

Juggling the Various Components of Stakeholder Engagement: A Hands-on Approach.

May 24, 2021

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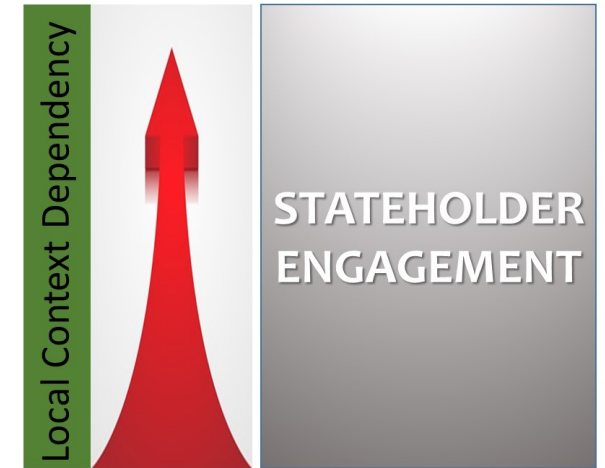
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Colorado Pragmatic
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Conference



Learning Objectives

- I. Understanding of the concept of stakeholder engagement as a multi-component, dynamic concept during the implementation of a pragmatic trial
- II. Awareness of practical approaches/methods for stakeholder engagement
- III. Learning of challenges and lessons learned from an illustration on the use of CBPR in a PCORI-funded pragmatic trial



1)Have you been part of a pragmatic trial before? Yes, no, I don't know

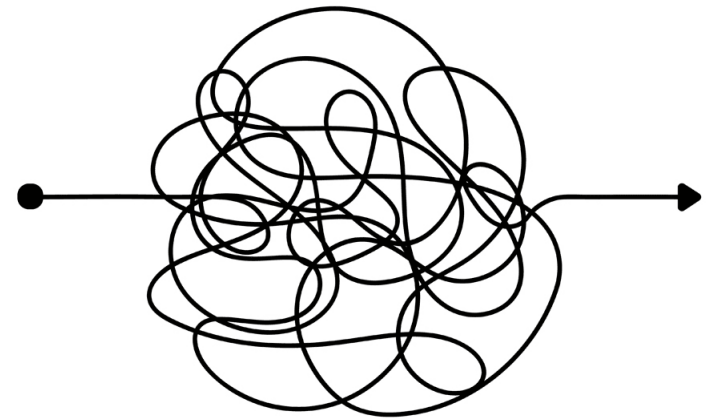
1)How do you consider yourself in terms of your experience engaging multiple stakeholders throughout a research study? Beg, intermediate, experienced

1)Which group from the list, do you feel is represented the least on your/your team engagement efforts?

Now that we are rolling out the pragmatic trial, how do I keep stakeholders engaged/meaningfully involved?

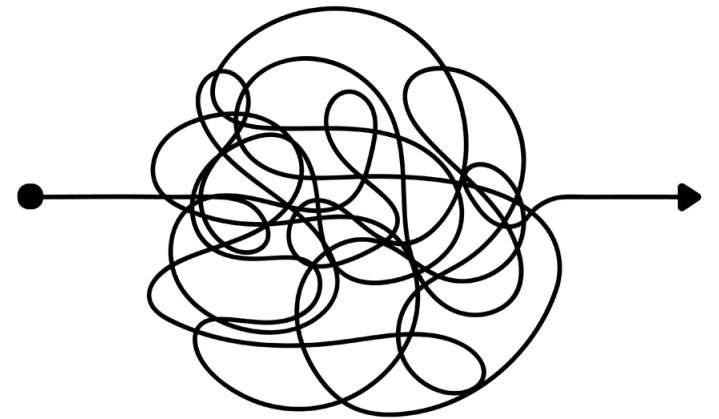


“Collaborations are messy.”
Cathleen Willgings 2021



Why?

I. Engagement within dynamic contexts!!



Contexts are dynamic!

REDUCING HIGH STAFF TURNOVER IN HEALTHCARE

STAFF RETENTION CHALLENGES IN HEALTHCARE

More than **\$3 TRILLION** is now being spent on healthcare in the U.S. Growth rates are expected to accelerate through 2024.

