

## Patient Partnership/Co-Leadership Checklist\*

In 2021, the Innovation and Value Initiative (IVI) published its [Principles for Value Assessment in the U.S.](#) to articulate how we put into practice the mission and goals of the organization. Our mission is to advance the science, practice, and use of patient-centered health technology assessment to support decisions that make healthcare more meaningful and equitable. Central to that mission is the principle that value assessment must **sustain authentic patient-centricity**.

IVI has identified four strategies to help put this principle into practice:

1. Patients and caregiver partners **co-lead the governance and strategic vision** of the organization. We welcome new and diverse voices in our work.
2. Lived experience and principles of health equity inform and have equal weight in all **research**, convenings, and thought leadership.
3. The **organization will commit resources** and support to ensure that patients and caregivers are full partners in all research and organizational initiatives.
4. The **organization will evaluate** the impacts of patient/caregiver partnership on the organization and on research findings and adjust our approach accordingly.

For each of these strategies, IVI, in partnership with its Patient Advisory Council, Board of Directors, and patient collaborators, has developed a series of publicly available tools to evaluate both the quality and the impact of our partnerships with patient advocates and caregivers in our organizational practices, research projects, and engagement activities.

By holding ourselves accountable to our principles and implementing concrete tools to improve our approach, we hope to learn from and collaborate with people with lived experience to ensure that our research, engagements, and organizational structure stay true to our principles of patient-centricity and set a benchmark for the VA/HTA field on principles and authentic practice of patient engagement.

### Sustain Authentic Patient-Centricity

IVI consistently establishes diverse patient partnerships in governance, priority setting, and the creation of economic models and healthcare research. Value assessors should lead robust research in patient preferences and data improvement to ensure HTA is authentic and relevant to patient experiences.

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\* Throughout our body of work, IVI uses the term “patients” and “caregivers” to refer to people who have health conditions or serious diseases or have cared for people who have experienced serious health conditions. We do not suggest that these individuals are their conditions. We intend to use this term with respect for individuals who have significant encounters with the healthcare system and the expertise and knowledge they bring to our common efforts to improve research and the healthcare system.

<b>Patients and Caregivers Co-Lead the Governance and Strategic Vision of the Organization</b>	
Require a minimum of two patient/caregiver representatives on the Board of Directors, Scientific Advisory Panel, and all IVI committees.	
Invite all patient/caregiver members to participate in the Patient Advisory Council and/or other leadership positions across the organization.	
Ensure that at least 30% of members are patient/caregiver representatives.	
Patient Advisory Council meets at least quarterly and ensure there is a liaison to the Board of Directors on the Patient Advisory Council.	
<b>Lived Experience Informs all Research and Practice</b>	
Include at least two patient/caregiver representatives on all research project teams.	
All multi-stakeholder advisory groups or committees include a minimum of a two to one ratio of patient/caregiver representatives.	
All projects develop a stakeholder engagement plan, with a focus on partnerships with patient/caregiver leaders.	
Ensure that diverse perspectives are included in partnerships and in research plans.	
Identify and ensure that health equity considerations are built into the research plan.	
All patient/caregiver partners and other stakeholder partners are given appropriate recognition for their contributions, including credit, co-authorship, or other acknowledgment.	
Contracts and SOWs with research partners include a component requiring appropriate recognition of patient/caregiver partners.	
All projects include patient/caregiver feedback components within the project plan steps, including adequate time for communication and review, with consideration of any accommodations that may be required.	
Ensure that project objectives include a practical or measurable benefit to patient/caregiver communities or are co-developed with patient/caregiver partners.	
Methods sections of any project deliverables includes discussion of how patient/caregiver perspectives were involved in the project, and how that involvement resulted in changes to the project, including research processes. <sup>1</sup>	
Per the Stakeholder Engagement Plan, review early results and findings with patient and caregiver partners before finalizing.	
Research findings are communicated in a way that is readily understandable to patients and caregivers, and include additional communications to explain technical findings when appropriate.	
Publicize patient leadership in all vehicles (newsletters, blogs, commentaries, research/scientific publications, presentations and posters, webinars, etc.).	

<sup>1</sup> Husereau D, Drummond M, Augustovski F, et al. Consolidated Health Economic Evaluation Reporting Standards 2022 (CHEERS 2022) Explanation and Elaboration: A Report of the ISPOR CHEERS II Good Practices Task Force. Value in Health. 2022;25(1):10-31.

The Organization Commits Resources to Patient/Caregiver Partnership	
Create dedicated roles and staff time committed to patient/caregiver engagement processes at the organization, including project and annual evaluations.	
Ensure that project budgets and staffing reflect the responsibility and time dedicated to patient/caregiver engagement.	
Require all project partners to complete a stakeholder engagement plan and demonstrate their practices to engage and include patients and caregivers in their work.	
Honoraria, stipends, and travel reimbursement are offered to patient/caregiver participants to reflect their contributions. <sup>2</sup>	
Travel, accessibility, and conference support offered to all patient/caregiver partners and members as appropriate.	
Evaluate and Learn from our Work	
Use evaluation surveys to request feedback from patient/caregiver and other stakeholder partners at the conclusion of each project.	
Conduct annual engagement survey with all members and partners to understand how IVI can improve its patient/caregiver engagement.	
Conduct an internal review of each project using the evaluation survey results to assess opportunities for process improvement.	
Conduct annual internal review of organization to evaluate achieving patient and caregiver partnership goals.	
Share evaluation results internally for process improvement. Define annual strategic goals and metrics based on this evaluation performance.	
Publish findings and recommendations for improvement to Board, committees, members, and public.	

<sup>2</sup> National Health Council Fair Market Value Calculator. Available: <https://nationalhealthcouncil.org/fair-market-value-calculator/>