Embedding Patient Experience in Managed Care Pharmacy

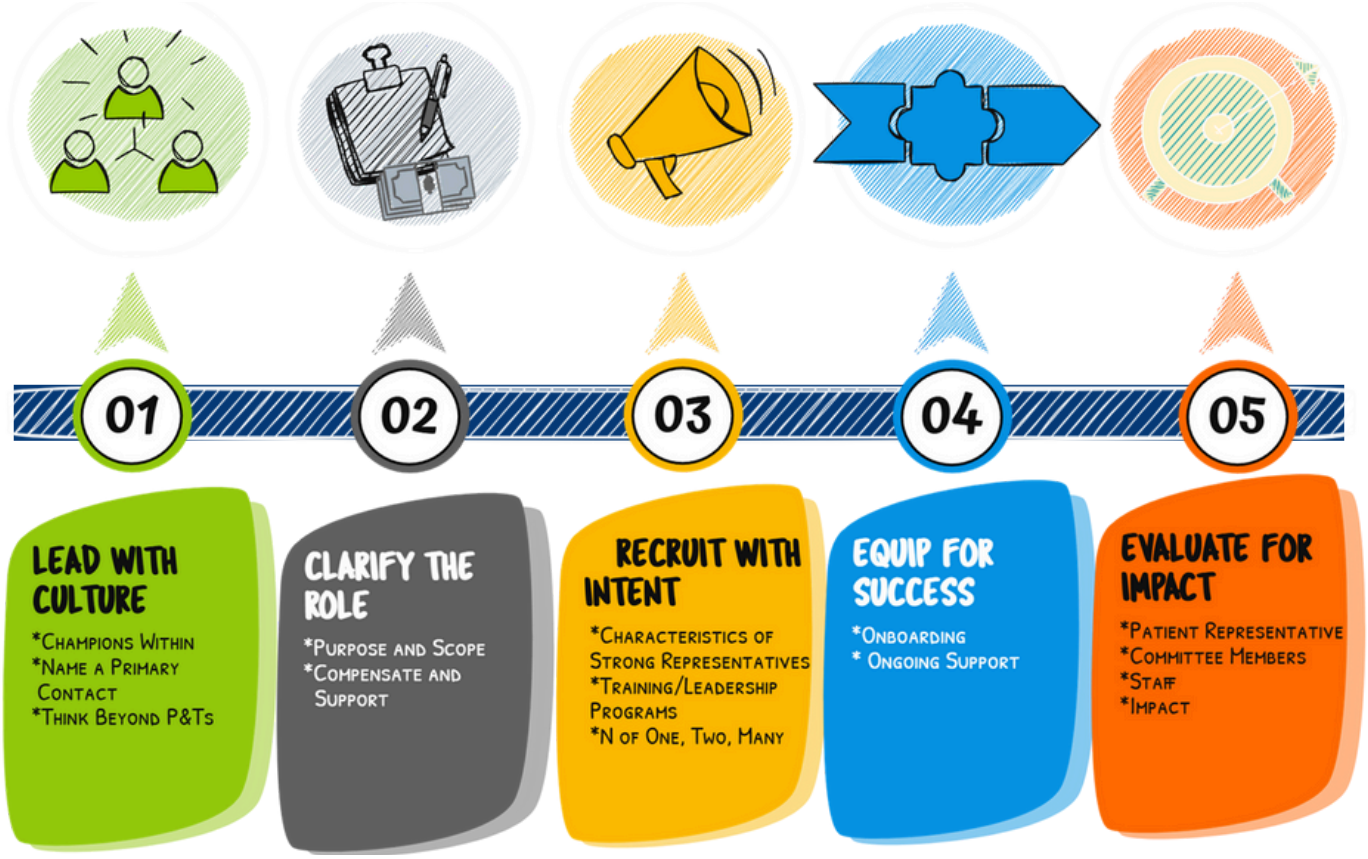
Lessons for Good and Better Practices from Medicaid Beneficiary Advisory Councils

Learning from Others

Stakeholders are still learning through trial and error how to best implement these new regulations to work for their beneficiary base and their own organization.

