ENGAGEMENT FRAMEWORK FOR PAYERS AND PATIENT ORGANIZATIONS

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Preface

This engagement framework was developed to encourage collaboration and guide discussion between payers and patient organizations regarding specific therapeutic areas. The objective is to enhance critical stakeholders' understanding of each other's needs, perspectives, goals, and objectives to improve patient outcomes and lower the overall cost of care. In this document, you will find various resources, tools, examples, and instructions to guide payers and patient organizations in opening lines of communication to assist with incorporating the patient's voice in decision-making processes.
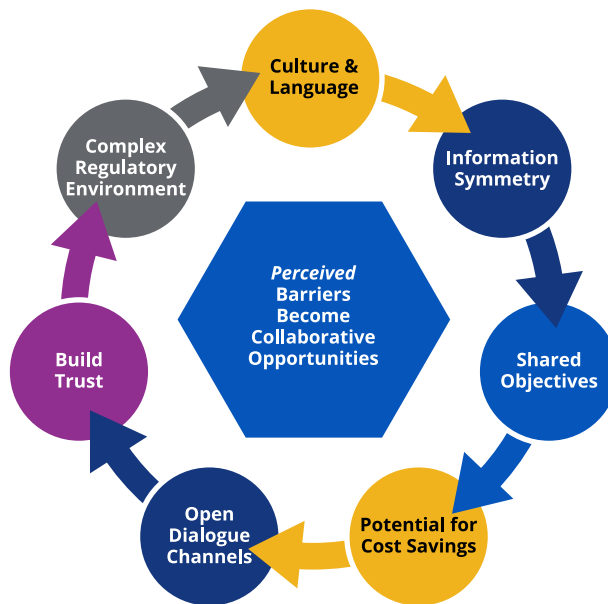

Figure 1. Payers and Patient Organizations: Viewing Perceived Communication Barriers as Opportunities.

1. Culture and Language: Payers and patient organizations may use different terminology when communicating. Providing glossaries that include commonly used managed care and patient community terms and definitions will minimize misunderstandings.

2. Information Symmetry: Payers benefit from understanding patients' needs and experiences, and patient organizations may need to fully comprehend the complexities of payer operations and decision-making processes. Payers and patient organizations would ideally educate each other on their goals, objectives, desired outcomes, challenges, and barriers.

3. Shared Objectives: Payers are focused on providing quality care, managing costs, and ensuring legislative and regulatory compliance, and patient organizations emphasize care quality, access, and patient rights. Identifying common goals and discussing opportunities to work together will assist in achieving shared objectives.

4. Potential for Cost Savings: Though payers and patient organizations have limited staff and financial resources, reviewing standard cost savings techniques, such as prior authorization and formulary management, to determine effectiveness and including the patient voice may identify new opportunities for cost savings for payers and patients.

5. Open Dialogue Channels: There may not be established or accessible channels for direct communication between payers and patient organizations. Developing lines of communication between payers and patient organizations may allow interactions to be more proactive versus reactive. For example, payers may opt to use an external-facing email address for patient organization communications.

6. Build Trust: A lack of understanding of each other's intentions and motivations can lead to incorrect assumptions and mistrust. Payers and patient organizations would ideally share priorities and desired mutually beneficial outcomes. Clear communication builds trust.

7. Complex Regulatory Environment: Sharing information may cause concerns about legal or compliance issues, hindering transparent communication. All parties must be aware of legal and regulatory restrictions and hold each other accountable.

Section 1 - Introduction

Due to therapeutic innovations and significant costs, managed care pharmacy decision-making has become increasingly complex. As payers evaluate products for coverage and reimbursement decisions, considering a patient perspective could be beneficial.

In 2008, patient-centered care was listed as an essential component of the Triple Aim, a framework for optimizing health system performance, targeting the "Improving the patient experience of care…" dimension.[1] The Triple Aim addresses the following:

- Improving the patient experience of care, including quality, safety, and satisfaction.
- Improving the health of populations.
- Reducing the per capita cost of health care.

