A Dialogue on Value Assessment that Meets the Needs of Patients and Employers

June 2021
Acknowledgements
This report was prepared by the National Health Council and National Alliance on Healthcare Purchaser Coalitions.

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- Co-Chair: John R. Miller, Executive Director, MidAtlantic Business Group on Health
- Co-Chair: Patrick Stone, Former Vice President, Advocacy and Government Relations, National Psoriasis Foundation
- Jennifer Bright, MPA, Executive Director, Innovation and Value Initiative
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- Miriam Goldstein, JD, Policy Director, Hemophilia Federation of America
- David Johnson, Vice President and Senior Consultant, Segal
- Janet McNichol, HR Director, American Speech-Language-Hearing Association
- Mary Richards, President & CEO, Amputee Coalition

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Funding: This project was supported by the Innovation and Value Initiative (IVI). The mission of IVI is to advance the science, practice, and use of value assessment in health care to make it more meaningful to those who receive, provide, and pay for care. Principles of the IVI value assessment approach are patient-centricity, transparency, and open-source modeling.

Table of Contents

Acknowledgements ........................................................................................................................................ 2

Introduction .................................................................................................................................................. 4

Project Overview .......................................................................................................................................... 5

Roundtable One ........................................................................................................................................... 5

Roundtable Two ........................................................................................................................................... 6

Group Discussions ....................................................................................................................................... 6
  Group Discussion: Collaboration and Engagement Capacity ................................................................. 6
  Group Discussions: Value Assessment Scope & Data Inputs ................................................................. 7
  Group Discussion: Value Assessment Outputs ...................................................................................... 9

Future Directions .......................................................................................................................................... 9

Conclusion .................................................................................................................................................. 9

List of Appendices ..................................................................................................................................... 13

Appendix 1. Roundtable One Agenda ........................................................................................................ 14

Appendix 2. Roundtable One Participants ................................................................................................ 16

Appendix 3. Roundtable Two Agenda ....................................................................................................... 18

Appendix 4. Roundtable Two Participants ............................................................................................... 20

Appendix 5. Roundtable One Pre-Survey ................................................................................................. 22

Appendix 6. Core Questions ...................................................................................................................... 27
**Introduction**

Value assessment (VA) is a process that brings together stakeholders to evaluate the clinical, economic, social, organizational, and ethical issues for a specific health intervention or health technology (such as a drug). VA does not refer to a specific methodology, but generally includes comparisons of clinical evidence, health care costs, and social and ethical impacts on the health care system and the lives of patients.\(^1\)

A value framework is a blueprint describing the methodology by a specific organization to conduct a value assessment.\(^2\) In response to rising health care costs and a desire to allocate limited resources to areas with the highest value, we have seen a proliferation of value frameworks emerging from professional societies, non-profits, and academic institutions,\(^3\)–\(^6\) many modeled after health technology assessment (HTA) outside the US. The development of such frameworks and their use in value assessment is intended to provide recommendations to guide decision-making by balancing costs with benefits and risks to patients.

In the US, the primary audience of VA recommendations are often health plans, insurers, and pharmacy benefit managers. These entities are typically third parties acting on behalf of taxpayers, employers, and ultimately patients. While most stakeholders welcome a dialogue on value, a common criticism of existing value frameworks is that some stakeholders’ priorities and related data inputs to capture those priorities have not been adequately incorporated into the frameworks and their resulting assessments.\(^3\)–\(^5\)\(^,\)\(^7\) Therefore, recommendations stemming from a VA may be inadequate to inform the complex decisions confronting clinicians, patients, and payers.\(^3\) Addressing the information needs of different stakeholders presents a significant challenge to value assessment bodies.\(^8\)

Two perspectives traditionally underrepresented in VA are those of patients and employers.\(^9\) Patients often express experiences with disease and desired outcomes that are not reflected in the available clinical trial data routinely used in VA. They also are concerned with increasing premiums and other out-of-pocket expenses, and they directly experience coverage and utilization management barriers.\(^10\) Employers are key health care purchasers in the US. They have a vested interest in balancing costs and promoting access to care, while ensuring employees have access to timely treatments most likely to meet individual employee and/or family needs.\(^11\)–\(^13\) Since many patients are also employees or the family members of employees, and their health insurance is an employee benefit, we sought to explore if these two stakeholder groups have similar perspectives on value assessment, including which data inputs are important when conducting VA to meet decision needs.

