THE Sumaira FOUNDATION

Building leadership capabilities for patient partners in clinical research

A patient-centered CER toolkit for patient advocacy organizations

The Sumaira Foundation

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ABOUT THIS TOOLKIT

Overview

This toolkit is intended for patient advocacy organizations (PAOs) seeking to expand their role in research and build capacity to engage in patient-centered comparative clinical effectiveness research (CER). Throughout this resource, the terms *patient, patient partner,* and *patient partnership* are used to refer to both patients and caregivers who bring lived experience and experiential knowledge to research.

A companion toolkit has been developed for clinicians, academic researchers, healthcare professionals, and others seeking to partner more effectively with patient organizations and patient partners. Please contact contact@sumairafoundation.org to request a copy.

About The Sumaira Foundation (TSF)

The Sumaira Foundation (TSF) is a patient-founded, patient-led organization dedicated to advancing rare neuroimmune disease research and supporting individuals living with neuromyelitis optica spectrum disorder (NMOSD), myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD), and other related conditions.

Through our international work across research, education, support, and advocacy, we partner with patient communities, clinicians, academic researchers, and industry partners to accelerate scientific progress and strengthen patient partnership across the field of rare diseases.

Acknowledgements

We extend our sincere gratitude to the patients and caregivers whose lived experience, advocacy, and leadership continue to shape the evolution of patient partnership in research. We also thank the patient partners, clinicians, academic researchers, and community collaborators who contributed to this toolkit, developed by Alanna Yee, Leyla Herbst, and Michael Devlin as part of The Sumaira Foundation's research initiatives.

Disclaimer

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SECTION 01

BACKGROUND & CONTEXT

UNDERSTANDING PATIENT PARTNERSHIP IN RESEARCH

SECTION OVERVIEW

Patient engagement and patient partnership are reshaping how research takes place. People with lived experience are moving beyond traditional fundraising or support roles and are becoming active partners in shaping how research is planned, designed, and delivered.

This section explores why this shift is happening, including growing evidence of the impact of patient engagement in research, increasing expectations from funders, regulatory agencies, and reimbursement bodies, the expanding role of patient advocacy organizations (PAOs) as research partners, and a growing focus on translating research into real-world treatment and care decisions through patient-centered comparative clinical effectiveness research (CER).

CASE STUDY: THE SUMAIRA FOUNDATION (TSF)

In 2024, The Sumaira Foundation (TSF) received a Patient-Centered Outcomes Research Institute (PCORI) Engagement Award to build our capacity to play an active role in research. Through this two-year initiative, we set out to strengthen patient partnership in rare neuroimmune disease research and lay the groundwork for more impactful, community-driven studies.

As part of this work, we established a multi-stakeholder research council of patients, clinicians, and researchers, developed a research agenda for neuromyelitis optica spectrum disorder (NMOSD) and myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) focused on patient-centered evidence gaps, and created these toolkits based on our learnings.

As our research infrastructure took shape and new partnerships emerged, we pursued an opportunity to address a key research priority identified by our community: which treatment is most effective at preventing relapses in NMOSD? Together with leading clinicians and researchers in the field, we developed a proposal that secured $9 million for TSF to lead a five-year international clinical trial comparing the effectiveness of NMOSD therapies. In later sections, we discuss the importance of patient-centered comparative clinical effectiveness research (CER) and draw on this experience as a case study to illustrate how building partnership capacity can create pathways to research leadership.

1.1 From Participation to Partnership

Gaps in traditional research models

Traditionally, research has been driven by clinicians and academic researchers, with patients involved as *participants* or *subjects*. While this participation is essential, involvement has typically been limited to providing data rather than inclusion as *partners* in shaping what research asks, measures, and aims to improve.

This model creates predictable gaps. Research questions may miss the realities of lived disease burden, while study designs may overlook feasibility factors such as symptom fluctuation, travel demands, caregiver burden, or cognitive fatigue. Outcome measures may focus on clinician-defined endpoints (e.g., relapse rates, imaging findings, or biomarkers) while missing the aspects of health that most affect patients' daily functioning and quality of life.

In response, there has been a growing shift across the research ecosystem – spanning funders, academic institutions, biopharmaceutical companies, regulatory bodies, and beyond – toward valuing patient partnership as a core component of high-quality research. This evolution is helping to produce studies that better reflect real-world needs and are more likely to generate outcomes that meaningfully benefit the communities they are intended to serve.

Exhibit 1: Ways that Patient Partnership Changes Research

Research Dimension	Traditional Research Model	Patient Partnership Model
Role of patients	Study participants / subjects	Partners and leaders
Research priorities	Driven by clinicians and researchers	Co-designed with patients
Governance & decision-making	Researcher-led decision-making	Shared decision-making structures
Study design	Limited patient input	Lived experience informs design
Recruitment strategies	Institution-led outreach	Community-informed recruitment
Compensation practices	Limited or inconsistent compensation	Structured compensation recognizing lived expertise

Evidence of impact

While patient engagement is often discussed in terms of values such as patient-centeredness, inclusion, and respect, its importance extends well beyond these principles. A growing body of evidence shows that research is stronger and more successful when patient partners are meaningfully involved.

Initiatives led by organizations such as PCORI demonstrate that meaningful patient engagement can strengthen the acceptability, feasibility, rigor, and relevance of research studies, improving elements such as:

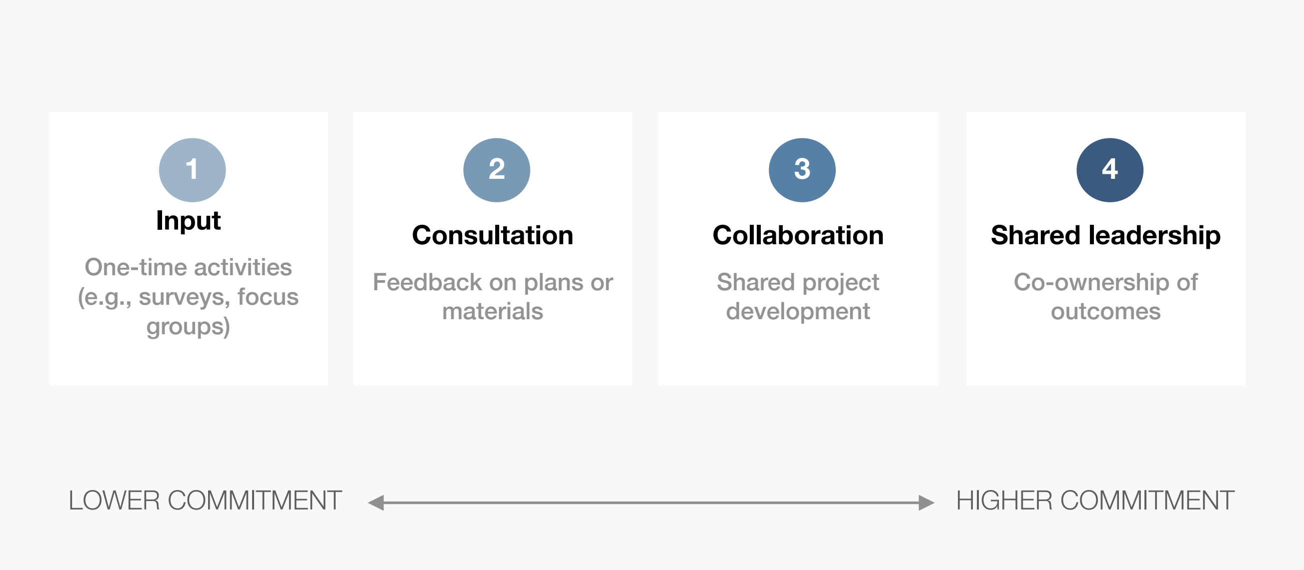
- How feasible study protocols and recruitment criteria are in real-world settings
- Selection of outcomes that matter most to patients
- Clarity, accessibility, and cultural sensitivity of study materials
- Trust between research institutions and patient communities
- Dissemination and translation of research findings into real-world practice

Patient engagement is increasingly recognized as more than symbolic or optional, with impact that can be seen across the research lifecycle.

