Credible, Capable, and Ready to Engage
A Three-Step Guide for Health Plans to Identify Patient Organizations for Engagement

Health plans and state Medicaid groups are increasingly encouraged and expected to build coverage, care management, and benefits based on patient engagement. These organizations already rely on clinical data and utilization trends, but without insights from patients' lived experiences, it's difficult to know if the benefits offered and treatments, services, or care deliver value to your members.

Patient organizations and lived experience data offer insights into:

- Diagnostic odyssey and the care journey
- Outcomes that matter to patients based on real-world experiences
- Access barriers to providers, services, and care
- Potential implementation challenges for new policies
- Insights from many (n-of-many) which extend beyond individual (n-of-1) experiences

> *"We worked with patient groups to provide patient-centered recommendations to support our benefit design changes to self-funded employers — including travel and fertility coverage for gene therapies."*
>
> — CLINICAL PHARMACIST, COMMERCIAL HEALTH PLAN

The Challenge

Payers need to turn patient stories into spreadsheets of data to inform benefits and coverage policies. While lived experience doesn't always fit neatly into clinical tables or economic models, patient organizations can bridge that gap. Yet, finding patient organizations to help inform decisions is a persistent challenge

> *"We tend to contact the same two or three groups over and over. We don't always know the reputable patient groups for different conditions."*
>
> — CLINICAL PHARMACIST, MANAGED MEDICAID PLAN

> *"Finding groups that aren't as well-resourced or well-known —particularly for rare conditions where there isn't broad public awareness — is where we struggle."*
>
> — CHIEF PHARMACY OFFICER, STATE MEDICAID AGENCY

Patient Engagement with Intention

To support informed and unbiased decision-making, health plans need organizations that are:

- Credible and trusted within their condition or rare disease
- Operationally capable of connecting patients, collecting information, and sharing insights
- Transparent about funding and partnership
- Prioritize patient needs
- Evidence-focused and able to synthesize lived experiences into population-level insights

Patient Groups are Ready to Engage. Is Your Organization?

This simple three-step framework helps you:

- Gather actionable input grounded in lived experience
- Access trusted contacts and vetted, credible patient organizations more quickly
- Align policies and population health strategies with your covered member priorities

EVERYLIFE FOUNDATION FOR RARE DISEASES

A Three-Step Framework for Identifying Credible and Capable Patient Organizations

1 Does the Patient Organization demonstrate transparency and accountability?

Look for certification from the National Health Council's Standards of Excellence Certification Program®. This voluntary program goes beyond the charity accountability standards, requiring patient organizations to meet 38 rigorous standards addressing:

- board governance and accountability
- human resources and infrastructure
- transparency in disclosures and conflict of interest management
- ethical operations in partnerships, fundraising, and patient engagement
- financial integrity and
- meaningful patient engagement practices

Certified organizations signal high standards for effectiveness, public stewardship, and patient focus.

> *"We lack staff to have regular dialogue with all the patient organizations we would like."*
>
> — CLINICAL PHARMACIST, MANAGED MEDICAID PLAN

2 Is the Patient Organization engaged in evidence, policy, and system change?

Seek condition or disease-specific organizations engaged in evidence development, policy engagement, and system change initiatives. These organizations understand the data-driven and operational contexts in which payers work and can help translate lived experiences into actionable insights.

For rare diseases: The EveryLife Foundation for Rare Diseases' Community Congress includes 200+ patient organizations. Find the current roster at: https://everylifefoundation.org/community-congress-members/.

For common conditions: The National Health Council's patient group members represent a wide range of diseases. Find their current membership at: https://nationalhealthcouncil.org/members/#patient-organizations.

3 Is the Patient Organization's financials transparent and available?

Use Candid (formerly GuideStar) to verify nonprofit status, assess funding diversity, and confirm commitment to transparency and accountability. While more established organizations typically have higher ratings due to their ability to devote resources to tracking metrics, new or small organizations may still demonstrate meaningful transparency and engagement.

Search for patient organizations at: https://www.guidestar.org/search.

Credible and capable patient organizations offer more than just patient voices and stories; they can help build better benefits, smarter policies, and more patient-relevant care.

EVERYLIFE FOUNDATION FOR RARE DISEASES

About the EveryLife Foundation

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.
everylifefoundation.org

Developed in partnership with Innov8 Health Policy
Learn more: everylifefoundation.org/patient-engagement-and-payment-decisions | info@everylifefoundation.org