Now, a Quintuple Aim emphasizes the well-being of the health care workforce and advancing health equity.[2,3]

Health technology assessment groups have also engaged with patients in the United States and globally for years. Through a multidisciplinary process, these organizations conduct analyses to provide input into policy decisions.[4] Within the United States, the Institute for Clinical and Economic Review (ICER) and the Innovation and Value Initiative (IVI) have developed patient councils to incorporate patient perspectives into their reviews and other initiatives.[5,6] International organizations, such as Health Technology Assessment International (HTAi) and the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), also engage patients in their work.[7,8] The Canadian Agency for Drugs and Technologies in Health (CADTH), the National Institute for Health and Care Excellence (NICE), and the European Medicines Agency collaborate with regional and national HTA bodies outside the United States to ensure patient access to new medicines.[9-11] In January 2025, a new European Union regulation will create a Member State Coordination Group on Health Technology Assessment to oversee joint clinical assessments;[12] and the Scottish Medicines Consortium (SMC)[13] have also sought patient input.

The U.S. Food and Drug Administration (FDA) has also prioritized the patient voice and developed a series of guidance documents to address how stakeholders can collect and submit patient experience data for medical product development and regulatory decision-making.[14]

Involving patients in managed care decision-making processes ensures the covered services align with the needs and priorities of covered members. The following are a few examples of how payers and patient organizations can proactively engage with each other to ensure the patient's voice is considered in all aspects of plan design:

1 Enhanced Understanding of the Patient Journey and Information Symmetry

Enhanced Understanding for Payers: Balancing cost and high-quality care is essential for payers and patients. Gathering input from patients can provide valuable insights into payers' specific health care requirements, challenges, and expectations. This can be accomplished using a patient journey map that includes insights beyond the traditional health care pathway. The following are examples of what could be included on a patient journey map:

- Diagnosis.
    - o Initial symptoms and impact on quality of life.
    - o Time to diagnosis since symptom onset.
    - o Diagnostic tests and previously tried medications.
- Following diagnosis.
    - o Access and barriers to appropriate specialist(s) or sub-specialist(s).
    - o Access and barriers to obtaining prescribed therapies.
    - o Out-of-pocket costs (e.g., copays, coinsurances for provider visits, medications, and other medical services).
- Other psychosocial or socioeconomic concerns.
    - o Travel requirements for appointments.
    - o Missed time from work/school.
    - o Impact on family and other relationships (e.g., co-workers, friends).
    - o Financial impact (e.g., the decision between paying for rent or medication).

A better understanding of these patient insights could positively impact benefit design and utilization management strategies, enabling the payer to consider coverage options that better align with patient needs.

- Health care providers can potentially avoid unnecessary medication use and minimize side effects by tailoring medication regimens to individual member needs and preferences, which could also lead to cost savings for payers and their members. For example, a patient organization can share data highlighting that certain off-label medications, though effective and supported by guidelines for a given disease, carry excessive burdens and are considered inappropriate step therapy options before patients receive coverage for a novel agent. This could lead to reduced prior authorization burden for payers and patients, earlier treatment with proper therapies, and potential long-term cost savings for payers.

Information Symmetry for Patient Organizations: Gaining insight from payers can provide valuable information about cost drivers and statutory or regulatory requirements that impact benefit design and cost. These insights can frame the "ask" from the payer. Patient organizations should focus on providing information that addresses patient needs to enable the payer to streamline benefit design and utilization management strategies.

2 Improved Access to Care

Involving patients in health care decisions provides payers valuable insights into barriers to accessing health care.

- Patients can provide data and feedback on network adequacy, affordability, disease progression, coverage limitations, and policy processes that may negatively impact timely access to care. Payers can use this information to understand better the disease state and its impact on the patient's quality of life.

- This information may help payers identify areas for improvement and work toward ensuring their members have appropriate access to the health care services they require and aligning drug policy requirements with the realistic landscape of care.

- Partnering with payers in constructive dialogue allows patient organizations to share how the involvement of patients in health care decisions can provide payers with valuable insights into barriers to accessing health care.

3 Increased Transparency and Trust

Involving patients in decision-making fosters transparency and trust between payers and patient organizations.
- When patients feel heard and valued, they are more likely to trust the payer and engage in proactive health care management.
- By listening to members' concerns and suggestions, payers can demonstrate commitment to improving the patient experience, building stronger relationships, and increasing members' confidence in the payer.

