

Engaging Parents and Stakeholders in Patient-Centered Pediatric Research and Research Agenda Setting

A Guide for Practice-Based Research Networks

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Colorado Children's Outcomes Network

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Preface:

Case Example Project

Entire process for COCONet Research Agenda Setting

How did we get here? The story of how we came to apply for our PCORI Engagement Award and the process of applying may be useful for other PBRN's considering similar proposals. While investigators within our research program had been doing practice-based research for many years, our PBRN wasn't formally registered with AHRQ until 2011. Our network director and network coordinator took over the PBRN in early 2014. One of our first priorities was to engage practicing clinicians in our PBRN to help develop research questions of interest. We hosted dinners, sent out newsletters, spoke at conferences – essentially anything we could think of to engage clinicians in the conversation. We generated a few ideas that we continue to pursue, but as we all know, clinicians are busy! We needed more strategies to generate research ideas. As a medium-sized PBRN with a medium amount of infrastructure, we were also always on the lookout for more infrastructure funding. We ran across the announcement for a [Eugene Washington Engagement Award](#)¹ and brainstormed ideas for how we might apply for this as a way to generate research ideas. In this process, we realized what was missing from our equation – the voices of the parents! We pitched this idea to our Steering Committee (comprised of 7 clinicians), our Research Advisory Board (comprised of 5 practice-based research academicians), and several community contacts. There was enthusiasm for this all around. “Great idea!” This would become a theme.

We put together our [letter of inquiry](#)² to PCORI based on this principle of parents informing our research process. We also actively sought out community partners for the project, and were fortunate to have one of our Research Advisory Board suggest Family Voices Colorado. Family Voices Colorado is an organization that advocates for children with special health care needs, so this partnership was perfect, as they would be able to work with us to recruit families to participate. After submission, we were fortunate to be asked to submit a full application, and the primary feedback we received was to consider including [other stakeholders](#)³ in our full application. This turned out to be sage feedback. Once we started using our contacts to reach out to other stakeholders, such as payers and public health officials, the potential for our project started to really blossom. We received a great deal of positive feedback from everyone we approached, and we also experienced a real snowball effect – “You should really talk to...” This not only led to many more interviewees and potential Working Group and Network Advisory Board members, but also to excellent feedback on what to put into our final application.

The details of what happened after we received funding are described throughout this workbook. In brief, due to the nature of the enthusiasm for this concept of developing research questions from non-research people, just about every step of our process has felt like a step in the right direction. While there have been many lessons learned along the way, this whole project has been a great experience. Community engaged research is really fun!

References

1. PCORI (Patient- Centered Outcomes Research Institute). Eugene Washington PCORI engagement Awards Funding Opportunities 2017; <https://www.pcori.org/funding-opportunities/announcement/eugene-washington-pcori-engagement-awards>.
2. PCORI (Patient- Centered Outcomes Research Institute). Online Application System User Manual: Submit a Letter of Inquiry. Eugene Washington PCORI Engagement Awards 2016; <https://www.pcori.org/sites/default/files/PCORI-Engagement-Awards-Online-User-Manual-Submit-LOI.pdf>.
3. PCORI (Patient- Centered Outcomes Research Institute). PCORI's Stakeholders. What We Mean by Engagement 2010; <https://www.pcori.org/engagement/what-we-mean-engagement/pcoris-stakeholders>.

Executive Summary

In 2015, when we embarked on a project to engage stakeholders, and specifically parents, in our pediatric practice-based research network (PBRN), we had a vision of what we wanted to accomplish. We

This guide is based on work done as part of a Eugene Washington Engagement Award. This was a 2 year contract designed to develop child health research questions based on input from patients, parents, and other stakeholders. The first year of the project was formative, with about 60 semi-structured – but mostly open-ended—interviews with parents, adolescents, and stakeholders to assess priorities for pediatric research and also generate specific research ideas. Topics were prioritized towards the end of the first year by our Network Advisory Board, a group comprised of parents, stakeholders. These priorities were distilled down to three Working Groups who were tasked with developing these general research priorities into answerable research questions.

were excited to develop a research agenda that addressed both provider and parent questions about pediatric health care. As the project developed, we were continually surprised and pleased with the innovation, honesty, and trust our stakeholders brought to the process. Our stakeholders collaborated with us to create research questions and proposals that could only have arisen with their engagement with our PBRN team. This guide describes our process, lessons learned, and advice for other pediatric PBRNs seeking to accomplish relevant research in partnership with their stakeholders.

Before you begin, a proposition...

Stakeholders have important experiences

and expertise about their lives and healthcare to share with PBRN researchers to inform the research process from question development through dissemination and implementation of findings. Furthermore, without stakeholder engagement in this process, pediatric health research lacks the relevance and nuance that is necessary to make it impactful and effective in improving the health of children and families.

We dove headlong into this project with the intention of building a PBRN research agenda that incorporated all our stakeholders and their needs. Throughout this process, we've built trusting relationships and developed a wealth of ideas about the questions our stakeholders need answers to and the research we hope to conduct. We've also learned a lot about collaboration in the pediatric PBRN setting and these lessons will be reflected throughout this guide.

A message from our stakeholders If you don't believe in this proposition, stop here . If you don't believe parent engagement will bring value to your PBRN research process, parents and other stakeholders will see your skepticism. Stakeholder engagement in your PBRN will fail if you do not believe it has value. Stakeholder engagement is based on relationships and connections between stakeholder groups. If you are skeptical of the value a group of stakeholders brings to the table, you will be unable to engage them in meaningful ways and stakeholders will not be willing to provide the input and ideas that are crucial to the success of engaged research work.

Key Themes

- **Trust the process.** You need to be flexible, iterative, open to the process taking you in directions you did not anticipate at the outset. Build flexibility into your process and trust that your community partners will take you in the right direction.
- **This is a team sport - rely upon and invest in your key partners.** Throughout the process you will need your professional networks to help you identify and engage stakeholders, and make connections for you. You will then need to invest in relationships, building trust among and between your team. People are generally eager to engage, if they know you are sincere and committed to their contributions. You must demonstrate that sincerity and build trust - rushing this process or skipping it all together will negatively impact your outcomes. A single researcher or a small, insulated team will not be successful in this work.
- **Quality is more important than volume.** This is labor intensive work and requires commitment and investment of time and personal capital. Be realistic about the scope of what you can accomplish and do the work well, rather than trying to take on too much. A few strong relationships with highly involved stakeholders will get you much further than a long list of stakeholders' email addresses.

Introduction

What is Engagement? Why does it matter?

Engagement is the meaningful participation of stakeholders in a process that has implications for their lives. In the Practice Based Research Networks (PBRN) setting, this means involving people outside the research enterprise in the health research process in ways that have real impacts on the research.

From **PCORI**

“By "engagement in research," we refer to the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. We believe that such engagement can influence research to be more patient centered, useful, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare

Ultimately, the work of a PBRN is intended to improve the health of the children and their families. When we undertake research that is not based on the experienced needs of those patients and families or does not include their perspectives, we limit the productivity and significance of the research we do. On the other hand, when we engage patients,

parents and families in setting the research agenda and answering their research questions, we add richness, relevance and depth to our research in ways we couldn't otherwise. In addition, research that stems from working alongside the people most affected by the health care system is more likely to result in findings that can be translated and implemented in real-life healthcare settings and address the patients' needs when they interact with that system.

Who to Engage?

PBRNs have long been engaging clinicians in the process of research. Some have taken the next step to engage patients in various capacities. However, most pediatric PBRNs have not engaged pediatric patients and their parents. These two groups are essential stakeholders to ensure that the PBRN research is relevant and responsive to our patients. As such, the authors of this guide suggest that pediatric PBRNs make concerted efforts to engage both parents of patients and pediatric patients themselves in the research efforts of their networks. Based on our experience, clinicians are highly supportive of this concept.

In addition, it is essential to maintain the engagement of your providers, clinicians and other practice staff. In order to conduct the research that is important to all our PBRN stakeholders, providers and other clinicians need to have the highest level of buy-in and engagement in the processes.

Finally, we encourage PBRNs, and especially those focused on pediatric health, to engage other stakeholders in children's health. We further discuss who these players are in Chapter I.

Partnership between providers and parents to address children's needs. Recognizing the parents' experience outside the office allows us to better address the whole child/whole life.

What to Engage Stakeholders In?

Once you have identified individuals, organizations, or other stakeholder groups you'd like to engage in your PBRN research process, you will need to decide on their roles. There are numerous models for stakeholder engagement in each of the phases of the research process. Throughout this workbook, we will describe two specific models for engaging stakeholders in a pediatric PBRN during the early phases of research including issue identification, question development, study design and grant development.

a. Identification of Health Issues and Topic Focus (Chapters III, IV, V and VI)

We describe a model for identifying the health issues on which your PBRN will focus using an engaged mixed methods approach consisting of interviews, focus groups, a survey and a stakeholder advisory board. Ultimately, this process is designed to inform a research agenda for the PBRN that is focused on important clinical and public health issues and is relevant to parents, children, clinicians, and other stakeholders.

b. Working Group Model (Chapters VII, VIII, IX and X)

We describe a Working Group model for taking the issues identified by stakeholders and narrowing them into research questions, study designs and grant proposals to funding the research within the PBRN setting.

What terms will I need to know?

- **PBRN**– Practice-Based Research Network
- **CTSA**– The Clinical and Transitional Science Award
- **NCATS**– The National Center for Advancing Transitional Sciences
- **Engagement Plan**- a strategy and timeline for involving stakeholders in your PBRN
- **IRB**– Institutional Review Board

1. PCORI (Patient- Centered Outcomes Research Institute). What We Mean by Engagement. Engagement 2014; <http://www.pcori.org/engagement/what-we-mean-engagement>.

Chapter I: Engagement

What is Engagement?

Put simply, engagement is the meaningful participation of stakeholders in a process or organization that has implications for their lives. In the PBRN setting, this means involving people outside the research enterprise in the health research process in ways that have real impacts on the research. Numerous other people working in a variety of fields have defined engagement with more nuance and precision, depending on the context in which they are working. Ultimately, engagement boils down to participation and connection.

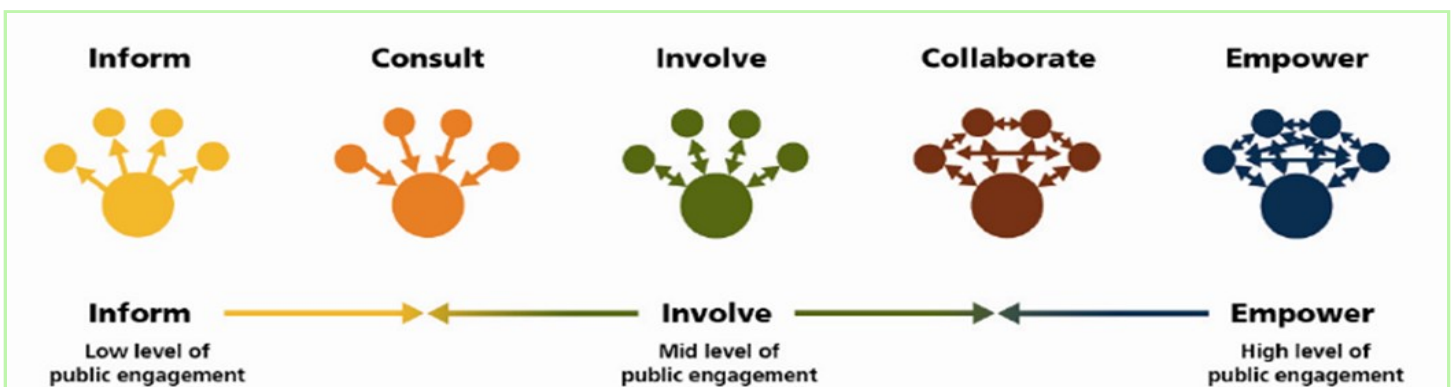
Engagement can come in many forms, levels of intensity, and directions of communication. In addition, engagement can be integrated into various stages of the research process from research question conception through interpretation and dissemination. Depending on the health issue at hand, the stakeholders you are engaging, and the nature of the research, engagement will look different.

We think of engagement as a continuum. As your PBRN moves from low levels of engagement to high levels of engagement, the nature of those relationships and processes change and evolve. (see figure 1)

At lower levels of engagement (Inform and Consult), communication tends to be unidirectional between the PBRN and its stakeholders. As engagement increases (Involve), communication becomes bidirectional, but the network or PBRN staff remains the broker of stakeholder relationships.

From PCORI

By "engagement in research," we refer to the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. We believe that such engagement can influence research to be more patient centered, effective, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare community."¹



[Figure 1: AP₂ Spectrum](#)² — In the context of PBRN stakeholder engagement, consider the central node your PBRN and its staff and the outer nodes your stakeholders. The arrows represent the directionality of communication and relationships between your PBRN and its many stakeholders.

At the highest levels of engagement (Collaborate and Empower), those relationship networks become more complex. There is bidirectional communication not just between the PBRN and the stakeholders, but between other stakeholders. The richness of the network with these higher levels of engagement leads to innovation and empowerment of stakeholders who can then take leadership roles in the PBRN’s research agenda. We will try to call out the level of engagement our stakeholders had at each stage of our process as we proceed through the remainder of this guide.

Table 1: IAP₂ PUBLIC PARTICIPATION SPECTRUM³

INCREASING LEVEL OF IMPACT				
Inform	Consult	Involve	Collaborate	Empower
Public	Public	Public	Public	Public
Participation Goal:	Participation Goal:	Participation Goal:	Participation Goal:	Participation Goal:
To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
Promise to the Public:	Promise to the Public:	Promise to the Public:	Promise to the Public:	Promise to the Public:
We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible	We will implement what you decide.
Example Tools:	Example Tools:	Example Tools:	Example Tools:	Example Tools:
<ul style="list-style-type: none"> • Fact sheets • Websites • Open houses 	<ul style="list-style-type: none"> • Public comment • Focus groups • Surveys • Public meetings 	<ul style="list-style-type: none"> • Workshops • Deliberate polling 	<ul style="list-style-type: none"> • Citizen advisory committees • Consensus-building • Participatory decision making 	<ul style="list-style-type: none"> • Citizen juries • Ballots • Delegated decisions

No one type of engagement on this continuum is right. Not every PBRN can support the highest levels of engagement, nor are these highest levels appropriate for every PBRN research project. Even in PBRNs that do have the highest levels of engagement, this is usually not sustainable on a continuous basis .

Risk of Poorly Done Engagement

It is important to keep in mind the risks of doing engagement work poorly in a pediatric PBRN setting. If you aren't sincere about engaging your stakeholders or you don't dedicate adequate resources to do this work well you lose trust with people you're engaging. It is very hard or impossible to repair that trust. It is better to be modest in what you take on and the level of engagement you promise, then, do it well and build from there. Taking on too much or promising more in-depth engagement than your PBRN has the capacity for can cause serious harm to your present and future stakeholder relationships. Ultimately, screwing it up may mean you may close the door to future opportunities to collaborate with parents, patients, physicians, and other stakeholders of your PBRN.