Recommendations on conducting value assessment published independently by the National Health Council (NHC), a coalition representing patients with chronic diseases and disabilities, and the National Alliance (National Alliance) of Healthcare Purchaser Coalitions, which represents purchasers including employers, indicates alignment between the two stakeholder groups exists. For example, the NHC’s Patient-Centered Value Rubric and the National Alliance’s Employer RX Value Framework each recommend inclusion more patient-centered outcomes, real-world evidence, and out-of-pocket costs.\(^11\)\(^,\)\(^14\) While employers and patients may share similar perspectives on the data inputs that should be included in value assessment, it should also be noted there is likely divergence in perspectives because employers and patients rely on VA to inform different decisions (employee health benefits vs. personal care decisions).

Thus, the NHC, in partnership with the National Alliance, assembled stakeholders from patient, employer, and VA organizations and facilitated two Roundtable dialogues to:
- Explore alignment between patient and employer evidence needs related to value,
- Identify what questions patients and employers want researchers to consider as a part of VA for a specific health care treatment or service (e.g., drug, device, surgery), and
- Discuss opportunities for VA approaches to better reflect both patient and employer end-user views, inputs, and needs.

The purpose of this white paper is to describe the Roundtable discussions between patient and employer representatives regarding: 1) alignment between patients and employers regarding value assessment, including opportunities for collaboration; and 2) recommendations for improving the relevance of value assessment to patients and employers.

**Project Overview**

The NHC and National Alliance hosted two virtual Roundtables in fall 2020. The Roundtables are described briefly below. See Appendices 1-6 for agendas, participant lists, and the pre-Roundtable survey questionnaire. The structure and content of the Roundtables was guided and developed by the Advisory Board (see Acknowledgements). Advisory Board members contributed to development of all materials and moderated discussions at the two Roundtables.

**Roundtable One**

The first Roundtable, held on October 27, 2020, primarily included representatives from the patient and employer communities [Patient community (n=10); employer/health care purchasers (n=11); and labor organization (n=1)]. Representatives from value assessment bodies (n=3), academia (n=1), and the biopharmaceutical industry (n=1) participated as observers and were invited to answer specific questions on occasion as directed to them throughout the Roundtable. Roundtable One objectives were to:

- Explore alignment between patient and employer evidence needs related to value.
- Identify opportunities for VA approaches to better reflect both patient and employer end-user views, inputs, and needs.

To ensure all participants were able to meaningfully participate, they were invited to join an optional pre-Roundtable introductory training, which was also pre-recorded and made available on-demand. Optional pre-reads distributed via email in advance of the Roundtable included an introductory [VA terminology infographic](https://example.com) and the [National Alliance Employer Rx Value Framework Report](https://example.com).

In addition, patients and employers completed a survey in advance of Roundtable One. The purpose of the survey was to solicit feedback on questions they would like third parties, often insurers or independent research bodies, to consider on their behalf as they assess the value of a specific health care treatment or service. The survey questions were co-developed by the project advisory board and project team.
Roundtable Two
On November 13, 2020, a follow-up Roundtable was held to identify tangible and feasible strategies to improve upon current approaches. Representatives from the patient, employer, and VA communities all participated [Patient community (n=9), employer/health care purchaser (n=10), VA (n=6), academia (n=2), and biopharmaceutical industry (n=2)].

The objectives of the second Roundtable were to:
- Review the set of questions developed during the first Roundtable regarding what researchers should consider as part of VA for a specific health care treatment or service.
- Identify strategies to improve upon current approaches to address these questions.
- Discuss opportunities for VA approaches to better reflect both patient and employer end-user views, inputs, and needs.

Group Discussions
Key comments, suggestions, and takeaways that emerged are summarized here by discussion topic:
- Collaboration and Engagement Capacity
- Value Assessment Scope & Data Inputs
- Value Assessment Outputs

Group Discussion: Collaboration and Engagement Capacity

**Challenge 1.** There is limited capacity for employers to engage on disease and product-specific value assessments (VAs).

The focus for value assessment is typically a specific drug or therapeutic area. Although disease-specific patient groups prioritize engagement on decisions at this level, in most cases, employers do not have the resources or need to engage at the disease-specific level. Instead, they rely on benefit consultants, pharmacy benefit managers, and health insurers to assist in treatment-specific decision making.

In general, Roundtable participants did not see a need for employers to engage in disease-specific value assessments, but agreed that organizations, such as the National Alliance or its regional coalition members, should have opportunities to engage in broader discussions related to value assessment such as: methods, data inputs, and communication.