4 Better Outcomes and Patient Satisfaction

Patients who feel comfortable engaging in dialogue with their payer representative are more likely to view them as a "partner in their care." When patients understand their coverage and how to utilize their benefits correctly, they may experience better health outcomes, such as improved adherence to their prescribed treatment regimen. Patient organization input can lead to developing benefits, policies, and coverage options that align with patient needs and priorities, resulting in improved overall satisfaction and a desire to be more engaged in their health care.[15]

Including the patient's voice in payment and decision-making is crucial for creating accessible, patient-centric coverage options. By considering the perspectives and needs of patients, payers can better serve their members and contribute to the overall improvement of health care systems.

Section 2 - Garnering Key Insights and Resources from Patient Organizations

The patient's experience encompasses interactions with various entities within the health care system, including hospital staff, clinics, pharmacies, other health care facilities, and payers. Health care gaps can be identified by patient journey mapping, which could prevent unintended consequences for patients and payers. For example, some conditions are treated with regimens that require health care coordination between a health plan's pharmacy and medical benefits. Consider a patient with a motor neuron disorder, such as amyotrophic lateral sclerosis (ALS), who is prescribed medication and durable medical equipment (DME). In this case, both treatments may require prior authorization, one under the pharmacy benefit and the other under the medical benefit. Physicians and patients have shared that the authorization for DME often comes much later than the pharmacy authorization.[16] In some cases, delayed approval for therapy may lead to a more rapid progression of the patient's disease, necessitating coordination between pharmacy and medical prior authorization processes to ensure the best patient outcomes.

Patient organizations directly engage with the patient community and the clinicians who treat them. These relationships uniquely position patient organizations to capture and report the patient perspective and identify areas for payers to improve plan design or processes.

Living with a chronic and rare disease can be overwhelming to patients and may affect their ability to adhere to their prescribed treatment regimen. This could lead to less-than-optimal outcomes and increase the overall cost of care. Payers recognize this challenge, and many offer disease management programs to their members designed to connect patients with chronic health conditions with trained experts to assist them through their care journey. To help optimize the success of these programs, payers may consider partnering with patient organizations to identify pain points patients experience when navigating their care.

Table 1 lists challenges and examples that members could experience.

Table 1: Examples of Patient Obstacles to Care

Challenges	Example
Emotional	Frustration with wait times for prior authorizations or confusion regarding coverage.
Psychological	Fear of failure to adequately navigate the health care system.
Physical	Transportation issues leading to missed provider appointments or appointments for other medical services.
Financial	Inability to pay out-of-pocket costs, such as copays, coinsurances, and travel expenses (e.g., fuel or bus fare).

Patient organizations may collaborate with payers in various ways to provide further insight into current standards of health care and treatment for patients. Some opportunities may include the following:

- Connecting payers to the patient organization's key contact and providing access to any resulting recommendations or guidelines.

- Providing educational presentations to payer staff from clinical and non-clinical key opinion leaders.

- Sharing information with payer decision-makers about current and evolving care best practices.

- Sharing resources on patient-centered communication strategies that include best practice guides and checklists.

Section 3 - Payer and Patient Organization Collaboration

Opportunities for collaboration among payers and patient organizations may vary depending on the market type (e.g., Medicaid, Medicare, self-insured employers, the commercial market). Consider what health coverage concerns or questions are most important to the population served and seek ways to engage in discussions surrounding those topics. For example, access to the appropriate therapy and the specialists who treat their condition is a top priority for many with a rare or chronic disease. Health care coverage can often come with challenges, such as network inadequacy, the prior authorization process, preferred drug list inclusions and exclusions, coordination among all the providers treating the patient for their condition, and patient understanding of how to navigate their policy benefits.

Table 2 suggests opportunities where patient organizations may serve as a resource for payers.