The spectrum of engagement

Patient engagement exists along a spectrum. While activities such as surveys or focus groups provide important input, they do not necessarily reflect partnership. Partnership implies shared influence, shared responsibility, and shared ownership of outcomes.

Exhibit 2: The Spectrum of Engagement



Organizations may engage at different points along this spectrum depending on capacity, experience, and strategic priorities. Understanding this progression helps PAOs reflect on how they currently engage and identify opportunities to deepen research partnership and leadership in the future.

1.2 How the Research Landscape is Changing

Funder expectations

As patient partnership becomes more embedded across the research ecosystem, expectations for engagement are becoming increasingly formalized.

Major research funders increasingly require evidence of meaningful patient engagement within grant applications, study design, and governance structures. Organizations such as the Patient-Centered Outcomes Research Institute (PCORI), the National Institutes of Health (NIH), Horizon Europe, and other international funding bodies have embedded patient partnership expectations into funding criteria, evaluation metrics, and reporting requirements.

Regulatory and reimbursement integration

Regulatory agencies responsible for approving medicines and reimbursement bodies that determine coverage and access – including the U.S. Food and Drug Administration (FDA), the European Medicines Agency (EMA), and health technology assessment (HTA) organizations such as Canada's Drug Agency (CDA-AMC) – are increasingly incorporating patient input into their decision-making processes. This includes greater patient engagement in clinical trial design, endpoint selection, and benefit–risk assessment, as well as the growing use of patient preference data, patient-reported outcomes, and lived experience insight.

Implications for patient advocacy organizations (PAOs)

For PAOs, this shift creates expanded pathways for you to engage as strategic partners within research, policy initiatives, and multi-stakeholder partnerships. Organizations that build the infrastructure and experience to support and lead meaningful patient engagement are becoming trusted collaborators within research teams and decision-making environments.

1.3 The Role of PAOs as Research Partners

Lived experience and experiential knowledge

PAOs hold a depth of expertise that is often underestimated, including by people within the organization themselves. The lived experience of your community is not just personal; it is a form of experiential knowledge grounded in day-to-day realities of diagnosis, treatment, access barriers, and long-term care.

This expertise extends beyond individual stories and includes insights into broader patterns across communities, unmet needs, and real-world care challenges that may otherwise be overlooked within traditional research settings. Recognizing the legitimacy and value of this helps you to step forward as confident, strategic partners in research.

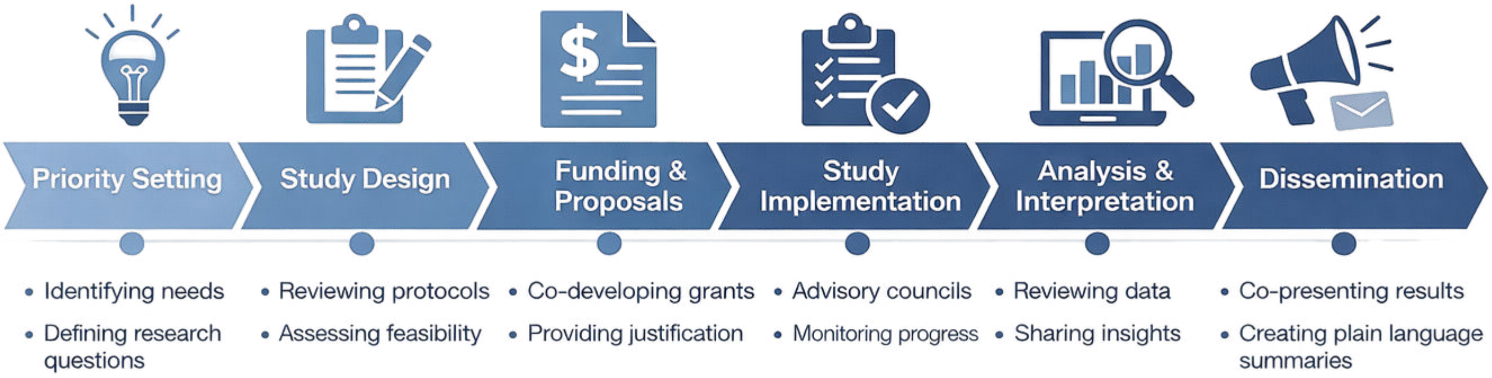
Exhibit 3: Example PAO Roles in Research

Partnership Role	Expertise
Co-designers of research agendas	Deep insight into community priorities and unmet needs
Contributors to defining research questions, treatment and care options, and outcomes	Ability to identify approaches that reflect daily functioning, quality of life, and treatment burden, and support real-world treatment and care decisions
Co-developers of study protocols	Lived experience perspective on study procedures and participant burden
Advisors on study feasibility and accessibility	Practical understanding of real-world barriers to participation and care
Co-authors and dissemination collaborators	Strength in knowledge translation and plain language communication

Expanded roles across the research lifecycle

PAOs can play a central role in research across the lifecycle. As organizations build sustainable research capacity, opportunities for partnership extend beyond episodic engagement toward multi-stakeholder collaboration and ultimately research leadership.

Exhibit 4: Patient Partnership Across the Research Lifecycle



Engaged in these capacities, PAOs can evolve from patient partners to research leaders that shape the direction, conduct, and application of research. This shift enables research to more fully reflect community priorities, lived realities, and real-world implementation needs.

1.4 Translating Research into Treatment & Care Decisions

From research evidence to real-world decisions

While research may generate evidence that advances scientific knowledge, it does not automatically translate into improved patient outcomes or inform real-world treatment and care decisions.

Traditional clinical trials are often conducted under controlled conditions with carefully selected patients and are most often designed to assess *efficacy*, meaning whether a treatment can work under ideal conditions. These studies may not reflect the full range of patients seen in practice, excluding patients such as those with multiple comorbidities, those taking other medications, or older adults. In addition, they often don't provide direct comparisons between available treatment options.

As a result, patients, clinicians, and health systems are often left to choose between multiple treatments without clear evidence on which is most effective in real-world settings. In practice, decisions must account for diverse patient populations and practical constraints such as side effects, access, cost, and daily life demands. Patients and clinicians need guidance that reflects these realities and shows how research evidence translates into practice.

The role of patient-centered comparative clinical effectiveness research (CER)

Patient-centered comparative clinical effectiveness research (CER) is a type of research that *compares* different ways of preventing, diagnosing, treating, or managing a condition to determine which works best, for whom, and under what circumstances. It examines healthcare interventions in practice, such as:

- Drug A vs. drug B
- Medication vs. lifestyle change
- Surgery vs. therapy
- Different care delivery models

CER incorporates outcomes that matter most to patients — such as quality of life, daily functioning, and treatment burden — and focuses on *effectiveness* rather than efficacy alone. Effectiveness refers to how well an intervention works in real-world settings.