Changing Levels Of Engagement

In addition, in most cases you cannot immediately jump to the highest levels of engagement. Engagement must be built over time through relationships, trust, and experience. PBRNs (and other community-engaged research efforts) generally will move up and down this continuum to meet the needs of the community, the organization, the research, and the people who are engaged in the process. Often, stakeholders will need a break and members of the partnership will opt to move to lower levels of engagement for some period of time. This might be because of other commitments to their career or family, or burnout from intense projects your PBRN has undertaken. When projects are in greater need of collaboration and empowered stakeholder leadership, the partnership will "ramp up" and display higher levels of engagement again. This is the normal ebb and flow of stakeholder engagement in research projects.

One part of your role is be sure that you've built a foundation of trust and relationships that allows your PBRN to increase these levels of engagement again after your stakeholders have taken a break. Another part of your role as a PBRN leader doing engagement work is to monitor and manage the tradeoffs between higher levels

of engagement and the time and energy commitment of your stakeholders. Have honest conversations with your stakeholders about the level of activity they are taking on for the PBRN and whether it aligns with their expectations and capacity. Adjust as needed to ensure you don't have burnout among your stakeholders.

Capacity for Engagement

As you begin the process of building networks of engaged parents for patient-centered pediatric research in your PBRN, take an honest inventory of your PBRN's capacity to support these different levels of engagement. Identify the level of engagement that currently exists in your PBRN and where you and your stakeholders would like that engagement to be. Then, we recommend you set goals for engagement that are ambitious and will extend your current capacity. However, be intentional about growing engagement strategically and sustainably .

Principles of Engagement

As you embark on engaging stakeholders in your PBRN, it is important to familiarize yourself with the principles of community and stakeholder engagement that have proven effective in other settings. Here we have compiled numerous examples of engagement principles you will want to consider in your approach.

PCORI

[The Patient Centered Outcomes Research Institute \(PCORI\)](#) highlights a few key areas of focus for beginning to plan for stakeholder engagement:

- **Reciprocal Relationships:** This principle is demonstrated when the roles and decision-making authority of all research partners, including the patient and other stakeholder partners, are defined collaboratively and clearly stated.
- **Co-Learning:** This principle is demonstrated when the goal is not to turn patients or other stakeholder partners into researchers, but to help them understand the research process; likewise, the research team will learn about patient-centeredness and patient/other stakeholder engagement, and will incorporate patient and other stakeholder partners into the research process.
- **Partnerships:** This principle is demonstrated when time and contributions of patient and other stakeholder partners are valued and demonstrated in fair financial compensation, as well as in reasonable and thoughtful requests for time commitment by patient and other stakeholder partners. When projects include priority populations, the research team is committed to diversity across all project activities and demonstrates cultural competency, including disability accommodations, when appropriate.
- **Transparency, Honesty, and Trust:** These principles are demonstrated when major decisions are made inclusively and information is shared readily with all research partners. Patients, other stakeholders, and researchers are committed to open and honest communication with one another.

These principles ensure equity and collaboration as you move forward in your PBRN engagement efforts. We suggest PBRN staff also review PCORI's Engagement Rubric when planning for any engagement effort as they provide clear and concise guidance for these types of projects.⁴

NCATS

The National Center for Advancing Translational Sciences (NCATS)⁵ and the Clinical and Translational Science Awards (CTSA) Program also provides guidance for engaging communities in the research process, with a focus on building community trust and meeting community needs. These two factors are also key to PBRN engagement success and should help to guide your parent and stakeholder engagement work.

From NCATS “To ensure community engagement in the research process, research institutions must collaborate with community organizations to identify and understand public health needs. Through the CTSA Program, NCATS supports a broad range of activities that engage communities in health initiatives and clinical research. Working with federal and nonprofit agencies, CTSA Program hubs collaborate with public health professionals, health care providers, researchers and community-based groups to:

- Develop methods of effective community dialogue and research.
- Ensure that updated health information is widely available.
- Provide information and access to clinical trials and studies.
- Promote participation in clinical trials.”⁵

Building Community Trust

To achieve successful community engagement, partnerships are built on respect and trust. Investigators supported by the CTSA Program value the role of community participation in translating research results into new treatments to improve health, including in underserved communities.

Meeting Community Needs

CTSA Program investigators conduct their research and outreach efforts through neighborhood service and community centers as well as in mobile units. Projects include education about, prevention of and management of a variety of conditions, including obesity, high blood pressure (hypertension), type 2 diabetes, dental disorders and drug addiction. Community members provide their input on clinical studies and health programs by serving on advisory boards to CTSA Program hubs.”⁶

Key Principles Summary

- Trust and Transparency
- Equity
- Partnership and Reciprocity
- Culture of Learning



What key principals does your PBRN uphold well?

What principles will you need to work to improve?

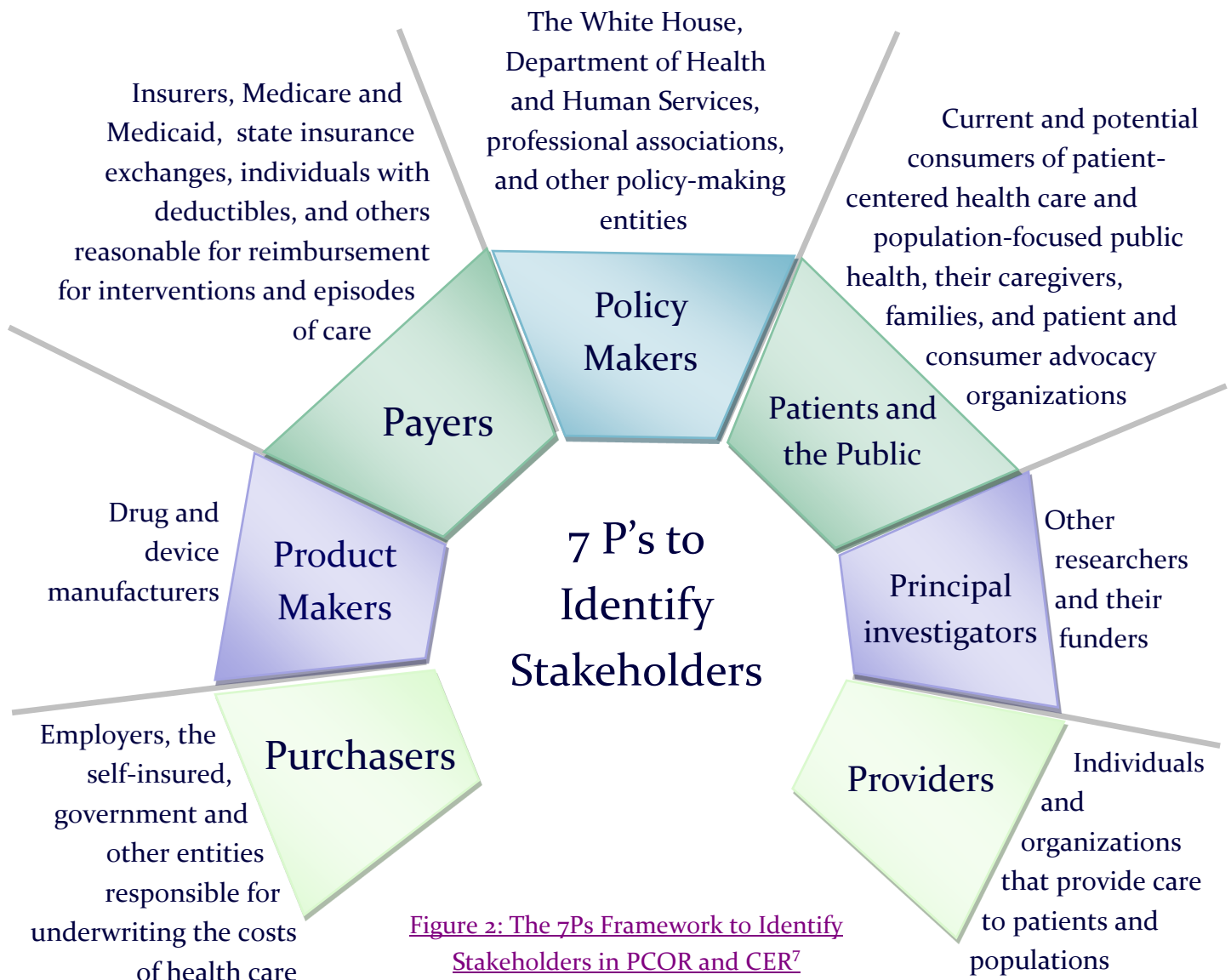


Figure 2: The 7Ps Framework to Identify Stakeholders in PCOR and CER⁷



Who are your Stakeholders?

	Current Stakeholders:	Desired Stakeholders
Purchasers		
Product Makers		
Payers		
Policy Makers		
Patients and the Public		
Principal Investigators		
Providers		

Who to Engage in Pediatric PBRN Research

Parents: Most pediatric practices' patients are young children whose parents (or other caretakers) are primarily responsible for their health care management and decision-making. In addition, children with special health care needs are represented by their parents even as they age toward adulthood. Parents provide important perspectives on the experiences of especially young patients and their needs. They speak for the youngest and most vulnerable patients.

Patients: In addition, patients, especially adolescents, can be engaged to speak for themselves in the research process. As pediatric patients age, they are more able to express and share their own needs and questions about health care with their providers and PBRN managers. We believe that leveraging this ability has multiple benefits for both adolescents and the PBRN. Engaging these older patients can both ensure that adolescent health issues are addressed by PBRNs in ways that are most relevant and acceptable for adolescents themselves and help to empower young people to take a role in health care research early.

Providers and practices: Health care providers and practices have "frontline" insights into what issues and concerns bring patients into their office as well as into areas of health where evidence based guidelines are lacking. They can bring insight into what types of research questions, data collection, and studies are practical to in a healthcare practice setting.

Examples of Colorado Stakeholders

- o Family Voices
- o Department of Public Health CO
- o Children's Campaign
- o Early Childhood Education Councils

Other stakeholders: In every community, there are other stakeholders who are involved and interested in pediatric health issues. In your own community, you should make efforts to identify and open conversations with these other stakeholders groups to find those who can bring diverse perspectives and important resources to the conduct of your research.

In COCONet, we have found non-profit organizations, advocacy groups, state government staff, and others have rounded out our conversations and advanced the quality and innovation of our research in ways we couldn't have anticipated. In addition, we found that these other stakeholders often brought the perspective of being a parent to the table, despite their varied professional identities. We advise other PBRN staff to be open minded about who the stakeholders are and how they can contribute to the research process, especially as you embark on your engagement efforts.

Developing an Engagement Plan

STAKEHOLDER ENGAGEMENT PLAN

In order to ensure that our PBRN stakeholder engagement project represented the voices of as many parent stakeholders as possible, we provided a number of methods for parents to engage with our COCONet project team. Each of these methods involved a different level of engagement and commitment, ensuring that we avoided excluding those parents who may have important insights and opinions to share with our team, but who do not have the ability to commit to ongoing membership on a Working Group or Network Advisory Board.

Here are levels of commitment that our project laid out and that your PBRN may consider.

1. At the first level of commitment, parents and other stakeholders can share their priorities for child health research through participation in a **Ranking Survey**. A ranking survey is a short survey asking for stakeholders to help prioritize issues in their community. The ranking survey process is describe in more detail in Chapter VI.
2. In the second level of commitment, parents and stakeholders take about an hour of time to participate in an **interview** with project staff to discuss research topics of interest to them. These participants may choose to increase their commitment after learning more.
3. A third level of commitment involves joining a **Working Group** and sharing about 10-15 hours of time with other stakeholders to develop research topics into specific research questions that the practice-based research network can pursue with future projects.
4. A fourth level of commitment for parents could be to join the **Network Advisory Board** and pledge a more sustainable role with COCONet after a specific project and into the future.
5. The fifth and highest level of commitment for parent stakeholders is to serve as members of the project team in the role of a **Parent Advisor**. These individuals will have a strong interest in child health research topic and commit to guiding key project decisions throughout a multi-year project.



What levels of engagement will you have available to stakeholders?

What is your timeline for an engagement effort in your PBRN? Months/ years



What are two goals you hope your PBRN can Achieve through engagement?

1.

2.

Measuring Engagement

When pursuing a project to engage stakeholders in the research of a PBRN, it is important to measure and evaluate the success of engagement efforts. Research projects conducted within a PBRN, it makes sense to always be equally committed to understanding what works and what doesn't work when engaging stakeholders. In addition to understanding, measuring engagement and eliciting feedback ensures adapting and changing to maximize the engagement of stakeholders and best support their ability to have meaningful impacts on our PBRN research.

For our engagement efforts we developed a short survey adapted from a n engagement framework on public private partnerships to track on progress. We discuss this more in detail in Chapter VI.



What instrument or tool will you use to measure and evaluate engagement?

When will you measure engagement during your process?

References:

1. PCORI (Patient- Centered Outcomes Research Institute). What We Mean by Engagement. Engagement 2014; <http://www.pcori.org/engagement/what-we-mean-engagement>.
2. Bangthetable.com. IAP2 Spectrum. In: IAP2- Symbols, ed. bangthetable.com.
3. Department of Environment and Primary Industries. IAP2 Public Participation Spectrum In: Spetrum IPP, ed. State Government Victoria.
4. PCORI (Patient- Centered Outcomes Research Institute). PCORI Engagement Rubric2014, Web site.
5. National Center for Advancing Transitional Sciences. Communities and Research 2017; <https://ncats.nih.gov/ctsa/community>. Accessed 6/8/2017.
6. Silberberg M, Cook J, Drescher C, McCloskey DJ, Weaver S, Zeigahn L. Principles of Community Engagement June 2011 2011.
7. Concannon TW, Meissner P, Grunbaum JA, et al. A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research. *J Gen Intern Med.* 2012;27(8):985-991.

Notes:

Chapter II: Community Partnership

Depending on the size and age of your PBRN, you may have many long-established relationships with community partners or very few. For older, more established PBRNs with several community partners, it is worth considering, “Who is missing?” For newer PBRNs, the more appropriate question may be, “Where do we start?” In this chapter, we will walk through the establishment of community partnerships with consideration to both ends of the PBRN spectrum.

PCORI has created several resources to assist with development of community partnerships, including the [Engagement Rubric](#)¹ and the [Methodology Standards for Patient Centeredness](#)². These resources contain PCORI’s six Engagement Principles, definitions, tips for funding applications, and examples. For this chapter, we will draw from these resources with special attention to how they apply to the pediatric setting.

Where to Start?

The establishment of community partnerships are often guided through specific projects. For example, if the research area of interest is improving care for children with Down Syndrome, you might reach out to a local Down Syndrome foundation. For our project, we were trying set research priorities for our PBRN from the perspective of the practices in our network and parents within those practices. Therefore, our first and most obvious community partners were our network practices. We had previously had difficulty eliciting research ideas from the **pediatricians** in our network on a consistent basis. As we all know, life is busy! However, when we approached them with the concept of a project to specifically develop research priorities through a structured process, including **parents** and other stakeholders, providers in our network were quite enthusiastic.



After establishing which providers wanted to take part in the process, we wanted **patients and parents from our member practices** as well. We purposely avoided a specific ‘job description,’ but simply asked pediatricians to suggest names once we described what the aims of our project were. We found that most pediatricians can name one or more parents from their patient panels who would be good fits for what we were trying to do. We’ll describe how we handled our parent partnerships in Chapters III—IX.