What are the steps to engagement?
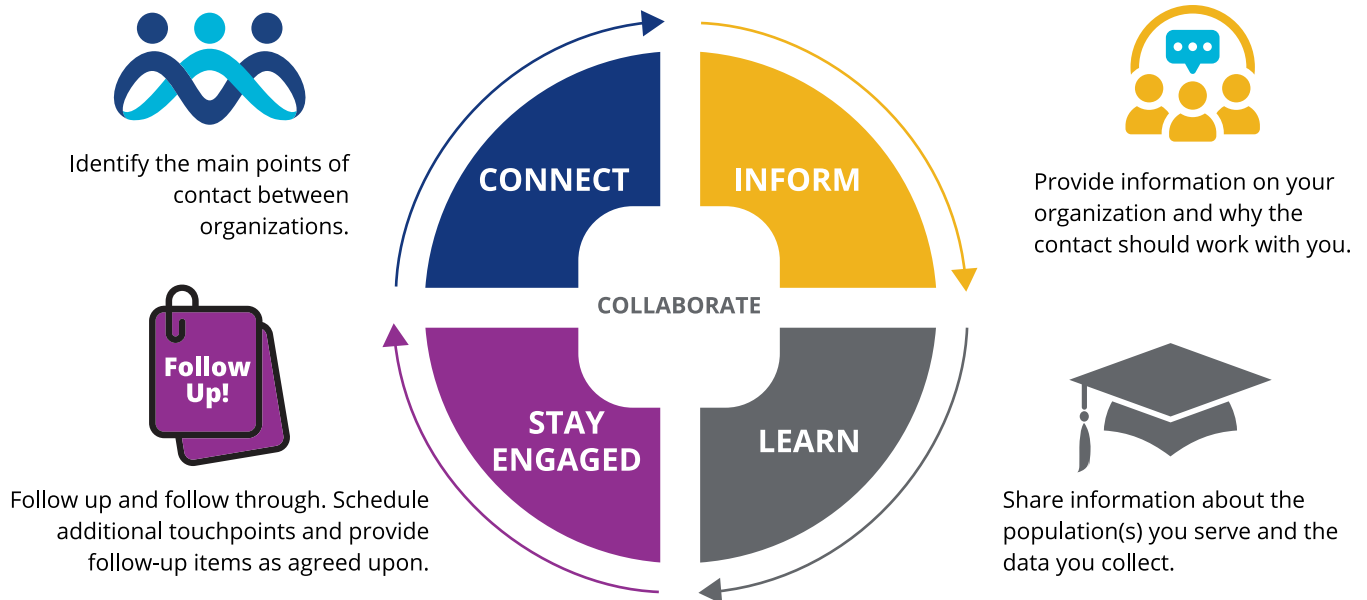
Steps to Engagement

Identify the main points of contact between organizations.

CONNECT

INFORM

Provide information on your organization and why the contact should work with you.

COLLABORATE

STAY ENGAGED

LEARN

Share information about the population(s) you serve and the data you collect.

Follow Up!

Follow up and follow through. Schedule additional touchpoints and provide follow-up items as agreed upon.

Table 2: Engagement Opportunities for Patient Organizations with Payers

Engagement Opportunity	Purpose	Participants	Action Item
Pharmacy & Therapeutics (P&T) Committee	The central role of the P&T Committee is to objectively appraise, evaluate, and select drugs for the health plan or pharmacy benefit manager's formulary.	Primarily physicians and pharmacists. It could also include nurses and other health care professionals.	Patient organizations can contribute to P&T Committees by providing patient journey information or by giving written or verbal testimony at P&T Committee meetings or subcommittee meetings ahead of time.
Prior authorization and utilization management review	A health care provider may need approval from a payer before coverage is granted for a prescription or a medical procedure or service. Guidelines are based on clinical efficacy, safety, and cost.	Pharmacists, nurses, and other health care professionals within a health plan or pharmacy benefit manager.	Patient organizations can review coverage guidelines and provide information regarding any challenges they foresee, such as access to a sub-specialist if required in the guidelines.
Health care coverage education for patients	Fact sheets that are available to patients that describe the various benefits within their coverage and why they are important.	Payer and patient organization education staff.	Patient organizations may conduct listening sessions or participate in an advisory board to better understand the patient's perspective. Patient organizations may also provide patient-vetted guidance on clarity and format of language.
Identification of key drivers in achieving optimal outcomes	To identify the key drivers motivating each stakeholder and determine how the drivers may differ from one another	Payer and patient organization education staff.	Patient organizations may be able to assist payers with a holistic review of blinded high-cost claims to develop solutions. For example, a self-insured organization worked with a patient organization and recognized an opportunity with pharmacy channel management, leading to payer and patient savings.