**Challenge 2.** There is limited capacity for employers and patients to engage on discussions around value and coverage.
Many employer and patient representative participants noted this was their first opportunity to engage with one another, and both groups thought it was an important learning opportunity. In general, neither of these organizations has the capacity to engage each other on an individual basis; however, regional coalitions can bring a number of their member employers together to engage various patient groups when there is mutual interest. Maintaining open lines of communication between patient groups and employers, for example, through engagement with regional coalitions can be an important collaborative avenue to build over time.

One area where participants believed collaboration could be particularly helpful is in raising awareness when treatment access challenges arise. Employers are cognizant that more senior employees may be more likely to raise access challenges they are experiencing to human-resource staff, while less senior staff may not be aware they can do so or feel comfortable doing so. One solution proposed by participants is an “access alert template” that could be filled in by patient organizations when they become aware of access challenges experienced by patients. The completed template would describe the scope and implications on patients of current access challenges. The completed template could be disseminated via regional coalitions through email alerts, periodic meetings, or a website. Participants believed this type of mechanism could help to raise awareness more equitably about access challenges experienced by patients.

Employer representatives stated they would be interested in engaging patient groups on disease-specific topics to learn more about patient-relevant data they may have access to through patient registries or other sources. For example, if an employer notes that they have high costs due to patient treatment options or issues with patient access, they might seek a dialogue with one or more group(s) focused on that specific disease to learn more about disease experience, patient needs and preferences, and access issues.

Group Discussions: Value Assessment Scope & Data Inputs

**Challenge 3.** Employers and patients rely on third parties to develop evidence, synthesize and evaluate it, and make coverage decisions on their behalf. Due to limited capacity to engage and limited expertise in these areas, employer and patient perspectives on value are often not adequately considered.

For patients, value assessment and coverage decisions impact both their ability to live a full life and their out-of-pocket costs. For employers, coverage decisions impact employee retention, performance (i.e., productivity), and total health care costs.

**Patient and Employer participants developed and refined the following set of questions** for third parties to consider as they assess the value of a treatment/health service:

- What is the intended disease it would be used for? How common is that disease?
- What does the treatment/health service do (i.e., benefits)? What is the best outcome? Is that outcome important to patients/people with this condition?
Does it work differently in different people? Does it work particularly well/poorly in certain groups of people? Which subgroups?

What are the risks or side effects? How common are they?

What are the alternatives? How does it compare to alternatives? If they don't do/take this, what are the outcomes?

How complex is it to use the treatment? Is travel required?

How long does it take to work? Are there appreciable differences in short-term vs. longer-term impact on the condition being treated or other related conditions?

Could an individual's privacy be impacted or infringed?

What is the cost to patients?

How much does it cost? What is the total cost? Cost offsets?

Are there additional services or treatments that impact how well it works? What is the burden of those services/treatments?

Will time off from work be required (by either the patient or a caregiver)? If so, how much?

What are other employers doing in terms of covering this treatment/health service under their health plans?

* It should be noted that some of these questions are addressed by existing value frameworks, while others are not.

The list is not intended to reflect all the questions or data inputs important to patients and/or employers but reflects a set of questions with broad agreement of importance across stakeholder groups. The list can serve as a checklist to:

1) Ensure questions important to employers and patients are considered when creating value frameworks and conducting a value assessment; and

2) Inform data collection during clinical research, including post-marketing studies.

Appendix 2 lists the original set of questions following refinement by the Advisory Board and reflects how the aforementioned questions might be framed from the perspectives of employers versus patients.

**Challenge 4.** Value assessment does not include many of the data inputs important to patients and/or employers. In many cases, those data are not systematically collected.

Employers and patients each emphasized the importance of considering “costs” holistically when assessing value. For example, out-of-pocket costs, total cost, and presenteeism/productivity costs are very important to patients and employers. Participants acknowledged a barrier to including these costs in health economic models due to data fragmentation and/or data not currently systematically collected across diseases and settings. There was a collective desire among participants to overcome this data gap through earlier agreement on which health outcomes and other impacts should be measured in clinical research and post-marketing studies.

In addition to capturing these data during clinical trials, participants are comfortable with high-quality, real-world data being used to complement clinical trial data. In many cases employers are asking for real-world data as well as additional metrics from insurers and benefits consultants to inform their decision-making. While value assessors have
sometimes been hesitant to use real-world data, participants noted that they try to rely on real-world data for evidence when available.