Ask Around

Once we had our provider partnerships for this project established, we needed to decide on **other potential community partners**. To be clear, we weren't really sure what we were looking for, and as it turns out, that's okay! We started by using the 7Ps framework (see Chapter I) to identify stakeholders in patient-centered outcomes research (Patients and the public, providers, purchasers, payers, policy makers, product makers, and principal investigators, see Chapter I). [PCORI's definition of stakeholders](#)³ is similar and also a useful guide (patients, clinicians, researchers, purchasers, payers, industry, hospitals and health systems, policy makers, training institutions). For the purposes of our project, while we sought input from all the different types of stakeholders, we made a clear distinction between those from whom we sought input only (purchasers, payers, industry, policy makers), those that we ourselves fit into (researchers, training institutions), and those with whom we felt it was important to partner for ongoing input into the process (patients, clinicians). Depending on your priorities and interests, a different mix of these stakeholders may be important for your partnerships. As it turns out, what we ended up with was different than what we envisioned when we started, but we'll get into that later.

To find community partners for our project, we found what worked best was to start with the contacts we already had within each group of stakeholders. In cases where we had none, such as payers, we were able to establish contacts through introductions from other groups of stakeholders with logical connections, such as policy makers and clinicians.

Advocacy

Fortunately for us, and likely for you too, once we described what our goals were, there was a great deal of enthusiasm to help. Universally, every stakeholder we approached loved the idea of eliciting research priorities for children from parents and other stakeholders. As we started the exploratory phase of our project, early community partnerships became obvious. For example, although we knew little about the organization at the time, several contacts suggested we make contact with Family Voices Colorado, an advocacy organization for children with special health care needs. The common ground of trying to improve the lives of children, them from an advocacy perspective and us from a research perspective, made for an obvious partnership. As a community partner, Family Voices was able to put us in touch with parents both for interviews and for participation in the project.

If you find a lack of enthusiasm, shift gears from eliciting help with your pre-defined goals to asking what your stakeholders need and how they might see your PBRN could play a role in improving child health. You may find that they have other innovative ideas about how you can partner with them.

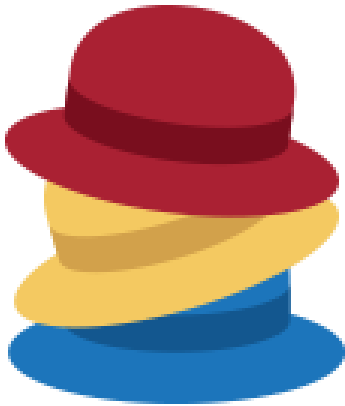
Community Experts

Through contacts at our state health department and another advocacy organization, the Colorado Children’s Campaign, we were able to find plenty of people who were passionate about children’s health. Though most were not researchers, they understood the importance of research and were able to share their policy making and advocacy expertise with us.

Points to Consider

Keeping an Open Mind

As mentioned above, who we envisioned as community partners in the beginning and who we ended up with was somewhat different. While parents and clinicians were obvious partners from beginning to end, what we found in the process was that the not-so-obvious partners were not only nice complements to our existing partnerships, they were crucial to the success of the project! In the end, we ended up with community partners from almost every defined group of stakeholders.



Multiple Hats

It is also important to remember that many stakeholders may actually represent more than one group – for example, a policy maker may also be a clinician. In the case of pediatric research, many people are also parents. In other words, finding community partners to work with that wear multiple hats can add a lot of strength to your project. As this became clearer as our project went on, we actively sought to fill out our Advisory Board and Work Groups with people who brought multiple different perspectives.

Parents In the Community

Selecting Parent Advisors

For our project, we sought to have essentially two categories of parent advisors. **The first was a group of parents who would be readily available to provide feedback** by email or phone and attend occasional meetings. We also wanted to have some **parents actually on the research team**, not just for occasional meetings, but actively engaged in completing the work and being paid as such (they were actually paid more per hour than most of our graduate research assistants!). The theory here was that working so closely with parents not specifically trained in research would help ensure that we remained true to our vision of developing research priorities that made sense to actual parents.

Input from parents For the first group of parents, we estimated we would want 5-10 parents to start with, expanding as needed depending on project needs. For this group, we recruited from our initial group of interviewees, partially based on their interest. We asked all parents we interviewed if they would be interested in participating further in the project, and we were pleasantly surprised that most parents were fairly enthused to contribute further. We also were advised by people with a great deal of community engagement experience to try to recruit ‘big picture’ thinkers, meaning people that are able to see beyond their own personal experiences. This criterion had less to do with educational or socioeconomic status but rather with circumstance: The degree to which our interviewees were able to speak about topics other than their own personal experiences was more about how acute their own children’s physical or behavioral health issues were (e.g. a parent of a child newly diagnosed with a complex condition versus a parent whose children went through a similar experience several years prior).

For the second group, those on the study team, we were looking for 2-3 parents. We first created a job description (see pg. 22). We were looking for parents that were willing to devote about 10-20 hours/month to the project – not a full time job, but a substantial contribution. We then circulated this job description to anyone and everyone we could think of that might know such a person interested in the position, including clinicians in our network, members of our Leadership Team, and other previously identified community partners.



The most important thing in retrospect in hiring for these positions was enthusiasm, and by using the personal recommendation approach, any parents who expressed interest were almost guaranteed to be enthusiastic. It was also important to recognize that most parents bring skillsets from their own work and experiences that can benefit a research project such as ours. For example, one of our parent advisors had prior experience as a patient navigator for an insurance company; another had worked in health policy. We hadn’t considered either of these in our job description, but their prior experience in these fields was of great benefit to our final products .

Developing a Network Advisory Board

Development of our Network Advisory Board was similar to recruitment of our parent advisors. We also created a job description for these positions (i.e. Network Advisory Board members), and were specific on time commitments and expectations. Again, we sought ‘big picture’ people, and specified this in the job description. We started fairly small with our study team parents, two members of our Leadership team, and a few parents from our initial interviews. We then expanded the Board with an ultimate goal of 12-15 members based on the findings from our interviews. For example, it was clear that mental health issues were going to be one of our top topics that would likely lead to a Working Group, and so we therefore sought a few parents with experience with mental health issues in their children. We asked members for a 2-year commitment, with the potential for ongoing participation depending on interest and needs of the Board .

*We address issues of cost and compensation of these stakeholders in Chapter XI

References

1. PCORI (Patient- Centered Outcomes Research Institute). PCORI Engagement Rubric 2014, Web site.
2. PCORI (Patient- Centered Outcomes Research Institute). PCORI Methodology Standards. 2017; <http://www.pcori.org/research-results/about-our-research/research-methodology/pcori-methodology-standards#Associated%20with%20Patient-Centeredness>.
3. PCORI (Patient- Centered Outcomes Research Institute). PCORI's Stakeholders. 2014; <https://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders>.

Notes:

Parent Advisor Description

Position Title: Parent Advisor to Pediatric Practice-Based Research Network
Funded by PCORI Stakeholder Engagement Award

Description of Organization: The Colorado Children's Outcomes Network (COCONet) is a practice-based research network (PBRN) of pediatric practices from across Colorado. Its mission is individual practices collaborating to improve children's health through investigation and quality improvement. COCONet is a member of SNOCAP, an umbrella organization that supports practice-based research networks at the University of Colorado Denver.

Position Objectives:

- 1) Engage in collaborative discussion to aid researchers and the research mission.
- 2) Provide feedback on stakeholder engagement, working groups, and grant/research ideas.
- 3) Provide guidance on the dissemination of research and best practice.

Position Summary: A parent advisor is someone that brings their unique background, health conditions, and health consumer perspective to the research arena. He or she engages as a stakeholder with University of Colorado researchers spanning the research process from stakeholder engagement and topic generation to dissemination and implementation of results. The parent advisors will also serve to assist COCONet staff in envisioning sustainability of stakeholder engagement through parent involvement, working groups, and the Network Advisory Board.

Training: Parents will participate in community-engaged research training in Spring 2016. Additional training will be available as appropriate.

Duties and Responsibilities:

- Shares perspectives, experiences, and suggestions during meetings and through online collaboration
- Commits to the Leadership Team by upholding its purpose through meaningful engagement
- Acts as a sounding board for COCONet grant and research ideas
- Presents ideas to improve research processes as consumers of the end product
- Respects the collaborative process and is willing to listen to differing views
- Encourages all board members to share ideas and viewpoints
- Respects participant and research confidentiality at all times
- Commits to attending quarterly 2 hour Leadership Team meetings and engaging electronically outside of meetings when necessary
- Commits to attending three (3) 2-3 hour Working Group meetings on the topic of interest to the parent advisor and engaging electronically outside of meetings when necessary

This is a flexible position. Parent Advisor duties may change based on their individual skills and interests as well as the needs of the project. We will expect some flexibility but hope this provides an outline of the expectations of the Advisors

Successful Advisors are able to:

- Share perspectives, insights, and information in constructive ways
- Show concern for more than one issue related to child health
- Listen well
- Respect differing opinions
- Speak comfortably in a group
- Look for opportunities to partner and collaborate on finding solutions
- Maintain open and productive communication with researchers
- Respect the limitations of the research environment in meeting individual needs

Compensation:

- Up to \$2400 annually, 2 year commitment

CONTACT: Sarah Brewer at 303-724-6927 or Sarah.Brewer@ucdenver.edu for more information

Chapter III: Parents Engagement, Recruitment and Identification

Getting off to a good start

The initial steps of engaging parents in a process like this are key to the long-term success of the project. You will need to introduce your project in a way that demonstrates your commitment to engagement and provides parents and other stakeholders with a road map for how they can be involved in the PBRN moving forward.

You have two goals in this initial phase of parent engagement. First, you are **engaging parents** in the PBRN research agenda setting process. You are asking them to share their experiences and commit their time to the research enterprise. Likely they've never been involved in a process like this and so, you are asking them to trust you that sharing their experiences will lead to an outcome that take their stories and needs into account.

Secondly, your goal is to **gather information** from a wide variety of stakeholders about the issues facing pediatric health in the context of your community and your PBRN. You want to know what issues they have faced personally, what questions they have had about their child's health that they didn't feel like there was good evidence about, what processes they think should be improved.

Goals:

- I. Engaging Parents in the Process (at a level that fits their abilities/ time)
- II. Collecting Information

Examples of Types of Diversity you may seek:

Race

Ethnicity

Language

Heath conditions

Geography (rural vs. urban)

Geography (neighborhood)

Socioeconomic status

Professional training/career

Children's age (eg, 0-5, 5-12)

Children's sex

Health literacy

Selection Matrix: Who are you looking for? How will you find them?

When you begin, you will want to identify which groups or "types" of parents you want to be sure are represented in your engagement process. Diversity is to your benefit here. You do not want to end up involving only parents with similar experiences whose children attend the same pediatric practices and have the same health conditions. In addition, you want to have a diversity of demographics among your engaged parents that resembles your practices and your community.

In pediatrics, one consideration is getting a mix of parents who have children with special health care needs and parents who have children who are generally healthy. These parents will each find different issues in pediatrics to be important and will prioritize research topics differently. Both perspectives are important to your PBRN.

For example, we found that parents who have children with special health care needs were much more interested in questions of interactions between primary care and specialists than other parents. On the other hand, parents of children who were generally healthy were more interested in topics of primary care, family-physician relationships and public health topics like obesity. Understanding the variety of issues faced by parents in your PBRN will ensure you are able to address a representative set of topics that concern your stakeholders.

As you engage parents, adolescents and other stakeholders you will want to keep both these goals in mind. Consider how you want to ensure representation of each of the following factors among your engaged parents and other stakeholders and how you will know if you've achieved that mix. Once you have identified the characteristics that you want to account for as you engage your PBRN community, you will need to set up a way to track these in your engagement and recruitment process. We recommend that you create an engagement matrix to help you keep track of your parent recruitment process and how many parents you have recruited that represent each characteristic you know you want involved. Remember that many parents will check many boxes and may bring multiple useful perspectives to the table. (see table 2)

Sensitive Issues Most of us recognize the inherent benefits of diversity. However, when we attempt to create diversity, we tread into dangerous waters by categorizing potential partners into boxes on a spreadsheet. A person isn't defined by his or her race any more than he or she is defined by where they live – it is simply part of who they are. Therefore, the categories we suggest are simply guidelines to consider to attempt to avoid a homogenous parent/stakeholder group. Care must be taken to avoid putting too much emphasis on a particular category though. We were fortunate enough that for much of our work, diversity naturally presented itself based on the demographics of Colorado. In situations where a specific subgroup is being studied but is not represented in your research team, our suggestion would be to address that issue directly. For example, if your priority is to develop an intervention to address injury prevention in an inner city, but you have no representation from the residents, reach out to community organizations and explain your dilemma.

Next begin to think about how you will find the parents and stakeholders who you want to engage. Ask pediatricians at your member practices to recommend parent leaders. Give them clear criteria for the parents you are looking to engage, but don't make your criteria so strict that every parent your providers recommend brings the same experiences to the table. For example, you want to involve parents who do not have a singular issue of interest, who have time to commit to a project, and who come to their children's visits with informed questions. You don't want every parent recommended to have the same experiences, but you also want to engage parents who are committed to advancing pediatric research broadly. We often say we're looking for thoughtful, curious parents, but not only the "usual suspects." Use the community partners you identified in Chapter II to find other parents who are leaders in other areas of child well-being. Ask these parents to participate in interviews about their experiences, both personally and in their communities.

Table 2: ENGAGEMENT MATRIX EXAMPLE*

Stakeholder Name	Stakeholder Type					Race					SES by insurance Type				Geography			Language	
	Parent	Provider	Other	White	Black	Asian	Hispanic	Other	Medicaid	Private	Urban	Rural	Suburban	English	Spanish	Other			
John	X			X					X			X		X					
Sue		X				X				X						X			
Joe	X						X		X				X						
Erica			X		X					X				X					
Beth		X								X			X						
Shawn	X					X			X		X					X			
Total Count	3	2	1	1	1	2	3	1	3	2	2	2	2	3	1	2			

**This is an overly simplified version of matrix with a limited number of characteristics. We recommend you create a customized version of this for you PBRN with all of the characteristics you want to be aware of as you engage community members.*

Snowball Sampling

As you interview these parents who have been recommended by your member practices and other community partners, ask these leaders to recommend other community members who you should also hear from. You can increase the diversity of the parents you recruit by asking:

- Do you know any parents who have had a similar experience to yours?
- Do you know any parents who have had a different experience from yours?
- Can you recommend any parents who would tell me a unique story about their experience in pediatric health care?
- If you were looking to engage parents in pediatric health research, who would you talk to first?



When parents recommend someone else in their community, ask them for contact information and ask them why they recommend that person. Continue this process with each person you talk to. Track all their names, contact information, and the characteristics shared by the recommender in your selection matrix. As you expand your search for parents to engage, you may not reach out to every parent, especially as you get recommendations that are similar, but these contacts may be useful later in your process, so keep a list of them all anyway.

Stakeholders – who else should be involved?

In addition to parents, you'll want to engage stakeholders who fall into the other 7Ps (see Chapter I). We recommend you interview at least one person who represents each of the other "Ps." Ask your community partners and your parent advisors to help you identify the key stakeholder in each of the 7P groups that you will start with when you begin gathering information. Consider who are the leading decision-makers and trendsetters in each group. You may choose to engage more than one in a particular stakeholder group if issues are arising that point to a particular stakeholder type. We will discuss this more in Chapter IV. Also check in with your Parent Advisors and your Network Advisory Board periodically to ensure everyone whose perspective should be represented in your process has been invited to become engaged. As you gather information, you (or your team!) will often realize there are key stakeholders who haven't yet been invited to participate who you should reach out to.