While these regulations are new, patient engagement is not. To develop these good and better practices, members of the following spaces were interviewed for their input and experience in engaging with the patient community in payer decision-making:

Good and Better Practices



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1 Lead with Culture

- **Champion from Within**: Identify senior sponsor to model and support
- **Name a Primary Contact**: Ensure primary point of contact builds trust and ensures resource needs
- **Think Beyond P&T**: Consider where patient experience and representation can inform care management programs, benefits or services, utilization management criteria

"It's more than a mandate, it is a key feature of our program."
~ State Medicaid Leader

"Leadership buy-in and the chain of command is critical. Your leaders must support this."
~ State Medicaid Leader

2 Clarify the Role

Purpose and Scope

- **Define the Role and Commitment:** scope, term length, time commitments, including meeting preparation
- **Be Intentional in Recruitment:** prioritize individuals living with conditions (or caregivers); consider what expertise is needed to support unheard voices
- **Lived Experience is Expertise:** both lived experience and professional expertise are valuable, but not always interchangeable; avoid over-medicalization of the patient experience
- **Distinguish Patient Representative Role:** a full voting member vs. non-voting advisor vs. advocate
- **Clarify Logistics:** Share meeting dates, format (in person vs. video calls), financial conflict of interest disclosures, and confidentiality requirements

Compensate and Support

- **Ensure Equitable Compensation:** onboarding, meeting time, and preparation
- **Be Flexible in Payment Options:** allow multiple payment options (stipends, gift cards, honoraria)
- **Address Accessibility:** identify and meet accommodations (e.g., visual, auditory, mobility, medical equipment, dietary)
- **Caregiving Support:** offer dependent or respite care to participants
- **Emphasize What Matters Most:** share examples of input that translate patient challenges into payment policy considerations

Black = Good Practices White = Better Practices

EVERYLIFE FOUNDATION FOR RARE DISEASES

About the EveryLife Foundation for Rare Diseases

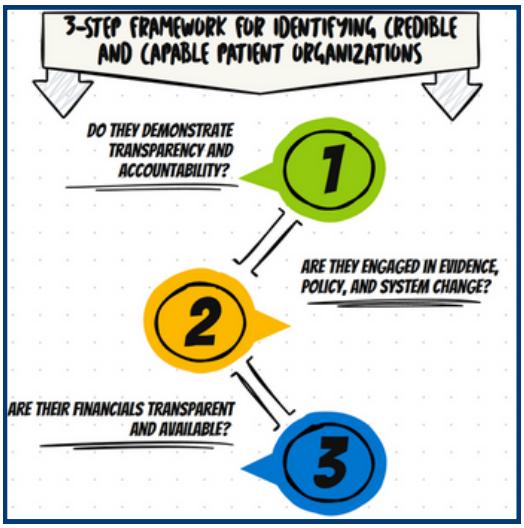
The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community.

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

3 Recruit with Intent

Characteristics of a Strong Patient Representative

- **Actively listens to diverse viewpoints, experiences, and expertise**
- **Thinks beyond personal experiences to reflect broader community perspectives**
- **Respects confidentiality, engages in sensitive discussions and constructive debates**
- **Committed to balancing clinical, population, and fiduciary responsibilities while raising practical considerations**
- **Comes prepared and asks insightful relevant questions**
- **Dedicates time for meeting preparation**
- **Connects practical and diverse patient challenges to policy opportunities**



Training/Leadership Programs Support Patient Engagement

- **Rare Disease Legislative Advocates (RDLA):** 12-month mentorship and training programs that coordinate a collaboration clearinghouse with local/state/federal policy efforts
- **Young Adult Rare Representatives Leadership Academy (YARR):** Prepares young adults (16-30) in advocacy roles related to regulatory issues, drug development, and public speaking
- **University of Maryland PATIENTS Professors Academy:** Equips patients to serve on advisory boards, research partnerships, and government agencies via a five-week training program and peer-network
- **National Health Council E-Learning Resources and Connections:** Self-guided resources to aid patient engagement, value-assessment, quality measurement, and CMS Medicare Drug Price Negotiation Process; focus on complex issues that impact chronic conditions
- **Global Liver Institute Advanced Advocacy Academy (A3):** Certification program that empowers the liver community to engage in policy, legislation, clinical trials, and patient engagement

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4 Equip for Success

Onboarding

- **Let Patients be the Expert:** Formalize with a simple contracting agreement similar to other external members
- **Start Strong:** Develop orientation materials that describe goals, roles, structure, and past committee templates
- **Demystify Materials:** Provide annotated monograph samples, glossary, etc.
- **Set Norms Together:** Review meeting guidelines and adapt as necessary

Sustained Partnership

- **Encourage engagement, not just attendance**
- **Create Support Channels:** peer-liaisons, pre-P&T meeting office hours
- **Share Impact:** record and share how patient input influenced decisions
- **Integrate Patient Experience Dossiers:** create channels for condition-specific patient experience dossiers to complement existing representatives

"We are trying to improve onboarding. We don't just want them there, we want to hear from them."
~ State Medicaid Leader

"Effectiveness depends on the support we give and the committee culture. We onboard them, introduce the committee, highlight where their unique input can be especially helpful."
- State Medicaid Leader

5 Evaluate for Impact

- **Include patient representatives' views**
- **Include P&T committee members' views**
- **Plan staff views**
- **Did the inclusion of a patient representative have a meaningful impact on**
  - **Decisions?**
  - **Decision quality or certainty?**
- **Incorporate learnings in future efforts**

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