



True Patient & Partner Engagement – How is it done? How can I do it?

GROUP TECHNICAL ASSISTANCE | JANUARY 18, 2017

COLORADO FOUNDATION FOR PUBLIC HEALTH AND THE ENVIRONMENT

Webinar Objectives

1. Describe patient and/or community engagement within research.
2. Describe how CBPR principles apply to your project.
3. Plan for how to engage patients and/or community members as equal partners in research.
4. Recognize the strengths and weaknesses of full patient engagement and partnerships in research.
5. Plan for the appropriate time and resources within projects to appropriately engage partners within the research.
6. Identify ways to use the P2P Program deliverables as a means of facilitating engagement among partners.

Defining Partnerships

- ▶ **Legal definition:** A voluntary contract between two or more competent persons to place their money, effects, labor, and skill, or some or all of them, in lawful commerce or business, with the understanding that there shall be a proportional sharing of the profits and losses between them.
- ▶ In our context:
 - ▶ The “persons” being patients, stakeholders, and researchers
 - ▶ Emphasis on the “**proportional sharing**”
 - ▶ To achieve patient and partner engagement, PCORI research is centered around cultivating authentic partnerships

Defining Engagement in Research

- **PCORI definition:** Engagement in research is the meaningful involvement of **patients, caregivers, clinicians, and other healthcare stakeholders** throughout the research process.
- This means involving these groups from topic selection → doing the research → sharing results back with the community.

- ▶ Want examples? View the PCORI Webinar: Promising Practices of Meaningful Engagement in the Conduct of Research - <http://encore.meetingbridge.com/MB005418/130919/>
- ▶ There are many different kinds of stakeholders! View this table of how PCORI defines stakeholders - <http://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders>

What Does a Partnership Look Like?

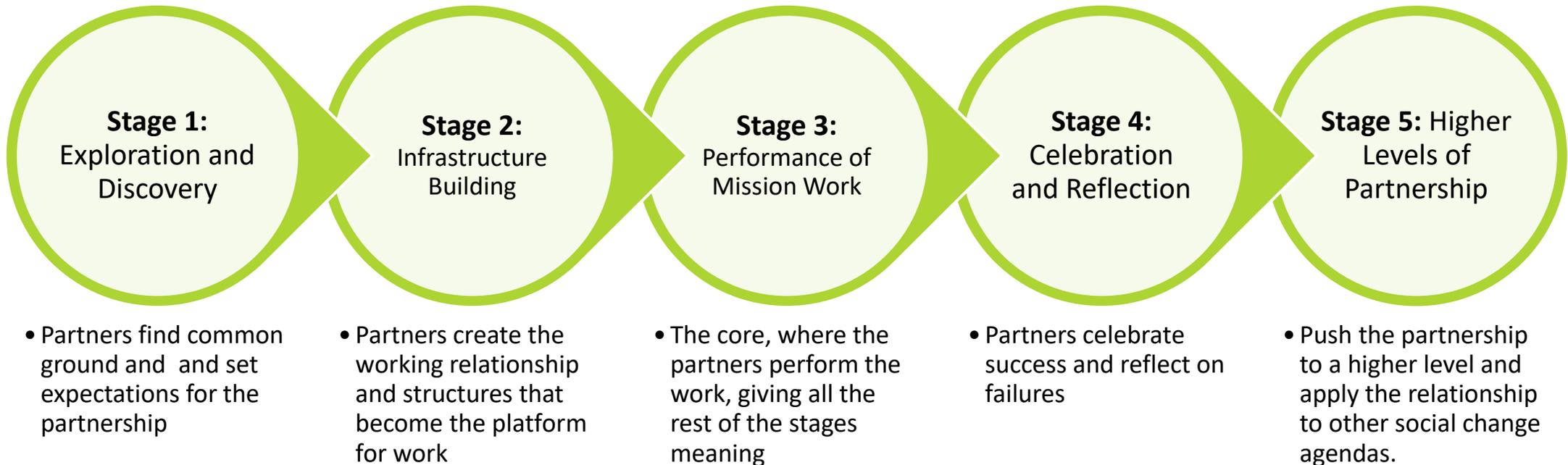


The four elements that help define an authentic partnership:

1. Guiding Principles of Partnership
2. Quality Processes
3. Meaningful Outcomes
4. Transformative Experiences

From the evidence-based model from the Community-Campus Partnerships for Health - <https://ccph.memberclicks.net/principles-of-partnership>

Partnerships & The Time it Takes



Read about this model in action from the West Virginia Rural Health Education Partnership:
https://depts.washington.edu/ccph/pdf_files/summer9-f.pdf

The PROS and CONS

PROS

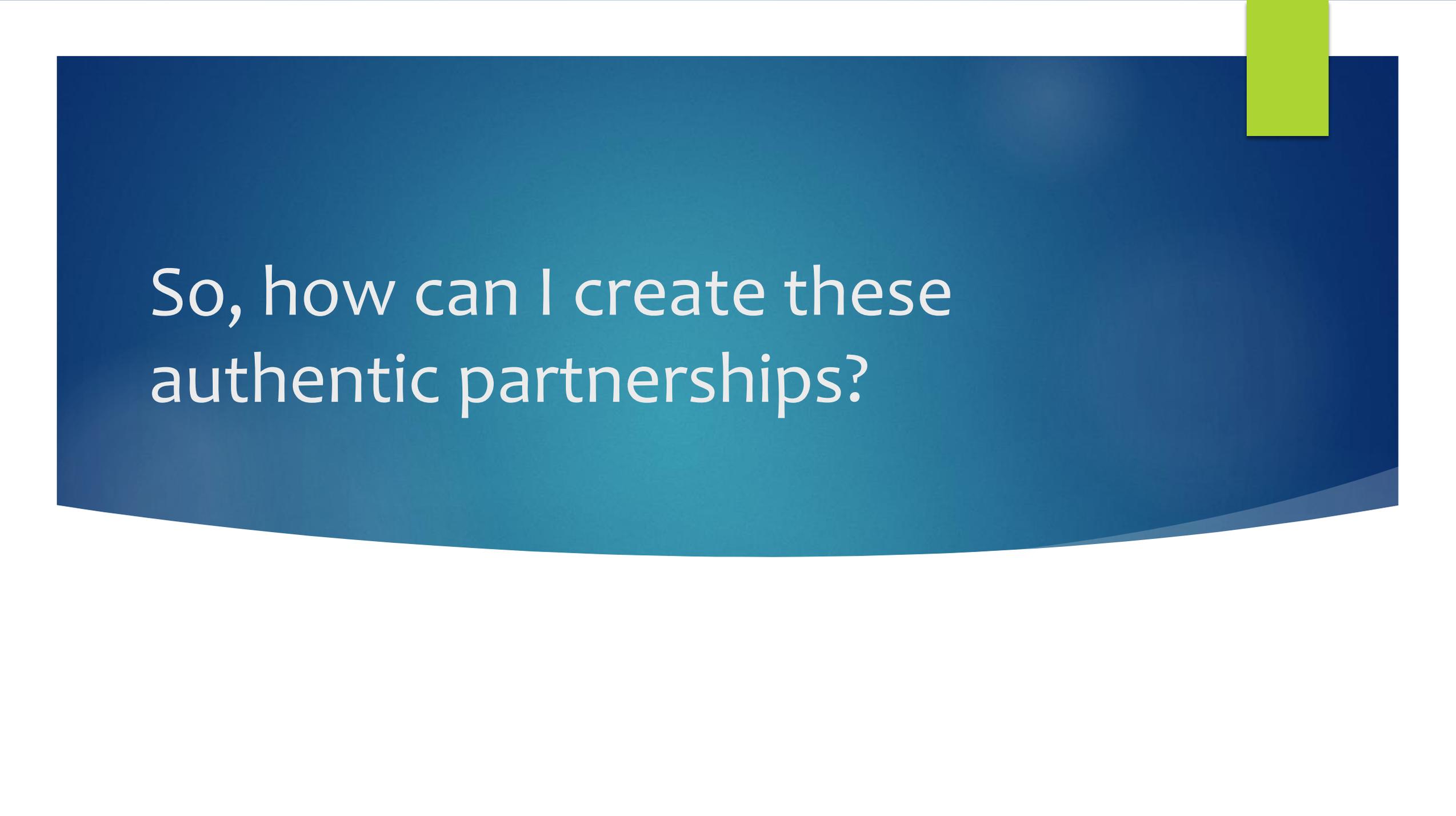
- ▶ Findings will be culturally and logistically acceptable to the population of interest.
- ▶ Recruitment into the research will be better.
- ▶ Partnership synergism will create greater benefits and more robust outcomes over time.
- ▶ Capacity to sustain momentum during unfunded times will be greater and more productive.
- ▶ Systemic changes and unanticipated new projects will be generated organically.