Instead of asking "Does this intervention work?", CER answers the practical questions patients and clinicians face when choosing between treatment and care options.

Exhibit 5: From Research Evidence to Real-World Decisions

Stage	Main question	How evidence is generated	What it produces
Basic science	How does the disease work?	Laboratory and preclinical studies	Biological understanding; potential treatment targets
Traditional efficacy trials	Does the intervention work under controlled conditions?	Explanatory trials in selected patient populations	Evidence of benefit and safety under controlled conditions
Comparative effectiveness trials (CER)	Which intervention works best in real-world care, and for whom?	Head-to-head trials, pragmatic trials, and studies using data from routine care	Comparative, real-world evidence across typical patient populations
Clinical care	What is the best option for this patient?	Clinical judgment and guidelines, shared decision-making	Individualized treatment and care decisions
Health economics and policy	Is it worth the cost and who should have access?	Evidence synthesis, guideline review, and health technology assessment (HTA)	Coverage decisions, access, healthcare system guidance

Why CER matters for PAOs

When a member of your patient community is sitting in a clinic or making a treatment decision, they are unlikely to be thinking in terms of study design, statistical endpoints, or clinical data. They're asking: *What are my options? Which one will best help me function, study, work, care for my family, and live my life given my personal needs?*

Engaging in CER gives PAOs a meaningful way to influence how these questions are answered. By partnering with other stakeholders to define research questions, treatment and care options, and outcomes, PAOs can help ensure studies compare the practical options patients face and measure what matters most to them in daily life.

CASE STUDY: TSF'S CER TRIAL

NMOSD is a severe neuroimmune condition characterized by recurrent inflammatory attacks that can cause irreversible damage including blindness and paralysis. Without treatment, patients may experience significant disability and, in some cases, death.

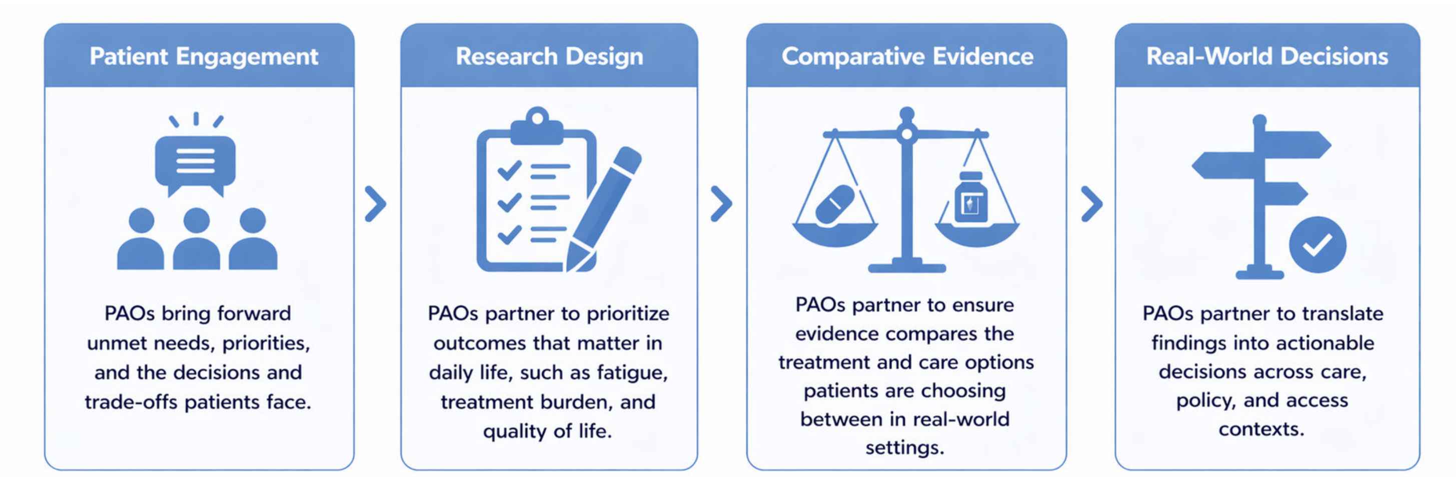
Since 2019, the FDA has approved several targeted NMOSD therapies proven to reduce relapse rates and improve outcomes. However, there is limited evidence comparing how these treatments perform relative to one another. This is a critical evidence gap for our community as NMOSD requires long-term management and treatment decisions have lasting impacts on disability, family planning, and quality of life.

To address this, TSF designed a CER trial to evaluate rituximab, a historical off-label standard, against approved therapies including ravulizumab, eculizumab, inebilizumab, and satralizumab. The protocol was co-developed with patient partners to reflect real-world needs and includes patient-reported outcomes such as pain, fatigue, mood, and quality of life.

This approach demonstrates how CER can generate patient-centered evidence to guide practical treatment decisions and support shared decision-making, and highlights the role that PAOs can play in shaping research that helps their community live and function in daily life.

CER offers PAOs a clear opportunity to support the generation of evidence that reflects real-world needs, priorities, and patient-centered outcomes that go beyond traditional clinical endpoints. This leads to more relevant and usable insights that can directly inform clinical decision-making, health policy, and access to care.

Exhibit 6: Practical Ways PAOs Can Shape CER



Patient Engagement

PAOs bring forward unmet needs, priorities, and the decisions and trade-offs patients face.

Research Design

PAOs partner to prioritize outcomes that matter in daily life, such as fatigue, treatment burden, and quality of life.

Comparative Evidence

PAOs partner to ensure evidence compares the treatment and care options patients are choosing between in real-world settings.

Real-World Decisions

PAOs partner to translate findings into actionable decisions across care, policy, and access contexts.

SECTION 02

GETTING STARTED

PREPARING FOR RESEARCH ENGAGEMENT

SECTION OVERVIEW

Many PAOs already hold strong foundations for research engagement: community trust, lived experience expertise, and established programs. As you move from grassroots activities toward structured partnership, it is important to put dedicated organizational capacity in place to support efforts that are both realistic and meaningful for your community.

This section provides practical frameworks and reflection tools to help you clarify research goals, assess organizational readiness, scope priority initiatives including those that may contribute to CER, and plan the resources needed for you to engage effectively in research.

2.1 Clarifying Your Research Goals

Why goal clarity matters

Spend time clarifying your organization's research goals upfront. Being specific about what you want to achieve helps ensure research efforts are purposeful, strategic, and rooted in what matters most to your community. You may identify multiple areas of interest, but prioritizing where to start helps prevent overextension or engagement in opportunities that don't align with your capacity or focus.

