RAND HEALTH

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CERP Faculty Seminar Series: Seminar 1

The Vision, Valley, and Victory of a CPPR Project

Vision Valley Victory

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CTSI

The Value of Engaging Community in Research

- Advances in research and clinical knowledge too often do not reach community settings
- This is true at least in part because community may view the research as:
  - irrelevant to community needs
  - insensitive to their culture
  - inconsistent with their resources
  - conducted by institutions with histories of poor community relations
- Partnerships can close this science-community practice gap

Community-Partnered Participatory Research is a process for developing partnerships

- A CPPR project:
  - Includes both community and academic partners in all phases of research and decision-making
  - Shares leadership and resources equitably
  - Highlights the critical importance of evidence while simultaneously valuing the relevance of experience
  - Emphasizes two-way capacity building
- Goal is to build a sustainable partnership that will support research and action that benefits community
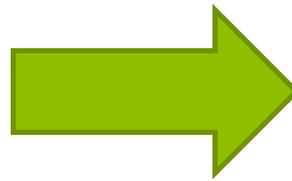
Objectives

1. **Review the principles that provide the foundation for a CPPR project**

2. Identify the players and the general approach to getting the work done

3. Describe what occurs in the three phases—Vision, Valley, and Victory—that characterize a CPPR project

Authentic Partnership Means Engagement, Not Involvement
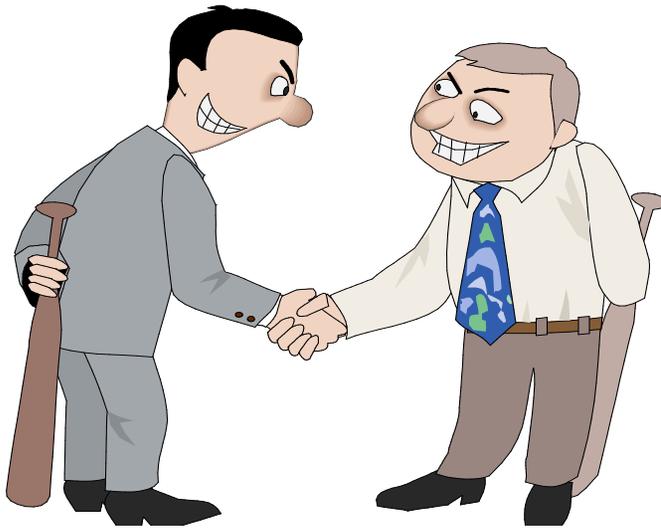
Not just "Involvement"

But Engagement

CPPR Projects Respects, Includes and Honors All Partners

- Five core values of engagement
  - Respect for Diversity
  - Openness
  - Equality
  - Redirected Power
  - Asset-based Approach

Core Values Translate into 11 Guiding Principles of Partnership Activities

1. Each activity is co-planned by community and academic leaders who have equal decision-making power

2. Each project is guided by a written agreement that outlines goals, rules of engagement, and ownership of products

3. Academic and community project leaders communicate regularly and recognize that conflicts and disputes are necessary to growth

Core Values Translate into 11 Guiding Principles of Partnership Activities (con't)

4. Academic partners help to obtain funding that supports the involvement of community partners

5. All leaders respect and follow community values and time frames

6. All leaders are committed to achieving the highest standards of productivity, impact, and accountability

Core Values Translate into 11 Guiding Principles of Partnership Activities (con't)

6. Academic leaders are quick to seek help from community leaders in resolving conflicts

7. Academic leaders work to understand community priorities and histories

8. Community input is formally recognized

9. Academic leaders ensure that their own institutional leadership understands and values the academic-community partnering process

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Circles of Influence

Model Illustrates the Stakeholder Structure of CPPR Initiatives

Stakeholders Roles

- Framing Committee (later the Steering Council)
  - Small group that plans and launches the initiative during the Vision phase and provides leadership through the Valley and Victory phases

- Working Groups
  - Diverse set of researchers and community members responsible for accomplishing specific tasks

- Community-at-large
  - Informed and consulted through community forums, exhibits, and events

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Vision

- A Vision Sets The Stage For What Will Be Done, Why, And Its Value

- The vision is the large idea underlying the project; its purpose and specific goals

- In the prior slide the work of the Vision stage is to frame the effort:
    - develop the big idea
    - ground it in the work and perspectives of the partners
    - bring additional partners to the table who can contribute to its selection and shaping
    - understand the context and the history of the partners with the issue
    - obtain broader partner and community input