CONS

- ▶ Building partnerships and trust takes time and dedication.
- ▶ Natural conflicts must be dealt with openly and often, with the goal of turning the conflict into productive negotiation and common understanding within the partnership.
- ▶ Institutions based on traditional research may not understand the value of patient and community engaged research.
- ▶ Traditional research journals and other publishers may not understand the importance of the patient and community voice and authorship.

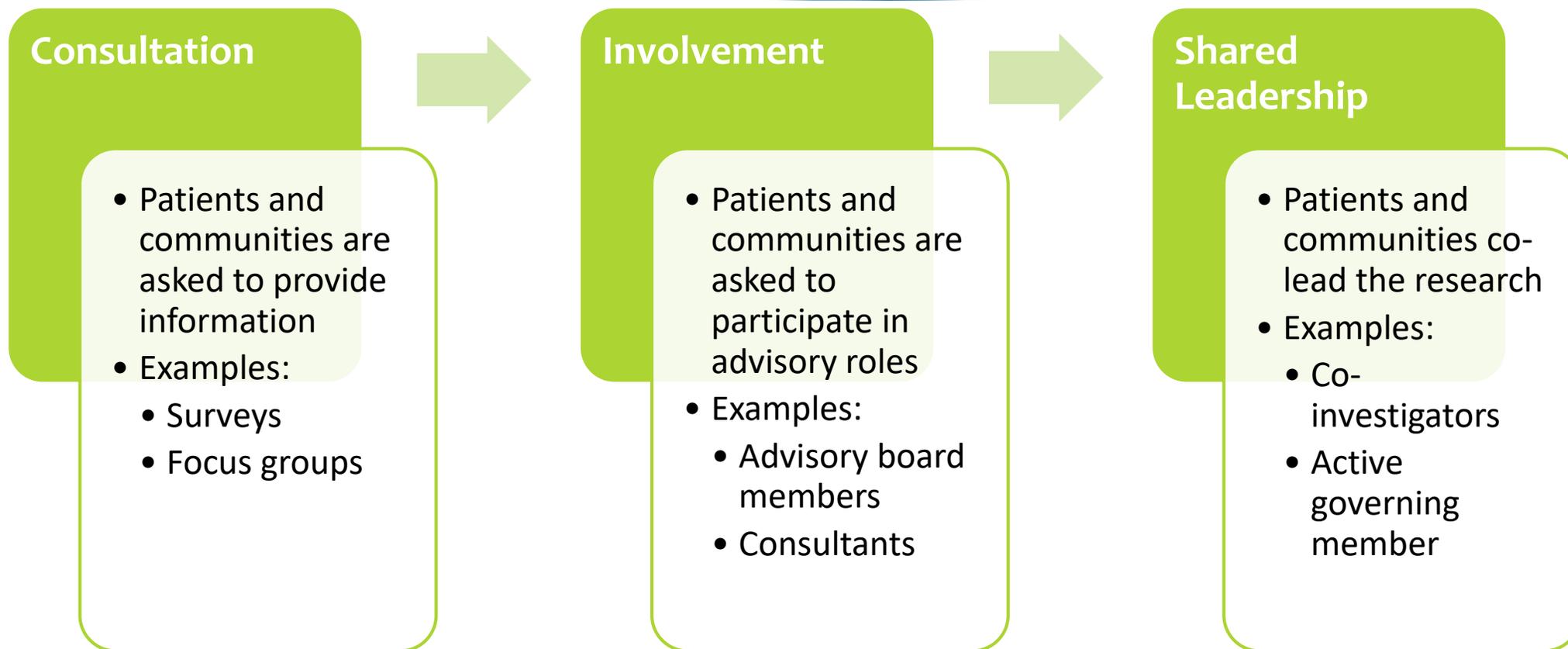
The benefits of Engaging Patients & Communities in Research