Exhibit 7: Reflections to Support Defining Your Organization's Research Goals

Consideration	Reflection Questions	Why It Matters
Advocacy alignment	How could research engagement support our advocacy or policy goals?	Ensures research efforts reinforce broader organizational goals
Research influence	Do we want to shape research priorities, study design, or dissemination?	Determines the level and type of partnerships to pursue
CER alignment	Do we want to play a role in generating evidence that shapes treatment and care decisions?	Helps prioritize opportunities that influence real-world treatment and care decisions
Community insight	Are we looking to gather structured input from patients or caregivers?	Helps guide method selection (e.g., surveys, advisory groups)
Capacity-building	Do we want to develop trained research partners or patient leaders?	Requires investment in education, mentorship, and support
Funding readiness	Are we preparing to partner on grant-funded research?	Shapes infrastructure and partnership needs

Aligning internally before engaging externally

Take time to ensure your specific research goals are aligned with your broader organizational mission. Ideally, your research goals will also intersect with your advocacy, community programs, and policy priorities. Clarifying this alignment early helps prevent mixed messaging or unrealistic expectations both internally and for research partners.

Exhibit 8: Reflections to Support Internal Alignment

Consideration	Reflection Questions	Why It Matters
Mission & vision alignment	How does research engagement support our core mission and long-term vision?	Ensures research efforts reinforce, rather than compete with, organizational priorities
Advocacy & program integration	How will research engagement connect with our advocacy, policy, education, and community support activities?	Promotes consistency across organizational efforts and strengthens overall impact
Leadership & staff buy-in	Do staff and leadership share understanding and support for research involvement?	Enables coordinated implementation and realistic workload planning
Community expectations	How do we communicate research engagement to our community?	Builds trust and ensures transparency about roles and impact

2.2 Assessing Capacity & Setting Priority Initiatives

Understanding your starting point

It is not necessary to have every resource in place before initiating research activities; many organizations build infrastructure iteratively as they gain more partnership experience.

At the same time, research engagement introduces real operational demands, including staffing, coordination, training, and administrative oversight. Taking stock of your current capacity helps you leverage existing assets while planning for the support needed to engage in future partnership efforts.

Exhibit 9: Assessing Capacity For Research Engagement

Capacity Area	Signals You May Need Additional Support
Staffing & leadership time	Prospective research activities are added on top of existing roles without dedicated time or ownership
Partnership coordination	Communication, scheduling, and follow-up with partners feel ad hoc or difficult to sustain
Training & preparation	Staff or partners feel unsure about research processes, terminology, or expectations
Administrative infrastructure	Contracts, compensation, or documentation processes are unclear or time-intensive to manage
Financial resources	Engagement costs (e.g., partner compensation, accessibility supports, travel) are not yet budgeted
Sustainability	Participation depends on short-term enthusiasm rather than long-term operational planning

Defining priority research initiatives

With research goals clarified and organizational capacity considered, the next step is to define clearly scoped initiatives, such as community surveys, patient registries, patient-driven data collection, advisory councils, or proposals for grant-funded research.

CASE STUDY: ORIGINS OF THE NMOSD/MOGAD RESEARCH AGENDA

Guided by our mission to illuminate the darkness of NMOSD, MOGAD, and related disorders, TSF has worked since 2014 to serve and mobilize the global neuroimmunology community. Initiatives such as our Coalition for Health Equity, Spark Research Grants, and TSF Ambassador program have identified persistent gaps in diagnosis, care, and access, and underscored the need for stronger alignment between community priorities and scientific activity. Our PCORI Engagement Award was designed to address this through the development of a NMOSD and MOGAD research agenda to guide future research efforts, specifically CER. Co-developed with patients, caregivers, clinicians, researchers, allied health professionals, and other stakeholders, this agenda aims to strengthen the alignment of research with patient priorities and support the generation of evidence that better informs real-world decisions.

Initiatives that contribute to decision-relevant evidence

As discussed in Section 1.4, PAOs can play a valuable role as partners in generating evidence that influences healthcare decision-making. However, not all activities contribute equally to this. As you define your initiatives, consider how they may lead to comparative, patient-centered evidence as this can help position your work to drive impact in clinical decision-making, health policy, and access to care.

Exhibit 10: Examples of CER-Related Research Activities

Research Goal Type	Example Activities	Potential Impact
Awareness & community insight	Surveys, listening sessions, community discussions	Amplifies community voice and builds understanding of unmet patient needs
Priority-setting & agenda development	Delphi processes, advisory councils, research agenda setting	Identifies and elevates community-driven research priorities
Partnership & capacity-building	Training patient partners, establishing research councils, supporting patient engagement in studies	Strengthens long-term ability to participate in research teams, advisory boards, and steering committees
Evidence generation to inform decisions	Partnering on CER studies that compare treatment or care options and measure outcomes that matter to patients	Contributes to evidence that informs real-world treatment and care decisions
Translation & Dissemination	Developing plain-language summaries and educational resources; sharing CER findings with patient communities, clinicians, and policymakers	Supports uptake of evidence in practice and helps ensure research findings are understood and used in real-world decision-making

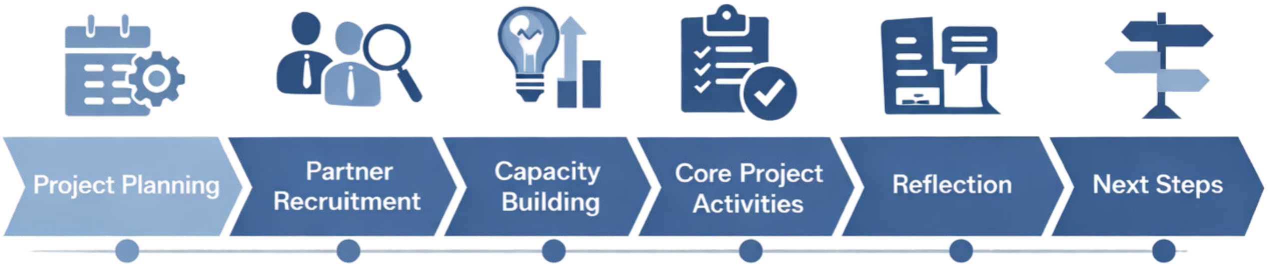
2.3 Planning & Budgeting Research Activities

Planning your project

Before jumping into execution, it's worth investing time upfront to think through a clear, actionable plan to ensure your initiative is well-coordinated and feasible. This includes defining objectives, setting realistic milestones and deliverables, establishing project timelines, identifying coordination needs, and determining who will be responsible for leading and supporting the work.

While research initiatives vary in scope, many follow similar phases – from project planning, to partner recruitment and onboarding, to capacity building, to core project activities, to dissemination of findings, to reflection and next steps.

Exhibit 11: Typical Operational Phases of Engagement Initiatives



Involve external stakeholders early as you plan your project – including patient partners, clinicians, researchers, industry partners, and other collaborators. This helps ensure expectations around roles, decision-making, and ongoing participation are aligned from the outset, and allows projects to be shaped by practical insight before plans are finalized.

We recommend capturing your plan in a simple one-page project summary that you can return to throughout the project. This shared reference point helps keep everyone aligned on purpose, scope, roles, and timeline, and makes it easier to course-correct early if expectations start to drift.

Budgeting and resourcing for engagement

A common oversight is under-budgeting for patient engagement. Engagement costs should be planned upfront, not retrofitted after other budget items are set. Investing in engagement activities is also an investment in your community that supports meaningful participation, builds trust, and strengthens long-term capacity. Consider partner compensation, capacity training, coordination needs and accessibility supports needed to make participation feasible to diverse members of your community including those balancing work, caregiving responsibilities, health needs, or other day-to-day demands. Refer to Section 4.2 for more detailed guidance.