The Work of the Vision Stage

- Establishing the framing committee

- Defining community

- Deciding who should be at the table

- Clarifying expectations regarding participation

- Formalizing an agreement on partnership principles

- Framing the issue

- Obtaining input and feedback from the community

Establishing The Framing Committee

- Typically between 5 and 10 members

- Equal representation of community members and researchers

- Co-led by an academic and at least one community representative

- Identify bridge builders who can bring in other partners and a commitment to the effort are critical

- The framing committee will evolve into the Steering Council

Defining Community

- Definition of community is critical
  - it will guide who should be involved in framing the project

- There are many ways to define a community but guarding against a definition that is too limited or too broad is key

- A useful definition of community combines both geographic and social network elements: *a community consists of persons who live, work, or socialize regularly in a given area*

Deciding Who Should Be at the Table

- Who needs to be at the table? Who is there already? Who is not? Answers will be guided by:
  - definition of community
  - community problems you seek to address
  - community resources

- Maintain the balance between academic and community participation

- Seek balance between representing a broad cross-section of the community and ensuring a manageable planning process —but err on the side of inclusiveness

- Community partners will best understand which community players need to be engaged at this stage

Clarifying Expectations around Participation

- Partners need to know
    - frequency and length of meetings
    - duration of commitment
    - required personal and organizational resources
    - how they will be compensated for time and infrastructure support

- Transparency regarding the available resources and their distribution

- Community members should be compensated

Formalizing an Agreement on Partnership Principles

- Everyone needs to understand the "rules of engagement"

- This is facilitated by the development of a detailed **Memorandum of Understanding** of documents;
  - agreements around shared leadership
  - rules for decision-making
  - power-sharing
  - resource allocation
  - ownership of and access to products and data, etc.

- This task needs to be accomplished early; it also needs to be revisited and updated as necessary

Framing the Issue: A Shared Process of Defining an Issue And its Context

- Can involve systematic assessments (including community surveys or dialogue groups) but core activity is discussion

- Checking and re-checking that the issue resonates with community—that an average community member can see its relevance

- Further defining the issue, understanding its meaning and relevance to different stakeholders, clarifying incentives, learning about the history from the issue for partners

The Process of Framing Can Change the Focus of the Work: *Witness for Wellness*

- Initial idea of focusing on depression in minority communities came from academic research that pointed to gains for minorities from QI interventions

- Months of shared discussion on concepts of depression, controversies over treatment approaches, community and consumer perspectives, neighborhood pressures led to a more expansive perspective

- Issue ultimately framed as *engagement of a diverse community in considering and taking action on depression*, rather than on how to implement evidence-based depression care.

Obtaining Input and Feedback from the Community

- Need to create opportunities to get feedback from the larger community on whether the issue is resonating and being framed appropriately

- Early community meetings to ensure that you're on the right track

- Conference toward the end of the framing process to:
  - Provide community with information on initiative
  - Encourage discussion in breakout sessions
  - Recruit working group members for the Valley phase

Reaching the End of the Vision Phase

- Through this process, one arrives at:
  - a firm grasp on the issue and a mission based on that
  - language used by and familiar to community
  - action that will be supported by community
  - list of interested players for working groups
  - the mission or broad goal for each specific working group
  - branding for the initiative that reflects the mission and honors the community's voice

Valley

- The Valley Phase Involves Performing The Tasks Required to Realize the Vision

- Planning, implementing, and evaluating the actual work of the project or intervention

- Developing and sustaining the required partnerships

- Organizing and managing working groups that accomplish key tasks and coordinating their efforts

- Continuing to work with the community-at-large at critical points to ensure that you're on track

The Work of the Valley Stage

- The actual work of a given project will be specific to its substance

- Common process issues:
  - Transforming the Framing Committee into a Council
  - Creating and promoting a brand
  - Developing working group action plans
  - Supporting effective working groups

Transforming the Framing Committee into A Steering Council

- Steering Council responsibilities
  - attending to the larger vision of the initiative
  - developing a mission for each working group
  - supporting the working groups in accomplishing their plans
  - integrating these plans into the whole

- Monthly meetings co-led by academic and community leaders with report backs and cross-group discussion

- Subcommittee structure facilitates the work, e.g., Executive, Evaluation, and Dissemination Committees

