

Partnering with Patients: Principles and Commitments

Executive Summary
Updated April 2020



*We know that the status quo – how we do value assessment **today** – doesn't have the patient front and center; we don't factor in the issues most important to real people when we assess the value of treatment. This is how we actively work to change that.*

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Overview

There is enormous pressure in the U.S. healthcare system to invest in high-quality, accessible care at an efficient cost. To drive this “triple aim,” numerous organizations have developed value frameworks to assess and compare the value of new therapies, particularly in pharmaceuticals. To date, these value frameworks have relied primarily on clinical trial data and real-world patient outcomes, or experience inputs are considered in the late stages of value assessments or as context rather than quantifiable factors. In the spring of 2018, the Innovation and Value Initiative (IVI) published its white paper, *Partnering with Patients*, to define our philosophy and approach to including patient perspectives at all stages of the design and execution of IVI research to improve the methods and tools used in value assessment. This document outlines the core principles identified in the white paper and articulates their continued relevance and importance to IVI’s future goals.

IVI’s mission includes a commitment to developing scientifically rigorous, patient-centered value assessment tools, including methods and models. Our approach aims to involve patients and patient organizations at the earliest stages of research design and throughout our stages of work, and to collaboratively define and consider the most relevant forms of patient input and data that represent value from their perspectives. We base our patient engagement approach on the principles identified in Figure 1.¹

¹ Partnering with Patients: Principles and Commitments, Version 1.0 (April 12, 2018). Innovation and Value Initiative.

Through intentional planning and practice, IVI seeks to demonstrate inclusion of patient perspectives in the inputs and outputs of our value assessment initiatives, and empower patients to participate in research design, execution, and evaluation. When we say that value assessment starts with the patient, we mean:

- **Value assessment must reflect the diversity in patient preferences and circumstance.** Not all patients are the same. Patients differ in their individual characteristics, personal preferences, progression of illness, and response to treatments. Value assessments must reflect this complexity in their models and designs.
- **Patients are equal partners in value assessment.** Patients and patient organizations must be equal partners in value assessment research to understand factors that define value for patients. IVI's Open-Source Value Project puts patients on equal footing with other stakeholders in the development of methods and models.
- **Value assessment methods must include patient experience.** What makes a treatment more or less valuable to a patient – the chances that it will work for them, the side effects, the impact on daily life, past experiences with treatments, and so on – are often left out of cost-effectiveness analysis and value assessment. IVI is working to identify these determinants of value, advance the scientific debate, and to build rigorous scientific methods needed for including them in value assessments.

Figure 1. Key Principles for Partnering with Patients



Partnership in Action: Progress to Date

To date, IVI has actively sought to partner with patient stakeholders in each of its core areas, including:

- **Strategic Decision Making.** IVI has created the Patient Advisory Council (PAC) to provide patient-led insight and evaluation to the organization and ensure that patient organizations are represented on our Board of Directors, Scientific Advisory Panel, and research committees. IVI has also worked with the wider patient organizations to raise awareness of our work.
- **Research Project Development and Planning.** Through its Value Blueprint Research brief series and other projects, IVI has conducted patient-driven research to define factors of patient experience and preference.
- **Open-Source Value Project (OSVP) Model Development.** IVI has engaged patient organizations in public review and comment for both the rheumatoid arthritis model (IVI-RA) and the EGFR+ non-small cell lung cancer model (IVI-NSCLC), and has specifically involved patient organizations in defining the scope of the oncology and arthritis OSVP focus areas.
- **Public Education and Communications:** IVI has published commentaries, white papers, and scientific presentations with an ongoing focus on patients and the need for greater transparency and understanding of patient perspectives.

Future Goals

IVI goals in the area of patient engagement include the following:

- Empower the Patient Advisory Council to inform efficient and effective engagement tactics, help ensure high-quality involvement of patients and patient organizations in IVI research, and communicate research findings with patients more effectively.
- Evaluate and improve our patient engagement processes in alignment with the IVI Partnering with Patients white paper and National Health Council rubric.²
- Engage in visible and consistent partnership with patients and patient organizations on IVI research projects and OSVP model design, development, public comment, and technical review and dissemination.
- Expand outreach via health care coalitions, public presentations, collaborative research projects, webinars, and membership recruitment campaigns to increase awareness of IVI work and to elevate messaging on patient-centricity of IVI research and initiatives.

² National Health Council. The National Health Council Rubric to Capture the Patient Voice: A Guide to Incorporating the Patient Voice into the Health Ecosystem. June 2019. Washington, DC. Available from: <https://www.nationalhealthcouncil.org/Patient-Engagement-Rubric>

About the Innovation and Value Initiative

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



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