SECTION 03

BUILDING PARTNERSHIPS

STRUCTURING EFFECTIVE MULTI-STAKEHOLDER PARTNERSHIPS

SECTION OVERVIEW

When building research capacity, it is important to look beyond your patient community and consider the full range of stakeholders involved in research. While patient perspectives remain foundational, the most effective collaborations often occur at the intersection of community insight, research expertise, and clinical knowledge.

This section focuses on how to thoughtfully assemble multi-stakeholder teams, define meaningful roles, cultivate trust-based collaboration, and support patient partners to grow as confident partners within multi-stakeholder research environments.

3.1 Bringing the Right Partners Together

Balancing experiential knowledge & technical expertise

In addition to patient partners, engagement teams may include caregivers, clinicians, academic researchers, allied health professionals, as well as partners from healthcare organizations, industry, and policy settings. Bringing these voices together helps ensure initiatives are informed by complementary perspectives on disease burden, care delivery, and the practical realities of designing and executing research. This alignment is particularly important in CER, where integrating lived experience and clinical perspectives is essential to defining meaningful treatment and care comparisons and patient-centered outcomes.

Exhibit 12: Complementary Experiential Knowledge and Technical Expertise

Patients & Caregivers	Clinicians, Researchers, and Other Partners
Lived experience with the condition	Scientific and methodological expertise
Insight into unmet needs and care gaps	Understanding of diagnostic and treatment pathways
Perspectives on treatment realities and quality of life	Expertise in study design and research methods
Awareness of participation barriers and accessibility needs	Knowledge of feasibility, safety, and regulatory considerations
Community trust and connection	Access to clinical populations and research infrastructure

Designing diverse & representative teams

As you consider which partners to bring into the work, it can be helpful to think about whose voices are represented and whose may be missing. Patient and caregiver experiences are not one-size-fits-all, and perspectives can differ based on factors such as geography, culture, race and ethnicity, financial circumstances, disability, or access to care. Being mindful of this variation helps ensure the priorities identified and solutions developed reflect the broader realities of your community, not just those most visible or easiest to engage.

Exhibit 13: Reflections to Support Building Diverse & Representative Teams

Consideration	Reflection Question	Practical Strategies
Representation	Does our partner group reflect the diversity of our community?	Outreach through support groups, registries, community networks
Range of lived experiences	Are multiple disease stages and experiences represented?	Include both newly diagnosed and long-term patients
Caregiver perspectives	Are caregivers included where relevant in the work?	Engage family partners to broaden insight
Skills and readiness	Do partners feel comfortable contributing in group settings?	Provide onboarding, orientation, and mentorship
Equitable outreach	Are we reaching individuals who may face barriers to participation?	Translate materials and partner with community organizations

Refer to Section 4.1 for practical guidance on recruiting for diverse and representative teams.

Selecting collaborators for partnership readiness

When identifying clinician, researcher, and other stakeholders, consider their prior experience working in patient-centered environments and their demonstrated openness to lived experience perspectives. Strong collaborators communicate in accessible language, engage patients and caregivers as peers, and value community insight as part of the research process. They also think ahead to how findings will be interpreted and applied in practice, policy, and access decisions. Look for these qualities in early interactions, as they often signal how collaboration will function and progress.

3.2 Clarifying Roles & Expectations

Structuring meaningful participation

Scheduling a meeting and bringing partners together is only the first step. Meaningful collaboration depends on setting clear, intentional expectations from the outset and clarifying who is responsible for what, what each partner is being asked to contribute, and how decisions will be made across the duration of a project.

How patient partners are positioned within this structure matters. If involvement is limited to reviewing materials or providing feedback after key decisions have already been made, opportunities for deeper contribution are lost. Creating space for patient partners to help shape priorities, contribute to study design, define interventions to be compared, identify patient-centered outcomes, develop materials, present alongside researchers, and interpret findings strengthens both the quality of the work and the development of patient leadership.

Establishing this clarity early supports coordination and accountability across the team. When partners understand their role and influence, collaboration tends to be more inclusive, productive, and sustainable.

Refer to Section 4.3 for guidance on designing governance and leadership structures.

CASE STUDY: ESTABLISHING A MULTI-STAKEHOLDER COUNCIL

TSF established a multi-stakeholder research council composed of patients, clinicians, and researchers. Roles and expectations were defined from the outset, with members co-developing community surveys, collaborating on research priority-setting activities through a modified Delphi survey process, supporting translation of materials into multiple languages, building consensus around the NMOSD and MOGAD research agenda to inform future CER, and authoring plain language communications. Patient members built partnership skills and confidence through targeted workshops, then applied them in collaborative, multi-stakeholder work sessions tied to specific outputs. This structure positioned patient partners not only as contributors, but as active collaborators and leaders while building their capacity for future research partnership.

Recognizing contributions and authorship

Authorship and acknowledgment considerations should be discussed early when defining partnership roles. When patient partners contribute to engagement outputs – such as resource development, priority-setting activities, data collection, communications materials, or dissemination efforts – their contributions should be appropriately recognized. Clarifying expectations around credit, authorship criteria, and acknowledgment practices helps ensure contributions are recognized equitably and prevents misunderstandings as projects evolve.

3.3 Building a Culture of Trust & Inclusive Collaboration

Addressing power dynamics and participation barriers

Research partnerships often bring together people with different types of expertise, professional backgrounds, and familiarity with research environments. It is important to recognize that these differences can shape how comfortable people feel participating in discussions and decision-making processes. Clinicians and researchers may be more accustomed to technical language and formal meeting structures, while patient partners may be newer to research terminology or group dynamics in academic settings.

Being mindful of these dynamics helps create more balanced participation. Simple structural choices – such as pacing discussions, clarifying terminology, and ensuring space for questions – can help reduce participation barriers and support more confident engagement from all partners.

Fostering trust and inclusive dialogue

Creating an approachable and productive collaboration environment requires consistency in communication, openness to differing viewpoints, and a shared commitment to mutual learning across stakeholder groups. Trust develops when partners feel their perspectives are respected, taken seriously, and reflected in decision-making. Fostering reciprocal relationships grounded in co-learning, transparency, honesty, and trust can also help balance inherent power differences across the group.

Thoughtful coordination and facilitation play an underestimated but central role in making this possible. Simple practices such as inviting patient perspectives early in discussions, using accessible language, and creating space for reflection or small-group dialogue can support more balanced participation and ensure conversations are not dominated by academic or institutional voices. Approaches such as moderated discussion rounds, breakout groups, or guided reflection can further help ensure contributions are not limited to those most comfortable speaking in professional or technical settings.

Facilitators help shape how dialogue unfolds. Establishing shared group values – including respect for diverse perspectives and openness to challenge – creates space for constructive disagreement and deeper insight. When practiced consistently, these practices strengthen trust, improve decision-making, and support more effective multi-stakeholder collaboration.

Exhibit 14: The Engagement–Trust Feedback Loop

3.4 Developing & Supporting Patient Partners

Building research literacy and engagement skills

Patient partners bring critical lived experience and experiential knowledge, offering insight grounded in real-world care realities and community priorities. At the same time, they may be newer to research concepts and processes. Building research literacy supports more confident participation and more meaningful contributions to discussions, decisions, and outputs. This may include orientation to study design fundamentals and terminology, as well as understanding how treatment comparisons are structured, how outcomes are selected, and how evidence informs real-world decisions. Skill-building may also be needed in areas such as reviewing materials, participating in meetings, public speaking, and contributing to collaborative decision-making.