**Group Discussion: Value Assessment Outputs**

**Challenge 5.** Evidence, including value assessments, to inform purchasing decisions is not efficiently communicated to purchasers.

Participants described the “many-to-many” relationships that make it very difficult to access all pertinent information in one place. There are different consultants and service providers for different information. This challenge is heightened as employers must also navigate potential conflicts of interest arising with intermediaries, whose profits may rely on increased sales of such information or of a specific analytic product.

**Participants suggested it would be helpful if an intermediary could create a one-stop shop for information needed by employers to make decisions.** Important attributes include:
- Data on patient insights, patient preferences for treatment attributes, or outcomes.
- Tools where data inputs could be customized (e.g., similar to IVI’s open-source models, ICER Analytics).
- Provide sample contract language (e.g., pharmacy benefit contract language).
- Consultant expertise on value assessment and insurance design.

**Future Directions**

A significant barrier to high-quality value assessment is the misalignment between data currently collected versus what is really needed and/or what really matters. For example, the lack of high-quality data important to patients and employers, including patient-centered health outcomes and other impacts such as workplace performance and financial toxicity or distress. Participants considered short-term fixes, including:
- What data could employers/health care purchasers contribute to value assessment?
- What data could patient organizations and advocacy groups contribute to value assessment?

There was broad agreement among participants that a more fundamental shift is needed, such as having a more standardized set of impacts for patient outcomes. An example provided at Roundtable Two was “patient-centered core impact sets” (PC-CIS). PC-CIS refers to an agreed upon, standardized set of impacts (including but not limited to health outcomes) on a patient’s daily life that should be gathered and reported at a minimum in research in specific areas of health or health care.

**Conclusion**

The Roundtables provided a remarkable forum for patient group, employer, and value-assessor representatives to engage in meaningful discussion with one another on what is
important to them regarding value assessment, including alignment in perspectives and needs, and strategies to improve current approaches. Those participating commented on how rare it was for them to interact and that they appreciated the opportunity to do so and valued the engagement. Participants highlighted discordance between evidence generated and evidence needed as one of the primary barriers. Inviting participants from each of these stakeholder groups into the value-assessment discourse is key to ensuring that approaches are relevant for decision-maker needs. The discussions highlighted the questions patients and employers want researchers to consider when data are collected in clinical research and, subsequently, included as part of value assessment for a specific health care treatment or service.
References


List of Appendices

1. Roundtable One Agenda
2. Roundtable One Participant List
3. Roundtable Two Agenda
4. Roundtable Two Participant List
5. Roundtable One Pre-Survey
6. Core Questions Table
Appendix 1. Roundtable One Agenda

Patient and Employer Roundtable on Value
October 27, 2020, 2:00-5:00 p.m. ET

This program is supported by a grant from the Innovation and Value Initiative, a non-profit research organization dedicated to improving the science and practice of value assessment.