Finding and engaging adolescents

Because adolescents are old enough to begin sharing their own experiences in the health care system and formulating informed opinions about what the most important issues for health care research are for their peer group, we recommend engaging adolescents in your PBRN research agenda setting process. As with your parent recruitment, we recommend leveraging community partners and youth organizations to identify adolescents who are ready to engage in this process.

Lesson Learned

Our initial approach to engaging adolescents in our PBRN was to recruit youth who were already engaged in other health-related projects through a local community partner. After a few interviews with these adolescents, we realized that they came to the table with an interest in a few specific health issues. However, these issues were exactly the issues the community partner was working on. We realized that one of two things were happening: (a) by recruiting through this organization, we were only recruiting adolescents with an interest in those issues, or (b) because these adolescents were involved with that organization, they adopted these issues as the most important, separate from their own personal experiences. While we believe recruiting through community partners is valuable and efficient way to find interested community members, this experience highlighted the need to diversify your recruitment to find community members who bring broad experiences to your PBRN and do not bring a pre-defined personal agenda to your PBRN program .

Notes:

Chapter IV: Gathering Information

Information Gathering

To identify a broad range of issues, we began with interviews. Interviews are structured or semi-structured conversations with stakeholders about a set of topics you have defined in advance. We primarily used a one-on-one semi-structured interview format to gather information from parents and other stakeholders. We created conversation guides that ensured similarity of topics covered across interviews. These guides were structured to elicit information from parents in four categories:

- I. Their child’s experiences in the pediatric health care system
- II. Their child’s experiences with health in their community
- III. The questions they have had about their/their child’s health and their satisfaction with the answers to those questions
- IV. Their perspectives on a list of 15 health issues that had been raised in our PBRN by clinicians or researchers

In order to capture the information we thought we’d need to guide our research agenda setting, we decided we need to both (1) keep it open ended and be open to what came up in conversation; and (2) have a list of pediatric health topics and ask people to react to those topics. We ordered the conversation from the most exploratory and open-ended (asking parents to share their questions with us) to most structured (asking parents their level of interest in our pre-defined list of health issues) so as to limit the influence of our questions on parents’ responses and ensure our findings were not affected by the issues that had previously been addressed by other stakeholders.

We chose to ask about the structured list of issues to ensure that we had gotten feedback from everyone we engaged in the interview process about the health issues most commonly raised in our PBRN setting and to assess the relevance to parents of the issues on which our PBRN had previously applied its focused .

Example List of Pediatric Health Issues

Preventative Care (or Primary Pediatric Care)
Immunizations/Vaccines
Obesity
School-Based Health Care
Behavioral Health—Such as ADHD
Sexual and Reproductive Health
Drug Use and /or Substance Abuse
Developmental Health
Mental Health Such as Depression, Anxiety or Suicide
Injury and Violence Prevention Towards others
Injury and Violence Prevention Towards Self
Allergies
Asthma
Children with Special Health Care Needs
Coordination of Care with Specialists
Developmental Screenings

Tracking Interests over time

Interview Debrief or tracking forms are helpful for starting to identify the interests of your stakeholders as you complete a large number of interviews with parents, adolescents and others. We recommend that you create a short, 1-2 page form that captures key information about each interview and summarizes the themes raised by each person engaged in this process. When you have completed about half of your planned interviews, these will be a useful tool for doing an initial summary of what you've heard and identifying the stakeholders you may need to add to your engagement plan.

These tracking sheets are also helpful for communicating with your parent advisors and your network advisory board about the progress and themes of the interviews. These engaged community members can easily flip through these 2- page summaries of each interview to see trends. Then, they can use this information to help make suggestions about how to change the conversation guides, expand the engagement efforts to other groups, or begin to narrow the scope of your information gathering as clear patterns arise. (see page 32 for sample)

Stakeholders

As you progress through your information gathering process, themes may begin to arise about issues that your PBRN may eventually choose to focus on. As these themes arise, you may choose to engage additional stakeholders from each of the 7Ps groups. If issues of health systems and processes are commonly being raised by parents, you may choose to engage additional provider organizations in interviews. If parents and providers are discussing health insurance coverage issues for a particular procedure, you may opt to involve more payers. Or, if issues of local or state regulations are coming up in conversations with parents and providers, you may engage additional policymakers in conversations about those issues. Ultimately, the mix of stakeholders you will engage in the information gathering process should be iterative and dependent upon what you're hearing and the advice of your parent advisors and network advisory board.

Lesson Learned

Our project engaged parents because they are the primary representatives, advocates, and decision-makers for children in the pediatric health system. We can rarely get the information we need to understand what research questions families and patients need answered from pediatric patients themselves. This process engages parents as proxies for their children. Remember to help parents focus on their experience in pediatric health care and their role as a parent and advocate for their children as patients. While they likely also have important experience of their own to share, you will want to focus on the questions they have regarding pediatric health.

Parents

Our process was primarily focused on engaging parents and adolescents in setting a research agenda for our PBRN. This means the majority of our interviews were with parents of children who attend a member practice in our network. A key thing to remember is that these parents are not researchers, health professionals, or otherwise involved in the work that we do in academia or PBRNs. However, they have a wealth of knowledge and experience to share if you ask the right questions.

Interviews vs. Focus Groups

You will need to work with you stakeholders to decide the best way to collect information from your stakeholders. For our project, we and our parent advisors largely agreed that individual interviews would be the best way to gather information from our stakeholders due to the flexibility of scheduling and the likelihood parents would share more in one-on-one conversations. Interviews worked very well for the majority of our stakeholders .

Table 3: Pros and cons of information gathering methods with stakeholders

Interviews		Focus Groups	
Pros	Cons	Pros	Cons
One-on-one relationship building	Little opportunity for brainstorming or idea generation between parents/adolescents	Greater opportunity for brainstorming or idea generation between parents/adolescents	Low opportunity for individual engagement and relationship building
Stakeholder more like to share personal information and experiences	Focus on individual may make stakeholder shy or uncomfortable	Allows individuals to engage in discussion with less pressure to answer every question	Not every stakeholder will be able to address every question
May be better suited for collected depth of information		May be better suited for groups less familiar with health issues or research	You may collect less depth of information

However, in our experience, interviews with adolescents were not very fruitful. Teens were not forthcoming with stories and did not have concrete questions about health care that they wanted answered. In one-on-one settings, teens often raised a single health topic that they found interesting and circled back to that idea again and again. After a series of similar interviews, we discussed with our parent advisors and our project team how else we could engage adolescents to have richer conversations about health. Once we

Examples of Organizations with existing youth boards from Colorado:

- Kaiser Permanente
- Colorado Department of Public Health and Environment
- Colorado Youth Matters
- Colorado Youth Advisory Council (advises the Colorado State Legislature)
- Children’s Hospital Colorado

[Web link to other examples compiled by a local non-profit¹](#)

shifted gears to adolescent focus groups, we found that we had much richer conversations. Conducted in existing organizations and existing boards of adolescent leaders , our focus group conversations were incredibly informative about the issues facing teens in our Colorado communities. In a focus group setting, adolescents were able to bounce ideas off of each other, formulate their thoughts as a group, and provide examples and justification for each other’s suggestions that brought depth to the discussion and more clarity to the issues they see among their peers and communities.

Recording your data

When you're in the midst of your information gathering, you will talk with a lot of people with diverse perspectives on the pediatric health care system. It is likely that as you have more discussions, you will start to form impressions, themes, and ideas in your head about the things you're hearing. These perceptions will be important as you move to your next phase. You also want an objective record of the issues raised by stakeholders. On these conversations, there is often a dense set of experience and concerns that cannot be completely "unpacked" within an hour discussion. As you start making the connections between conversations, your objective record will help you link some of the nuance raised in an interview that wasn't unpacked at the time. In order to capture the detail and nuance of the information you've gathered, we recommend taking a multi-pronged approach to recording that information.

First, Record your conversations. Take a small audio recorder with you and ask your stakeholders if it's ok that you tape your discussion. This will allow you to capture everything that is said while you focus on building trust and rapport with that person. We'll discuss in the next chapter what to do with these recordings.

Second, Take notes. If you've gotten your stakeholders permission to record the conversation, then you won't need to write down much. Jot down key themes you hear the person coming back to. Make note of the questions they raise that you can follow up on— either by providing information to the person after the interview, or rounding out your own knowledge to inform this PBRN agenda setting process. Keep track of the mood as you move through the interview can also help you understand what your stakeholders are experiencing day-to-day and how your PBRN can help to address and improve those experiences for patients and their families.

Third, use your debrief form to capture the themes you saw in that individual interview and the links you're seeing to prior interviews. Especially after you have talked with 40-60 stakeholders, these summary notes can be invaluable to reminding you of the impressions you had in interviews.

Lesson Learned

Be flexible in how you collect information and ask your stakeholders for new ideas when you aren't getting the information you want.

References

1. Colorado 9to25. Colorado Youth Advisory Boards Web2012.

Notes:



ACCORDS
UNIVERSITY OF COLORADO
CHILDREN'S HOSPITAL COLORADO



Sample Debrief Form

Study ID: _____ Date of interview: _____ Time of Interview: _____

Duration of interview: _____ Place of interview: _____

Interviewee's contact information (if relevant): _____

Summary of Interview Data:

What themes or issues relevant to my research question emerged from the interview? What topics related to child health were most prominent in this interview

Did the interviewee say something particularly noteworthy/interesting in response to one or more of the interview questions? If so, for what questions did s/he provide noteworthy responses (if any)?

Question number and/or topic	Brief description (4-6 words) about what was said

Themes/issues that came up in this interview that would be worth following up on during the next interview:

- (a)
- (b)
- (c)
- (d)

Assessment of Interview:

To what degree did the interviewee provide interesting detail/insight/data? Describe to the right:

___ Little interesting detail, insight, and/or data

___ Some interesting detail, insight, and/or data

___ Lots of interesting detail, insight, and/or data

Based on the interviewee's responses, body language, etc., how engaged/comfortable did s/he seem with/ during the interview? Describe any areas where comfort/engagement were especially high/low.

How easy/difficult was it to establish rapport with the interviewee? Why do you think this was so?

Were there any problems with/during the interview? If so, describe. How can this be improved for the next interview?

Did the interview guide/questions work well? Does anything need to be altered or improved?

Is the interviewee willing to be contacted again?

- Ranking Survey Working Group Network Advisory Board Other

Have I promised to send any information or supply them with the results? If so, what?

Chapter V: Synthesizing Issues

After you have gathered information from your stakeholders, you will need to have a method for synthesizing those issues into a clear and concise list of topics that you can address with research studies. For some PBRNs, this will be a new process and the health issues being raised may be broad and unrelated. For others, the issues raised by your stakeholders may be specific, nuanced and related to a particular overarching health issue. In both situations, it is important to accurately summarize the diverse ideas raised by your stakeholders and to narrow those ideas into themes and patterns that your parent advisors and network advisory board can efficiently and effectively absorb and respond to. In this chapter, we will walk through a process for synthesizing this list of health issues raised in your Information Gathering phase.

Documents of your interviews

In Chapter II we recommended recording your interviews with stakeholders. As you prepare to synthesize what you've heard from stakeholders into a list of issues that your PBRN can start to address and examine, you need to decide how you will do this. Depending on the number of stakeholders from whom you have had conversations and gathered information and the detail of the notes you have taken, you have some options. It may be that you have taken detailed notes and completed detailed debrief forms on a relatively small number of conversations. If this is the case, you may be able to synthesize what you heard using these field notes and use your recordings only to confirm or supplement your summary. If your PBRN is working on a very limited budget, this may also be the most feasible option. If this is the case, continue with caution to ensure you are not losing the voices of your stakeholders in the remaining steps in this chapter.

If you've collected less detailed notes or conducted a large number of conversations with your stakeholders, we recommend you transcribe (have someone turn the recordings into written documents of the verbatim conversations) the recordings you made. This will ensure that you have as much detail about what your stakeholders told you and that their voices are accurately represented and that you can best identify the similarities and differences across your stakeholder groups.

We had conducted a large number of interviews with moderately detailed notes and debrief forms. Because of the richness and nuance in some of the conversations we had, and the large number of conversations, we chose to transcribe all our interviews and focus groups. We chose to complete this process without any identifying information and instead used interview numerical IDs.



Coding or Categorizing issues

After you have decided which documents you will use to summarize your conversations, you will need to decide how to approach these documents. Those of us with qualitative research experience are likely to leap straight to a coding software program like [ATLAS.ti](#) or [NVivo](#) at this point in the process. However, few of your stakeholders will be familiar with these software programs nor will these encourage the maximum engagement from your advisors. We think this is a good point to stop and assess the capacity of your research team and your parent advisors to determine your next steps.

Coding: First you should determine who will review the transcripts to start this process. On our project, that task was led by a member of our PBRN team with qualitative research training and our parent advisors assisted with the process .

Software: In our project, our parent advisors were excited to help us review what we heard in our conversations and start to synthesize the themes. However, they didn't really want to spend the time learning formal

qualitative analysis. Rather, they felt like they could accomplish the same process with skills they already had – like using a tracking changes functionality in a word processing program. However, our PBRN staff were concerned about managing so many transcripts in a program like Word. Ultimately, our team compromised. Our parent advisors used track changes to mark text in the transcripts that aligned with specific issues and our research team translated those tracked text segments into codes in the qualitative software program called ATLAS.ti so we could more easily manage the large quantity of text and use the query function to look at the information more strategically.

There are other qualitative software programs available, such as NVivo, so before purchasing a specific product, consider which one will best suit your needs.

Research or not? You will need to determine in advance if your engagement efforts are research or not. If it is research, your community stakeholders will need IRB human subjects training to participate in activities like coding. If it is not categorized as research, you should consult your institutions IRB to determine if there are any barriers to your stakeholders engaging in these activities.

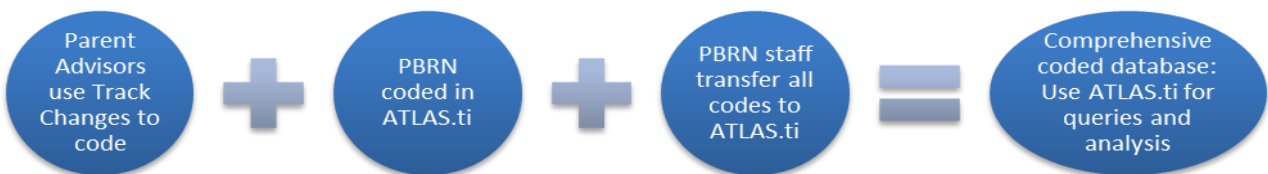


Figure 3: Using a combination of ATLAS.ti and Microsoft(R) Word, we were able to combine coding on interview transcripts by both researchers and stakeholders into one comprehensive database for running queries and analyzing our interview information. This model maximized stakeholder involvement in this process without the need for extensive training in research-specific software programs.

