Value Proposition Playbook for Participant-Driven Research in Health Care

JULY 2021

Value Proposition Playbook for Participant-Driven Research in Health Care is a practical guide developed by and for patient/participant-driven research communities (PDRCs) to support sustainability by demonstrating value to their participants and partners.

NORC at the University of Chicago

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Value Proposition Playbook Contents

Credits: The Value Proposition Playbook for Participant-Driven Research in Health Care is a product of the Enabling Sustainable Business Models Workgroup of the Patient/Participant-Driven Research Community Learning Network (PDRC LN) sponsored by the Patient-Centered Outcomes Research Institute (PCORI), under IDIQ Task Order #9-N ORC-AOSEPP-ENG to NORC at the University of Chicago.

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About this Resource

Participant-driven research communities, or PDRCs, work to amplify the voices of people with lived experience and elevate their priorities for and participation in research. As such, PDRCs play an increasingly vital role in the health care research ecosystem through their relationships with providers, academic institutions, pharmaceutical companies, biotech firms, and other entities. PDRCs' success and sustainability rely, in part, on their ability to collaborate with multiple partners, demonstrate value to their participants, and obtain funding from diverse sources to support their projects and operations.

The **Value Proposition Playbook for Participant-Driven Research in Health Care** (the Playbook) was developed by and for organizations that are part of PDRCs to sustain participant-driven research by crafting and delivering value propositions that resonate with their target audiences. It is the product of a year-long sustainability workgroup composed of different types of PDRCs that participated in a learning network for PDRCs funded by PCORI. Together the workgroup agreed that the business model that PDRCs must employ to achieve sustainability is complex and often involves multiple partnerships with diverse collaborators. As with all effective partnerships, PDRCs must understand the goals and needs of the partners, how the PDRC can help partners achieve those goals, and articulate the value for these partners in working with the network. With this in mind, the workgroup sought to create an action-oriented resource to help PDRCs develop a strong value proposition to their external partners, including funders and participants.

Drawing from the direct experience of PDRCs, as well as evidence and resources on partnership development and nonprofit sustainability, the Playbook provides strategies and tools for PDRCs to identify their strengths, understand areas for growth, identify priority audiences, and tailor their propositions to those audiences. These guided activities are recommended to be time intensive in order for the user to gain a more thorough understanding of their organization's needs. To learn more about what is included in the Playbook and how to use it, please begin with the Roadmap.

Roadmap

What is a patient- or participant-driven research community (PDRC)? A PDRC is an organization or group of individuals/organizations that is led and/or governed by patients/participants (people with lived experiences) and/or caregivers. A PDRC's primary purpose is to enable research that is a priority to those patient/participant or caregiver communities. (Note: For the purposes of this resource, we will use "participant-driven.")

PDRCs' critical feature is that they are led or governed by the individuals they serve. PDRCs provide a broad range of services that include leading research studies, collaborating on implementation and research protocols, collecting and sharing patient-generated health data, and recruiting research participants. In the Playbook, we use "participants" when referring generally to individuals who represent the population the PDRC aims to serve, which include patients, caregivers, and/or members of a representative population.

What gap does the Playbook fill? While many resources address how mission-driven organizations can fulfill their missions, PDRCs are unique in that the business model necessary to achieve sustainability and meet their goals is complex and often involves multiple partnerships with diverse collaborators. The playbook emphasizes the importance of understanding an individual organization's assets and strengths, as well as its ability to collaborate with external partners to leverage resources and achieve shared goals.

What does the Playbook cover? The Playbook draws from current evidence and resources on partnership development and nonprofit sustainability, PDRC experiences, and interviews with stakeholders in the participant-driven research ecosystem. The playbook provides a series of guided exercises to help PDRCs define their strengths, understand areas for growth, identify priority audiences, and communicate effectively with those audiences.