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>1:30-1:50 p.m.</td>
<td>An Introduction to Value Assessment (Optional Pre-Meeting Session):</td>
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<tr>
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<td>• Joey Mattingly, PhD, PharmD, MBA, Associate Professor of Pharmaceutical Health Services Research, University of Maryland School of Pharmacy, will address the question:</td>
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<td></td>
<td>o What is value assessment? Who conducts value assessment? What evidence goes into a value assessment? What medical services undergo value assessment?</td>
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<td>o Who uses outputs of a value assessment? What decisions can it impact?</td>
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<td>1:50-2:00 p.m.</td>
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<td>2:00-2:20 p.m.</td>
<td>Welcome and Introductions</td>
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<td></td>
<td>• Michael Thompson, President &amp; CEO, National Alliance of Healthcare Purchaser Coalitions</td>
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<td></td>
<td>• Eleanor M. Perfetto, PhD, MS, Interim CEO &amp; Executive Vice President, Strategic Initiatives, National Health Council</td>
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<td>2:20-2:50 p.m.</td>
<td>Session 1: Exploring Alignment Between Patient and Employer Perspectives Value</td>
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<td>Presentation and Group Discussion</td>
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<td>Moderator: Elisabeth M. Oehrlein, PhD, MS, Senior Director, Research &amp; Programs, National Health Council</td>
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<td>• Which health services (e.g., drugs, devices, surgeries, preventive services) should we conduct a value assessment for?</td>
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<td>• What questions do patients and employers want third parties (e.g., insurers or independent research bodies) to consider as they assess the value of a specific health care treatment or service (e.g., drug, device, surgery)?</td>
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<tr>
<td>2:50-3:00 p.m.</td>
<td>Break</td>
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Note: This is a pre-recorded session. It is also available in advance of the Roundtable via this link.
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<th>Time</th>
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| 3:00-3:50 p.m. | **Session 2**: How Can We Better Address Patient and Employer Questions on Value?  
**Group Discussion**  
Moderator: **J. David Johnson**, MBA, Vice President, Senior Consultant, Segal  
The primary objective of this session is to hear from representatives from the patient and employer communities. A small group of Advisory Board members representing value assessment, academia, and industry are invited to answer questions or provide context.  
- Where are current approaches sufficient?  
- Where are the gaps? Are the gaps due to insufficient engagement, data infrastructure, methodology and/or how information is communicated?  
- How can we improve upon current approaches to addressing questions?  
- What questions should we be asking that we aren’t? |
| 3:50-4:00 p.m. | Break                                                                  |
| 4:00-4:40 p.m. | **Session 3**: Developing Feasible Actions and Next Steps  
**Group Discussion**  
Moderator: **Margaret Rehayem**, Vice President of Initiatives & Programs, National Alliance of Healthcare Purchaser Coalitions  
In this session, we will take our group dialogue to the next level and begin to outline some tangible, feasible actions that can be taken to improve value assessment decision making.  
- What areas should we address first?  
- Who is responsible? Whose purview/control?  
- What are the roles of different stakeholders? Who leads?  
- What does tangible and feasible look like? |
| 4:40 – 5:00 p.m. | Wrap Up and Adjourn                                                   |
Appendix 2. Roundtable One Participants

Patient Community
- **Cat Davis Ahmed, MBA**, Vice President, Policy and Outreach, The FH Foundation
- **Wendy Smith Begolka, MBS**, Vice President, Scientific and Clinical Affairs, National Eczema Association
- **Miriam Goldstein, JD**, Policy Director, Hemophilia Federation of America
- **Jason Harris**, Director, Public Policy, Lupus Foundation of America
- **Anna Hyde**, Vice President, Advocacy and Access, Arthritis Foundation
- **Kenny Mendez, MBA**, President and Chief Executive Officer, Asthma and Allergy Foundation of America
- **Rachel Patterson, MPA**, Senior Director, Government Relations & Advocacy, Epilepsy Foundation
- **Mary Richards**, President & Chief Executive Officer, Amputee Coalition
- **Patrick Stone**, Vice President, Advocacy and Government Relations, National Psoriasis Foundation
- **Patrick Wildman**, Vice President, Advocacy and Government Relations, Lupus Foundation of America

Employer Community
- **Kim Dwyer**, former Vice President, Benefits, Advocate Health Care
- **Pamela Hannon, MBA, CEBS**, Retirement & Healthcare Leader, GE
- **J. David Johnson, MBA**, Vice President and Senior Consultant, Segal
- **Cheryl Larson**, President & Chief Executive Officer, Midwest Business Group on Health
- **Janet McNichol, SPHR, CAE**, HR Director, American Speech–Language–Hearing Association
- **Carole Mendoza, MBA**, former Director, Global Health Benefits and Wellness Strategy, IBM
- **John R. Miller**, Executive Director, MidAtlantic Business Group on Health
- **Sherri Samuels-Fuerst, MILR**, Vice President, Total Rewards, Sargento Foods Inc.
- **Bruce Sherman, MD, FCCP, FACOEM**, Chief Medical Officer, National Alliance of Healthcare Purchaser Coalitions, Medical Director, Population Health Management, RightOpt, Conduent HR Services
- **Tom Sondergeld, MHA**, former Vice President of HRIS, Global Benefits & Mobility for Walgreens Boots Alliance, Inc.

Labor Community
- **John DeVirgiliis**, Administrator for the Service Employees International Union (SEIU) Health & Welfare Fund

Observers
- **Jennifer Bright, MPA**, Executive Director, Innovation and Value Initiative
- **Sarah Emond, MPP**, Executive Vice President & Chief Operating Officer, ICER
- **Joey Mattingly, PhD, PharmD, MBA**, Associate Professor of Pharmaceutical Health Services Research, University of Maryland School of Pharmacy
• Kimberly Westrich, MA, Vice President, Health Services Research, National Pharmaceutical Council
• Richard Xie, PhD, MA, HEOR Research Manager, Innovation and Value Initiative