Codes: You will also need to think about how you will categorize what you heard. We started with a list of pre-determined issues that we had asked about in the interviews. These included topics addressing the health care system, the relationship between patients and physicians, and specific health issues and diagnoses. That list formed our initial codebook. In addition, we reviewed the debrief forms to identify themes that were identified as the interviews were conducted. These were added to the codebook when there was agreement between the PBRN team and the Parent Advisors.

We also agreed on a process for adding codes to our codebook as they emerged from the transcripts. When the PBRN staff or the parent advisors identified statements they deemed important to the process but not reflected in the codebook, they marked them and raised them for discussion with the team. All these sections were reviewed together to identify themes, discuss if they should be included, and whether a new code was warranted. Consensus was required to add codes to our list to identify these emergent themes.

Finally, for our PBRN, we identified a need to distinguish between issues that were raised with passion and enthusiasm and those mentioned without much emotion. We felt this was important because throughout the information gathering phase, we saw a pattern of parents talking about the issues they heard about from the local media, but with little energy or direct experience tying them to those issues. Often later in the conversation a parent would bring up another issue that they were clearly passionate about. **We were particularly interested in the issues parents wanted to see more research on that were otherwise not being addressed.** Thus, we created a set of codes to indicate the level of enthusiasm or emotion that accompanied an issue raised by our stakeholders.

Categories to Consider when Preparing a Code Book

- Anticipated health issues based on the Interview Guide
- Additional issues noted on debrief forms
- Unanticipated issues raised by stakeholders and a process for adding these
- Level of enthusiasm or emotion



What are your codes?

Summarizing and Synthesizing

Once the team had reviewed and coded all the transcripts from our stakeholder interviews and focus groups we came to the task of summarizing what we heard. We used a number of approaches to this. Because we chose to use ATLAS.ti, we could use a number of analysis tools to summarize the data. First, we produced two reports: (1) the co-occurring codes matrix (which codes overlapped on the same text) and (2) the code-transcript matrix (how many times did each stakeholder raise each issue/code).

Table 4: Code Co-occurrence Example

	Code 1	Code 2	Code 3	Code 4	Code 5	Code 6
Code 1	0	9	8	3	2	13
Code 2		0	3	6	7	10
Code 3			0	19	4	6
Code 4				0	26	12
Code 5					0	7
Code 6						0

Based on the code co-occurrence matrix, we were able to identify which codes went together. We ultimately didn't decide to combine codes, but this helped us to think about some "buckets" of codes that might go together. It also helped us to see codes that didn't logically go together, but that seems to be mentioned together. For example, codes 4 and 5 in our example have a very high level of co-occurrence. This might indicate a need to group these as you move forward, or it may help you think about how parents see these two codes as related ideas.

Table 5: Code-Transcript Example*

	Transcript 1	Transcript 2	Transcript 3	Transcript 4	Transcript 5	Transcript 6
Code 1	3	4	9	9	3	4
Code 2	0	1	4	1	4	2
Code 3	1	1	1	1	2	2
Code 4	0	1	0	11	3	4
Code 5	2	4	2	0	1	1
Code 6	2	1	6	14	4	3

*This table shows the frequency of each code by same transcript allowing your team to distinguish between codes with high frequency because everyone you talked to brought it up and codes with high frequency because a few stakeholders talked about them a lot. You can use this kind of information to help your Network Advisory Board better understand the interest from stakeholders in various issue areas and topics.

Using the code-transcript matrix function in ATLAS.ti, our team could look at whether code counts were the result of many stakeholders all raising the same issues or a small number of stakeholders talking a lot about an issue. This helped us to find the issues that many of our stakeholders were raising and that multiple types of stakeholder had told us were important. Through these two summary reports, our team identified a number of queries they wanted to review in more depth.

The PBRN project team and the parent advisors reviewed numerous sets of text associated with the codes they identified and ultimately whittled the list of issues down to their top 6 issues. Your PBRN could choose any number of issues at this stage. For our project, these “top 6” were clearly reflected more strongly by our stakeholders than the next group of 8-10 issues, which were retained for future work with our stakeholders. Selecting a limited set of issues at this point does not mean you can never go back to the other things you’ve heard from your stakeholders; it only gives your PBRN a limited scope for the present.

Rating the Issues

Once we had identified our Top 6 list, we needed to both report out to our stakeholders and to ask them to help us decide which of these to focus on first. To do this, we created an online survey, distributed via email, for our stakeholders. Working with our parent advisors, we agreed that the survey should take less than 10 minutes to complete and should accomplish the dual function of reporting back to our stakeholders the issues we heard and getting their feedback for our next steps.

The survey was 8 pages long and consisted of one page for each issue and one page of limited demographic information, and one page asking the stakeholder to report their future interest in working with our PBRN on addressing these topics. Our parent advisors helped us to create a format that was easy for stakeholders of all kinds to understand and respond to and to identify the limited criteria on which we wanted them to rate the issues to which we had narrowed our scope.

Each issue page included three components:

- I. A summary of the issue as it was described by stakeholders in the interviews
- II. A summary of the gaps in research about that issue, or research questions as defined by the stakeholders
- III. Two questions asking the stakeholder to rate the importance of the topic on a 1-10 for (1) its overall importance and (2) the importance of researching that issue.

Top 6 Stakeholder-Identified Research Issues

1. Access to and availability of care including mental health
2. Coordination of Care with and among Specialists and PCP’s
3. Immunization refusal and Colorado’s low rates
4. Pediatric Mental Health – Coordination, Communication and/or Integration with PCP
5. Models for improving the Doctor-Patient Relationship
6. Training Parents (or Teens) as Advocates for Care with Goal of Improved Health Outcomes

Why did we ask them to rate, not rank? Each of the issues identified for our “Top 6” list was a really important issue for pediatric health care. Based on evidence from survey design research and the preferences of our stakeholder advisors, we didn’t want to ask parents to directly compare issues to each other on importance. Instead, asking stakeholders to rate the issues individually allowed them to have ties between issues on either of the criteria without conflicts. In addition, their ratings resulted in more granular data that allowed us to better determine the average importance of each issue to our stakeholders.



Have a conversation with your stakeholder advisors: what criteria should you use to rate the top issues in your PBRN? How will you ask for your stakeholders’ input on those criteria?

Notes:

Chapter VI: Choosing Issues for your Research Agenda

Using your Network Advisory Board (NAB)

We started this project with two advisory groups for our PBRN, one of physicians and one of researchers. We did not yet have an Network Advisory Board that included other stakeholders. Thus, as we developed our Network Advisory Board, we were clear with each potential member that one of first tasks of the Board would be as final decision-makers for the priorities identified through the interviews, focus groups, and survey. To do this, we planned the first Board meeting to occur after the formative work was finished and analyzed, approximately a year into the process. Recognizing that our Board members are busy overscheduled people, we started the process of scheduling the meeting about 3 months before the planned date, and planned for a 3 hour meeting.

Framework for Considering Potential Research Questions

Potential research questions were evaluated under the following framework: 1) Is this a question answerable by research? 2) Is this question unique? 3) Is the answer to this question known? and 4) Is this question relevant to the care of children in Colorado and elsewhere? Questions were not refined at this point in the process. Rather, the Network Advisory board left the refinement process to the Working Groups where they will be refined using the PICO format (patient/problem, intervention, comparator, and outcome)^{1,2,3}

JLA Model adaptation

The [James Lind Alliance](#)⁴ is a non-profit organization based in Great Britain that has developed extensive methodology for “Priority Setting Partnerships.” Similar to our aims, the aims of the JLA are to bring patient and clinician groups together on equal footing, identify treatment uncertainties which matter to both groups, work with both groups to jointly prioritize the uncertainties, and produce a final list of jointly agreed research priorities, publicize them widely, and make that other uncertainties they have discovered are available for researchers and research funders to access. We modeled several aspects of our process on those described in the [JLA Guidebook](#)⁵, and these are described in more detail below.

If you already have a stakeholder advisory board, by all means engage them earlier in the decision-making process. Get their input on selecting Parent Advisors for your study team, interview questions, community partners, etc. If, like us, you don't have that board in place, we found that engaging them at this point in the process was effective because it gave the NAB a clear first task to accomplish as well as the information we had gathered from stakeholders to inform their decisions.

Criteria for Ranking Priorities

To determine which of our identified priority areas would lead to one of our three Working Groups, we asked our NAB to consider several criteria in their discussion. In addition to the aforementioned framework for considering research questions, we asked the NAB to also take into account several other factors. The first was feasibility. Would we be able to address the research question within our PBRN? Some questions, and even whole topic areas, while important, are probably not feasible to do within a single state, single-specialty PBRN. For example, in interviews with parents and stakeholders, the problem of access to mental health providers was a recurring theme. There simply aren't enough mental health providers in the state of Colorado to meet the demand, and this problem is compounded in certain areas. However, as a PBRN, it is not within our abilities to create more providers, or provide the funding or incentives to increase the number of providers over time.

Key criteria for issue priorities

- Feasibility
- Potential impact
- Interest across stakeholder groups
- Other stakeholder-identified criteria

We also asked them to consider the potential impact of any research questions and topic areas under consideration. What is the potential for a particular intervention, if successful to improve the lives of children in Colorado?

Third, we also asked them to consider how much interest there was across the different stakeholder groups that we interviewed. For example, if a priority area emerged as moderately important across most of the stakeholder groups, that may take precedence over a priority area identified as highly important in only one or two stakeholder groups.

Finally, we asked the group to identify up front any other criteria they wanted to use in the decision-making process.



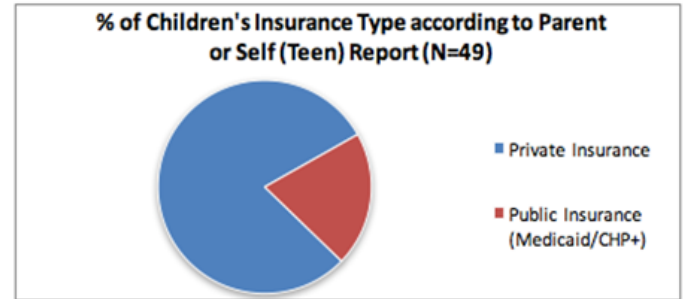
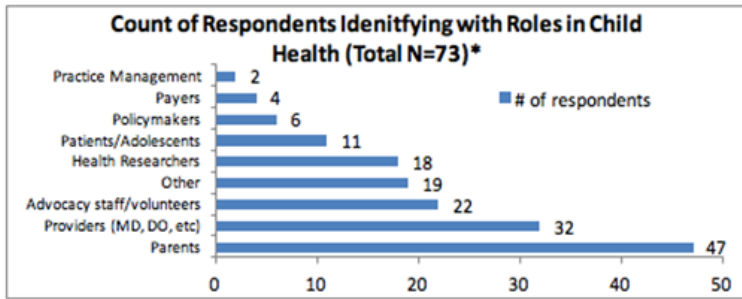
What criteria do you and your advisors want to rate your topics on?

Presenting qualitative and quantitative data to parents and stakeholders

To inform this process, we went through the exercise of summarizing our findings from the qualitative work as well as the survey in lay terms. We wanted it to be long enough to adequately relay findings but also short enough that people would actually read the report. To do this, we created a simple one page set of tables and figures that included the priority areas identified from the qualitative work with the results from the ranking survey. This was shared in advance by email with interviewees and stakeholders, and the NAB, with a brief description.

Results of the Ranking Survey

Total Responses = 75 people (75/98 = 76.5% response rate)



*These categories are not mutually exclusive. All respondents could identify with multiple roles.

Mean Scores of Issue Importance

	Rating of Overall Importance in Colorado (on 10 point scale)			Rating of Research Importance in Colorado (on 10 point scale)		
	Mean	Min	Max	Mean	Min	Max
Access to and availability of care including mental health	8.51	1.90	10	7.46	0.60	10
Coordination of care with and among specialists and PCP's	8.04	4.00	10	7.35	0.40	10
Immunization refusal and Colorado's low rates	8.40	1.40	10	7.27	0.20	10
Pediatric mental health – coordination, communication and/or integration with PCP	9.24	6.00	10	8.59	0.10	10
Models for improving the doctor-patient relationship	7.58	1.80	10	6.50	0.20	10
Training parents (or teens) as advocates for care with goal of improved health outcomes	7.93	2.80	10	7.26	0.20	10

Expressed Interest in Participation in Working Groups by Issue

	Number of Respondents Interested in Working Group Participation
Access to and availability of care including mental health	20
Coordination of Care with and among Specialists and PCP's	17
Immunization refusal and Colorado's low rates	17
Pediatric Mental Health – Coordination, Communication and/or Integration with PCP	34
Models for improving the Doctor-Patient Relationship	14
Training Parents (or Teens) as Advocates for Care with Goal of Improved Health Outcomes	24

Figure 4: This document is an example of how we summarized the Ranking Survey findings for our Network Advisory Board. Most of our engaged parents had high school or college education, but presenting this information in a simplified and graphic format helped to ensure that all our stakeholders had equal opportunity to view and interpret the results of the survey and its implications for our priority-setting process. This document did not tell our stakeholders what their decision should be, but rather provided the basis for a conversation among our stakeholders about how to proceed.

Lesson Learned

These people have a lot to offer, let them steer the conversation!

Decision-making process

For the meeting with the NAB, we purposely created a very loose agenda. While we wanted to keep our group on task, we also wanted plenty of time for open-ended discussion.

To start the meeting, we laid out some general ground rules for discussion, and included Figure 5 (page 44) as to how we suggested we pursue this process. We also had paper copies of the results of the ranking survey. We then stated the basic goal of the meeting, which was to come to a consensus on the general topic areas for our three work groups by the end of the meeting. We also committed, as the study team, to speak as little as possible and let the NAB do the work.

Fortunately for us, our NAB worked well together, and while there were some minor disagreements and point-counterpoints during the discussion, the various members worked nicely as a team. Several people in the room had more experience than we did in their own work settings in processes such as these, so we as the study team did not have to say much to steer the discussion .

Facilitation If no one on your PBRN staff has formal facilitation experience, we recommend seeking out training and guidance for this skill set. Hosting well-facilitated meetings will go a long way to ensuring successful and collaborative engagement of your stakeholders.

Based on the ranking survey and the knowledge of the people in the room, it was clear that something to do with access to mental health was a top priority. Therefore, it was unanimously agreed almost immediately that one of the Working Groups would focus on pediatric mental health access.

Lesson Learned

Make the obvious decisions quickly to spend more time on the more difficult ones.

The rest of the discussion was then devoted to determining the other two Working Groups. At this point, the ranking survey wasn't as helpful, since pediatric mental health was really the only thing that stood well above the other topic areas. Some of the members brought up the concept of taking elements from more than one of the identified priority areas to create a single Working Group. A very open-ended discussion followed, which led to more focus for the already created Mental Health

Working Group (it could also include care coordination), as well as our two other Working Groups. It was decided that one of these would focus on training parents (or teens) as advocates for care, potentially with an emphasis on transitions of care, and possibly incorporating models to improve the doctor-patient relationship. This could include transitions for children with special health care needs and/or healthy adolescents. For the final Working Group, addressing vaccine hesitancy was chosen, and this choice was based on feasibility – a few NAB members were aware that vaccine delivery research was a particular strength of our larger research group, and thus felt that it was a logical choice since we could bring a patient-centered perspective to existing infrastructure.

Lesson Learned

It's okay to be practical when the decisions aren't obvious.