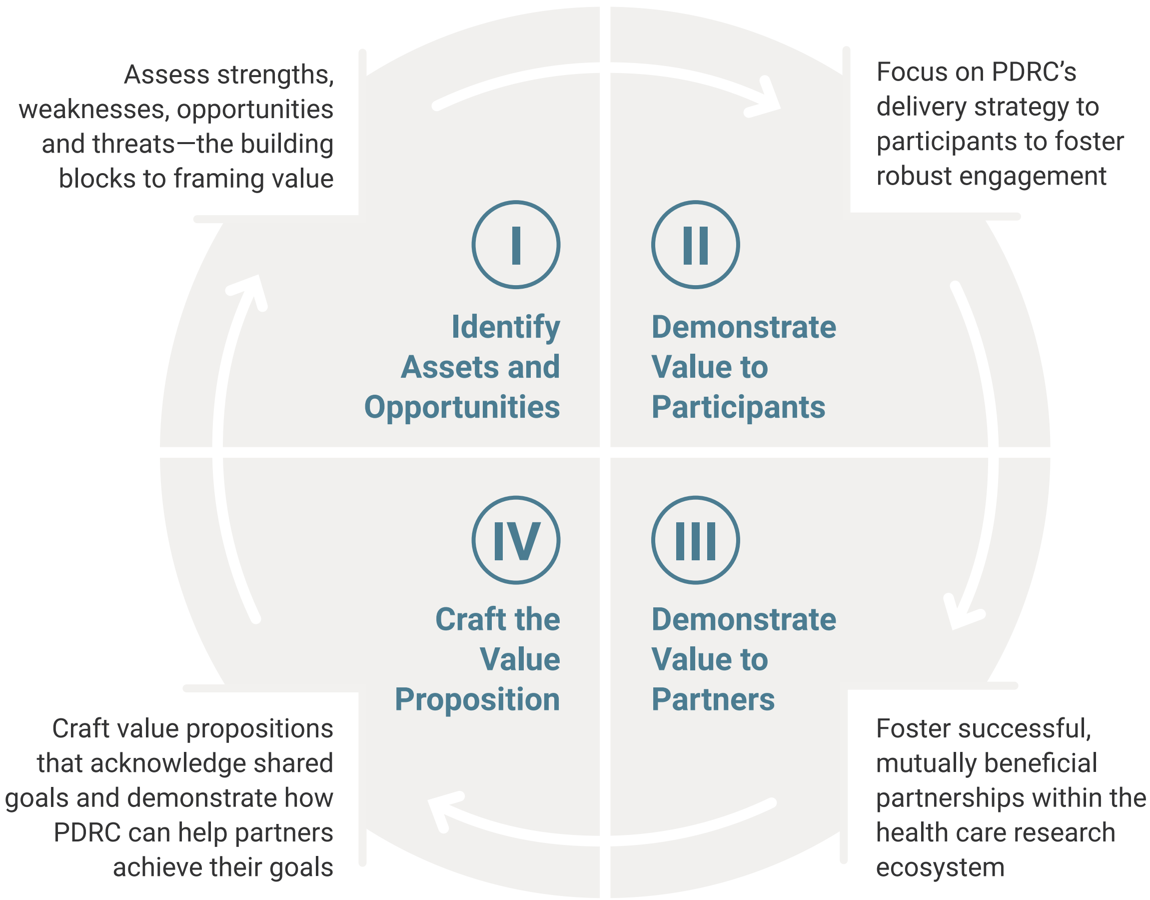
Who should use the Playbook? The Playbook is designed for organizations that have PDRCs and that aim to better engage their participants (individuals with lived experience with a condition or disease, their caregivers, or members of a population group that a PDRC aims to serve) in research and build and maintain partnerships with collaborating entities and funders.

The Playbook takes the perspective of entities that share financial and operational resources through a common organizational structure, such as a 501(c)3 or tax identification number. However, if your PDRC identifies as a consortium, with a less formal organizational structure, you may find it useful to approach some sections, such as Section II - Demonstrate Value to Participants, from the perspective of your individual organization as well as from the broader consortium.

How should you use the Playbook? The Playbook is designed to be used in whole or in part, as various sections and activities may be useful at different stages of planning and outreach. A PDRC may also find it useful to revisit different activities and discussion questions. PDRCs have suggested that one individual at an organization take ownership of the process of using these tools; however, we also acknowledge that smaller PDRCs may not have the bandwidth for full activities. For those smaller PDRCs, it may be helpful to just get a sense of potential processes to pursue in the future. The content and flow of the playbook is presented below.

Roadmap

Overview of content and flow of Value Proposition Playbook for Participant-Driven Research in Health Care



Assess strengths, weaknesses, opportunities and threats—the building blocks to framing value

Focus on PDRC's delivery strategy to participants to foster robust engagement

Foster successful, mutually beneficial partnerships within the health care research ecosystem

Craft value propositions that acknowledge shared goals and demonstrate how PDRC can help partners achieve their goals

I. Identify Assets and Opportunities explores the strengths, weaknesses, opportunities, and threats (SWOT) related to your PDRC's mission and work (**Activities 1** and **3**). The SWOT provides the building blocks of understanding your PDRC's value in the health care research ecosystem. The assessment includes a reflection on the financial climate in which your PDRC is operating (**Activity 2**).