National Alliance Staff
• Margaret Rehayem, Vice President, National Alliance
• Juan Hidalgo, MBA, Manager, Project, Financial, and Relationship, National Alliance

NHC Staff
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• Eric Gascho, Vice President, Policy and Government Affairs, National Health Council
• Elisabeth M. Oehrlein, PhD, MS, Senior Director, Research and Programs, National Health Council
• Jennifer Dexter, Director, Policy, National Health Council
• Silke Schoch, Manager, Research and Programs, National Health Council
• Ashley Cheng, Associate, Programs, National Health Council
# Appendix 3. Roundtable Two Agenda

## Patient and Employer Roundtable on Value Assessment

November 13, 2020, 10:00 a.m. - 1:00 p.m. ET

*This program is supported by a grant from the Innovation and Value Initiative (IVI), a non-profit research organization dedicated to improving the science and practice of value assessment*

The goals of this Roundtable discussion are to:

- Review a set of questions developed by patients and employers/health care purchasers describing what they would like researchers to consider as part of value assessment (VA) for a specific health care treatment or service (e.g., drug, device, surgery).
- Identify strategies to improve upon current approaches to addressing these questions.
- Discuss opportunities for value assessment approaches to better reflect both patient and employer end-user views, inputs, and needs.

### Schedule

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tr>
<td>9:50-10:00</td>
<td>Open line/audio check</td>
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<tr>
<td>10:00-10:15</td>
<td><strong>Welcome and Introductions</strong></td>
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<tr>
<td></td>
<td>- <strong>Michael Thompson</strong>, President &amp; CEO, National Alliance of Healthcare Purchaser Coalitions</td>
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<td></td>
<td>- <strong>Eleanor M. Perfetto</strong>, PhD, MS, Interim CEO &amp; Executive Vice President, Strategic Initiatives, National Health Council</td>
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<td>10:15-10:35</td>
<td><strong>Session 1: Exploring Alignment Between Patient and Employer Perspectives on Value: Recap of Roundtable 1</strong></td>
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<td>Summarize key takeaways from Roundtable 1 where patients and employers met to discuss perspectives and alignment on evidence needs related to value assessment.</td>
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<td>- <strong>Elisabeth M. Oehrlein</strong>, PhD, MS, Senior Director, Research and Programs, National Health Council</td>
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<td>- <strong>Margaret Rehayem</strong>, MA, Vice President, National Alliance of Healthcare Purchaser Coalitions</td>
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<td>10:35-11:10</td>
<td><strong>Session 2: Engaging Patients and Employers During a Value Assessment to Get their Questions Answered</strong></td>
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<td>Identify strategies to improve upon current approaches to address topics discussed during Roundtable 1.</td>
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<tr>
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<td>Moderator: <strong>John R. Miller</strong>, Executive Director, MidAtlantic Business Group on Health</td>
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Group Discussion
- If we can make one change, what would it be? What would be a meaningful step forward from both community’s perspectives?
- How would employers like to be engaged? What can the value assessment community do to support engagement? What can employers do to be prepared for engagement?
- How can we leverage what has been learned from current approaches?

11:10-11:20 a.m. Break

11:20 a.m. - 12:20 p.m. Session 3: Reflections from Stakeholders: What’s Possible?
Reflect upon strategies identified in Session 2 and outline tangible, feasible actions that can be taken by stakeholders to enhance value assessment in the near-term, longer-term.

Remarks & Group Discussion
Moderator: Patrick Stone, Vice President, Advocacy and Government Relations, National Psoriasis Foundation
- Value assessment: Jennifer Bright, MPA, Executive Director, Innovation and Value Initiative (IVI)
- Value assessment: Sarah Emond, MPP, Executive Vice President & Chief Operating Officer, Institute for Clinical and Economic Review (ICER)
- Academia: Joey Mattingly, PhD, PharmD, MBA Associate Professor of Pharmaceutical Health Services Research, University of Maryland
- Industry: Kimberly Westrich, MA, Vice President, Health Services Research, National Pharmaceutical Council (NPC)

12:20-12:25 p.m. Break

12:25-12:50 p.m. Session 4: Planning for Next Steps
Open discussion to prioritize tangible, feasible actions and identify immediate and longer-term next steps.

