of value is the focus? Value to whom?</i></li> <li>• <i>Who frames the questions? Who are the researchers and authors – do they have experience in equity work?</i></li> <li>• <i>What lived experience perspectives are included? From whom?</i></li> <li>• <i>Who does the work? Who gets hired? Who is on the team? Who leads?</i></li> <li>• <i>Who is at the table? Who is heard?</i></li> <li>• <i>Who decides?</i></li> <li>• <i>Are skills and compensation fair and balanced?</i></li> </ul>
Methods and Data	<ul style="list-style-type: none"> <li>• Design for equity in how data are collected, analyzed, and used – don't forget culture and language, health literacy and accessibility</li> <li>• Clarify up-front what is being valued and what disparities are of interest (e.g., which outcomes examined)</li> <li>• Report demographic data (race, ethnicity, age, and gender) for all samples</li> <li>• Specify what data are missing and why (e.g., how it relates to research, design, data collection methods, historical practices)</li> <li>• Examine, acknowledge, and mitigate biases in algorithms</li> <li>• Contextualize quantitative data with qualitative stories</li> <li>• Prioritize mixed methods approaches to data</li> <li>• Include social, political, and historical context within all discussions and analyses of value</li> <li>• Make value assessment an iterative process with updates over time to reflect additional data and evidence shifting context, and broader inclusion</li> </ul>	<ul style="list-style-type: none"> <li>• <i>How can we measure upstream factors?</i></li> <li>• <i>Why is a particular practice infeasible? What will make it feasible?</i></li> <li>• <i>Which questions get asked and which get funded?</i></li> <li>• <i>How can work be considered reliable and valid if it is not representative?</i></li> <li>• <i>How does society value equity? How do we handle variation in value in equity?</i></li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Be clear that equity is part of the culture of health technology assessment – rather than a method or procedure, it is an embedded way of thinking and acting</li> <li>• Be transparent about how value assessment practitioners integrate equity through their processes (e.g., report equity-specific practices, demographics of practitioners) and practitioners' own biases</li> <li>• In reports, distinguish disparities from root causes by tying language on disparities in outcomes to upstream factors that drive those disparities</li> <li>• Use plain language to communicate value assessment findings to policymakers to ensure equity-centered value assessments are acted upon</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Does value assessment do more harm than good? For whom?</i></li> <li>• <i>Do value assessments center data gaps and limitations that may obscure analysis of equity impact?</i></li> <li>• <i>Do value assessments explicitly discuss the equity implications of analyses and directions?</i></li> </ul>

## Conclusion

Across these interviews, we heard broad consensus that **there is no value without equity**, so an intentional focus on equity is essential from the beginning and throughout the process of health technology assessment. Figure 2 reflects the adaptation of our original Framework to reflect the cyclic process and the importance of people, processes, and communications to building an environment of trust and equity that supports measurement of value.

Key informants called out that equity in processes is essential to achieve equity in outcomes. In practical terms, informants noted that there must be equity in who does the work of value assessment, and equity should be integrated throughout all value assessment processes. Examples of practical and intentional change for value/health technology assessors that were suggested by interviewees include:

- Make time and invest to build authentic and meaningful partnerships with patients and communities;
- Clearly prioritize lived-experience expertise in leadership, design, and execution;
- Increase representation from marginalized communities, both among value assessment practitioners and in quantitative and qualitative data used within assessments;
- Define and invest in equity expertise as an essential skillset for researchers and others involved in health technology assessment; and
- Be consistently transparent about biases and gaps in decision-making, data, methods and algorithms used in health technology assessments.

Additional areas key informants called out as needing further exploration and development included:

- Combining quantitative and qualitative data through mixed methods and conceptualizing value assessments by identifying differences across populations, understanding health disparities, and acknowledging social, environmental, and historical factors driving health inequities.
- Rethinking time frames within value assessments, including considering longer term outcomes, acknowledging differing views on value along the care journey, and updating assessments iteratively over time.
- Increasing transparency in who does the work of value assessment, who frames research and value questions, and whose perspectives are reflected within value assessments. Informants also emphasized transparency in reporting biases and missing data.

In the coming months, IVI will continue to develop and refine its Framework, identifying promising practices, and developing actionable guidance for equity-centered value assessment. We are grateful for the time and thoughtful insight from key informants and our steering committee, who are deeply committed to equity in their own professional and personal journeys.



# APPENDIX

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## Appendix 1. List of Key Informants Interviewed

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

15. *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 also ask informant:

- *Is there anything 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.*

### Appendix 3. Figures

Figure 1. Visual Representation: Framework for Equitable Value Assessment

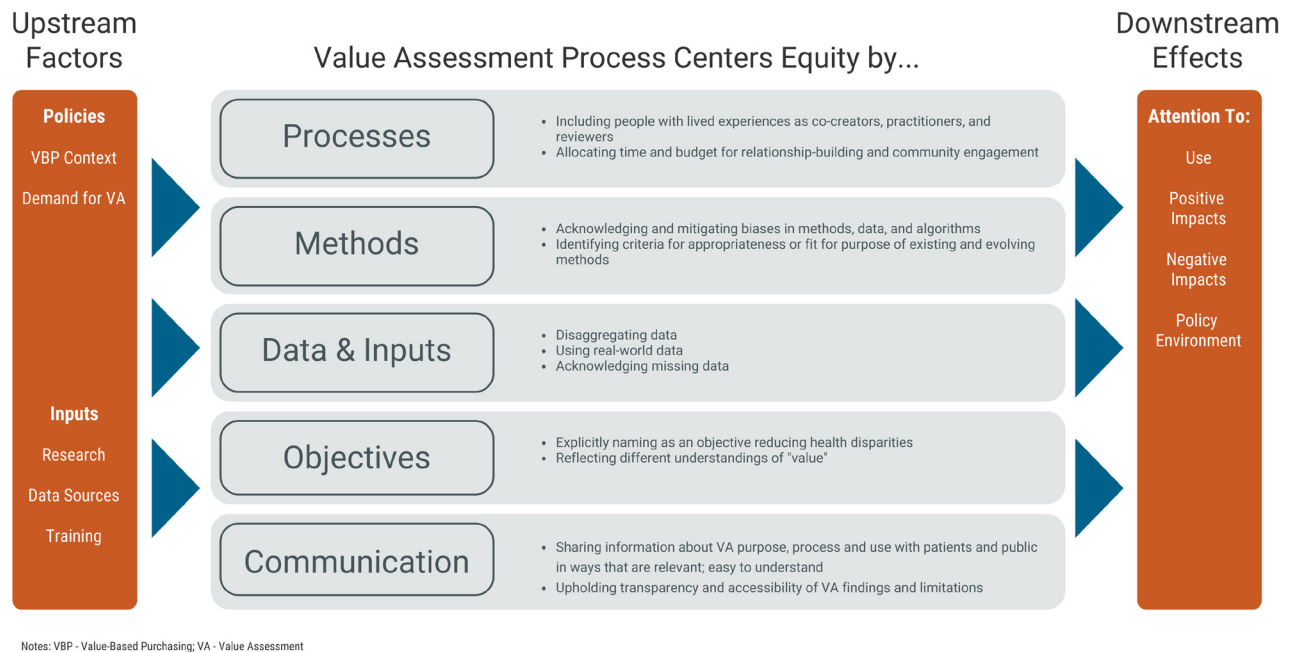
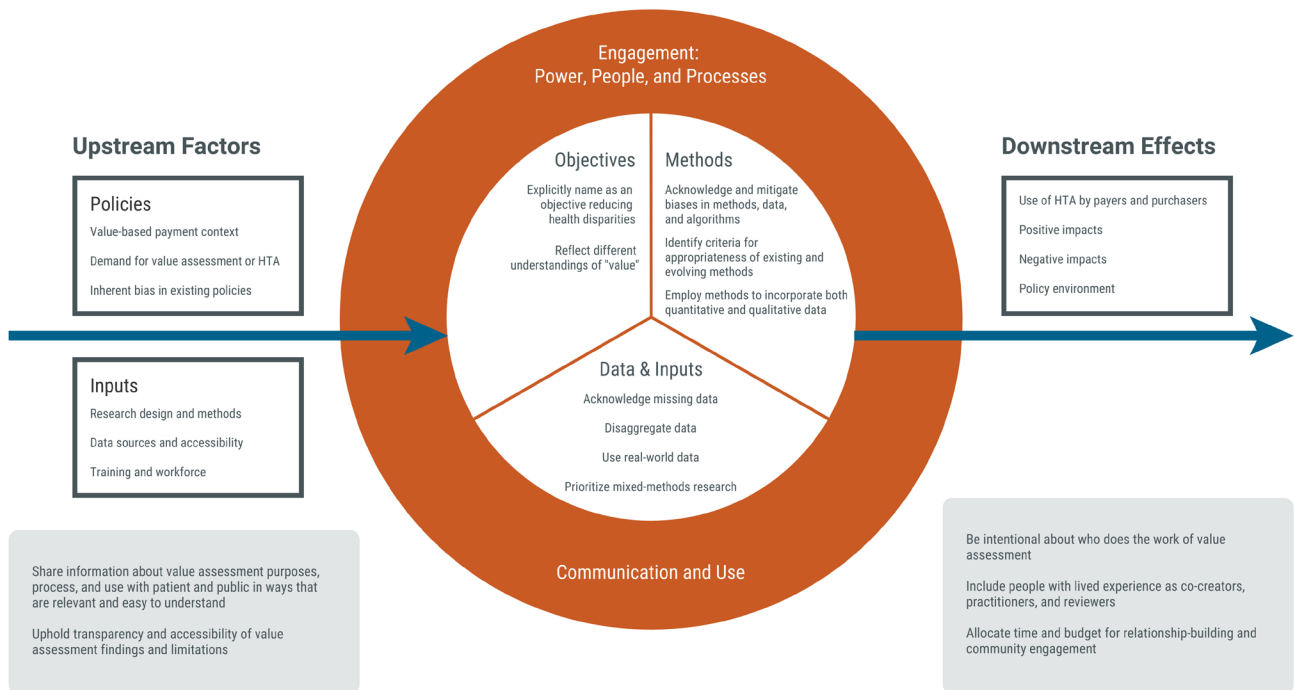


Figure 2. Revision of Framework, Accounting for Key Informant Insights

### Health Technology Assessment Centers Equity Through...





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