II. Demonstrate Value to Participants considers the extent to which your PDRC is using different strategies to engage and deliver value to participants (**Activity 4**) and potentially identify new strategies.

III. Demonstrate Value to Partners explores the range of partners in the health care research ecosystem that may provide funding, in-kind services, or otherwise help expand the capacity of your PDRC. In addition, this section considers the goals and needs of partners and how your PDRC can demonstrate value in helping partners achieve those goals (**Activities 5** and **6**).

IV. Crafting the Value Proposition uses the information and understanding developed throughout the playbook to craft value propositions for different audiences (**Activities 7** and **8**).

I Identify Assets and Opportunities

What value does your PDRC offer its participants and partners? Is it as a research partner? An advocacy partner? Is your organization uniquely positioned to ask participants about their perspectives and identify research topics? Does your organization have built-in research capacity?

SWOT analysis is a technique that PDRCs can apply to develop a comprehensive understanding of their position in the participant-driven research ecosystem and to inform their value proposition. This section includes activities and guided questions to help identify the PDRC's internal strengths and weaknesses (S-W) as well as broader opportunities and threats (O-T). Each activity builds upon the others to allow the user to complete the SWOT analysis below.

STRENGTHS	WEAKNESSES
OPPORTUNITIES	THREATS

Activity 1. Identify Existing Assets and Growth Areas (Strengths and Weaknesses)

Activity 1 assesses the extent to which different assets—resources, competencies, and attributes that support a PDRC's overall mission and work—are available in your organization. Consider the assets listed in the following table and identify whether each is presently a strength or a weakness for your organization. Regardless of whether an asset presently exists, note which stakeholders—participants, research partners, or funders—would value this asset. The value of an asset may not solely accrue to the PDRC; it can benefit partner organizations. If an asset is not relevant to the work of your organization, indicate so with not applicable.

An asset is any capacity or resource that helps an organization reach its goals. For example, it might be patient reach; credibility; technological, scientific, or other expertise; highly sought-after relationships; or fundraising skill.

	Strengths	Weakness	Who Would Value this Asset?*
PDRC's role in research			
Leads participant-driven research studies			
Collaborates with outside entities to conduct participant-driven research studies (apart from recruitment)			
Collects, aggregates, or shares participant-generated data			
Funds research			
Connects stakeholders to advance participant research priorities			
Translates/disseminates research findings to participants and other stakeholders			
Coordinates or conducts advocacy for policies and funding to support research			
Participant community representative that functions as a trusted intermediary or neutral convener			
Publishes research			
Recruits participants for studies			
Supports or leads the uptake or implementation of research results			
Other			
PDRC has capacity to train and educate participants and stakeholders to prepare them for research			
Tools and resources			
Programs, trainings, events, or conferences			
Communications platform or forums			
Other			

*Participants, Research Partners, Funders

I. Identify Assets and Opportunities

	Strengths	Weakness	Who Would Value this Asset?*
PDRC has access to digital data and digital platform capacity for participant-driven research			
Access to PDRC-specific mobile applications			
Wearable devices			
Registry data			
Biorepository data			
Member survey data on patient-reported health information			
Clinical data connected to electronic health record (EHR)			
Virtual forums for research topic development and/or community			
Other			
PDRC has access to stakeholders that advance research agendas and enable research implementation			
Participants			
Foundations			
Other PDRCs			
Researchers			
Advocacy organizations			
Regulators			
Industry			
Other			
PDRC's financial base, sources of income			
Grant funding			
Fee for service			
Industry			
High donors			
Membership model			
Other			

*Participants, Research Partners, Funders

After you complete this exercise, reflect on the following questions:

- What are your PDRC's existing assets (strengths)?
- Which existing assets can pivot to new uses? Is your organization able to pivot quickly if necessary and offer something unique to the space?
- Which existing assets can be expanded so that the PDRC has more to offer?
- What resources, competencies, or relationships can be added to augment PDRC value?

Activity 2. Assess Organization's Financial Status

Activity 2 is a series of questions to prompt reflection on the financial context in which your organization is operating, as well as the extent to which it is a strength or weakness and facilitates the organization's ability to leverage opportunities and mitigate threats. Please note that PDRCs can have various structures—some are embedded within much larger organizations so it might be appropriate to assess certain aspects of their PDRC from different organizational levels—and PDRCs can tailor the steps in the playbook to fit their needs.

What are the ongoing expenses of the organization (e.g., staffing expenses, occupancy expenses, technology maintenance, recruitment)?

- Which activities are not covered by existing revenue or resources? Are these core activities?
- What are the core functions of the organization?
- How much flexibility is there to ramp up or scale down spending on nonessential activities?