- Ensures the right questions are answered and that those answers will be acceptable and more quickly adopted by patients and spread throughout the broader community they represent.
- Engaging patients and their communities, as partners, in research can reduce the fear and mistrust that can inhibit quality research from doing the good it intends.
- Working with patients and their communities to publish the findings of research adds credibility to the research amongst those who need it most.



So, how can I create these authentic partnerships?

Continuum of Research Engagement



Set Appropriate Expectations

- ▶ Acknowledge the time it takes
- ▶ Collectively define what kind of engagement you are aiming for.
- ▶ Know what others are expecting of you, the situation, and other partners
 - ▶ Use negotiation, consensus, and agreement when not everyone accepts each other's expectations.
 - ▶ Find out as clearly and early as possible what the others **believe**, **want**, and are **willing to give**.
- ▶ Be clear about the purposes and goals of the effort and who you want to engage.

Neither you or your partners are mind readers! Communicate these expectations.

FOR ENGAGEMENT TO OCCUR, IT IS NECESSARY TO...

- ▶ Build relationships and get commitments from formal and informal leaders.
- ▶ Create space for collective self-determination as the responsibility and right of all community members.
- ▶ Establish trust and actively maintain that trust over the long term.

ENGAGEMENT: Expectations & Shared Goals

Sharing goals increases their effectiveness. Shared goals enable greater **collaboration, communication,** and a greater degree of **unity**. Shared goals also help establish:

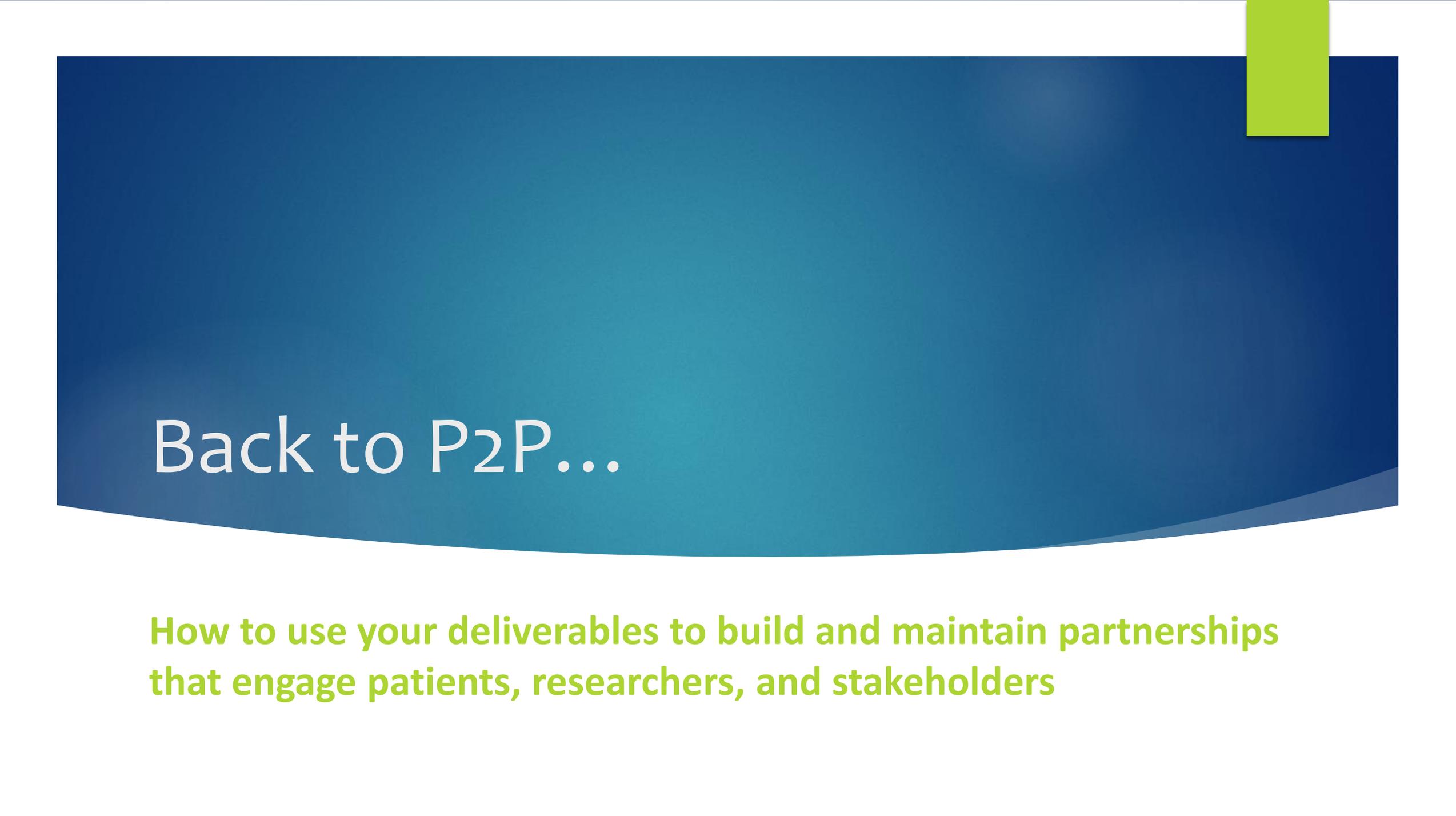
- Accountability
- Productivity
- Clarity
- Cooperation