While collaborating, patient organizations may use terms specific to their experiences, while payers may be utilizing terminology more particular to the medical industry. Clear and coherent communication is critical to a successful collaboration and requires all parties use mutually recognized terminology. AMCP has a managed care glossary of terms and abbreviations available as a resource.[17]

Patient organizations are encouraged to create "Disease at a Glance" documents to assist payers in better understanding their patients. The documents could include the following:

- Disease statistics, including the incidence and prevalence.
- Community-specific terminology.
- Typical disease trajectories, including diagnostic considerations, time to diagnosis, and impact on quality of life.
- Case for access to appropriate pharmacy, medical, and other services.
- Providers patients have typically seen, including specialists and Centers of Excellence.
- Information from medical/scientific boards for the disease.
- Patient journey mapping, including insights beyond the typical care pathway.
- Quantitative and qualitative data on patient goals, challenges, and concerns across their disease journey (e.g., managing complex medications through life stages, such as family planning and aging).

Further examples of these documents can be found in the **Appendices**.

Section 4 - Payer Promotion of Disease Awareness and Health Coverage Education to Members

Payers may offer a variety of programs to their members, including disease management and case management programs. To inform members of these and other programs available through the plan, payers may use various modes of communication, such as telephone calls or letters. The goal is to provide information and support members' overall well-being.

These same considerations can be applied when developing patient communications designed to help guide members through navigating their health plan and, more specifically, their responsibilities for utilizing their benefits. Processes connected to health coverage, such as appeals, balance billing, prior authorization, and medical exception processes, can be complex for patients to navigate. Easily understood communications educating patients about these topics may reduce patient confusion.

Table 3 contains considerations that payers may include when developing such communications.

Table 3: Considerations for Effective Patient Communications

Considerations	Comments
Accessible Language	Use language all members can easily understand.
Content	Consider alignment with patient organization disease management education.
Distribution	Distribute the correct information in the proper format at the right time.
Feedback Mechanism	Establish a way for members to provide feedback about the communications they receive. This can assist with gauging its effectiveness and making future improvements.
Format and Medium	Consider email, printed letters, video messages, text messages, or a combination. Graphics and photos may assist with conveying the messages.
Open Dialogue	Encourage members to ask questions or seek clarification. Provide a payer point of contact and other credible, referenced sources. If members are encouraged to talk to their primary care providers, sending the communication to providers may help as well.
Privacy and Sensitivity	If disease state education pertains to a sensitive health condition, emphasize the confidential nature of the information. Assure members their privacy will be respected, and they can choose whether to engage with the educational materials.
Relevance	Targeting messages may be helpful.
Resources and Further Information	Provide resources for members who wish to learn more about their disease state or related topics. Consider including contact information for the national or local patient organizations serving that patient population.

Section 5 - Disclosure of Organizational Funding

Payers typically have disclosure requirements for P&T Committee members and supporting staff. As a result, payers may also require patient organizations to disclose organizational funding. Specific requirements may vary per payer organization.

The following is a sample template that may be considered:

[Patient Organization] is dedicated to our mission of advocating for and supporting patients with *[specific condition or disease]*.

We believe in transparency regarding our funding sources. We are committed to ensuring these relationships do not compromise our patients' independence, integrity, or best interests. We receive funding from individuals, local and national corporations, pharmaceutical companies, governmental entities, and philanthropic foundations.

Pharmaceutical and Payer Company Support:

[Patient Organization] has received financial support from pharmaceutical companies and payers, including grants and sponsorships. This funding primarily supports specific programs, events, and initiatives related to [*condition or disease*]. The nature of support may include the following:

- Unrestricted Educational Grants: These grants fund educational initiatives, such as disease awareness campaigns, patient education materials, and support for medical conferences and symposia.

- Sponsorship of Events: We may partner with pharmaceutical companies to sponsor conferences, seminars, or patient-focused events to enhance patient education and engagement.

- Advertising and other fee-for-service arrangements

Independence and Integrity statement: Funding received from pharmaceutical companies does not influence our advocacy efforts, decision-making processes, or the information we provide to patients. We maintain a strict policy of independence and integrity in our work.

Transparency: We are committed to transparency in our financial relationships.