Providing structured opportunities for learning and practice helps build a strong foundation of informed, confident partners who are equipped to actively shape research and represent community priorities across research teams and collaborations.

In practice, this may look like patients partnering to determine which treatment options are compared, identify outcomes to include in surveys or data collection, or review protocols to ensure they reflect real-world feasibility and patient realities.

Supporting leadership pathways and peer mentorship

Considering the motivations, skills, and strengths of partners can help identify pathways to deepen partnership over time. Cultivating a broad base of capable patient partners – rather than relying on a small number of experienced advocates – strengthens long-term research infrastructure and organizational capacity.

Capacity-building should be approached as an ongoing process, with learning integrated into meetings, supported through self-directed resources, and reinforced through peer mentorship models. Whenever possible, learning should be paired with immediate opportunities for application – for example, reviewing a study document after an orientation to protocol design, or practicing feedback techniques within live project discussions. Pairing newer partners with experienced members further supports confidence-building, knowledge transfer, and peer learning while creating space to translate new knowledge into practice.

Anticipating collaboration challenges and sustaining participation

Even thoughtfully structured partnerships will require adjustment as the work unfolds. Multi-stakeholder research initiatives operate within real-world constraints, with tight project timelines, competing priorities, and evolving partner availability. Approaching partnership with a mindset of responsiveness rather than rigidity allows teams to adapt as needs and circumstances emerge.

Participation may shift as patient partners balance engagement alongside health needs, caregiving responsibilities, employment, or other life demands. Similarly, the intensity of research activities may rise and fall across project phases, with some periods requiring more concentrated input than others. Building flexibility into how and when partners contribute, as well as planning for continuity across project phases, can help maintain stability even as individual involvement fluctuates.

Exhibit 15: Building Stronger Partnerships by Anticipating Collaboration Challenges

Challenge	Potential Manifestation	Strengthening Approaches
Project pacing & timelines	Limited time to review materials or provide feedback	Build in realistic input windows and clearly signal priority areas for partner feedback
Role clarity & scope of influence	Uncertainty about where input is expected or how it informs decisions	Define roles, decision points, and engagement expectations early and revisit throughout the project
Power dynamics in group settings	Academic or clinical voices unintentionally dominating discussions	Use facilitated dialogue, structured input methods, and inclusive meeting practices
Emotional labor of sharing lived experience	Fatigue or discomfort related to recounting health experiences	Offer flexibility, content advisories, and supportive facilitation approaches
Representation burden	Individuals feeling responsible for representing an entire community perspective	Clarify that partners are contributing perspective, not serving as sole representatives of the entire community
Sustaining participation	Engagement fluctuating due to health, caregiving, or employment demands	Offer multiple participation formats and plan for transitions to maintain continuity if involvement changes over time

SECTION 04

OPERATIONALIZING PARTNERSHIPS

SYSTEMS & EXECUTION

SECTION OVERVIEW

With the foundations of multi-stakeholder partnership established, this section turns to how engagement is operationalized in practice. This includes designing accessible participation environments, selecting appropriate engagement methods, coordinating activities, documenting insights, and evaluating partnership quality as initiatives progress.

While research projects themselves may differ, the day-to-day work of partnership tends to follow similar systems, processes, and coordination needs. This section offers concrete actions and operational tactics that enable partnership to function effectively in practice, including within CER studies and related initiatives.

4.1 Partner Recruitment & Onboarding

Inviting and onboarding partners for engagement

As outlined in Section 3.1, organizations should be intentional about who they engage and why. Prospective partners should reflect a mix of lived experience, skillsets, and collaborative readiness aligned to the objectives of the initiative.

Recruitment outreach should be clear, transparent, and grounded in assessing mutual fit. Early conversations are an opportunity to share the purpose of the work, why the individual's perspective is valued, and what participation will involve. Being upfront about key considerations helps partners assess fit and engage with realistic expectations. This may include:

- Anticipated time commitments
- Meeting cadence and duration of involvement
- Level of decision-making influence
- Compensation and available supports

Recruitment dialogue should create space for prospective partners to ask questions, share motivations, and raise accessibility or capacity considerations. Establishing this clarity early supports alignment on both sides and lays the foundation for more sustainable, long-term participation.

CASE STUDY: RECRUITING PATIENT PARTNERS

To recruit patient partners, we engaged members of our TSF Ambassador program: a community network of over 100 patients, caregivers, and clinicians who serve as peer leaders, educators, and regional connectors. Ambassadors support and lead awareness campaigns, support groups, and other initiatives across diverse geographies and care contexts. Engaging this network provided a useful starting point for identifying partners with both lived experience and demonstrated commitment to community partnership.

Planning for engagement continuity

As initiatives progress, it is also important to anticipate natural shifts in partner participation. Over multi-year projects, some partners may step back due to health changes, caregiving demands, or evolving personal priorities. Anticipating this from the start – for example, by lightly over-recruiting advisory groups – helps maintain continuity if participation fluctuates.

4.2 Compensation & Participation Supports

Recognizing lived experience as expertise

Unlike clinicians or researchers, patient partners are usually not participating as part of their paid professional role. Engagement often requires stepping away from work, caregiving responsibilities, or personal time in order to contribute.

Without compensation, participation may unintentionally be limited to those who have the time, financial flexibility, or health stability to volunteer. Providing compensation that reflects fair market value affirms patient partnership as valued expertise rather than voluntary contribution. PCORI's Financial Compensation Framework recommends aligning compensation for patient and caregiver partners with the time, effort, expertise, and responsibilities associated with their role. In practice, TSF has seen rates begin within the $50-$100 per hour range, with higher levels for roles involving greater responsibility, preparation, or leadership.

Before designing compensation structures, it is important to consider how payments may intersect with disability or income-dependent public assistance benefits. Offering flexible options – or inviting patient partners to share preferences around compensation structure – can help support participation in ways that are responsive to individual circumstances.

Exhibit 16: Example Partner Compensation Models

Engagement Activity	Compensation Considerations
Advisory or council participation	Per-meeting stipends or term-based honoraria
Document review or feedback	Hourly compensation or flat review fees
Governance or leadership roles	Expanded stipends reflecting level of engagement (refer to Exhibit 3)
Conference presentations or dissemination activities	Speaker honoraria and travel coverage
Research collaboration (e.g., co-investigator roles)	Contracted compensation aligned with scope of work

Resourcing participation supports

Organizations should also think about the practical supports that help patient partners participate fully. This can include covering travel and lodging for in-person meetings, providing technology access such as internet stipends, devices, or required software platforms, and ensuring accessibility accommodations like captioning, assistive technology, or mobility supports. Some partners may also require caregiving or respite reimbursement in order to participate, while others may benefit from translation or interpretation services to support language access. Putting these supports in place and clearly communicating their availability helps create inclusive conditions where partners can engage meaningfully and participate on more equitable footing with other stakeholders.

4.3 Governance & Leadership Structures

Embedding patient partners within formal project structures

It is important to establish clear project governance and leadership structures early to ensure that patient partners are embedded within initiatives rather than positioned on the sidelines. As you design these, be mindful of where influence sits, how input is incorporated, and how accountability is shared across stakeholders.