4 MILLION NEW JOBS will be created by the U.S. healthcare industry by 2026.

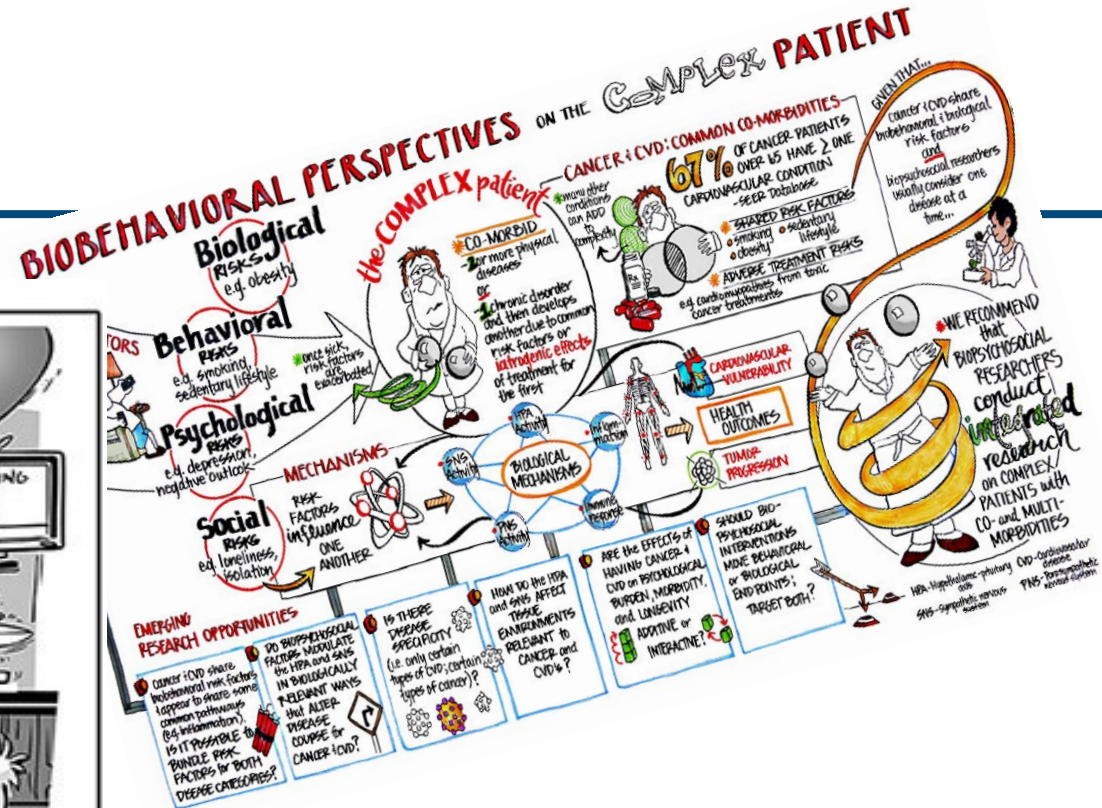
THE COST OF STAFF TURNOVER

US healthcare organizations spend on average between \$28,000 to \$59,700 to replace a single registered nurse.

10% INCREASE in patients rating hospitals as excellent increases margin by 1.5%.

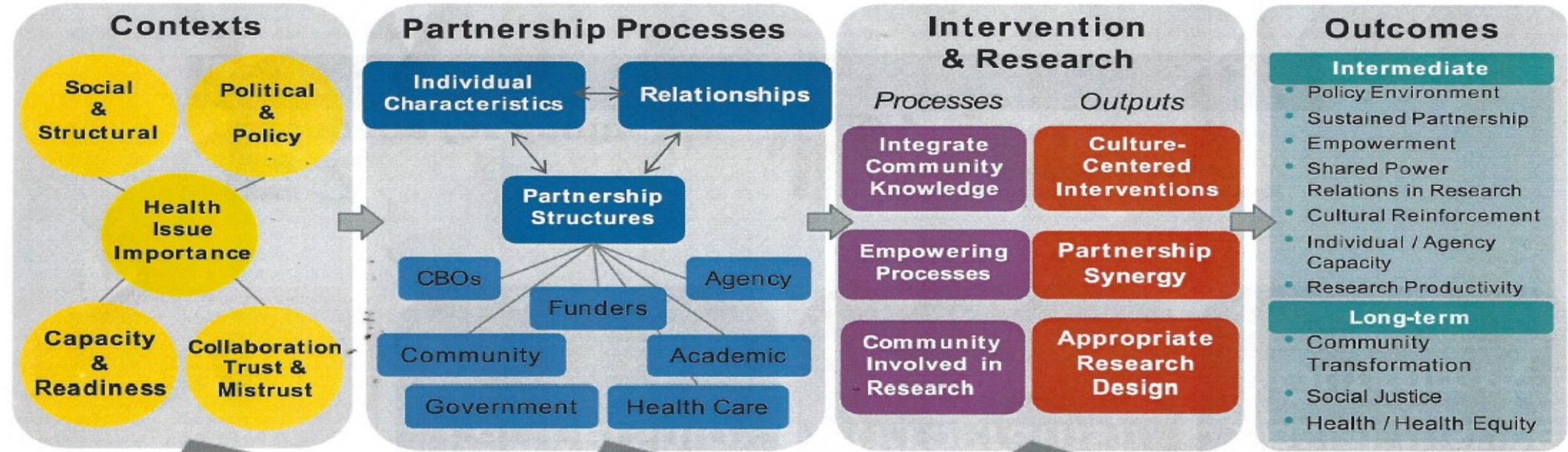
Better patient experience correlates with lower medical malpractice risk for physicians and lower staff turnover ratios.

NetDimensions LMS | INFOGRAPHIC



CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2018, <https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html>