Group Discussion
- Moderator: Eleanor M. Perfetto, PhD, MS, Interim CEO & Executive Vice President, Strategic Initiatives, National Health Council

12:50 – 1:00 p.m. Wrap Up and Adjourn
- Michael Thompson, President & CEO, National Alliance of Healthcare Purchaser Coalitions
Appendix 4. Roundtable Two Participants

**Patient Community**
- **Wendy Smith Begolka, MBS**, Vice President, Scientific and Clinical Affairs, National Eczema Association
- **Miriam Goldstein, JD**, Policy Director, Hemophilia Federation of America
- **Jason Harris**, Director, Public Policy, Lupus Foundation of America
- **Anna Hyde**, Vice President, Advocacy and Access, Arthritis Foundation
- **Kenny Mendez, MBA**, President and Chief Executive Officer, Asthma and Allergy Foundation of America
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- **Patrick Wildman**, Vice President, Advocacy and Government Relations, Lupus Foundation of America

**Employer Community**
- **Kim Dwyer**, former Vice President, Benefits, Advocate Health Care
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- **Tom Sondergeld, MHA**, former Vice President of HRIS, Global Benefits & Mobility for Walgreens Boots Alliance, Inc.

**Value Assessor Community**
- **Jennifer Bright, MPA**, Executive Director, Innovation and Value Initiative
- **J. Samantha Dougherty, PhD**, Senior Director of Policy and Research, PhRMA
- **Sarah Emond, MPP**, Executive Vice President & Chief Operating Officer, ICER
- **Terrell Johnson, MPA**, Manager, Policy & Advocacy, National Comprehensive Cancer Network
- **Joey Mattingly, PhD, PharmD, MBA**, Associate Professor of Pharmaceutical Health Services Research, University of Maryland School of Pharmacy
- **Rupesh Panchal, PharmD, RPh**, Postdoctoral Fellow, Health Economics and Outcomes Research, University of Utah Health
• Alyssa Schatz, MSW, Senior Director of Policy & Advocacy, National Comprehensive Cancer Network
• Surya Singh, MD, President, Singh Healthcare Advisors, Attending Physician at Brigham and Women's/Faulkner Hospitals
• Kimberly Westrich, MA, Vice President, Health Services Research, National Pharmaceutical Council
• Richard Xie, PhD, MA, HEOR Research Manager, Innovation and Value Initiative

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• Jennifer Dexter, Director, Policy, National Health Council
• Silke Schoch, Manager, Research and Programs, National Health Council
• Ashley Cheng, Associate, Programs, National Health Council
Appendix 5. Roundtable One Pre-Survey

Patient and Employer Roundtable on Value Assessment: Pre-Survey

The purpose of this survey is to identify what questions patients and employers would like third parties, often insurers or independent research bodies, to consider as they assess the value of a specific health care treatment or service (e.g., drug, device, surgery). We will discuss the survey results during our upcoming Roundtable. Please note, individual results will not be shared, only aggregate results.

*1. What stakeholder group are you representing during the Roundtable?

- [ ] Patient
- [ ] Employer
- [ ] Consultant/medical director

*2. How important is it to you that third parties (e.g., insurers, value assessment research organizations) consider these questions as they assess the value of a treatment/health service on your behalf?

Note: This list of questions was developed by the project team and the Advisory Board. The premise is that patients and employers have many of the same questions about a treatment/intervention, but frame the questions slightly differently based on their own needs/perspective. For more information, click here.

<table>
<thead>
<tr>
<th></th>
<th>Very important</th>
<th>Important</th>
<th>Somewhat important</th>
<th>Not very important</th>
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<tbody>
<tr>
<td>What does it do (i.e., benefits)? Is that important?</td>
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<td>What are the risks? How common are they?</td>
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<td>What are the alternatives? How does it compare to alternatives?</td>
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<td>What is the intended disease it would be used for? How common is that disease?</td>
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<td>Does it work differently in different people? Does it work particularly well/poorly in certain groups of people? Which subgroups?</td>
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<td>How much does it cost?</td>
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<td>How complex is it to use? Is travel required?</td>
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<td>Are there additional questions you would add to this list?</td>
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<td><strong>Will time off from work be required? If so, how much?</strong></td>
<td>Very important</td>
<td>Important</td>
<td>Somewhat important</td>
<td>Not very important</td>
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<tr>
<td><strong>Are there additional services or treatments that impact how well it works? What is the burden of those services/treatments?</strong></td>
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<td><strong>How long does it take to work?</strong></td>
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<td><strong>Are there privacy concerns (e.g., wellness apps, digital therapeutics)?</strong></td>
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3. What are the top five most important questions that third parties (e.g., insurers, value assessment research organizations) should consider as they assess the value of a treatment/health service on your behalf? (#1 is most important)