Many projects involve a tiered leadership model. This may include a core decision-making council, smaller working groups responsible for specific deliverables, and a broader community engaged for consultation or dissemination. Structuring engagement in this way allows patient partners to participate at varying levels of influence matching their skills, aptitudes, desires, and capacity.

Clarifying representation and authority

When designing leadership and decision structures, consider:

- How patient representation is embedded across groups
- The scope and responsibility of each body
- Participation expectations and term structures
- Alignment with compensation and resourcing models

Establishing these structures early helps manage expectations and ensures patient perspectives are integrated into decision-making processes rather than layered on as an afterthought.

4.4 Meeting Planning & Execution

Preparing inclusive meeting environments

Meeting design is a key determinant of how meaningful patient partnership will be in practice. Engagement does not occur simply because patients are present; it occurs when collaboration is intentionally prepared for, facilitated, and followed up on in ways that enable all partners to contribute their expertise.

Agendas that are overly technical, rushed, or dominated by academic voices can limit participation. In contrast, well-designed meetings create space for reflection, clarification, and dialogue, allowing patient insights to more directly inform project activities and decisions.

Exhibit 17: Meeting Preparation Considerations

Preparation Area	Key Questions	Practical Approaches & Tactics
Scheduling & Timing	Are meeting times workable across health, caregiving, and work realities?	Consider variable partner needs when scheduling meetings, and explore options such as rotating or standing times to support participation.
Session Length & Pacing	Is the meeting length realistic for participant stamina and focus?	Limit duration, build in breaks, and prioritize high-value discussion items.
Participation Format	Can partners engage in ways that suit their capacity and preferences?	Offer virtual, in-person, and hybrid options; include opportunities for asynchronous participation where possible (e.g., written feedback, surveys, document comments, recorded briefings)
Advance Preparation & Context	Do partners have adequate time and context to prepare and engage in discussion?	Offer optional pre-meeting briefings or primers, particularly for new partners or technical topics. Share agendas, slide decks, and background materials in advance (ideally ≥72 hours).
Clarity of Requested Input	Is it clear what type of feedback or expertise is being sought?	Clarify whether the discussion is exploratory, feedback-focused, or decision-oriented and what input is intended to inform (e.g., research questions, treatment outcomes, or outcome selection) so partners can prepare accordingly.
Language & Content Accessibility	Are materials understandable to non-technical participants?	Use plain language, define terminology, and provide glossaries or briefing notes to reduce jargon barriers.
Accessibility & Accommodation Planning	Have participation supports been proactively addressed?	Arrange captioning, translation, interpretation, disability accommodations, and confirm needs in advance.
Technology Readiness	Do partners have the tools and supports needed to participate fully?	Provide tech orientation, troubleshooting support, and alternative dial-in options.

Refer to Section 3.2 for more conceptual guidance on preparing for meaningful participation.

Facilitating inclusive dialogue in practice

The quality of facilitation determines how inclusive and meaningful dialogue will be. Skilled facilitation helps balance participation, encourages contribution from all partners, and ensures patient perspectives are actively surfaced and integrated into group discussion and decision-making.

Exhibit 18: Meeting Facilitation Considerations

Facilitation Area	Key Questions	Practical Approaches & Tactics
Opening & Context Setting	Are partners oriented to the purpose of the discussion?	Begin with a brief overview of objectives, agenda flow, and where partner input is most needed.
Balanced Participation & Accessible Dialogue	Are all partners able to engage meaningfully in discussion?	Invite input across stakeholder groups, use round-robin prompts, define terminology in real time, and encourage clarifying questions.
Power Dynamics & Psychological Safety	Do partners feel comfortable sharing candid or dissenting perspectives?	Actively invite patient perspectives, validate contributions, and redirect discussion if certain voices dominate.
Breakout Discussions	Are smaller formats being used to support deeper participation?	Use breakout groups or paired discussions to create space for reflection and encourage input from quieter participants.
Engagement Methods & Participation Tools	Are varied formats being used to support different communication styles?	Incorporate live polls, guided reflection, chat input, icebreakers, or visual exercises to broaden participation.
Real-Time Synthesis & Capture	Are partner insights being captured and reflected accurately?	Summarize discussion themes, confirm interpretations, and reflect back key points before moving forward.
Facilitation Support Roles	Are team roles structured to support effective dialogue?	Assign facilitators, note-takers, timekeepers, and technical support to ensure discussions run smoothly.

Refer to Section 3.3 for more conceptual guidance on building trust-based, inclusive partnership environments.

Translating discussion into action

Follow-up is where partners determine whether their participation truly mattered. How insights are captured, communicated, and acted on after meetings shapes whether engagement feels meaningful or merely symbolic. Clear documentation, visible next steps, and transparent communication all play a role in sustaining momentum and reinforcing trust in the partnership process.

Follow-through also helps preserve what your organization is learning through engagement. Capturing not only decisions, but the discussions and reasoning behind them ensures that knowledge is retained over time. This makes partnership more sustainable, transferable to future work, and less dependent on any single staff member or partner remaining involved.

Exhibit 19: Meeting Follow-up Considerations

Follow-Up Area	Key Questions	Practical Approaches & Tactics
Documenting Insights & Decisions	Were discussion themes, partner contributions, and decisions accurately captured?	Compile synthesized notes reflecting key insights, areas of consensus, open questions, and agreed decisions.
Capturing Additional Reflections	Were partners given space to share input not raised live?	Offer asynchronous follow-up channels such as surveys, written reflections, or email feedback opportunities.
Sharing Materials & Tracking Commitments	Do participants have access to meeting outputs and clarity on responsibilities moving forward?	Distribute slide decks, recordings, summaries, and supporting documents alongside action logs, assigned leads, deliverables, and timelines.
Archiving & Institutional Knowledge	Is engagement documentation preserved for continuity and learning?	Store notes, outputs, and engagement artifacts in centralized repositories to support onboarding, institutional memory, and long-term partnership infrastructure.
Sustaining Engagement Continuity	Do partners understand how their input informed direction and remain connected between meetings?	Share post-meeting recaps outlining decisions, rationale, and next steps. Provide interim updates and progress reports to sustain engagement and visibility into project momentum.

Refer to Section 3.3 for more conceptual guidance on building long-term partnerships.

4.5 Staying Connected Between Meetings

Maintaining and growing momentum through feedback and reflection

Meaningful partnership requires ongoing attention between formal meetings. Without intentional touch points, collaboration can become episodic, reducing alignment, and making it harder to identify emerging needs as initiatives progress.

Continuous engagement creates space to understand how partners are experiencing the work, surface challenges early, and reinforce shared investment in the initiative. Building in opportunities for reflection and demonstrating openness to adjusting engagement approaches helps ensure partnership remains responsive, adaptive, and positioned for long-term success.

Exhibit 20: Continuous Engagement Considerations

Engagement Area	Key Questions	Practical Approaches & Tactics
Ongoing Partner Check-Ins	Are partners being supported between meetings?	Conduct periodic 1:1 or small-group check-ins to understand partner experience, workload, and emerging needs.
Partnership Feedback & Reflection	Do partners feel comfortable sharing candid feedback?	Use surveys, reflection prompts, pulse polls, and milestone discussions to gather input on meeting experience, communication, and partnership dynamics.
Adapting Engagement Approaches	Are partnership structures being refined based on partner input?	Use feedback to adjust not only meeting practices, but also project activities, priorities, and partnership approaches as the initiative evolves.
Sustaining Communication & Partner Value	Do partners remain informed, connected, and motivated?	Share interim updates, highlight how input is shaping decisions, acknowledge contributions, and celebrate wins between meetings.
Transition & Exit Learning	When partners step back, is learning being captured?	Conduct brief exit conversations to understand partner experience and identify improvements for retention and future recruitment.