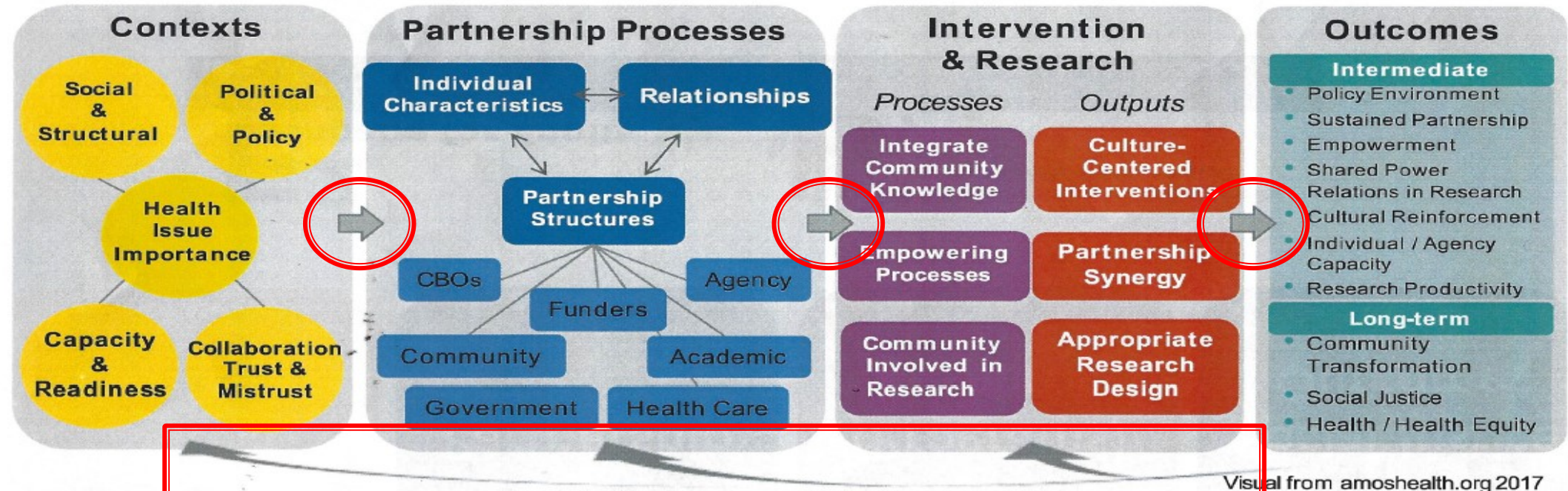


Visual from amoshealth.org 2017

Contexts	Partnership Processes	Intervention & Research	Outcomes
<ul style="list-style-type: none"> • Social-Structural: Social-Economic Status, Place, History, Environment, Community Safety, Institutional Racism, Culture, Role of Education and Research Institutions • Political & Policy: National / Local Governance/ Stewardship Approvals of Research; Policy & Funding Trends • Health Issue: Perceived Severity by Partners • Collaboration: Historic Trust/Mistrust between Partners • Capacity: Community History of Organizing / Academic Capacity/ Partnership Capacity 	<p>Partnership Structures:</p> <ul style="list-style-type: none"> • Diversity: Who is involved • Complexity • Formal Agreements • Control of Resources • % Dollars to Community • CBPR Principles • Partnership Values • Bridging Social Capital • Time in Partnership <p>Individual Characteristics:</p> <ul style="list-style-type: none"> • Motivation to Participate • Cultural Identities/Humility • Personal Beliefs/Values • Spirituality • Reputation of P.I. <p>Relationships:</p> <ul style="list-style-type: none"> • Safety / Respect / Trust • Influence / Voice • Flexibility • Dialogue and Listening / Mutual Learning • Conflict Management • Leadership • Self & Collective Reflection/ Reflexivity <p>Resource Management</p> <ul style="list-style-type: none"> • Participatory Decision-Making • Task Roles Recognized <p>Commitment to Collective Empowerment</p>	<ul style="list-style-type: none"> • Processes that honor community and cultural knowledge & voice, fit local settings, and use both academic & community language lead to Culture-Centered Interventions • Empowering Co-Learning Processes lead to Partnership Synergy • Community Members Involved in Research/Evaluation Design that Reflects Community Priorities • Bidirectional Translation, Implementation, Dissemination 	<p>Intermediate System & Capacity Outcomes</p> <ul style="list-style-type: none"> • Policy Environment: University & Community Changes • Sustainable Partnerships and Projects • Empowerment – Multi-Level • Shared Power Relations in Research/. Knowledge Democracy • Cultural Reinforcement / Revitalization • Growth in Individual Partner & Agency Capacities • Research Productivity: Research Outcomes, Papers, Grant Applications & Awards <p>Long-Term Outcomes: Social Justice</p> <ul style="list-style-type: none"> • Community / Social Transformation: Policies & Conditions • Improved Health / Health Equity

CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2018, <https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html>

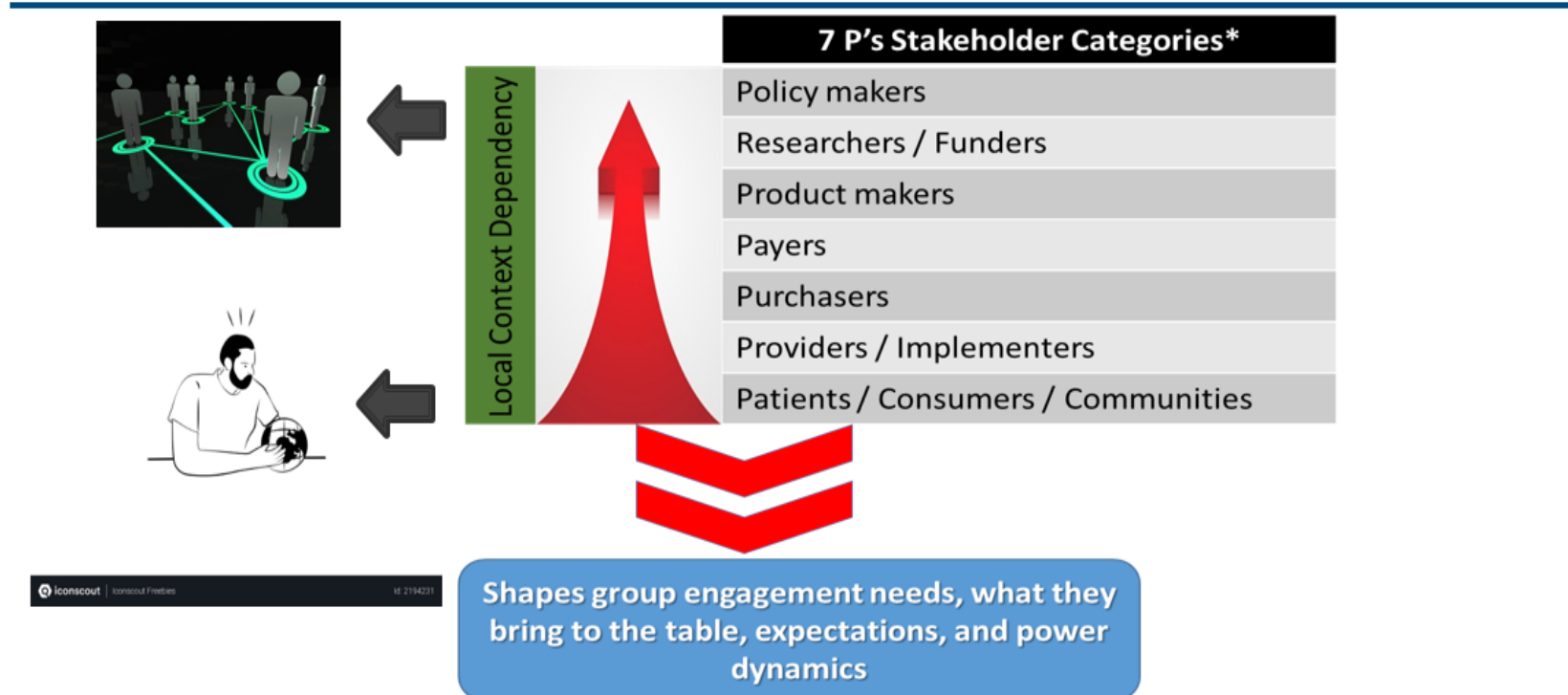


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Contexts	Partnership Processes	Intervention & Research	Outcomes
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Engagement within dynamic contexts!