Make sure everyone understands what's in it for them, and there is a real emotional commitment to the achievement of the goals.

- One tool you can use to define a shared goal: SMART goals

- Specific outcome
- Measurable
- Achievable
- Relevant

You can use this [group activity](#) to make SMART goals.



Back to P2P...

How to use your deliverables to build and maintain partnerships that engage patients, researchers, and stakeholders

Recruitment Strategies Document

- ▶ *From the Recruitment Strategies Guidance Document:*
'The P2P Recruitment Strategies Guidance Document is a tool to establish agreement among the stakeholders in your partnership about your plans to broaden the “community” of patients and other potential stakeholders who are interested in participating in or supporting your project efforts.'



- ▶ This aligns with good partnership development! Specifically (not limited to):
 - ▶ Open communication
 - ▶ Figuring out how to find your partners
 - ▶ Establishing reciprocal relationships

Governance Structure Document

- ▶ Your Governance document (finalized version due in Tier II), can help you formalize expectations and put them into writing regarding your partnerships. Specifically, you can map out your (but not limited to):
 - ▶ Shared Goals
 - ▶ Transparency expectations
 - ▶ Decision making guidelines



Evaluation Measures

- ▶ Remember: All partnership development processes are unique
- ▶ The deliverables PCORI requests are intended to help and not be busy work, so make them your own.
- ▶ Partnerships don't have to use our templates, but they do need to meet expectations that we will evaluate them on.



Evaluation Measures

From the evaluation documents...

- ▶ **PARTNERSHIP AND DISSEMINATION STRATEGIES:** Awardee has created a list of effective recruitment *strategies used to develop the partnership* and description of *how those strategies can be translated into dissemination strategies*.
- ▶ **GOVERNANCE DOCUMENTS:** Awardee has developed a thorough governance document that describes *how patients, researchers and stakeholders work collectively* to support patient-engaged CER projects in their community.