SECTION 05

SUSTAINABILITY

MAINTAINING & SCALING PARTNERSHIPS

SECTION OVERVIEW

While effective meeting design, facilitation, and follow-up are essential to operationalizing patient partnership, sustaining engagement involves additional planning and support. As initiatives grow, organizations should consider how to maintain relationships, preserve what they are learning, and resource the work in ways that allow patient partnership and CER capacity to continue and scale.

Sustainability emerges through the intentional cultivation of partnerships, knowledge infrastructure, and resourcing pathways that support engagement to persist, evolve, and scale in impact. This section outlines the practices that help you sustain partnership momentum and build durable, long-term infrastructure.

5.1 Building Long-Term Partnerships

Strengthening trust, visibility, and leadership pathways

When partners feel respected, valued, and meaningfully included, they are more likely to remain engaged and to bring forward new ideas, networks, and collaboration opportunities. This can create a compounding effect, where trusted relationships open doors to additional initiatives, partnerships, and resourcing opportunities.

Recognizing partner contributions through authorship, co-presentation, and public acknowledgment can further strengthen long-term engagement. Visible credit not only reflects equitable partnership practices, but also supports the professional development and leadership progression of patient partners.

CASE STUDY: PAO-DRIVEN PARTNERSHIP FOR A CER TRIAL

As we developed the NMOSD and MOGAD research agenda to inform future CER, partners identified funding opportunities aligned with community-defined priorities. When PCORI released a targeted rare disease CER funding opportunity, TSF's executive team, including patient leaders, worked alongside our Medical Advisory Board and other collaborators to develop the proposal, integrating input from our multi-stakeholder research council into the study concept, outcomes, and engagement approach. This progression — from PCORI-funded engagement to a full-scale CER study — brought together scientific rigor and lived experience, and resulted in TSF securing $9 million to lead a five-year international study comparing NMOSD relapse prevention therapies.

5.2 Strengthening Engagement Infrastructure

Embedding partnership within organizational systems and practices

As engagement activities expand, sustaining momentum requires more than strong relationships alone. Embedding partnership across organizational functions helps ensure engagement is coordinated, resourced, and positioned to inform multiple areas of work rather than operating in isolation. Over time, this foundation can evolve into evidence-generating infrastructure, including patient registries or longitudinal datasets that contribute to CER.

When integrated across research, advocacy, education, and policy activities, partnership efforts become mutually reinforcing – strengthening program relevance, preserving institutional learning, and enabling insights generated through engagement to inform broader strategic priorities and direction.

5.3 Scaling Impact & Sustaining Resources

Expanding reach, partnerships, and funding pathways

Early engagement initiatives are often focused on building capacity and exploring partnership approaches. With thoughtful planning, this initial work can build its own momentum – generating outputs that ripple across your field, developing patient leaders, and strengthening organizational experience beyond a single project.

As partnership capacity becomes more visible, organizations may find that researchers and collaborators begin seeking them out directly. Documenting and sharing engagement successes including through presentations, publications, and professional networks can strengthen organizational positioning and open new partnership opportunities. Demonstrating the ability to contribute to CER can also strengthen funding opportunities, as funders and partners increasingly prioritize research that produces comparative, real-world evidence to inform decision-making.

Scaling engagement often involves a few parallel areas of focus: sharing what has been built so others can learn from it, identifying new funding pathways to sustain the work, and creating opportunities for patient partners and organizational expertise to contribute across an expanding ecosystem of research, advocacy, and policy initiatives.

Exhibit 21: Sustaining & Scaling Engagement Infrastructure

Infrastructure Area	Key Questions	Practical Approaches & Tactics
Knowledge Continuity & Field Leadership	Is partnership learning being retained, shared, and extended beyond the initiative?	Document processes, decisions, and outputs in centralized repositories. Pair experienced partners with newer members to transfer knowledge. Translate learnings into trainings, advisory roles, and peer support for other organizations.
Visibility & Evidence Dissemination	Are partnership activities and outcomes visible and contributing to the broader field?	Share webinars, reports, newsletters, toolkits, conference presentations, and publications to communicate impact and sustain engagement interest.
Evolving Needs & Priority Alignment	Are emerging partner and community priorities being surfaced over time?	Facilitate sustainability conversations, feedback touch points, and priority refresh exercises to guide future initiatives.
Organizational Integration	Is engagement embedded across broader organizational work?	Integrate partnership across research, advocacy, education, and policy initiatives to strengthen continuity and influence.
Network & Collaboration Growth	Are external partnerships expanding engagement opportunity?	Build relationships with advocacy groups, research networks, and health system partners to support joint initiatives and shared learning.
Resourcing & Funding Pathways	Are resources in place to sustain and grow engagement work?	Pursue grants, sponsorships, fundraising, and research partnerships to support long-term capacity.
Organizational Capacity for Scale	Does the organization have the infrastructure to support growth?	Assess staffing, governance, systems, and leadership capacity; invest in operational supports and professional development to sustain expansion.

CLOSING REFLECTIONS

THE FUTURE OF PATIENT PARTNERSHIP

The learnings captured in this toolkit reflect the ongoing work of building patient partnership in practice. What begins as a single initiative can evolve into sustained relationships, strengthened infrastructure, and expanded opportunities for impact, including the ability to engage in and lead CER that improves patient outcomes, informs policy, and expands access to treatment and care.

In this evolution, PAOs become not only partners in research, but architects shaping the ecosystems in which research is conceived, designed, and advanced. This shift is increasingly visible across the field, with organizations stepping into roles as capacity builders, conveners, and research leaders.

At TSF, this work is being operationalized through practice-based learning. Research engagement efforts initiated in 2024 have focused on building partnership infrastructure, training patient partners, and co-developing a research agenda for NMOSD and MOGAD to inform future CER. This foundational work directly supported TSF in securing $9 million to lead a five-year international CER trial funded by PCORI, with TSF serving as study sponsor. In this role, TSF is leading the coordination of the trial, overseeing implementation, and ensuring patient engagement remains embedded throughout its execution.

While the future of patient partnership continues to take shape and expand, this progression within one PAO illustrates how strategic investment in community partnership can translate into stronger research infrastructure that supports more effective and equitable health systems. When lived experience is seen, heard, valued, and systematically integrated, research becomes more relevant, more responsive, and better positioned to generate patient-centered, comparative evidence that translates into real-world treatment and care decisions.

Sustaining this momentum will require ongoing collaboration across patient communities, clinicians, researchers, funders, policymakers, and beyond. No single individual or organization advances this work alone. Progress emerges through shared learning, partnership, and a collective commitment to ensuring research reflects the needs, priorities, and lived expertise of the communities it serves.

LOOKING FOR ADDITIONAL SUPPORT?

TSF continues to build research partnership infrastructure, train patient leaders, and advance multi-stakeholder collaboration across the field of rare diseases. To learn more about collaboration opportunities, visit sumairafoundation.org or email contact@sumairafoundation.org.

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REFERENCES & ADDITIONAL RESOURCES

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