Conflict of Interest Mitigation: Our organization has established rigorous policies and procedures to prevent conflicts of interest. Our board members, staff, and volunteers must disclose any financial or personal interests that may impact our advocacy work. We diligently manage and mitigate any conflicts of interest to safeguard the trust and well-being of our patient community.

Conclusion

With growing consensus for the greater health care community to become more patient-centered, there is a need for guidance and tools on how payers and patient organizations can partner to best incorporate the patient perspective into managed care pharmacy decision-making. AMCP created this engagement framework to advance this work. This framework helps payers and patient organizations identify themes that emerged from AMCP's Patient Voice Advisory Group's discussion, which included assembling and drawing upon successful examples and best practices; recognizing different levels of engagement; building trust and relationships proactively; creating defined access points and open dialogue channels; incorporating the patient perspective as an element of coverage decision-making; leveraging existing patient data and reports; crystallizing a pivotal message to further common goals; and facilitating ongoing education and learning. These themes and the related practices identified in this framework will inform AMCP and their members and partners as they continue this critical effort.
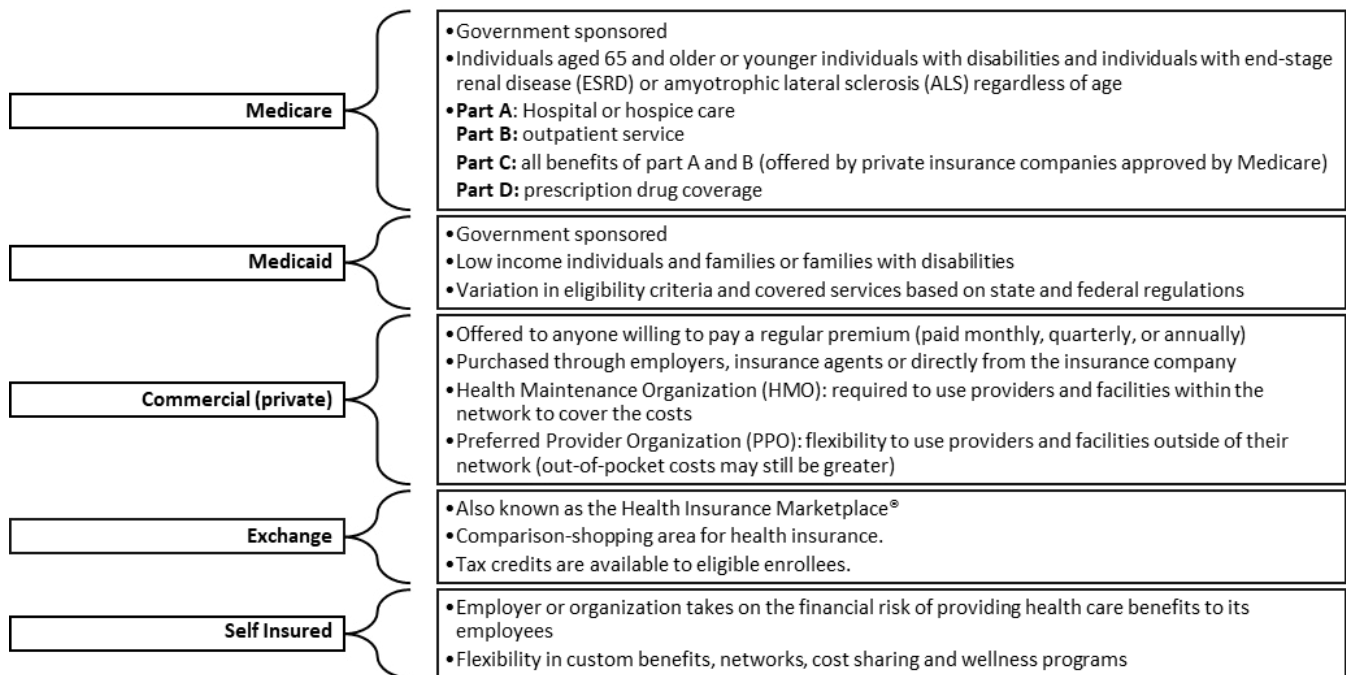
Acknowledgments