Resources

- Jagosh, Bush, Salsberg, et. al. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Public Health* (2015) 15:725
- Carman, Dardess, Maurer, et. al. Developing Interventions And Policies Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs*, 32, no.2 (2013):223-231
- <http://patientfamilyengagement.org/>
- PCORI's engagement definition: <http://www.pcori.org/funding-opportunities/what-we-mean-engagement>
- Authentic partnerships from CCPHN: <https://ccph.memberclicks.net/principles-of-partnership>
- Assumption exercises: <https://depts.washington.edu/ccph/cbpr/u4/u41.php>

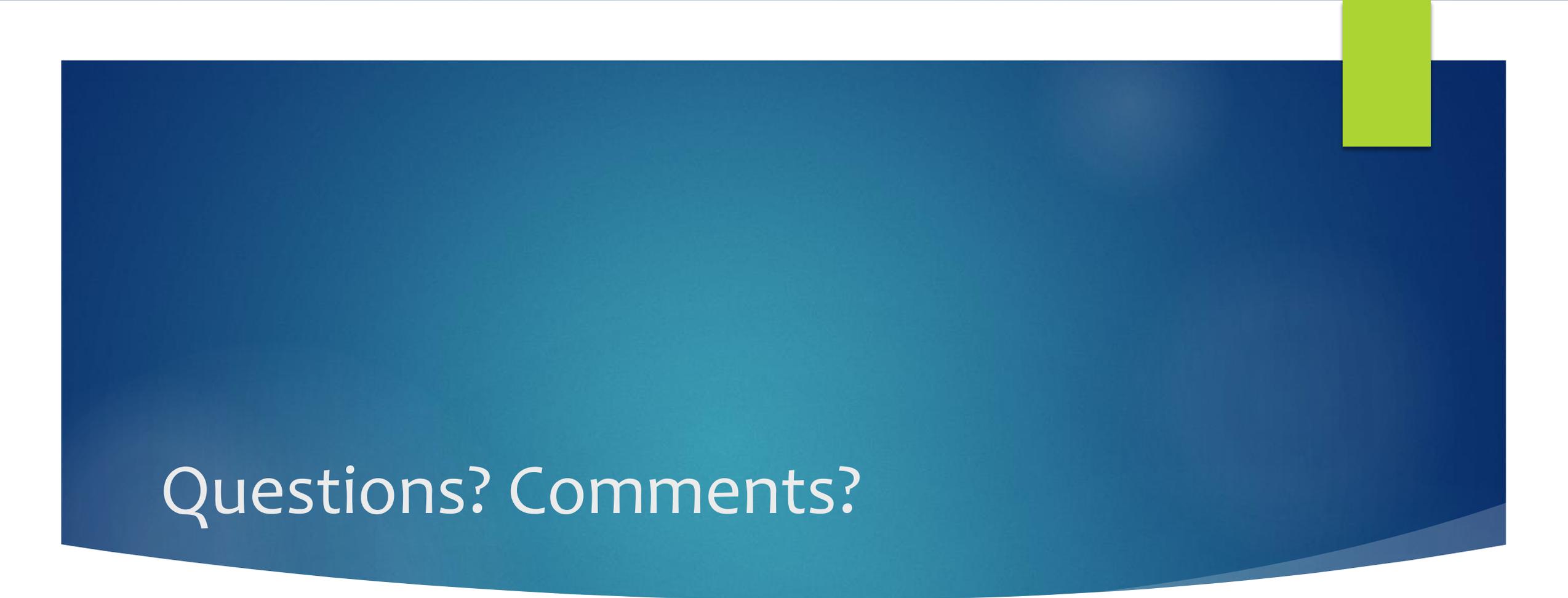
BEST PRACTICES FROM AWARDEES ROUND TABLE DISCUSSION NOTES

Contents

Overview.....	1
What are good communication/outreach strategies for partnerships in community engaged research? ..	2
How do you ensure equality of voices around the table? ..	2
How do you attract and engage patients in your partnership? ..	3
How do you integrate patient-engaged research into your life? ..	3
Is there a difference between patient advisory boards and patient partners? ..	4
How do you maintain momentum for your project? ..	4

Overview

Roundtable discussions were held at the PCORI Pipeline to Proposals Awardee Convention in Denver on November 7, 2014. The goal of the discussions was to share experiences and knowledge with fellow Awardees. Awardees were asked to answer one in a series of questions. The questions and answers from Awardees make up the remainder of this document.



Questions? Comments?

Thanks for joining us!