Creating and Promoting a Brand

- An effective brand tells the community who you are, what you do, and how you will do it

- Promotional materials can include flyers, brochures, posters, ads and public service announcements, toolkits and websites

- A brand can also be promoted through free seminars and sponsored events

- The goal is to get the attention, support, and involvement of the community

Witness for Wellness

Guiding Principles

Trust
Respect
Participation
Knowledge
Experience

Witness for Wellness

SUPPORT
- Promote Policy
- Advocate for vulnerable populations

BUILD
- Community Outreach
- Quality Services

TALK
- De-mystify Depression
- Building Community Strength

SHARE
- Information
- Resources

LOOK/LISTEN
- Community Voices
- Evidence Based

RECORD
- Impact
- Process

Developing the Working Group Action Plans

- The action plan specifies:
  - The overall goal for that working group
  - Objectives
  - Activities
  - Responsible party(s)
  - Timeline
  - Evaluation measures

- Action plan should be updated periodically to meet the needs of a changing environment

Five Suggestions for a Partnered Action

1. Organize a brainstorming meeting with the working groups and representatives of the community-at-large

2. Develop a draft action plan, attending to whether it gives overall direction, matches resources and opportunities, minimizes resistance and barriers, reaches those affected, and advances the mission

3. Design do-able objectives that follow the SMARTIE rule: Specific, Measurable, Achievable, Realistic/ Relevant, Time-Sensitive, Inclusive, and Engaging

Five Suggestions for a Partnered Action Plan(con't)

4. Check your proposed action plan for completeness, accuracy, whether it contributes to the Vision, and consistency with other working group action plans

5. Present the action plan back to the community and make any desired adjustments
   – Plan should be co-presented
   – This is an opportunity to show what real partnership looks like

Supporting Effective Working Groups

- Much of a working group's effort occurs in meetings
    - Make it easy for community members to attend meetings (by attending to time, site, and compensation)
    - Share leadership
    - Have clear ground rules and structure, especially around listening and decision-making
    - Develop trust through building rapport, listening, consistency, and ethical behavior
    - Ensure equal participation and emphasize strength-based thinking

Victory

The Victory Phase Involves:

- Developing products and having impact

- Disseminating products in ways that are appropriate to the relevant audiences

- Acknowledging and celebrating success and those that contributed to it

- Sharing the journey with others

- Ensuring sustainability and related policy changes

Developing and Disseminating Products

- Different stakeholders require different documentation
  - Community members may prefer to lay-oriented exhibits or pieces in local newspapers
  - Providers will want to see a manual or toolkit
  - Academics will expect a published article or presentation
  - Policy makers will make best use of a policy brief or publication in a policy review journal

- All of these should be pursued using a partnered approach

Academic Forms of Dissemination Can Pose a Unique Set of Challenges

- Academic conferences don't typically expect partnered presentations
  - Turning an individual invitation into a partnered one
  - Working out the logistics of travel expenses
  - Blending presentation styles
  - Modeling partnership through interaction

- Holding true to meaningful co-authorship takes work
  - Capacity-building around methods and research
  - Innovative strategies for capturing voice and input

Acknowledging and Celebrating Success

- This aspect of Victory occurs throughout the project

- Look for the early wins

- Grab onto opportunities to express gratitude and celebrate accomplishments

- Learn about wins and victories by observing the reaction of guests who step into the process

- Celebration facilitates a strong and enduring partnership

Concluding Thoughts

- Working within a CPPR approach is time-consuming, intense, and sometimes conflictual

- These apparent negatives can actually be victories

- The time and energy that goes into building partnership and engaging in partnered work yields better prepared community and academic leaders—and more relevant and impactful findings and products

- This substantial return on investment makes the hard work well worth it in the end

Suggested Reading

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- Wells K., Jones L., Commentary, "Research" in Community-Partnered Participatory Research, JAMA. 2009;302(3): 320-321

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Suggested Reading

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- "Chapter 1: Community Engagement: Definitions and Organizing Concepts from the literature." & Chapter 2 National Institutes of Health Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2nd Edition, 2011.

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- US Department of Health and Human Services. HHS Action Plan to Reduce Racial and Ethnic Health Disparities. 2010;

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- Los Angeles Urban League. State of Black LA report. 2011.

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- Israel, B. A., Schulz, A. J., Parker, E. A. et al. Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health, 1998; 19:183-202.