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Appendices

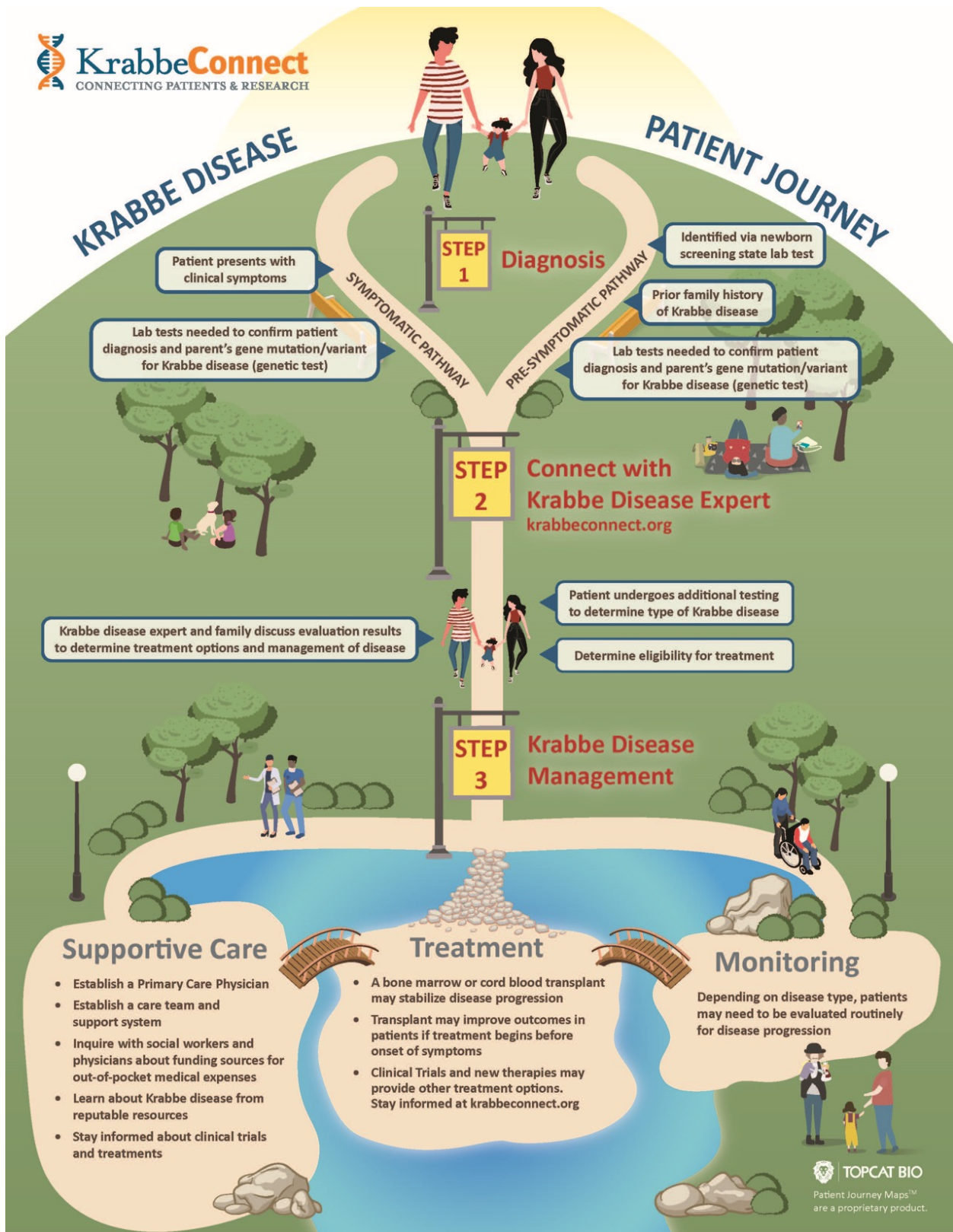## A   Health Plans and Risk Pools

Health care plans pay for medical and surgical expenses incurred by the insured individual and, where applicable, their covered dependents. By serving a more significant patient population, the insurers protect policyholders from the high costs of medical care and provide access to necessary health care services. Typically, health care policies cover various medical services and treatments, such as hospitalizations, provider visits, prescription drugs, preventative care, mental health services, maternity care, and other specialized therapies. All policyholders must pay a premium amount (usually per month) based on their age, location, coverage level, and insurance provider. An individual must choose a plan that suits the policyholder's needs and budget while providing adequate coverage to avoid financial burdens from unexpected medical expenses and access to necessary medical services.[18]