Context Dependent Engagement



*Adapted from: 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.

What could make stakeholder engagement more challenging in dynamic, diverse, and complex settings?

If stakeholders' needs and priorities change throughout the implementation process, how can you maintain their engagement while still meeting your study set goals and milestones?

II. What practical approaches/methods for stakeholder engagement are available to researchers?



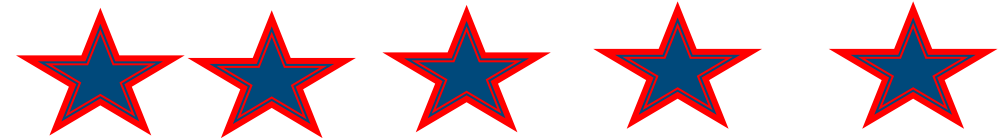
What is the TOP method of engagement that YOU have used?

Engagement strategies

Interviews with leaders	Grow the group outwards and include their feedback and buy-in
Workgroup meetings	Ongoing group to discuss the broader area on an ongoing basis. Meetings used to brainstorm and discuss the partnership itself for example
DCE	Prioritize and narrow options
Consensus conference / Citizen's jury	A group of stakeholders (expertise) present a case with pros and cons to a panel of stakeholders who 'cross-examines' experts, deliberates and provide a report
Carve out time for planning, designing, implementing/analyzing and disseminating phases	Each phase may involve different stakeholders, needs and processes. Keep a core group but expect rotations
Keep a BALANCE between professionals and patients/consumers and community members	A much higher number of professionals may overpower patients/consumers. Consider using prep and debriefing meetings OR separate meetings. Ask for their preference. They will know you 'get it'

Discrete Choice Experiments (DCE)

- Assessing choices
- Narrowing and weighting priorities



Statement	Best	Worse
User friendly		
Accessible		
Available in multiple languages		
Includes examples		

Statement	Stars
User friendly	
Accessible	
Available in multiple languages	
Includes examples	

Engagement strategies

Include members of under-represented communities in higher level decision making	Make sure your own research team reflects the community you care about. Create opportunities for stakeholders to suggest changes when there is time to make them!
Discuss conflict, turn over, loss of interest/availability...	From day 1 and have a plan of action in place
Consider task shifting	Can community members be trained and paid to deliver your group sessions as coaches?
Keep asking ‘when, how and who’ should be at the table	Contextual changes can make our arrangements/engagement efforts irrelevant and much faster than we realize
Selection of real-life and meaningful processes and intervention outcomes	Make sure study outcomes make sense for the community and research procedures are as close as possible to your partner doing it on their own (e.g., is it feasible to offer childcare for participants? Will they be able to do it without the grant funding?)

Budgeting for stakeholder involvement

- Decide the appropriate recognition to their time
 - Incentives
 - Support with childcare, transportation
- If gift cards or cash is provided, the amount can be decided with input from the organization and end-users as well
 - Same incentive amounts as professionals?
 - Different amounts?
- Always check with upper and middle management about offering incentives to their staff/personnel for participation in advisory work group and/or data collection activities (this can be a **sensitive issue** and often linked to the organization's culture and climate)
- Your IRB also need to be involved and in agreement
- These stakeholder groups may not always agree...rely on IRB and funders guidelines

Engagement Rubric

Engagement Rubric

Engagement Rubric: Guidance for Completing Each Section of the Engagement Plan
Each numbered section below corresponds to a numbered section in the Engagement Plan.

1. PLANNING THE STUDY: Describe how patient and stakeholder partners will participate in study planning and design.

Potential activities include:

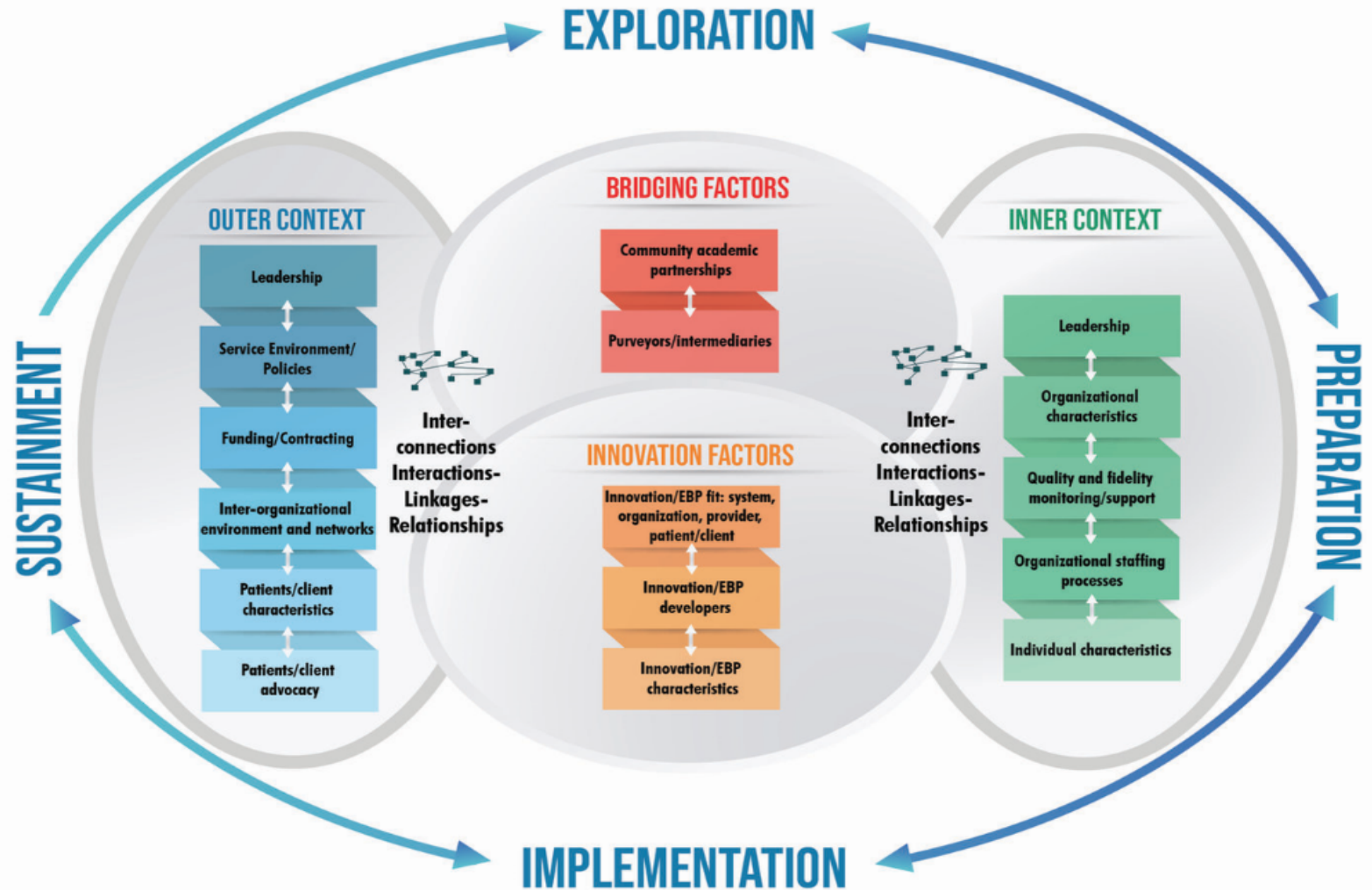
- Identifying the topic and developing the research question and comparators to be studied
- Defining the characteristics of study participants
- Designing the study to minimize disruption to patients and other stakeholders participating in the research; aligning study activities to be consistent with ongoing care

Examples of how to demonstrate this in your proposal:

- Providing letters of support from patient and stakeholder partners that clearly describe the origin of the study topic and the role of the patient and stakeholder partners in defining the question, outcomes, comparators, goals and outcomes, and so on
- Describing meetings, focus groups, and other events convened to engage patient and stakeholder partners in the planning of your study, including key guidance on study design offered by your patient and stakeholder partners
- Discussing how the engagement of patients and other stakeholders helped refine your study's research

<http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf>

EPIS Framework – The how and when!



Key Principles of CBPR

1. Acknowledges community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
4. Fosters co-learning and capacity building among all partners.
5. Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6. Focuses the local relevance of public health problems and ecological perspectives on multiple determinants of health.
7. Involves systems development using a cyclical and iterative process.
8. Disseminates results to all partners and involves them in the wider dissemination of results.
9. Involves a long-term process and commitment to sustainability.

Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (2013). Introduction to methods in community-based participatory research for health, 2nd edition. In B. A. Israel, E. Eng, A. J. Schulz & E. A. Parker (Eds.), *Methods in community-based participatory research for health*. San Francisco, CA: Jossey-Bass.

10. Openly addresses issues of race, ethnicity, racism, and social class, and embodies “cultural humility.”
11. Works to ensure research rigor and validity but also seeks to “broaden the bandwidth of validity” with respect to research relevance.

Minkler, M., Garcia, A., Rubin, V., Wallerstein (2012). *CBPR: A Strategy for Building Healthy Communities and Promoting Health through Policy Change*, Policy Link, Oakland.

Guiding Principles for Decolonizing and Indigenizing Research

1. Reflection

True partnerships begin with *reflection* upon the privileged statuses from which most partners operate and the emotionally difficult task of acknowledging the pain of Native communities and developing empathy.

2. Respect

Research partners must value and prioritize indigenous epistemologies, knowledge, cultural protocols, and healing practices.

3. Relevance

The community should contribute to defining research problems and strategies, which should respond to their own self-identified needs and concerns.

4. Resilience

All aspects of the research must acknowledge the community's strengths and resilience.

5. Reciprocity

The partnership should be collaborative and mutually respectful with knowledge exchanged in both directions.

6. Responsibility

Research partners are obliged to enhance community capacity to conduct Indigenous and Western research, disseminate research findings in culturally meaningful ways, and anticipate the implications.

7. Retraditionalization

Traditional knowledge and methods must be actively integrated into the formulation of the research questions and the process of scientific inquiry.

8. Revolution

Research partners and community members must actively seek to decolonize and indigenize the research process to transform science as well as themselves, their communities, and the larger society for the betterment of all.

Walters, K.L., Stately, A., Evans-Campbell, T., Simoni, J.M., Duran, B., et al., (2009). "Indigenist" collaborative research efforts in Native American communities. In A. R. n (Ed.), *The field research survival guide*. (pp. 3-26). New York, NY: Oxford University Press.



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Parent Engagement in a Comparative Effectiveness Study Examining Parent Activation and Mental Health Services for Children



ACCORDS
UNIVERSITY OF COLORADO
CHILDREN'S HOSPITAL COLORADO



Colorado Clinical and Translational
Sciences Institute (CCTS)
UNIVERSITY OF COLORADO DENVER | ANSCHUTZ MEDICAL CAMPUS



Acknowledge our Partners

- **Parents who have participated in the Mentor Parents Group**
- **Mental Health Community-based partner clinic**
- **Research team:** K Thomas (PI), M Martinez, SJ García, G Stein, L Guzman, C Williams, B Sleath, J Prandoni, A Kulish, A Hoet and J Morrissey
- **Funding:**
 - PCORI: The Patient Centered Outcomes Research Institute (AD-12-11-4900)
 - National Research Service Award Post-Doctoral Traineeship - AHRQ sponsored by The Cecil G Sheps Center, UNC-CH, Grant No. T32-HS000032

María's Story



Research & Results

OUR PROGRAMS

RESEARCH WE SUPPORT

HOW WE SELECT RESEARCH TOPICS

RESEARCH METHODOLOGY

PCORNET: THE NATIONAL PATIENT-CENTERED CLINICAL RESEARCH NETWORK

RESEARCH IN ACTION

Padres Efectivos (Parent Activation): Skills Latina Mothers Use to Get Healthcare For Their Children



Principal Investigator

Kathleen Thomas, MPH, PhD

Organization

University of North Carolina Chapel Hill

State

North Carolina

Year Awarded

2013

Funding Announcement

Addressing Disparities

Project Budget

\$1,478,811

Project Period

3 years



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

RESUMEN DE INVESTIGACIÓN

INFORMACIÓN DEL PROYECTO

Noviembre de 2017

Cómo enseñarles a los padres de familia latinos estrategias para tramitar los servicios de salud mental para sus hijos

Investigadora principal

Dra. Kathleen Thomas

Organización

University of North Carolina at Chapel Hill

How did we meet expectation for PCORI and for parents like Maria?

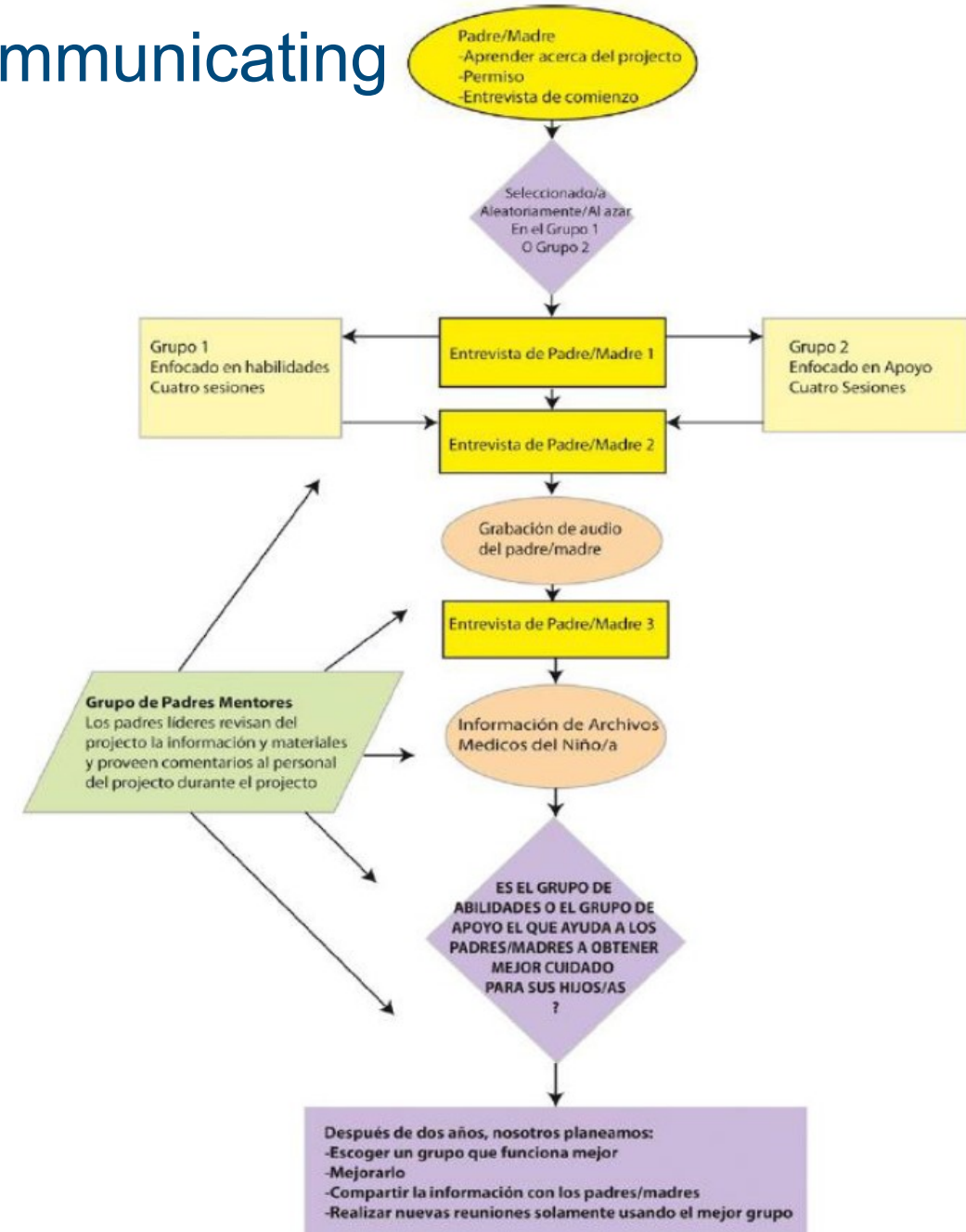
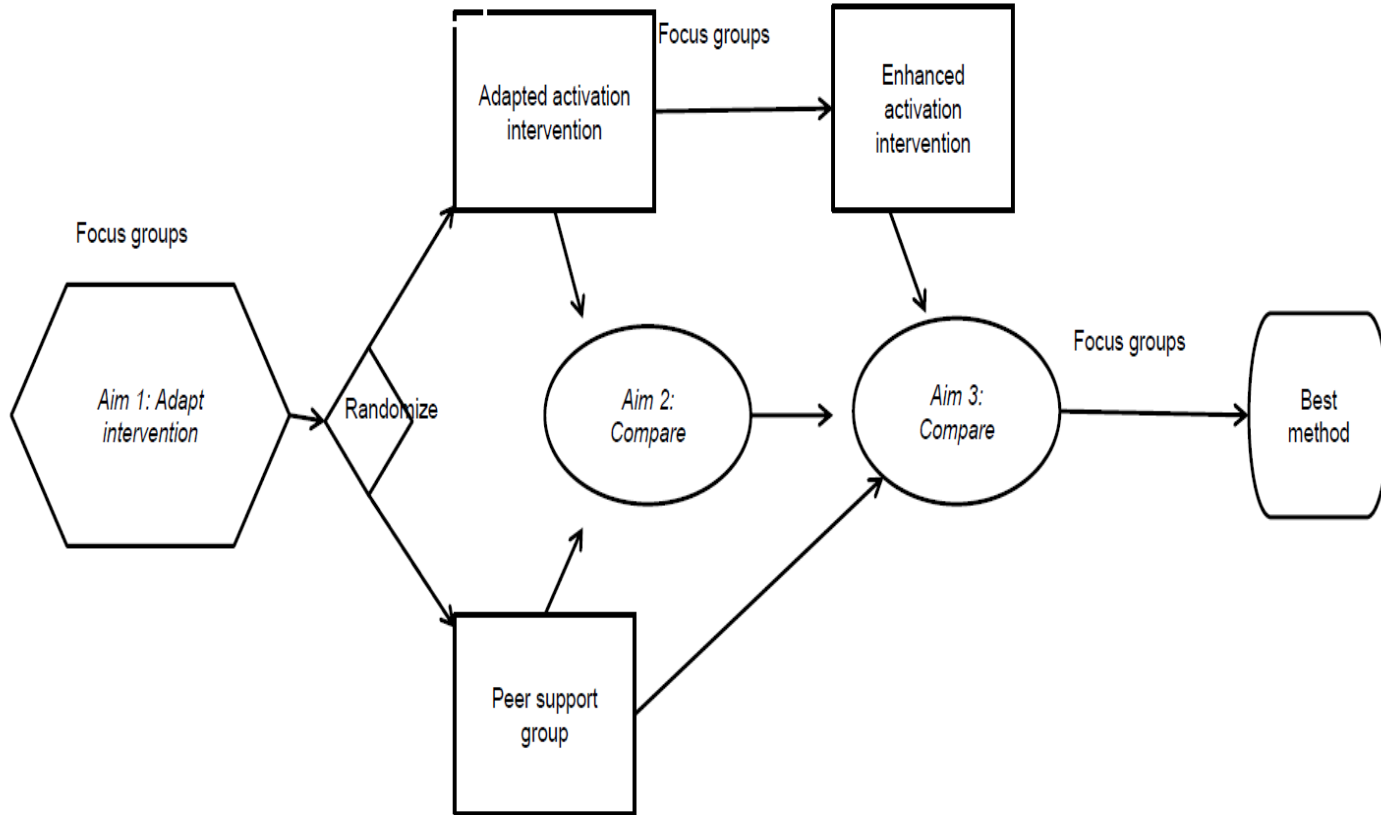
1. Creating a structure for parent mentoring
2. Using parents' input to inform study protocols

1. Creating a structure for parent mentoring

- **Mentor Parent Group**
 - **Parent graduates**
 - **Meet in a trusted context**
 - Meet to prepare a PCORI report/presentation
 - Growing group size
 - Thank you notes (\$20)
 - Sharing feedback

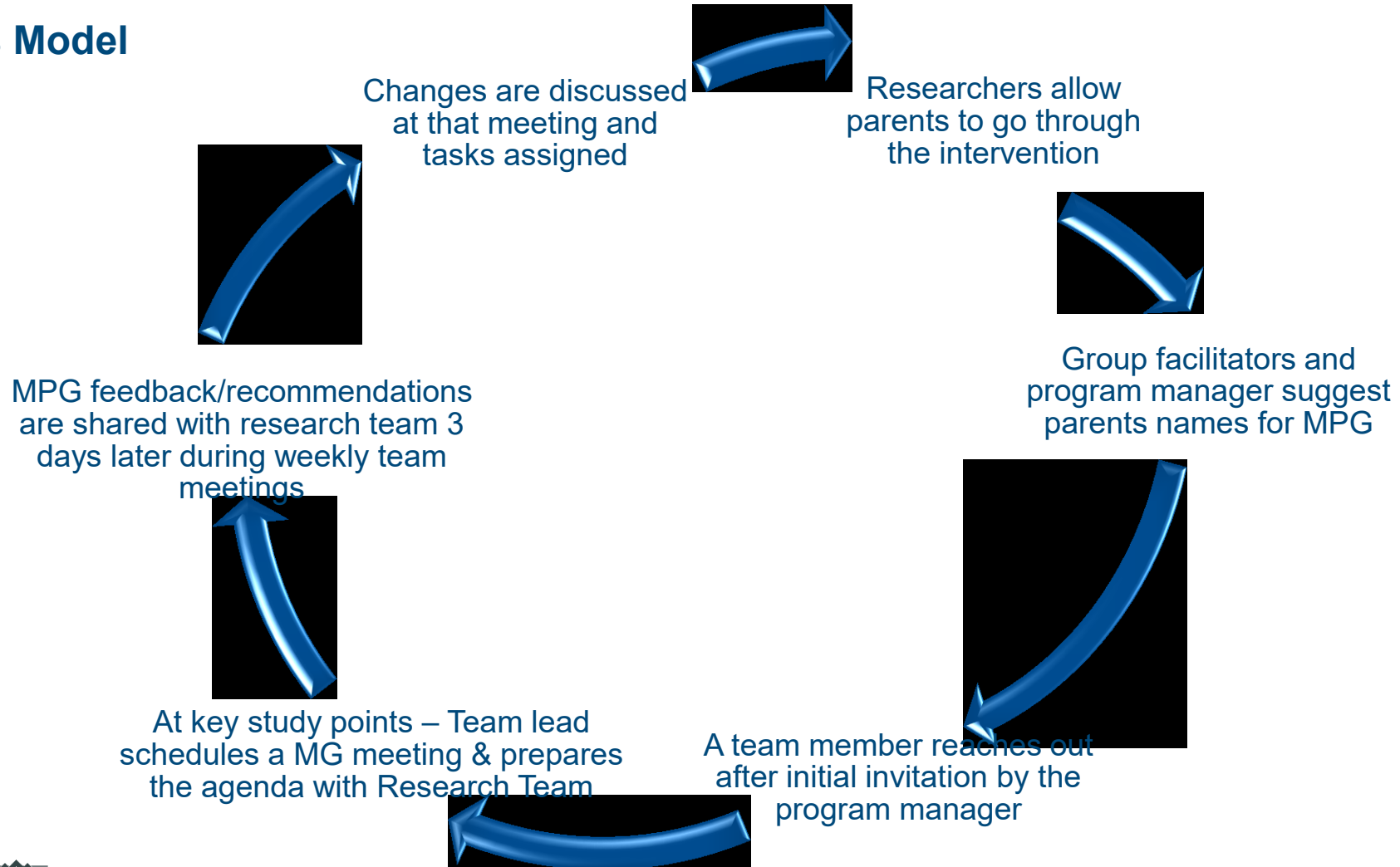


Academic vs Stakeholder Ways of Communicating



Embedding stakeholder input in the study's feedback loop

PDCA Process Model



Medida de los niveles de activación de los padres/madres (PAM)

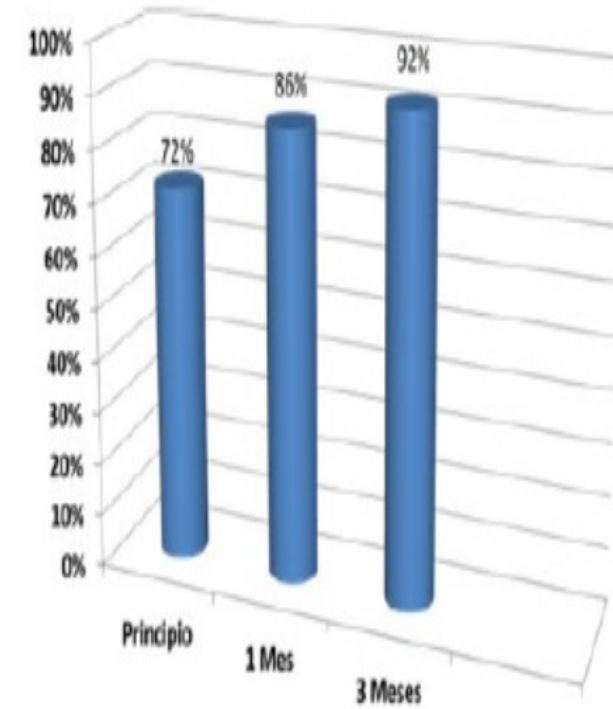


FIGURE 1 Visual aids created by researchers to convey research data to mentor parents

2. Informing study protocols: Recruitment

MPG Recommendation	Our actions	Contribution to the study
Welcome parents in the group even if they have missed a meeting or their child is no longer receiving services at the clinic	<ul style="list-style-type: none">*Allow parents enough time to find a group*Invite them to return to a group even if they had to miss a session*Offered 'En Accion' group at the end for all parents who wish to attend further	Number of participants consented and baseline completed: 95% Among those completing baseline, attended any group session: 92%

2. Informing study protocols: Measures

MPG Recommendation	Our actions	Contribution to the study
Include school issues such as lack of communication with teachers	Include a school activation measure	School activation scores increased from baseline (75 pts) to 3 months (84 pts)
Be mindful that parents new to the system and those with experience are different	Identify novice vs. experienced parents	Activation scores significantly increased among novice parents compared to non-novice ($p < 0.05$)

2. Informing study protocols: Measures

MPG Recommendation	Our actions	Contribution to the study
<p>Need to distinguish between:</p> <ul style="list-style-type: none">a) Self-reported activation (enthusiasm) andb) Actual implementation of activation skills	<p>Validation of our measures: a) self-reported PAM & b) audio-recorded visit qualitative data</p>	<p>Working on coding of qualitative data</p>

Lessons Learned

- The MPG has shown our commitment to our partners
- Easier implementation of study protocols for vulnerable families within a ‘trusted context’
- A formal structure to incorporate parent / patient input in study protocols in a timely manner has contributed to successful implementation

Involving Latina/o parents in patient-centered outcomes research: Contributions to research study design, implementation and outcomes

Mónica Pérez Jolles PhD MA^{1,3} | María Martínez PhD³ | San Juanita García PhD³ |
Gabriela L. Stein PhD² | **Mentor Parent Group Members**³ | Kathleen C. Thomas PhD MPH^{3,4}

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²Psychology Department, University of North Carolina at Greensboro, Greensboro, NC, USA

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Funding information

Patient-Centered Outcomes Research (PCORI) Grant; # AD-12-11-4900; Kathleen Thomas (PI). 08/01/13-07/31/16. Padres Efectivos (Parent Activation): Skills Latina Mothers Use to Get Healthcare for Their Children. The objective of this study was to examine the comparative effectiveness of an intervention to build activation among Latino families and improve service use of their children with mental health needs compared to a control

Abstract

Background: Comparative effectiveness research (CER) is supported by policymakers as a way to provide service providers and patients with evidence-based information to make better health-care decisions and ultimately improve services for patients. However, Latina/o patients are rarely involved as study advisors, and there is a lack of documentation on how their voices contribute to the research process when they are included as collaborators.

Objectives: The purpose of this article was to contribute to the literature by presenting concrete contributions of Latina/o parent involvement to study design, implementation and outcomes in the context of a CER study called Padres Efectivos (Parent Activation).

Methods: Researchers facilitated a collaborative relationship with parents by establishing a mentor parent group. The contributions of parent involvement in the following stages of the research process are described: (i) proposal development, (ii) implementation of protocols, (iii) analysis plan and (iv) dissemination of results.

Results: Mentor parents' contributions helped tailor the content of the intervention to their needs during proposal, increased recruitment, validated the main outcome measure and added two important outcome measures, emphasized the importance of controlling for novice treatment status and developed innovative dissemination strategies.

Health

Parents advise investigators on mental health treatment in children

Trials with Latina mothers take place in settings where the research can promptly benefit the patient

BY **Cynthia Monticue** • JANUARY 13, 2017



<https://news.usc.edu/114758/parents-advise-investigators-on-mental-health-treatment-in-children/>

Dissemination Product



https://youtu.be/9Ri_oYz1mvc

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