

Action Guide for PATIENTS AND CAREGIVERS



Patients and caregivers, and especially the organizations that represent and advocate on their behalf, are essential partners in equity-centered health technology assessment (HTA) practice. Below, we focus especially on actions for patient organization leaders to help establish partnerships with other HTA stakeholders. Since each patient organization has its own leadership structure, we focus on actions for individuals playing a wide variety of leadership roles (e.g., CEO; program, policy, or advocacy lead; research directors; board members).

Patient organization leadership actions to center equity in HTA:

- Raise awareness among patients and caregivers about how HTA informs payer and purchaser decision-making and help individuals find opportunities to partner with researchers conducting HTAs.
- Expand efforts to diversify the community of patients and caregivers who are available and prepared to partner in research and HTA. Emphasize representation of communities most impacted by health inequities.
- In expanding outreach to marginalized communities, collaborate with community-based organizations, equity-focused consulting firms, and minority-led organizations.
- Build into outreach plans time for earning trust within marginalized communities. Maintain these relationships over time and across initiatives.
- Partner with research institutions and professional associations to:
 - Build capacity among patient communities to participate in HTA.
 - Develop and provide training and learning communities for patients and caregivers regarding HTA terminology, processes, and participation.
 - Provide training and support on the peer-reviewed publication process for patient and caregiver partners.
 - Establish fair market rates for compensating patients and caregivers who partner in HTA.
- Set expectations for and help patients and caregivers negotiate compensation at fair market rates.
- Sponsor scholarships or fellowships that support patient advocates pursuing careers in HTA.



Resource Spotlight: Tools for Patients and Caregivers

- Through the [PATIENTS Professors Academy](#), the University of Maryland School of Pharmacy provides free training to patients and caregivers to prepare them for engaging in patient-centered research, including HTA. The 5-week on-line program teaches a 10-step framework for continuous patient and stakeholder engagement to equip patients and caregivers to drive research within their communities.
- EveryLife Foundation for Rare Diseases led development of the [Guide to Patient Involvement in Rare Disease Therapy Development](#), a resource created BY the community and FOR the community to optimize rare disease product development efforts. The Guide focuses on including patient experience in therapy development for rare diseases, including demonstrating the value of therapies to patients with rare disease and their families.
- National Health Council partnered with patients and caregivers to co-create a guide, the [Patient-Centered Core Impact Sets \(PC-CIS\) Blueprint](#), to address inconsistencies between what health impacts are important to patients and what outcomes are typically collected in research or used in HTA. A PC-CIS is a standardized, patient-derived and patient-prioritized list of the most important impacts a disease and/or its treatments have on a patient's health and daily life, and that of their family and caregivers. Using PC-CIS in HTA will focus coverage and reimbursement decisions on what patients care about most.