Lesson Learned

Keep the surveys short and make them very easy to access.

Measuring Engagement - Surveys

It is important to understand at key points in the project the level of engagement and collaboration of community partners, parents, and other potential stakeholders. Such information is helpful in projects such as ours to help adjust processes if necessary to achieve higher degrees of engagement and/or collaboration. To measure engagement and collaboration, we modified tools from prior work (such as The Partnership Development Continuum⁶). We surveyed our collaborators after every major meeting in the project, including all meetings of the Network Advisory Board and all Working Group Meetings. We also conducted short online surveys of our stakeholders to assess their

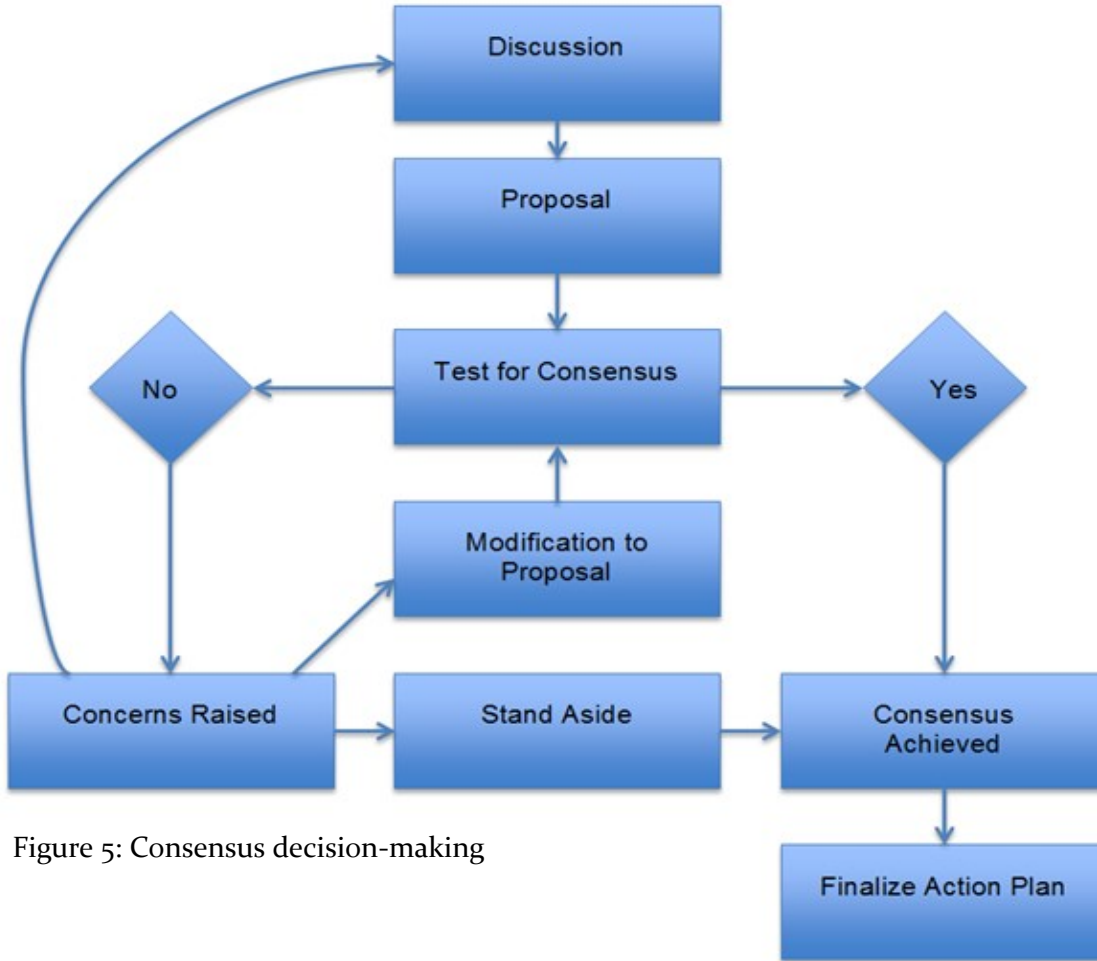


Figure 5: Consensus decision-making

Troubleshooting this is not to say that there weren't hiccups and challenges along the way. If you experience challenges, we recommend having open and honest conversations with your Parent Advisors and your Network Advisory Board about how to improve on the work that you are doing. These stakeholders have invaluable insights into what works and, if you seek their feedback, they are likely to be happy to brainstorm innovative solutions to these challenges.

satisfaction with group dynamics, topics of discussion, group direction and progress, as well as any topics we were not able to discuss as a group. In general, we had very high participation in these surveys.

We also found that almost without exception, all participants expressed a high degree of satisfaction with engagement and collaboration with our project. Our plan was working!

References

1. Riva JJ, Malik KM, Burnie SJ, Endicott AR, Busse JW. What is your research question? An introduction to the PICOT format for clinicians. *The Journal of the Canadian Chiropractic Association*. 2012;56(3):167- 171.
2. PCORI (Patient- Centered Outcomes Research Institute). PCORI Methodology Standards 2017; [https://www.pcori.org/research-results/about-our-research/research-methodology/pcori-methodology-standards#Causal Inference Methods](https://www.pcori.org/research-results/about-our-research/research-methodology/pcori-methodology-standards#Causal%20Inference%20Methods).
3. Lansing Community College Library. What is PICOT. Nursing 2017; <http://libguides.lcc.edu/c.php?g=167860&p=1102882>.
4. James Lind Alliance. The James Lind Alliance 2017; <http://www.jla.nihr.ac.uk/>.
5. James Lind Alliance. JLA Guide Book 2017; <http://www.jla.nihr.ac.uk/jla-guidebook/>.
6. Frey BB, Lohmeier JH, Lee SW, Tollefson N. Measuring Collaboration Among Grant Partners. *American Journal of Evaluation* 2006;27(3):383-392.

Notes:

Network Advisory Board (NAB) Member Description

The Colorado Children's Outcomes Network (COCONet) is seeking thoughtful engaged parents and child health stakeholders to serve as board members for our research network to help guide us to pursuing parent- and patient-engaged research to improve pediatric health.

Position Title: Board Member of the Colorado Children's Outcomes Network (COCONet)

Description of Organization: The Colorado Children's Outcomes Network (COCONet) is a practice-based research network (PBRN) of pediatric practices from across Colorado. Its mission is individual practices collaborating to improve children's health through investigation and quality improvement. COCONet is a member of SNOCAP, an umbrella organization that supports practice-based research networks at the University of Colorado Denver.

Position Objectives:

- 1) Engage in collaborative discussion to aid COCONet in achieving its research mission.
- 2) Provide feedback on stakeholder engagement, working groups, and grant/research ideas.
- 3) Provide guidance on the dissemination of research and best practice.

Position Summary: A board member is someone that brings their unique background, experience, and health consumer perspective to the research arena. Board members engage as stakeholders in pediatric health research spanning the process from stakeholder engagement and topic generation to the sharing of research results. Board members will also assist COCONet staff in envisioning sustainability of clinician and parent involvement, network research agenda selection, funding support, and other COCONet business.

Training: Board members will receive in community-engaged research training annually.

Duties and Responsibilities:

- Shares perspectives, experiences, and suggestions during meetings and through online collaboration
- Commits to the NAB by upholding its purpose through meaningful engagement
- Acts as a sounding board for COCONet grant and research ideas
- Presents ideas to improve research processes
- Respects the collaborative process and is willing to listen to differing views
- Respects participant and research confidentiality at all times
- Commits to **attending quarterly meetings** and engaging electronically outside of meetings as necessary

Board Member duties may change based on individual skills and interests as well as the needs of the project. We will expect some flexibility but hope this provides an outline of the expectations of the Board.

Successful Board Members are able to:

- Share perspectives, insights, and information in constructive ways
- Appreciate the 'big picture' regarding child health issues in Colorado
- Listen well
- Respect differing opinions
- Speak comfortably in a group
- Look for opportunities to partner and collaborate on finding solutions
- Maintain open and productive communication with researchers
- Respect the limitations of the research environment in meeting individual needs

Compensation:

- No compensation is available for board members at this time
- A small stipend may be available for participation in the community-engaged research training

CONTACT: Sarah Brewer at 303-724-6927 or Sarah.Brewer@ucdenver.edu for more information.

Chapter VII: Working Group Recruitment

Re-Engaging Parents by Selected Issues

Once we selected the top three issues that our pediatric PBRN would focus on, we started the process of building a Working Group of stakeholders to address each issue. A Working Group is group of 7-10 people tasked with addressing a particular topic and developing it into a research question and proposal. A Working Group is different from an advisory group in that it is not providing advice for another work, but is actually collaborating and producing research questions through a structured process. Our Working Groups brought together stakeholders (parents, clinicians and researchers) to build on the interview findings and develop research questions, agendas, and a sustainable engagement model.

To reiterate, for this project we wanted the driving force to be the **parents**. For example, depending on the findings from your stakeholder interviews or focus groups, it may be that there are clearly different issues for **urban, rural, and Spanish-speaking** parents, so that these would form the Working Groups. Conversely, it may be that parents across demographics identify **childhood obesity** and **mental health** as key topic areas, in which case Working Groups could form for these domains.

We chose a “Working Group” model because we wanted to emphasize the active nature of these groups. We wanted each group to be empowered to develop and produce ideas together, rather than advise a researcher who would could apply their feedback to their own work. As their name suggests, our Working Groups did a lot of work!

Who to recruit to your Working Groups?

Upon identification of the Working Group designations and topic areas, we sought to convene a group for each topic that consisted of a **majority parents**, alongside providers and clinicians, professionals who

worked with children, and other stakeholders from the 7Ps framework. Ultimately, each group consisted of 7-11 members. Each had 50% or more parent stakeholders. In addition, each group had at least one provider and one other professional (school social worker, child psychologist, etc.). One of the groups included a policymaker and a payer representative .



Recruiting Stakeholders to Working Groups

Once you've selected the issues and decided on the ideal stakeholder representation for each Working Group, you'll need to decide who you will reach out to and invite to the Working Groups. We recommend a few key steps. First, develop a list of key qualities that you want Working Group members to possess. We worked with our Parent Advisors to discuss the qualities they thought were most important .



Figure 6: Examples of Qualities of Working Group Members as identified with our parent advisors.

Next, we revisited the list of people who had engaged in conversations with us during the information gathering phase and who had responded to the Ranking Survey expressing their interest in being on a Working Group. We identified the people who had raised the issues we were focusing on, who had professional or personal experience related to those issues, or who otherwise aligned with the qualities the team identified. From this point, we had developed a list of people we thought would comprise three great Working Groups, if they all agreed to join. However, we still had a few gaps in either stakeholder representation, personal experience, diversity, or other qualities we thought were important. Third, we cast a wider net. We talked to our Parent Advisors, our community partners, and many others to expand our list of possible members to fill some of those gaps. For example, our team thought we needed more parents of children with special health care needs represented on the transitions Working Group. To address this, we worked with physicians to identify parents of children with special health care needs who were approaching the age of transition to adult care or who had recently navigated that transition for their adult children.

Finally, we sought to have diversity in each of our Working Groups, both as we developed potential member lists and as we recruited members to join. We reiterated and checked in with our Parent Advisors regularly to ensure they were happy with the representation of roles, community groups, socioeconomic, race, gender and other types of diversity in each group. Overall, we hope to continue to improve in this area, but we were able to achieve greater diversity in these groups than we had previously achieved in other PBRN groups.

Researcher Partners

Researchers in the identified topic areas were also contacted by the study team to assess their interest in potential collaboration with the Working Groups. Our PBRN management team met with each of these researchers to describe our anticipated Working Group process and the potential role of the research in that process. In meetings with researchers, we covered a number of topics, including:

- the issues as we had heard about the from our stakeholders and finalized them with the Network Advisory Board.
- Stakeholders.
- the role of the researcher as an equal partner with our stakeholder, not as leader of the group.
- the anticipated timeline for Working Groups and their deliverables (research questions and draft aims).



Figure 7: Qualities of a Successful Researcher Partner as identified with our parent advisors

Lesson Learned

Be wary of the stakeholder who brings their own agenda: The overall goal of engagement is to bring into your PBRN research process the stakeholders who bring real experience to the issues you are investigating and to inform your research with their perspectives. This means that you want people with varied experiences with the school and health care systems, and likely a passion for improving health care for children. However, you will want to identify these parents with some caution. Some parents will express interest in your PBRN project because they have a specific experience, cause or issue that they want to further through your PBRN. In some cases, these are exactly the people you want engaged in your network. They can bring the enthusiasm and commitment that few parents can. However, you will want to have clear conversations with parents and other stakeholders you hope to bring on in ongoing collaborative roles about the nature of your PBRN research agenda and the likelihood that you will be addressing many types of issues and will not be solely focusing on the issue they bring to the group. We recommend providing clarity about the scope of their role and the possible ways the PBRN may or may not address their specific interests.

How to (re-)engage them?

Much like we recruited our Parent Advisors and our initial Network Advisory Board members, we started our Working Group recruitment by creating a “job description” (see below) for the role. This document laid out the commitment, expectations, and benefits of Working Group participation and was shared with each person who was being asked to consider joining a Working Group.

After discussing the possible make-up of each Working Group in detail with the Parent Advisors, seeking feedback from Network Advisory Board members and discussing with our community partners, we started reaching out to invite stakeholders to join the Working Groups. First, our PBRN staff emailed each stakeholder with an invitation to participate in the Working Group process along with a copy of the job description outlining the role. Second, our PBRN staff made personal phone calls 3 days later to discuss the Working Group invitation, answer questions, and discuss the logistics of the first meeting, if they agreed to join.

Because stakeholders in pediatric health are, in our experience, quite busy, we answer a lot of questions about the commitment from most of the people we invited to the Working Groups. In these discussions, we emphasized the possibility for impacting child health in Colorado and the potential for a meaningful experience working with other passionate stakeholders on an issues they had expressed a personal interest in.

To our surprise, nearly all the stakeholders we invited to a Working Group agreed to take part .

Lesson Learned

Effective Aspects of Stakeholder recruitment to Working Groups

- Show Appreciation for their prior engagement
- Provide Clear expectations for their role on the Working Group
- Review your interview notes and ensure you’ve matched their interested with the Working Group topics
- Express how you think they will contribute to this particular group in valuable and unique ways

Factors that will contribute to your recruitment success

- Develop a job description (see page 51)
- Develop a list of potential members
- Invite possible Working Group members by email
- Make personal calls
- Make logistics easy for committed members

Notes:

Working Group Member Description

Position Title: Working Group Member – COCONet Pediatric Practice-Based Research Network
Funded by PCORI Stakeholder Engagement Award

Description of Organization: The Colorado Children's Outcomes Network (COCONet) is a practice-based research network (PBRN) of pediatric practices from across Colorado. Its mission is individual practices collaborating to improve children's health through investigation and quality improvement. COCONet is a member of SNOCAP, an umbrella organization that supports practice-based research networks at the University of Colorado Denver.

Position Objectives:

- 1) Engage in collaborative discussion to aid COCONet in achieving its research mission.
- 2) Collaborate with other Working Group members to develop research questions on one of three topics:
 - a. Immunization Refusals and Parent Social Networks
 - b. Mental Health Access, Communication and Coordination
 - c. Parent and Adolescent Advocacy Training for Health Care and Transitions

Position Summary: A working group member is someone that brings their unique background, experience, and health consumer perspective to the research arena. Working group members participate in collaborative discussion to create research questions and goals for which the Working Group and the COCONet PBRN can pursue funding and research.