What sources of revenue fund the organization?

- How diverse are all incoming revenue sources?
- How consistent is the revenue stream? Is it variable year-to-year?
- Does the PDRC receive any in-kind donations? How are these leveraged?
- Are there other potential sources of revenue, not yet captured?
- How much funding is research project driven or restricted use?
- Is there any support for capacity-building? Where?

For additional resources on funding, consider completing Activities 5 and 6.

What is the organization's breakeven point?

- What are your total fixed expenses (e.g., rent, utilities)?
- What are your variable expenses (i.e., those that vary depending on volume of activity)?
- Which expenses are discretionary?
- How dependent is the organization on a single revenue source?
- Can you reduce your variable or discretionary expenses in the event that one revenue stream ceases?
- Can the organization use available resources in a different way to attract additional funding if needed?

Notes

Activity 3. Assess Opportunities and Threats

Consider the external factors that your PDRC does not control. These may include developments in the following areas:

	Opportunities	Threats	Who is Affected*
Societal & environmental factors			
The economy—local, national, or international			
Demographics—changes in the age, race, gender, culture of participants			
Legislation/regulatory environment			
Local, national, or international events			
Advances/shifts in the research ecosystem			
Technological advancements			
Developments in disease treatment/trajectory			
Presence of researchers willing to integrate participant voice, participant-reported data into research			
Disappearance/creation of potential partner organizations			
Disappearance/emergence of similar organizations			
Financial factors			
Funding sources to support infrastructure			
Funding sources for research that is important to participants			
Presence of funders willing to support integration of participant voice and participant-reported data into research			
Diversity of potential funding sources			
Internal factors			
Organizational rules regarding funding partners			
Organizational rules regarding research partners			
Trust in quality of participant-reported data			

*Participants,
Research Partners,
Funders

Adapted from **The Community Tool Box**, Center for Community Health and Development, University of Kansas

After you complete Activity 3, reflect on the following questions:

- To what extent do these opportunities and threats affect you or your (potential) partners?
- Of your PDRC's strengths, which can be used to take advantage of opportunities or mitigate threats for your PDRC or your partners?
- Of your PDRC's weaknesses, which can be overcome by taking advantage of opportunities in the broader landscape?
- How might your organization compare to other organizations in the landscape that may be newer and less established?
- What do potential partners in your space look like? What kinds of resources or capacities do they have that your PDRC does not?
- Who is leading in this space and what can your PDRC do to uniquely add value that is within the scope of your mission/capabilities?
- What unique resources or capacities does your PDRC have?

II Demonstrate Value to Participants

Roadmap

PDRCs demonstrate value to their participants by providing resources, empowerment to influence their research agenda, opportunities to participate in research activities, and access to a broader community with shared experiences. What do the participants in your PDRC value? What does the broader community of those with lived experience value? How do you deliver this value? In this section you will consider strategies your PDRC may use to provide value to participants and encourage robust engagement.

A participant is an individual who represents the population your PDRC aims to serve. They are individuals with lived experience with a condition or disease, caregivers of individuals with a condition or disease, or members of a population group. Participants have a central role in the PDRC's activities, such as providing data, participating in research, identifying priorities, and contributing to the growth of the organization or network.

Participants can be involved in a PDRC's activities in many ways that can range from being a member of the PDRC's community at large to playing an active role on research and leadership teams.

Activity 4 lists examples of strategies a PDRC may employ to foster the engagement of its members and, in turn, demonstrate the value of participation. **For each, first identify if your organization currently uses the strategy or if it represents an opportunity to extend the value the PDRC provides its participants.** For those strategies the organization currently uses, reflect upon what you know about the nature and quality of participant engagement in these various activities. Are there ways to build on a strategy to further enhance participants' experiences and the value they receive?

Activity 4. Assess Strategies to Deliver Value to Participants

Type of strategy

PDRC engages participants at different stages of the research life cycle

Participants serve as members of or lead research teams.

Examples:

- Respond to calls for research proposals or research questions
- Participate in crafting research questions through informal or formal mechanisms
- Assist or manage recruitment efforts, implementation of interventions, measurement and interpretation of outcomes
- Attend or give presentations to provide the participant's perspective of research findings

Currently using	
Opportunity area	

Type of strategy

PDRC engages participants at different stages of the research life cycle

Participants advise research teams.

Examples:

- Provide input early in the research design process on the project's impact on patients/participants
- Test an application or platform
- Review impact and scientific sections of research proposals to help articulate and consult on the project's importance to people affected by a condition
- Provide feedback on research procedures and policies (e.g., data sharing, consent forms, recruitment strategies), resources, and patient-facing materials developed by the research team

Currently using	
Opportunity area	

Participants volunteer for research projects.

Examples:

- Supply personal information, biological material, or EHR data for inclusion in a database or registry
- Participate in research projects, including clinical trials, surveys, and focus groups
- Support clinical trial development by providing input on potential barriers to recruitment and helping develop participant education materials

Currently using	
Opportunity area	

Research results are communicated back to participants and informed by participant voices.

Examples:

- Use communication channels with participants/PDRC community at large to share research results
- Establish research-sharing practices using lay language that will be understood by the general public
- Supply opportunities for participants to inquire about future, ongoing, and completed research projects

Currently using	
Opportunity area	

Type of strategy

PDRC's policies and procedures ensure that participant voices are heard and included

Participants volunteer for research projects.

Examples:

- Review research grant/funding applications the PDRC receives and provide input
- Identify research priorities and design research agendas that inform future strategies for the PDRC
- Take on the role of co-author or lead author role in the publication

Currently using	
Opportunity area	

Participants are partners in PDRC leadership and governance.

Examples:

- Serve in governance roles with shared power and accountability
- Inform plans, principles, and courses of action that serve as the basis for decision-making

Currently using	
Opportunity area	

Participants are partners in pursuing the research agenda.

Examples:

- Identify what advocacy related to participant-driven research agenda is needed (e.g., making treatment widely available, seeking government funding for clinical trials, or allocations for a certain type of research)
- Set the internal PDRC agenda for the network's community
- Pursue research agenda with funders and policymakers
- Connect the PDRC with researchers/funders to share priorities and strategic vision for future organization activities

Currently using	
Opportunity area	

Type of strategy

PDRC provides supportive resources to facilitate broad participation of members at large

Participants have access to content and process knowledge to meaningfully engage in research activities.

Examples:

- Develop tools, devices, and platforms to engage the PDRC’s network in activities
- Engage in education and training materials to become informed about research methods and processes
- Consult on services and resources to ensure that they are culturally competent in that they reflect the diversity of the audience and are designed to meet their specific needs

Currently using	
Opportunity area	

Participants actively engage with the broader community.

Examples:

- Share personal stories in groups or forums
- Sign up for newsletters
- Respond to calls for ideas for research topics
- Invite members to participate in focus groups/feedback sessions
- Invest in app-based/online communities
- Foster a shared community identity through common terminology and standard communication

Currently using	
Opportunity area	

III Demonstrate Value to Partners

Partners strengthen PDRCs by providing resources, monetary funds, or in-kind services that expand the breadth of assets available to advance participant-driven research goals. Through partnerships, PDRCs can mitigate challenges due to limited funding, participation, progress, and communication of results. Partnerships can also lend legitimacy to a specific venture or organization.[i]

Successful partnerships are characterized by mutual influence, interdependence, mutual respect, joint participation in decision-making, mutual accountability, trust, and transparency.[ii,iii,iv] To achieve such partnerships, value propositions to partners should emphasize alignment between the work and needs of your PDRC with those of partners. This section builds on the foundational work in **I. Identify Assets and Opportunities** with activities to help PDRCs enhance, extend, and sustain their work through bi-directional partnerships. The section begins by identifying different goals of partnership and concludes with a deep-dive on demonstrating value to financial partners.

> **A partnership is "a dynamic relationship among diverse actors, based on mutually agreed objectives, pursued through a shared understanding of the most rational division of labor based on the respective comparative advantages of each partner."[V]**

Goals of Partnership

PDRCs engage with a number of different players in the health care research ecosystem for purposes that include supporting **advocacy** to integrate patient voice in the research process, bolstering **research infrastructure and capacity**, conducting **research**, incorporating clinical data and expertise, and obtaining **financial** support. The scope of collaboration with any one partner may be project-specific or cut across projects and span more than one area. The table below shows examples of bi-directional partnerships for different strategic goals.

Increasing reach of communication and dissemination

Partners have a shared goal of reaching a specific audience or population with a certain health issue/concern.

Examples:

- PDRCs and advocacy organizations could jointly share the cost of disseminating findings, a campaign message, and/or a call to action. Costs associated with outreach could be minimized by providing consolidated messages to the same audiences. In other words, there are economies of scale to be gained if outreach efforts are coordinated. Any cost savings accrues to both the PDRC and the advocacy organization.
- Partners can collaborate to expand their individual reach by helping one another identify and reach potential new audiences.
- Researchers at PDRCs and other institutes co-author papers to disseminate research findings. Legitimacy and broader appeal benefit both parties.
- Partner organizations could collectively conduct message testing or better understand primary communication platforms to determine how best to reach patients or potential audiences.

Building organizational infrastructure, skill, or research capacity

Each partner organization has a unique skill set or capacity that the other lacks

Examples:

- An organization with a data platform partners with a PDRC wanting to integrate multiple types and sources of data. One partner lacks the infrastructure or capacity, while the other may not be as successful at gaining access to a varied stream of data (e.g., biometric, demographic, bio-marker, claims, clinical).
- PDRCs and academic researchers jointly pursue grants for shared research interests.
- A health plan or payer aims to build capacity to enhance member experience and integrate patient voice. A PDRC partners with a health plan or payer to involve patients in designing and informing the systems and processes that impact the quality and experience within the health care system.
- A PDRC promotes cultural competency and sensitivity issues facing a patient population by sharing knowledge about the audience with organizational partners that can augment gaps in their capacity.

Improving efforts to collect data easily and efficiently

A partner collaborates with the PDRC by sharing data or resources to enhance PDRC assets and contribute knowledge to the field at large.

Examples:

- A health system provides a PDRC access to its clinical network to build disease registry, and PDRC shares registry data with health system.
- EHR vendor collaborates with multiple PDRCs so that de-identified data can be provided in a more standardized and efficient way to patient-driven organizations to support research. Improved access to data benefits the PDRC and the EHR vendor can provide data more efficiently with less customization.

Ensuring operations are financially sustainable

A partner provides financial support to help sustain a PDRC.

Examples:

- A foundation or large donor can provide funding and also help leverage and attract additional resources that will better diversify the PDRC's revenue stream and improve its organizational viability.
- A PDRC can provide access to funders or payors that would be interested in tapping into researchers' or patients' perspectives on a routine basis to inform their own organizational investments. The PDRC gains visibility and shows the value it creates by having access to a diverse network, while funders can have a current, up-to-date understanding of the shared interests of the patient/participant populations.

Partnerships will take shape based on the needs of the PDRC and the partner and the extent to which the assets each can offer the other complements existing resources to meet those needs. To that end, engaging with partners requires that the PDRC has a clear and shared understanding of its goals with respect to partnering, as well as a clear sense of the needs and interests of potential partners. The types of needs PDRCs or their partners may seek to address through collaboration include **obtaining resources** to support and expand the work they currently have underway, **expanding the number or types of users** of their research and services, and **obtaining funding** for programs and infrastructure.

Roadmap

Activity 5 builds on the results of the SWOT analysis in **I. Identify Assets and Opportunities** by identifying potential partners and mutually beneficial areas of partnership to achieve shared goals.

Action items!

Ensure that your PDRC's activities are concrete. What are you trying to accomplish as a direct result of these partnerships?

- **Expand community reach**
- **Identify investigators**
- **Identify collaborators**
- **Enhance research infrastructure**
- **Expand research expertise**
- **Articulate gaps in research capacity**

Activity 5. Identify Potential Partners and Areas of Partnership

In what ways do partners bolster your opportunities and strengths? Using the results of the SWOT analysis in which you identified your PDRC's existing assets and areas for growth **(Activity 1)**, assessed the PDRC's financial climate **(Activity 2)**, and assessed external opportunities and threats to the work and sustainability of the PDRC **(Activity 3)**, consider the following questions, which may evolve over time as your PDRC expands.

WHO

Who are potential partners?

- Who are the stakeholders involved in your PDRC's work?
- Who would benefit from your PDRC's assets or services? How so?
- To what extent is your PDRC currenty reaching its stakeholders and those who might value or benefit from access to its resources and services?
- Are there others in the health care research ecosystem that have access to these stakeholders?
- Who has products, services, or resources that would help your PDRC address any weaknesses, mitigate threats, and take advantage of opportunities to achieve its participant-driven research goals?
- Are these potential partners credible entities that will help advance your organization's mission?

Roadmap

WHAT

What is the PDRC asking from potential partners? What would potential partners get in return?

- What funding, resources, skills, or expertise do potential partners offer to help your network meet its needs?
- What kinds of resources and compentencies do your partners need?
- What are potential partners trying to achieve? What problems are they trying to solve?
- What interests and concerns do potential partners share with the PDRC?
- What does the PDRC offer that addresses potential partners' needs?

HOW

How can collective assets help partners fulfill their needs and achieve goals?

- How are potential partners currently addressing their needs? (i.e., what is their alternative to partnering with your network)?
- How will your PDRC and potential partner support each other through a relationship based on reciprocity and a shared mission?
- How would you communicate this to potential partners?
- How well does your PDRC understand the motivations of potential partners?
- Can your PDRC and potential partners be honest and authentic about what's in it for both organizations? How can you understand this?
- How will your PDRC and potential partners establish transparency in regards to each organization's interests?

Deep Dive: Understand Potential Funders and Their Needs

Potential partners can also take on the roles of funders of your organization. Communicating your PDRC's value to funders requires an understanding of the needs and interests of these potential partners. In particular, what types of information are they looking for? What questions do they need answers for? How do they perceive their role in the research lifecycle? For example, potential funders may be seeking the following:

- Share in planning, conducting, and disseminating research
- Recruitment of patients to studies
- Access to pilot grant/proof-of-concept research
- Access to de-identified data and tissue samples
- Name/brand identification with a "good cause"
- Opportunities to leverage existing resources collected in the field (e.g., consortiums of researchers around a rare disease)

Notes

Consider the following illustrative list of types of funders PDRCs may be seeking out and their areas of interest and types of activities they fund. Consider this information as you work on Activity 6, in which you will assess current and potential revenue from these types of funders and ways to increase the PDRC's attractiveness to these funders relative to their interests and needs.

Types of funders and their interests[v]

Areas of interest and activities funders support	Foundations	Government*	Health plan providers	Patient groups	Private funding**	Product manufacturers	Professional societies	Pharmaceutical industry "hybrids"
Research questions related to clinical or comparative effectiveness, natural history of disease, performance of health care providers based on accepted measures of quality of care	●	●	●	●	●	●	●	
Ensure patient-friendly clinical trial designs via patient involvement through a standing multi-event, multi-meeting task force	●						●	●
Advance beyond transactional approaches of patient engagement toward a transformational model	●			●	●		●	
Review and track long-term outcomes of agents, devices, groups of drugs, or procedures		●	●			●		●
Increase the importance of patient-centered outcomes data in reimbursement		●			●		●	●
Contribute to the rapidly evolving drug regulatory context—e.g., the US FDA's Patient-Focused Drug Development (PFDD) initiative and upcoming guidance and standards						●		●
Demonstrate the effectiveness and/or safety of existing products in real-world use						●		●
Champion research for rare diseases and/or disadvantaged disease patient subgroups of interest for more common conditions	●			●	●			
Promote practical clinical research as a tool for providing evidence for health coverage and health care decisions		●	●					
Provide in-kind support	●		●	●			●	

* Federal agencies (NIH, CDC, CMS, AHRQ, FDA) and state agencies

** Private philanthropic individuals or charitable foundations and trusts

Adapted from AHRQ's Registries for Evaluating Patient Outcomes: A User's Guide [Internet] 3rd edition. https://www.ncbi.nlm.nih.gov/books/NBK208631/

Activity 6. Evaluate Current and Potential Funding Sources

Funding source	What percent of revenue or dollar amount does this funding source represent today?	Potential to increase or add this funding source in the future?	How can you increase your attractiveness to increase or add this funding source?
Foundations			
Government			
Federal agencies (NIH, CDC, CMS, AHRQ, FDA) and state agencies			
Health plan providers			
Patient groups			
Private funding			
Private philanthropic individuals or charitable foundations and trusts			
Product manufacturers			
Professional societies			
Professional society/ pharmaceutical industry “hybrids”			
High donors/ champions			
Other			

Activity 7. Consider Fit of Potential Funders for Your PDRC

To what extent do the needs and interests of the PDRC align with the potential funders with whom you aim to build or expand partnership? Consider the following: **How important is each consideration to the PDRC? To what extent do these align with the interests, needs, and resources of the potential funder?** This activity can be repeated for different funders.

Funder:		
Alignment considerations	**Important**	**Alignment**
Does funder's interest align with your goals?		
What are potential future partnering limitations?		
To what extent would partnering with this funder affect the PDRC's credibility?		
What is the PDRC's role in the study or partnership?		
Use and ownership of data?		
Publication policies?		
Patient/caregivers roles?		
Mechanisms to pass results to participants?		
Collaboration, who is PI, and who has final decision?		
Contracts?		

IV Crafting the Value Proposition

Using the information and insights generated throughout the Playbook, develop your PDRC's value proposition. The value proposition will clearly communicate the following critical information:

1. Needs of target audience
2. PDRC's product, service, or solution
3. Key benefits of PDRC's product, service, or solution
4. Key competitors of PDRC's product, service, or solution
5. Most important reasons why PDRC can provide product, service, or solution

The value proposition may be modified and tailored to reach different partners or highlight different services or solutions. The end of this section includes examples of value propositions created by members of this workgroup.