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<th>#1</th>
<th>#2</th>
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<th>#5</th>
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<tbody>
<tr>
<td>What does it do (i.e., benefits)? Is that important?</td>
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<tr>
<td>What are the risks? How common are they?</td>
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<tr>
<td>What are the alternatives? How does it compare to alternatives?</td>
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<tr>
<td>What is the intended disease it would be used for? How common is that disease?</td>
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<td>Does it work differently in different people? Does it work particularly well/poorly in certain groups of people? Which subgroups?</td>
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<tr>
<td>How much does it cost?</td>
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<tr>
<td>How complex is it to use? Is travel required?</td>
<td>☐</td>
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<tr>
<td>Will time off from work be required? If so, how much?</td>
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<tr>
<td>Are there additional services or treatments that impact how well it works? What is the burden of those services/treatments?</td>
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<tr>
<td>How long does it take to work? As compared to other treatments?</td>
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<tr>
<td>Are there privacy concerns (e.g., wellness apps, digital therapeutics)?</td>
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Comments?
4. Provide a brief perspective on how current approaches to value assessment should be enhanced to produce findings that are more applicable to patient and employer information needs?

5. What are one to two specific, tangible, feasible actions that could be taken on the part of researchers/brokers/value assessors to improve usefulness of VA for decision makers?

6. Other comments/ideas we should consider during the Roundtable?
# Appendix 6. Core Questions

<table>
<thead>
<tr>
<th>Core Questions*</th>
<th>Employer</th>
<th>Patient</th>
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</thead>
<tbody>
<tr>
<td><em>in regard to a particular new health service/treatment</em></td>
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</table>

## What does it do (i.e., benefits)? Is that important?
- Does it keep my workers healthy? Their family?
- Will it help my workers get better? Their family member?
- Will it keep me healthy? My family?
- Will it help me get better? My family member?

## What are the risks? How common are they?
- What are the risks? How do those risks compare to the alternatives?
- Am I comfortable with those risks?

## What are the alternatives? How does it compare to alternatives?
- Is it better than what I already cover? How so?
- How do costs, convenience, and other variables differ?
- Is it better than what I already receive/take? How so?
- How do costs, convenience, and other variables differ?

## What is the intended disease it would be used for? How common is that disease?
- Who will access this health care service? How prevalent is a condition or disease to my workforce population?
- Is this an option for me? Is this an option for my family? My children?

## Does it work differently in different people? Does it work particularly well/poorly in certain groups of people? Which subgroups?
- How well will it work in my employees? How likely is it to work among my employees?
- Does it work well in people like me?

## How much does it cost?
- How much will it cost me? How will that impact premiums? How much will it cost my employee? Can I afford it? Can they afford it?
- How much will it cost me? How will that impact my out-of-pocket costs? Can I afford it?
<table>
<thead>
<tr>
<th>Question</th>
<th>Sub-questions</th>
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<tbody>
<tr>
<td><strong>How complex is it to use?</strong></td>
<td>• Are my employees likely to be adherent?</td>
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<td></td>
<td>• How does that fit into my day-to-day life? Is that realistic?</td>
</tr>
<tr>
<td><strong>Will time off from work be required? Is travel required? If so, how much?</strong></td>
<td>• What is the impact on presenteeism? How does that fit in with other benefits?</td>
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<td>• How does that impact my employment? Do I have sick leave to cover that time?</td>
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<tr>
<td><strong>Are there additional services or treatments that impact how well it works? What is the burden of those services/treatments?</strong></td>
<td>• Do I already cover those? How much will they cost? What is the burden of those services on my employees?</td>
</tr>
<tr>
<td></td>
<td>• How much do those services/treatments cost? What is the burden of those services on my employees? If it is an app, will my employer have access to data stemming from that app?</td>
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<tr>
<td><strong>How long does it take to work?</strong></td>
<td>• How long until it works?</td>
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<tr>
<td></td>
<td>• How long until it works? Will it help me attend an event important to me? Get back to normal life?</td>
</tr>
<tr>
<td><strong>Are there privacy concerns (e.g., wellness apps, digital therapeutics)?</strong></td>
<td>• Who will have access to the data? Would my employee be comfortable with that?</td>
</tr>
<tr>
<td></td>
<td>• Who will have access to the data? Am I comfortable with that?</td>
</tr>
</tbody>
</table>