Training: Board members will participate in community-engaged research (CEnR) training on May 21, 2016. In addition, they will receive topic-specific training as needed throughout the process.

Duties and Responsibilities:

- Shares perspectives, experiences, and suggestions during meetings and through online collaboration
- Commits to the Working Group by upholding its purpose through meaningful engagement
- Presents ideas to improve research questions and goals
- Respects the collaborative process and is willing to listen to differing views
- Respects participant and research confidentiality at all times
- Commits to **attending 4 meetings between May 2016 and April 2017** and engaging electronically outside of meetings as necessary. Each working group will use these meetings will focus on one of the three topics above.

Working group member duties may change based on individual skills and interests as well as the needs of the group. We will expect some flexibility but hope this provides an outline of the expectations of the working groups.

Successful Working Group Members are able to:

- Share perspectives, insights, and information in constructive ways
- Appreciate the 'big picture' regarding child health issues in Colorado
- Listen well
- Respect differing opinions
- Speak comfortably in a group
- Look for opportunities to partner and collaborate on finding solutions
- Maintain open and productive communication with researchers
- Respect the limitations of the research environment in meeting individual needs

Compensation:

- CEnR training: May 21, 2016 - Participants will receive a \$50 gift card
- Meetings: Members will receive stipend of \$100 per working group meeting, totaling up to \$400 between May 2016-April 2016.

CONTACT: Sarah Brewer at 303-724-6927 or Sarah.Brewer@ucdenver.edu for more information.

Chapter VIII: Community Engaged Research Training

Why do a Training? After we identified and confirmed parents and other stakeholders to serve on the Working Groups, we recommend that you train all these stakeholders in Community-Engaged Research and how to engage in this process with your PBRN and its affiliated researchers.

Why do a Community-Engaged Research training?

Providing a training on community-engaged research provides a common starting point for all stakeholders and a foundation on which everyone can bring their perspectives and experiences to bear on the topics at hand. In particular, this can reduce the power dynamics between different types of stakeholders and ensure that everyone involved in the Working Groups sees their role as important and valuable to the engaged research process.

In planning our trainings, our parent advisors specifically encouraged us to focus on demystifying aspects of the research process that could otherwise be intimidating to stakeholder. This ensured that as we began our Working Groups, no one was coming in feeling like they didn't have enough knowledge about the overarching health care setting or research process to make meaningful contributions.

In addition, hosting a training on Community-Engaged Research helps to build personal relationship and mutual accountability amongst the stakeholders who are participating in this process. Ideally, you will introduce and draw connections between people who are all interested in aspects of pediatric health care, answering important research questions, and improving health in your communities. This training can help to channel that passion into your PBRN's work and to ignite collaboration among this group.



Challenges

What to expect when planning a Community-Engaged Research training

There are a number of challenges you can expect when preparing for your Community-Engaged Research training. The most likely is that the stakeholders who are likely to be interested and committed to participating in a Working Group are also likely to be committed to other causes and organizations. Thus, you can expect that it will not be easy to find a full day when this training will be convenient to everyone you'd like to have there. Nevertheless, we recommend you make scheduling a full day, retreat-style training a priority.

If a full-day, retreat-style training is not feasible, consider other options for allowing everyone to participate in the community-engaged research training and all the subsequent meetings to ensure strong cohesion in the groups and a collaborative process that includes all your stakeholders.

Some options include: webinars; online slide decks with in person reflection/discussion; multimethod approaches to fit parent needs, online collaboration platforms like slack or basecamp and many others.

Tips for Planning:

- o Schedule a seminar at a time convenient to Working Group members
- o Arrange a location convenient to most community members
- o Provide meals and refreshments
- o Provide child care as needed
- o Identify and schedule faculty and community experts to help lead the seminar
- o Develop and use a pre- and post-evaluation

Lesson Learned

In Chapter 8, we have described the ideal model for training stakeholders to engage with research in a pediatric PBRN setting. In our project, we had significant scheduling and logistical challenges that prevented us from doing a full day training with all three groups. Due to our challenges, we had separate trainings for each Working Group and condensed the training material into about an hour.

While this served the purposes of each Working Group and prepared our group members to participate in developing research questions and aims, we did have to spend time in our third meetings to supplement our initial training and further discuss how to develop good research questions. In addition, we did not have the opportunity to foster relationships across Working Groups in the way we would have liked. As we further developed the Network Advisory Board toward the end of the Working Group process, our stakeholders all expressed significant interest in further cross-group interactions and relationship building. Based on this experience, we recommend other groups prioritize a full day training with all engaged stakeholders.

Training Content:

In collaboration with our parent advisors, we developed our training agenda to cover topics from defining research and community to beginning to explore the specific topic areas each Working Group would be addressing. As you prepare, you may want to involve experienced facilitators and professionals with community-engaged research experience to help guide the discussions and orient all of those involved. Here we provide an example list of topics to cover during this training. You will need to tailor this list and the content to your PBRN. We have noted with (*) the topics we think are the minimum necessary to prepare your stakeholders to engage in research with your PBRN.

- De– Mystifying research
 - Define Community-Engaged Research or community-based participatory research (CBPR)
 - Discuss why community engagement is valuable in research
- Orientation to your overall project*
 - Identifying and developing stakeholder-driven research questions or projects
 - Discuss the ultimate goals of parent engagement for your PBRN
- Defining Community
 - Identify and discuss the communities your stakeholders are a part of
 - Discuss how your stakeholders define community and which communities your PBRN serves
- Health Disparities
 - What are they?
 - What do they look like in your community? In your PBRN?
 - How does your PBRN play a role in addressing health disparities?
- Stakeholder Roles*
 - What are the roles of Working Group members?
 - What are the roles of Network Advisory Board members?
 - What are the roles of PBRN staff and researchers?
 - Discuss the length of commitment for stakeholders
- Developing Norms/Expectations*
 - How will each group operate? What are your “rules of engagement”?
 - What does your PBRN expect of engaged stakeholders?
 - What can your stakeholders expect of you?
 - How will you handle disagreements? Unmet expectations?

- Research basics (questions, process, timeline)*

- What is research?

- What makes a good research question?

- Timelines:

- What is the timeline for typical research projects (randomized controlled trials, retrospective observational studies, pilot studies, others)?

- What does a typical funding timeline look like for your PBRN?

- Discuss typical publication and dissemination timelines and what your stakeholders can expect in terms of sharing your results.

- Research Funding

- Topic introductions

- We recommend providing a short (45-60 minute) orientation to each Working Group topics in breakout sessions as part of your training. This breakout session might include a summary of the current state of the health topic in the local state or community and the gaps in the research. In addition, this can provide an objective view of the issue to foster a common base of knowledge among stakeholders who are joining the Working Groups with some prior interest and experience of their own.



**What community- Engaged Research Topics do you need to include in your agenda?
Are there things Specific to your PBRN you need to share up front?**

We have chosen not to provide here the detailed information we included in our training largely because it was tailored to our project, our PBRN, and the Colorado community. However, we would be happy to discuss the training as we presented it with other interested PBRNs. Please contact us if you have questions about developing a community-engaged research training for your stakeholders.

Trainings differences for Working Groups vs. Network Advisory Board

You may choose to have separate or combined trainings for your Working Groups and your Network Advisory Board, depending on the level of overlap and prior engagement with your PBRN by the stakeholders who commit to these groups. If you choose to hold combined trainings, then you may put extra consideration into the breakout session to provide information for your Network Advisory Board while Working Groups are learning about specific health topics. You may also choose to have separate trainings for these groups, you may want to consider other ways to foster relationships between your engaged stakeholders and cross-pollinate across these groups.

Notes:

Chapter IX: Facilitating the Working Group Process

Overview and Setting Expectations

Once the Working Groups are recruited, established, and trained, we used a combination of face-to-face meetings and virtual discussions to develop research questions and specific aims. Each Working Group had at least three 2-hour face-to-face meetings. Each in-person meeting was facilitated by a PBRN staff member with extensive facilitation training and experience in facilitating community-engagement processes.

At the first meeting of each group we had explicit discussions with each Working Group about the process that each group would undertake and the environment the group wanted to foster during the process. In each of the three separate groups, we encourage them to develop a unique culture and set of expectations.

We specifically focused on three major topics :

1. **Shared Ownership:** Each member of the Working Group had equitable ownership of the process, the ideas, and the ultimate end products of the Working Group. We were clear that the PBRN staff or the researcher partners were not the owners of the research resulting from this group. We saw these groups as collaborative settings and hoped they would see themselves as co-owners of the work.
2. **Agreed upon norms:** In each group, we discussed the norms of engagement for meetings, between-meeting interactions, and expectations for each other. For this discussion, we proposed some basic ground rules for the group (raise hands, respect differing views, etc .) and asked for feedback, changes and additions before beginning the remainder of the discussion. Each group set slightly different norms, but ultimately, this simply set a tone and expectation of respect and collaboration in the groups. Because parents sometimes feel intimidated by the presence of clinicians and/or researchers in these Working Group Meetings, and to encourage participation from all members, we also used a variety of variations on Nominal Group Technique (NGT)³³ and consensus decision making³⁴ in order to reach decisions within each group. The key elements of consensus decision-making include inclusivity, participation by all members, collaboration, agreement-seeking, and cooperation .
3. **Assigning To-Dos and Accountability:** We also discussed how the group would like to handle action items developed by the group in meetings. We gave each group full rein to decide whether they wanted to take on tasks outside the meeting, when that would be appropriate and acceptable, and how they would handle things if a task was not completed as agreed.

Again, each group set different expectations for assigning tasks and enforcing accountability. Some agreed that tasks should be assigned at the end of each meeting and completed and shared with the group before the next meeting. Another group decided they were all too busy to take on tasks between meetings and decided they would rather meet more frequently to accomplish tasks together, or ask the PBRN staff to complete minor tasks for them. You will need to work with your Working Groups to find a balance that works for the availability of your group members.

Communication and Virtual Engagement

As with assigning tasks, you may also want to work with your Parent Advisors and your Working Group members to understand how they want you to communicate with them and engage them between in-person meetings. Again, each group is likely to want a different level of engagement and have different preferences for how you contact them.

Between meeting engagement is challenging; it's your job to acknowledge the challenges and provide possible solutions to best balance busy schedules and the need for ongoing engagement. Long intervals between meetings can leave parents unclear or disappointed about their contributions to the Working Group. Missing a meeting can exacerbate that feeling, especially if there isn't a good way to stay involved in the process. Because our stakeholders were busy, we often had a member or two missing at each meeting. When this happened, the PBRN staff serving as facilitator for the group was sure to **send meeting notes to everyone as quickly as possible** and **follow up with absent members by phone to review the decisions and discussion** that occurred. This helped maintain the engagement of members when they couldn't be present.

You can also maintain engagement by **being consistently clear about the value stakeholders add to the process**. Tell them often how much they are contributing and how much more rich the work is with their input. There are many ways to appreciate your stakeholders, but we have found one of the most effective for maintaining engagement is to highlight the value they add to the project, the PBRN and the research.



How are your stakeholders benefiting your PBRN research process?

How can you tell your stakeholders about the value they are adding?

Also, make a point to ensure you **reflect their input in the process and the end products**. Take their feedback. Put it into practice. Find synergies between their experiences and your expertise. Help connect the dots so their input can be reflected throughout your research agenda setting process. When your stakeholders see you act on their input, they are better able to trust that you see value in their contributions and want to engage further.

Lesson Learned
Every group is different and your PBRN staff will need to display flexibility to accommodate each group’s unique make-up and needs.

Virtual Interactions

Between Working Group meetings, further discussion was encouraged through use of a virtual discussion forum to complement the in-person discussions. We used BaseCamp (www.basecamp.com) to share documents from each meeting, keep track of tasks Working Group members and PBRN staff volunteered to complete, and have discussions about the topic between meetings. We found that the use of the virtual discussion forum alleviated some reticence from group members to fully participate, encouraged quieter members to share their thoughts offline, and maintained momentum of group interaction and idea generation between meetings. Some groups used BaseCamp extensively, others only periodically. However, we received positive feedback from all three Working Groups that they liked having all the documents related to each group available at any time and having the ability to quickly share thoughts with the group in a well-tracked format.



What mechanisms for virtual interaction can you present as options to your Working Groups? Does your PBRN have an existing platform? Will you use something else?

Relationships are the key

Ultimately, engaging stakeholders in Working Group or any other mechanism is about authentic interactions and relationships between all the people involved. You and your stakeholders need to get to know each other as human beings outside the roles you have in the PBRN. Share things about yourself and ask questions about them. Be interested. Find and foster the “glue” that brings people together in your groups. Build trust in as many ways as you can. Encourage your stakeholders to build relationships with each other. No one wants to engage in a group with people they don’t know and like. When scheduling is challenging, people will skip your meeting if they don’t feel a commitment and connection to the others in the group. In short, when you have authentic, personal relationships within your stakeholder network, you have the foundation for sustained, meaningful engagement that will drive your PBRN to new, innovative research.



What can you do at your first meeting to build relationships between your stakeholders?

Road Map to Working Groups

We designed an approach to Working Groups that developed research questions in a series of three meetings of 2-3 hours each. This worked particularly well for our stakeholders because once we had them in a meeting, we could have extended discussions to grapple with the important issues of the group. Shorter and more frequent meetings may work well for other stakeholder groups.

Meeting 1

The purpose of this first meeting was to introduce the group to one another, describe and agree upon the group's processes and mission, present and discuss the findings and conclusions from our information gathering phase, and to provide a summary of the current state of the topic of the group and any current relevant research into the topic. In addition, we focused on relationship building between all the group members and the PBRN staff. After accomplishing these tasks and summarizing the topic, each group spent time talking about the various facets of their topic, defining how the group saw the topic and narrowing their focus if they could. All three groups identified areas in which they wanted more information about the current literature and requested literature reviews of the PBRN staff or a volunteer group member for the next meeting .



What action items came from Meeting #1?

What topics/subtopics did the group raise at this phase?

Meeting 2

Meeting Two began with introducing the academic researcher(s) to the rest of the group followed by a review of Meeting Group One and any virtual discussions that had occurred since the first meeting. The bulk of this meeting was spent discussing and refining the identified research questions .

Groups aimed to narrow and focus the topic based on what they learned in the literature reviews and through discussion about the issues specific to Colorado.

In addition, one group invited members of a team working on their issue (vaccine hesitancy) in another state to learn about their project and how aspects of it could apply in our PBRN setting. These guests attended by web conference, presented on their project and answered questions from group members for nearly an hour. The group then discussed their project and its possible implications, links to Colorado's challenges, and challenges in translating their work to practice-based settings.