In Activity 8, consider your responses to each question. These questions are meant to flesh out the components you will address when formulating your PDRC's value proposition statement:

Activity 8. Communicate the Need the PDRC Addresses

Question	Answer
What stakeholder group are you writing this particular value proposition for? • As discussed in this Playbook, PDRCs bring value to a number of different recipients (participants, partners, funders, etc.)	
What is the problem that needs to be addressed?	
What is the current solution to the problem? • What services address the issue or your audience's needs? • What is the impact of this current solution? What are the pros and cons associated with it? • What are the adverse consequences of this solution?	
Why are your services beneficial for this population?	
Who else in the ecosystem is providing similar services?	
Why can your PDRC provide these services?	

Oftentimes, these key components can be placed into a simple value proposition template:[vi]

> "For [the stakeholder group your PDRC wants to bring value to], our [research/community/service] **provides** [benefits] **significantly better than** [status quo/competitors/etc.] because [ways your PDRC successfully provides these benefits]."

Create a Value Proposition

Example value propositions

LymeDisease.Org value proposition:

> "For clinical trial recruitment in Lyme disease, LymeDisease.org provides faster, less expensive, and more geographically diverse access to patients than other advocacy organizations, clinicians, and clinical research organizations because we are the largest and most trusted web-based communications network in Lyme disease."

lymedisease.org
ADVOCACY, EDUCATION & RESEARCH

IBD Partners value proposition:

> "For patients living with inflammatory bowel disease (IBD), health management is a constant challenge. IBD Partners, a patient-centered online research network, enables the collection of longitudinal, real-world patient-reported data helping researchers better understand how treatments affect patients' ability to manage symptoms and maintain their quality of life and generate actionable, real-world evidence on a large, geographically diverse population. Interested investigators can access pre-existing longitudinal patient-reported outcome data going back 10 years and/or leverage the existing study population and research infrastructure and strong track record for new data collection, either cross-sectionally or longitudinally."

IBD
PARTNERS

Example value propositions

PARTNERS value proposition:

> “For conducting patient-centered research in pediatric rheumatology, the PARTNERS consortium provides a 1-stop solution for all project needs leveraging the research expertise of CARRA, quality improvement expertise of PR-COIN, patient and caregiver partner broad experience at all levels along the engagement continuum, and enormous community footprint of the Arthritis Foundation, Lupus Foundation of America, and CureJM.”

iConquerMS value proposition:

> “As the only people-powered research network for multiple sclerosis and a trusted partner to those affected by the disease, iConquerMS facilitates meaningful and impactful collaboration between people affected by MS, researchers, and funders, harnessing patient and caregiver insights to accelerate MS research on the topics that matter most to them.”

- **Nonprofit Readiness for Health Partnership** (Nonprofit Finance Fund, 2017)
- **Partnership Assessment Tool for Health** (Nonprofit Finance Fund, 2017)
- **Return on Investment Calculator** (The Commonwealth Fund, 2018)

Value Proposition Playbook for Participant-Driven Research in Health Care

NORC at the University of Chicago prepared this Playbook as part of the Patient-Driven Research Community Learning Network (PDRC LN) funded by the PCORI. The objective of the overall project is to build the capacity and foster the sustainability of PDRCs, which are defined as an organization or group of individuals/organizations that is led and/or governed by patients/participants and/or caregivers whose primary purpose is to enable research that is a priority to their communities. With the eight PCORI patient-powered research network (PPRN) Engagement Awards (EAs) as the foundational members of this network, the PDRC LN kicked off in August 2019 and is working to create an environment for sharing and synthesizing knowledge across projects to advance the role of PDRCs in clinical and care delivery research. Integral to this process is establishing an understanding of the current landscape of PDRCs and their role in clinical and care delivery research.

As part of this effort, three PDRCs took part in a sustainability-focused workgroup to develop the Value Proposition Playbook for Participant-Driven Research in Health Care, a deliverable meant to guide patient-driven research communities' development of their own value proposition. We reviewed peer-reviewed and gray literature on value proposition development and related activities. This work illuminated common features of PDRCs and also the heterogeneity across PDRCs that helped inform the activities provided throughout the playbook.

The Playbook draws from current evidence and resources on partnership development and nonprofit sustainability, PDRC experiences, and interviews with stakeholders in the patient-driven health care research ecosystem. The playbook provides a series of guided exercises to help PDRCs define their strengths, understand areas for growth, identify target audiences, and communicate effectively with those target audiences.

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