Figure 1: Examples of Health Plan Options[17-19]

Medicare
- Government sponsored
- Individuals aged 65 and older or younger individuals with disabilities and individuals with end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS) regardless of age
- **Part A:** Hospital or hospice care
  Part B: outpatient service
  Part C: all benefits of part A and B (offered by private insurance companies approved by Medicare)
  Part D: prescription drug coverage

Medicaid
- Government sponsored
- Low income individuals and families or families with disabilities
- Variation in eligibility criteria and covered services based on state and federal regulations

Commercial (private)
- Offered to anyone willing to pay a regular premium (paid monthly, quarterly, or annually)
- Purchased through employers, insurance agents or directly from the insurance company
- Health Maintenance Organization (HMO): required to use providers and facilities within the network to cover the costs
- Preferred Provider Organization (PPO): flexibility to use providers and facilities outside of their network (out-of-pocket costs may still be greater)

Exchange
- Also known as the Health Insurance Marketplace®
- Comparison-shopping area for health insurance.
- Tax credits are available to eligible enrollees.

Self Insured
- Employer or organization takes on the financial risk of providing health care benefits to its employees
- Flexibility in custom benefits, networks, cost sharing and wellness programs

A patient participates in a risk pool by enrolling in a health care plan. A risk pool is created when a group of individuals' medical costs are combined to calculate the cost of premiums, therefore allowing the lower costs of the healthy to offset the higher costs of those less healthy. Collecting premiums from many policyholders and spreading the financial risk across a more extensive group protects more policyholders against losses and unexpected events. The critical principle of risk pooling is that some policyholders will experience loss simultaneously. With a larger pool of policyholders and funds, the insurer may negotiate better rates with health care providers, lowering costs for all parties involved. The advantages of a more significant risk pool are lower premiums, more comprehensive and expanded coverage options with higher limits, expanded customer service, and long-term commitment.[20,21]

B | Patient Journey Map

KrabbeConnect
CONNECTING PATIENTS & RESEARCH

KRABBE DISEASE **PATIENT JOURNEY**

STEP 1 **Diagnosis**

SYMPTOMATIC PATHWAY

Patient presents with clinical symptoms

Lab tests needed to confirm patient diagnosis and parent's gene mutation/variant for Krabbe disease (genetic test)

PRE-SYMPTOMATIC PATHWAY

Identified via newborn screening state lab test

Prior family history of Krabbe disease

Lab tests needed to confirm patient diagnosis and parent's gene mutation/variant for Krabbe disease (genetic test)

STEP 2 **Connect with Krabbe Disease Expert**
krabbeconnect.org

Krabbe disease expert and family discuss evaluation results to determine treatment options and management of disease

Patient undergoes additional testing to determine type of Krabbe disease

Determine eligibility for treatment

STEP 3 **Krabbe Disease Management**

Supportive Care

- Establish a Primary Care Physician
- Establish a care team and support system
- Inquire with social workers and physicians about funding sources for out-of-pocket medical expenses
- Learn about Krabbe disease from reputable resources
- Stay informed about clinical trials and treatments

Treatment

- A bone marrow or cord blood transplant may stabilize disease progression
- Transplant may improve outcomes in patients if treatment begins before onset of symptoms
- Clinical Trials and new therapies may provide other treatment options. Stay informed at krabbeconnect.org

Monitoring

Depending on disease type, patients may need to be evaluated routinely for disease progression

TOPCAT BIO
Patient Journey Maps™ are a proprietary product.

C   Patient Burden Poster

Disease Burden and Treatment Considerations in Krabbe Disease: The Caregiver Perspective

D   Employer Toolkit

The hemophilia toolkit was created for employers by Midwest Business Group on Health.

URL: Hemophilia and Bleeding Disorders Toolkit: Midwest Business Group on Health (mbgh.org)

E   Sample Patient Organization Communication to Patients

Sick Cells offers patient education on the topic of access and coverage on their website. This is an example of how patient organizations educate patients on payers and how patients can provide feedback to payers and other stakeholders.

URL: Sick Cells Access & Coverage