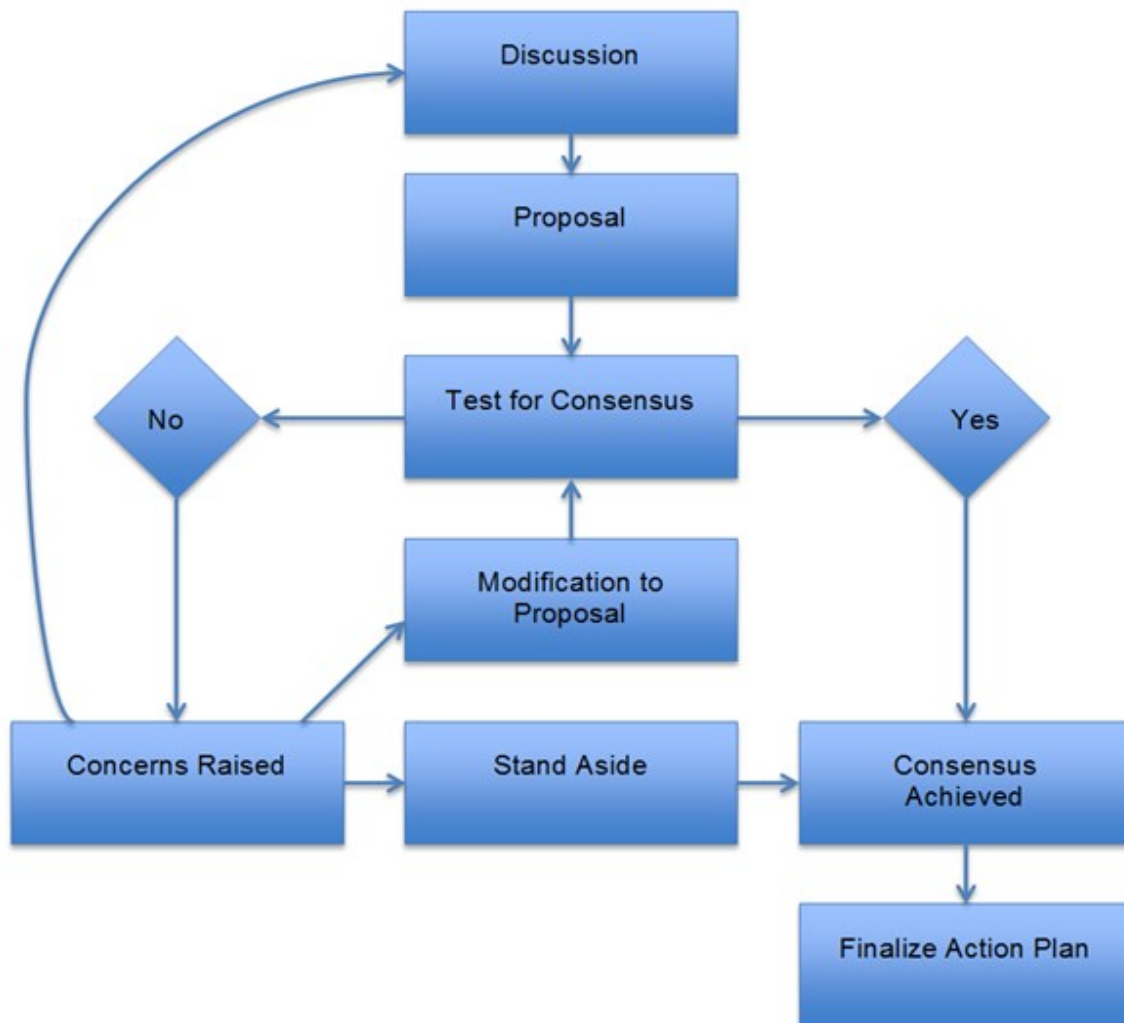


Figure 8: Throughout the Working Group series, we used the Consensus Decision-making model to make decisions and move each group forward. This model provided a framework for incorporating each person's voice and perspective and ensuring everyone found decisions acceptable.

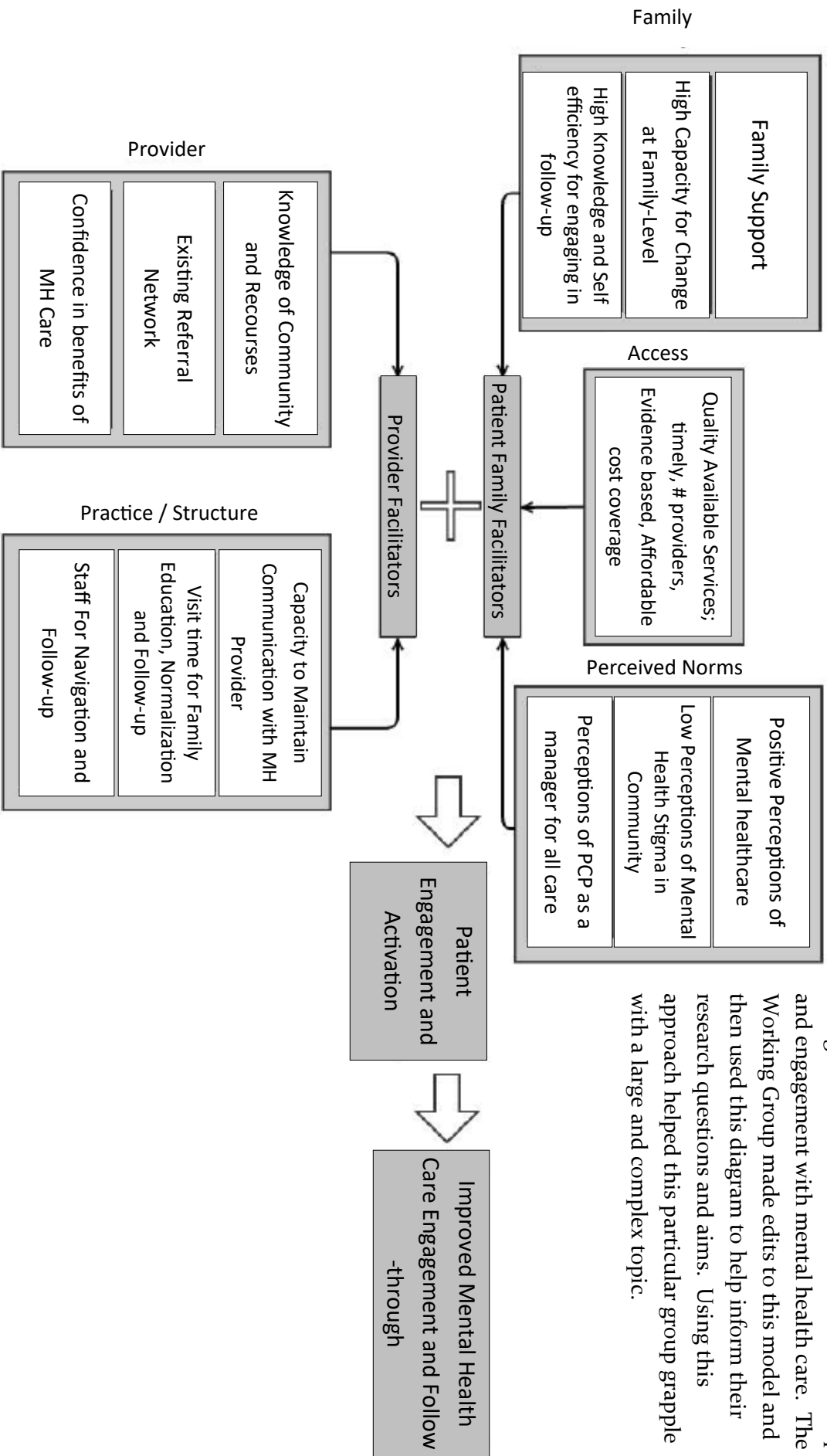


Figure 9: In our Working Group focused on pediatric mental health, we spent much of our second meeting discussing the barriers and facilitators families faced when faced with a referral from primary care pediatricians to mental health care providers. Based on the discussion, we drafted a conceptual model of what we thought went into successful referral follow-up and engagement with mental health care. The Working Group made edits to this model and then used this diagram to help inform their research questions and aims. Using this approach helped this particular group grapple with a large and complex topic.



What action items came from Meeting #2?

What is the current definition of the topic after Meeting #2?

Meeting 3

The third meeting was devoted to creating an action plan for development of a project proposal in the identified question(s) of interest. Group members focused on developing the research question(s), using the PICO(TS) model to frame the basics of a research design, identifying funding options, and setting goals for how to pursue funding such as writing an aims page, writing a Letter of Intent and developing a full proposal.

This third meeting involved more preparation by PBRN staff in advance including preparing a list of potential funding mechanisms, understanding basic requirements of these funders, and collecting PICOs from all group members in advance of the meeting for review at the meeting.

The product of this third meeting was an action plan that included a specific research question (or questions), an identified PI and co-investigators, community partners, a funding mechanism (or mechanisms), deadlines for the next steps (usually sharing an aims page or LOI draft), and a plan for continued virtual discussion and engagement.



What is your targeted funding mechanism?

Who is responsible for the next steps in the Action Plan? When are they due?

Notes:

Chapter X: Sustainability and Follow Up

When developing your Network Advisory Board, Working Groups, and other infrastructure for your PBRN, it is important to consider sustainability from the start and throughout the entire process. When initially engaging parents and other stakeholders in the process of developing your Board and Working Groups, seeking people who are aware of your commitment to sustaining the engagement beyond the timeline of the initial project may weed out those individuals with less interest and therefore lead to more enthusiastic partners.

For our project, we undertook several strategies. First, when we first engaged parents and stakeholders about participating in our Board or Working Groups, we were clear up front about the duration of the commitment we were asking for. For our Board, this was a term of 3 years, with the potential to be longer depending on interest and needs. We also provided written job descriptions which were clear on time commitment, so participants knew up front what they were getting themselves into (see appendix for examples of job descriptions).

In addition, we had frank discussions at frequent intervals about continued willingness to participate in the process. Our use of frequent short surveys measuring engagement and collaboration helped with this as well. We also started off all of our Board meetings with a discussion of ground rules, and sought input from Board members on how they wanted to see the Board function. Rather than us telling them what we thought they should do, we asked them to tell us what they thought made the most sense. Using this approach, we have had no turnover in Board membership to date.

Another important step we took to ensure sustainability was to keep track of our potential Work Group and Board members. As described, we gauged interest among all of our interviewees regarding participating further in project. We also asked if we could remain in contact with them, which essentially all of them agreed to. We keep a spreadsheet of all of these potential Work Group and Board members, with specific areas of interest listed, their stakeholder roles, and certain demographic information, such as urban or rural. Even if we did not invite these people for the first set of Working Groups or board membership, we kept all of them updated on the project and ‘in the loop.’ Therefore, if we have vacancies to fill on our Board or a member for a specific Working Group, we have a long list of potential contacts.

Finally, we thought it was important to be clear about the nature of funding in the academic world to our Board and Working Group members. While our participants brought many amazing and interesting backgrounds, few had experience in academia or research. As discussed in detail in Chapter XI, it is important to compensate people for their valuable time as funding allows. We were up front, though, in describing the funding challenges of academia. We could guarantee funding for the duration of the grant, and we were committed to seeking funds for participation beyond the two years of the grant, but let them know that there may be gaps in funding.

Chapter XI: Compensation, Cost and Logistics

Throughout this process, it is important to remember that your stakeholders are not volunteers. Your stakeholders have lives, jobs, and commitments outside of the PBRN roles they are taking on. In addition, their contributions are valuable to the work of the PBRN in many ways and we wouldn't expect things of value for free in any other context. As such, make every effort to compensate your stakeholders for the time, effort, and ideas they bring to your process. In addition, think of the other ways you can make it easy for stakeholders to be involved in your process that aren't just payment for their time.

Compensation

There are a few ways you can compensate your stakeholders for their engagement in the process. You will need to figure out what works for your PBRN and, ideally, work with Parent Advisors, your Network Advisory Board, and other stakeholders to come up with a compensation plan that works for your PBRN and your engaged stakeholders.

Some of the options for compensating your stakeholders are to set an hourly wage for their work, pay them stipends for completion of a set project or group, pay cash or gift card for specific engagement activities, or develop another compensation model that works for you, your stakeholders, and your HR constraints.

Table 6 : Sample Model Addressing Fair Compensation for Engaged Research Partners: Engagement Spectrum with Examples: an Ideal Moving toward Greater Collaboration¹

Engagement Activity Levels	I. INFORM	Simply informing	Communicating plans to the patient	Varying Compensation Levels
	II. CONSULT	Consulting on decisions	Offering options, advise, feedback	
	III. COLABORATE	Deciding together Acting together	Joint decisions solicited taking actions jointly	
	IV. STAKEHOLDER DIRECTED	Encouraging independent initiatives	Leading to patient/caregiver/ organization generated research	

For our project, we used three compensation structures. First, we paid our Parent Advisors an hourly wage of \$40 per hour on a monthly basis. Our Parent Advisors were integral to the oversight and key decisions of the whole process of this project. Without their insights, our project would not have been nearly as successful. Second, for our Network Advisory Board and our Working Group members, we provided stipends for their overall commitment to 1 or 2 years terms. Working Group members received a \$400

stipend for a 1-year commitment and received that as \$100 gift cards at each training and meeting. Third, we paid parents \$100 for participating in interviews with our staff. This acknowledged the travel time, experiences shared, willingness to participate in future steps in the project and our overall appreciation of their openness to share personal stories with us.

PCORI provides a nice framework for considering compensation of your stakeholders based on their contributions to the project. ¹ We loosely followed this model in combination with discussions with our stakeholders to find the right fit for our PBRN.



Which of your stakeholders should be compensated? Where can funding for stakeholder compensation come from? What is the minimum level of compensation you will provide engaged stakeholders?

Food

In short, feed people. It builds relationships and shows your acknowledgement that people are taking time away from meals with their family to attend your meetings. We typically budgeted \$100-150/meeting to provide meals and refreshments for our Working Groups.

Childcare

This project is specifically focused on pediatric stakeholders, which means you're mostly exclusively asking people with children to take time away from their day to be at your meetings. Whenever possible, provide childcare during your meetings to facilitate the attendance of your stakeholders. We used a local sitter service that (a) provided us a guarantee of a sitter with 48 hours notice (b) for a reasonable price; (c) provided activities for kids to do in our office spaces; and (c) had the insurance required by our university for childcare.

For our project, we worked with our engaged stakeholders to figure out the best way to handle childcare. What we decided was that parents needed to give us 2-3 days notice if they wanted or needed a sitter during meetings. Then we would book a sitter and have a conference room for the sitter and children to be in during the meeting. This allowed us to offer a sitter but only pay for child care when a parent needed the service.

Locations

Consider the convenience of your meeting locations throughout this process and check-in with your stakeholders that the location (and any other logistics like parking!) are working for them. If you can, meeting with your stakeholders outside your office somewhere in the community.

In our case, the office building housing our PBRN has free parking, is near a major highway exit, and has large conference rooms with big windows. Despite offering to move our Parent Advisor, Network Advisory Board, and Working Group meetings out into the community every time we scheduled a meeting, our stakeholders kept telling us they liked coming to our offices. *This is unusual!* In our prior experience, most communities prefer that you come to places nearer to them. Regardless, we recommend offering to leave your PBRN space and go out to community places as often as possible. Keep in mind there may be small fees associated with renting meeting space at community centers, libraries or other places in the community, but these small costs are worth the relationship building gains.



What locations are more convenient to your stakeholders?

Reference

1. PCORI (Patient- Centered Outcomes Research Institute). Financial Compensation of Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCORI- funded Research as engaged Research Partners. 2015.

Notes:

