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Authors

Wennerstrom, Ashley
Springgate, Benjamin
Jones, Felica
[et al.](#)

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Ashley Wennerstrom, PhD, MPH¹; Benjamin F. Springgate, MD, MPH²;
Felicia Jones³; Diana Meyers, RN⁴; Norris Henderson⁵; Anthony Brown³;
Anjali Niyogi, MD, MPH¹; Dolfinette Martin⁵; Jessie Smith, III¹; Angela
L. Kirkland¹; Loretta Jones, MA, ThD, PhD³; Keith C. Norris, MD, PhD⁶

The Patient Centered Outcomes Research Institute (PCORI) supports patient-centered clinical comparative effectiveness research (CER) including health disparities and engagement portfolios. In 2013, PCORI launched the Pipeline to Proposal (P2P) mechanism to support development of novel patient- and stakeholder-centered partnerships focused on designing clinical CER funding proposals. By providing a tiered structure of successive small contracts and technical assistance, the P2P mechanism encourages development of new research partnerships among diverse stakeholders. As a comparatively new field, patient-centered outcomes research (PCOR) has few well-delineated methods for engaging patients and other non-scientists in effective teams with academics or clinicians to develop and implement rigorous, scientific research proposals. Community partnered participatory research (CPPR) provides a useful framework for structuring new partnerships.

In this article we highlight the origins, development, and prospects of three current examples of funded P2P initiatives based in New Orleans and Los Angeles. We outline how these projects – Prisoner to Patient, the NOLA Partnership, and Resilience Among African American Men – use CPPR principles. We also describe how they have collaborated with, and contributed to, a two-way learning and knowledge exchange among members of the PCORI-funded Community and Patient Partnered Research Network. Lessons learned may be applicable to other groups planning to create new partnerships focused on implementing PCOR. *Ethn Dis.* 2018;28(Suppl 2):303-310; doi:10.18865/ed.28.S2.303.

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BACKGROUND

Health disparities and inequitable quality of care among under-resourced populations in the United States are large and essentially undiminished over the last 30 years, despite decades of tracking data, research, and efforts to improve access and quality of care nationally.^{1,2} Improving the quality of health care for all and reducing disparities remain national priorities,^{3,4} yet broadly effective solutions either have yet to be discovered or implemented at scale. Trust in health care and in health research is limited in many communities, particularly communities of color as well as sexual and gender minority communities, owing to histories of abuse.^{5,7} As one option, community-based participatory research (CBPR) or community part-

nered participatory research (CPPR) have been proposed to reduce disparities and enhance trust in health research.^{8,9} CBPR and CPPR are both collaborative research approaches that integrate the unique strengths of all partners to solve complex socio-medical questions. We prefer to use the term CPPR to emphasize partnering with communities rather than merely conducting research based in the community, which is how CBPR is sometimes misrepresented.¹⁰ CPPR's effective model of community engagement as well as methodological successes involving partners equitably in all phases of research have worked in recent studies of large urban neighborhoods,¹¹ but CPPR has yet to find application in multi-state or national studies.

The Patient Centered Outcomes Research Institute (PCORI) supports

tory Research; Patient Centered Outcomes Research; PCORI; Community-Academic Partnership; Health Disparities Research

¹ Tulane University School of Medicine, New Orleans, LA

² Louisiana State University Health Sciences Center, New Orleans, LA

³ Healthy African American Families II, Los Angeles, CA

⁴ Anna's Place, New Orleans, LA

⁵ Voice of the Experienced, New Orleans, LA

⁶ Geffen School of Medicine at UCLA, Los Angeles, CA

Address correspondence to Ashley Wennerstrom, PhD, MPH, Tulane University School of Medicine; 1430 Tulane Ave. SL-16 New Orleans, LA 70112; 504.988.4007; awenners@tulane.edu

patient-centered clinical comparative effectiveness research (CER) including health disparities and engagement portfolios.¹² Clinical comparative effectiveness research typically seeks to demonstrate benefits and risks associated with testing two or more alternatives for

We identify how these three projects use CPPR and have collaborated with and contributed to a two-way learning and knowledge exchange among community and academic partners of the CPPRN.

diagnosis or treatment. Since 2012, PCORI has funded studies that engage a broad range of stakeholders, including patients, in developing research on an array of health conditions.¹² While not uniformly applied in all PCORI studies and approaches, the explicit involvement of patients (and/or family, caregivers, and other stakeholders) in the design, implementation, analysis, and dissemination phases of some PCORI-funded research may enhance effectiveness of research and relevance to populations affected by disparities.

As part of its engagement portfolio, in 2013, PCORI launched the

Pipeline to Proposal (P2P) mechanism to support development and capacities of novel patient- and stakeholder-centered partnerships focused on designing clinical CER funding proposals. By providing a tiered structure (initially with three, now two tiers) of successive small contracts and technical assistance, P2P has been used to support inexperienced or new stakeholders in CER to: develop partnerships between patients, clinicians, and other parties interested in conducting patient centered outcomes research (PCOR); develop CER questions that might be translated into effective research proposals; and write CER proposals.¹³

As a comparatively new field, patient-centered outcomes research (PCOR) has few well-delineated methods for engaging patients and other non-scientists in effective teams with academics or clinicians to develop and implement rigorous, scientific research proposals. CBPR¹⁴ and CPPR⁸ provide useful frameworks for structuring new partnerships. CBPR and CPPR also represent potentially valuable conceptual models to translate PCORI funding for smaller initiatives such as P2P projects to multi-state or national scales. Affiliation with national entities such as the Community and Patient Partnered Research Network (CPPRN)¹⁵ may facilitate learning, collaboration, and growth to scale for and among smaller P2P initiatives. CPPRN is a patient powered research network funded by PCOR-Net to support PCOR with populations impacted by behavioral health problems or facing social risk factors for behavioral health problems

that uses similar CPPR approaches.

In this article, we highlight three current examples of P2P-funded projects – their origins, development, and prospects. We identify how these three projects use CPPR and have collaborated with and contributed to a two-way learning and knowledge exchange among community and academic partners of the CPPRN.

CASE STUDIES

Below we describe in detail three P2P projects that employed several of the foundational principles of community academic partnership described initially by Jones & Wells,⁸ and subsequently refined by other groups such as the REACH NOLA collaborative,¹⁶ community partners in care¹⁰ (CPIC) and the CPPRN.¹⁵ These guidelines include shared leadership, written agreements about governance, financial resources for community partners, and participation of all project members in each aspect of the work. Table 1 contains an overview of each P2P project and how CPPR guidelines were used. Table 2 contains a summary of the events that each group hosted during the first two years of collaboration. It is important to note that research is not permitted under the P2P funding mechanism. As such, none of the collaboratives described engaged in formal data collection. All information on partnership development presented below comes from de-identified project planning notes, communications, meeting minutes, recollections, and process evaluations. Co-authors affiliated

Table 1. Overview of structure of three Pipeline to Proposal projects using CPPR methods

	Prisoner to Patient	NOLA Partnership	Resilience Among African American Men (RAAM)
Patient population/health issue	Formerly incarcerated persons (FIP)	Individuals with serious mental illness	African American men
Project location	New Orleans, LA	New Orleans, LA	Los Angeles, CA
CPPR Principles			
Community-academic co-leadership	Community co-lead (NH) -Non-profit serving FIPs -Member of population Academic co-lead (AW) -Academic medical center -Friend and caregiver to members of population	Community co-lead (DM) -Faith based agency -Clinician and advocate Academic co-lead (BS) -Health sciences center -Clinician -Family of population served	Community co-lead (AB) -Non-profit focused on health equity -Member of population Academic co-lead (KN) -Academic medical center -Member of population
Written agreements to establish governance	Advisory board Decision by majority vote, deference to FIPs if FIPs all disagree 12 members include -CBO leaders -Researchers -Clinicians -Patients/family -Dept. of Corrections -Attorney	Governance board Decision by majority vote 10 members include: -Clinicians -Patients/family members with SMI -Community advocacy groups	Executive council Decision by majority vote 8 members include: -CBO leaders -Researchers -Faith-based representatives -Clinicians -Entrepreneurs
Community partners should receive financial resources	Contract based at academic institution, with subcontracts to two community partner agencies Stipends provided for all formerly incarcerated board members	Contract based at community agency Stipends provided for all advisory board members	Contract based at community agency Stipend for participating in community dialogues Stipend for co-planning a community dialogue
Transparency, involvement of all partners in all aspects of work	Community-academic teams plan and co-facilitate community events	Community-academic teams conduct literature reviews and co-facilitate community events	Community leads planning of community conference, with academic support, if needed

with each case study collaboratively reviewed and discussed project development processes and activities to determine key components of the work and develop the case studies.

Prisoner to Patient

The United States leads the world in incarceration rates, and Louisiana has more people under correctional control per capita than any other state.¹⁷ Formerly incarcerated persons (FIPs) have an elevated risk of death in the immediate post-release peri-

od,¹⁸ suggesting a need for health and social services to support societal reintegration. However, numerous social, logistical, and financial barriers may preclude recently released individuals from accessing much-needed care.^{19,20}

In 2013, a university-based physician, an executive director of a non-profit agency that organizes and advocates for FIPs, and a researcher with expertise in community-academic partnered research agreed to collaborate to improve health services for FIPs in New Orleans, Louisiana. All

three shared the common experience of caring for incarcerated or formerly incarcerated individuals. The physician had treated prisoners at the public hospital where she worked; the executive director had created a hospice program during his nearly three decades of incarceration; and the researcher had helped provide end-of-life care for two formerly incarcerated friends. Along with a medical student, the team conducted formative research on the needs of FIPs in Louisiana.²⁰ Based on findings, the

Table 2. Overview of Pipeline to Proposal project stakeholder engagement activities

Stakeholder engagement activities	Prisoner to Patient	NOLA Partnership	Resilience Among African American Men
Number of advisory/executive board meetings	12	14	6
Community/patient engagement activities	6 community forums	4 community forums 2 community fundraisers	7 small group community dialogues 1 community conference
Number of participants in community events	64	31	42

physician led the team in developing a transitional care clinic to serve individuals upon release from prison. The clinic saw its first patients in 2015.

As a separate, but related effort, the team began the Prisoner to Patient project in 2015 to develop a research agenda focused on the unique health needs of FIPs. The researcher and the executive director agreed to co-lead the P2P-supported project. Together, the team formed an advisory board that includes FIPs, family members of FIPs, clinicians, experts in community-academic partnered research, a re-entry program manager, an attorney who specializes in health litigation for currently and formerly incarcerated individuals, and a representative from the Louisiana Department of Corrections. Using CPPR as a guideline, the board developed a shared governance structure to ensure accountability to all partners, particularly FIPs. The board met, on average, bimonthly.

Between September 2015 and January 2017, the members of the advisory board co-planned a series of six community forums to engage a wide variety of stakeholders in developing CER questions. These events were hosted at several community-based locations, including community cen-

ters and the office of a FIP-serving organization. The first gathering was co-facilitated by the project leads and focused on introducing the project and members of the board to the community to help build trust with stakeholders. During the second forum, two researchers introduced the concept of PCOR and CER. Later events included small- and large-group discussions during which feedback on topics of interest for research were recorded. The advisory board successively narrowed topics, conducted a literature review, and wrote draft CER questions. During the final forum, the board presented these draft CER questions and asked for additional feedback. The members of the project now anticipate engaging in a strategic planning process to divide the work of making final revisions to the research question and developing a PCOR proposal.

NOLA Partnership for Mental Health

The NOLA Partnership for Mental Health (NOLA Partnership) was started in 2015 to address serious mental illness (SMI) by engaging a broad range of partners (eg, patients, family members, care givers, clinicians, advocates, policy makers, and

academic researchers) to improve outcomes. Many people with SMI die more than 20 years earlier than age-matched cohorts, and experience profound disparities in health care quality and health outcomes.²¹ The founding co-chairs of the NOLA Partnership are a nurse director of a mission at an urban church with a strong focus on health, education, and social investment in the community, and a primary care physician with a background in developing community-academic partnerships for health and who, as a family member, caregiver, clinician, and researcher has been involved in advocating and improving mental health care. The co-chairs began working together after Hurricane Katrina and over the prior decade had developed community-academic partnered work, along with others, in implementing evidence-based services at scale to address post-disaster mental health issues, bolstering community resilience, training community health workers, integrating care for mental health in primary care and community social service organizations, developing interpreter training services for application to health care settings, and deploying mobile health services for uninsured and under-resourced

communities after disaster.^{16,22}

The co-chairs assembled a board for the NOLA Partnership that includes people with SMI, care givers and family members of people impacted by SMI, clinicians from a range of backgrounds (inpatient social work, community and academic psychiatry, nursing, and primary care), mental illness advocacy organization representatives, peer advocates, and researchers. Three board members had previously worked with the co-chairs, but most board members had not previously worked on community-academic partnerships, or partnered research, including for mental health.

During its first two years, the NOLA Partnership hosted a total of four community forums on mental health, with topics ranging from public policy (eg, insurance reform, and special populations including incarcerated people with mental illness) to development of CER questions. Community forums provided benefits of expanded group discussions with community participants often eager to bring new ideas and perspectives to partnership efforts. Forums included guest speakers including policy makers (eg, director of city health department, executive director of regional public mental health agency), service providers, and individuals living with SMI. In the context of community engagement activities to advance interests of partners participating in CER question development, the board also participated in fundraisers for the local chapter of a national organization that provides services and resources to people affected by SMI.

Based on issues raised during

community events, the NOLA Partnership board worked to identify clinical CER questions. Community-academic and clinician-community teams of board members collaborated to gather literature and presented findings back to the entire board. Teams wrote CER questions and then presented them to the board. The board voted to determine which questions they preferred to pursue.

Resilience Among African American Men (RAAM)

The RAAM project is based in Los Angeles, California at a community organization whose founder is one of the developers of CPPR.⁸ In 2006, the organization began the Black Men's Depression Project, which included formative research to better understand, and ultimately address, the underlying causes of disparities in depression among African American men. Findings from more than 300 interviews indicated structural causes of depression such as community violence, insufficient financial resources, and racism. Depression was reported to cause difficulty in finding work, managing relationships, and substance use. Based on these findings and a 10+ year history of successful collaboration, community- and university-based researchers, partnered to create the RAMM project, with the aim of developing CER questions through a CPPR approach.

RAAM created an executive council to direct the project. Members included representatives of community organizations, researchers, and leaders of faith-based institutions. The council members co-planned a series of six community

dialogues and hosted a community conference to solicit input from a board range of stakeholders. Various members of the council took leadership on planning each event. Board members were expected to be active participants in all meetings and complete "homework" assignments between meetings. For example, they were charged with suggesting topics for community engagement meetings, as well as identifying guest speakers. In some cases, researchers and community-based members worked in pairs to ensure that various perspectives were represented.

In addition, council members divided the responsibility for advancing the group's research agenda by leveraging individuals' different strengths. Faith-based leaders aimed to introduce the purpose of the project to their congregations to reduce stigma around mental health and promote participation in local events. Community organizations helped identify and provide education about relevant existing resources to support resilience, and the academic partners took the lead on presenting research and explaining information from the funding agency in terms that people inexperienced with scientific studies could understand easily.

DISCUSSION

We have described three examples of P2P projects that used CPPR strategies to engage patients, family members, caregivers, researchers, and other stakeholders to create a PCOR agenda for their respective populations.

All three groups benefited from

having prior CPPR models from which to draw, as well as perspectives from board members new to using this framework. There were challenges and lessons learned that may be relevant to other groups. For example, members of the Prisoner to Patient project learned the importance of literally meeting people

All three groups benefited from having prior CPPR models from which to draw, as well as perspectives from board members new to using this framework.

where they are when the partnership initially experienced difficulty in getting FIPs to participate in advisory board meetings, which were held at the health center where the transitional care clinic for FIPs is housed. In response, the meeting location was changed to the FIP-serving agency, as it was more familiar to and accessible for FIPs. The board also increased outreach by FIPs to bolster the number of individuals attending community forums. Other partnerships might also consider hosting meetings at times and locations that are convenient and welcoming for patient or community-based populations, as well as employing members of the patient population to conduct outreach.

RAAM found success in using the CPPR technique of “getting on and off the bus,”²³ meaning that participants had the freedom to join and take breaks from the project, as needed. When a member was out of touch, an executive council member would contact the person to determine the reason for non-participation, troubleshoot difficulties, and to try to re-engage the participant. Other multi-stakeholder groups may consider developing similar processes to keep in touch with and re-activate members whose life or professional circumstances may temporarily preclude full participation. All projects found value in describing the purpose and value of PCOR at community-based meetings. This helped to dispel concerns about research generally and encourage various stakeholders to contribute ideas. Nonetheless, all three partnerships faced the challenge of keeping discussions focused on developing PCOR, as stakeholders often expressed an immediate need for services and resources to address more immediately pressing challenges. Re-iterating the CPPR principle of long-term partnership (ie, beyond the life of a single contract or grant) was helpful in reassuring participants that groups could pursue multiple funding opportunities to respond to non-research priorities. In addition, all three projects addressed concerns for immediate services by providing resources for agencies engaged in direct service provision. Groups new to developing PCOR may benefit from taking a similar approach.

Another important consideration for PCOR is ensuring that patient and family members’ desires are not

overshadowed by other stakeholders. Prisoner to Patient addressed this, in part, by including in its governance agreement a clause stating that deference would be given to FIPs in the case of disagreements. Another strategy for ensuring balance is to conduct iterative community engagement processes. All three projects alternated between larger community meetings with a variety of stakeholders in attendance and smaller advisory board/council meetings. These smaller meetings allowed advisory board members to evaluate whether ideas generated at community forums were truly representative of patient and family needs and, if so, how best to incorporate them.

Others seeking to implement PCOR should note that one critical commonality among these projects was trust, both among co-leaders and between the community and co-leaders. In the case of Prisoner to Patient, co-leaders developed trust in one another based on mutual interest in advocating for a highly underserved, heavily stigmatized population. The community-based co-lead was trusted by the population as a formerly incarcerated person himself, and he brokered relationships between FIPs and the academic co-lead. The heads of the NOLA Partnership had developed a solid relationship by providing health services together for over a decade, and the church at which the project was based has a strong reputation of community engagement. Similarly, leaders involved in RAMM had a long history of collaboration, and the community organization through which the project operated had been providing well-received

services for more than a decade.

The three P2P projects also linked with and found value in the national efforts of CPPRN to provide researcher and community mentorship in CPPR. Specifically, P2P leaders participated in the executive councils of the CPPRN and its associated projects. The opportunity to solicit from a national network perspectives and critiques on process and products of efforts proved to be vital in the early stage, nascent work of each of the projects. Ties to the CPPRN will continue to be helpful as the P2P projects embark upon CER proposal submissions. In addition, the shared experience with other P2P projects that use the CPPR framework also provided an opportunity for mutual input and an important sense of community. The boards have also begun exploring possibilities for collaboration on future proposals.

Finally, the experiences described in this article may have implications for funders that wish to engage researchers, patients, and other stakeholders in establishing or expanding PCOR portfolios. Specifically, funders may consider educating new grant or contract recipients about established frameworks for successfully establishing multi-stakeholder collaborations and executing partnered research. They may also build into their requirements mechanisms that promote use of CPPR principles. These could include, for example, explicit requirements for power sharing among researchers and community or patient co-leads or budgetary guidelines to ensure appropriate compensation for non-scientists. Funders may

also consider supporting mentorship programs that connect new research partnerships to established networks.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Wennerstrom, Springgate, F Jones, Meyers, Brown, Niyogi, Martin, Smith, Kirkland, L Jones, Norris; Acquisition of data: Wennerstrom, Henderson; Data analysis and interpretation: Wennerstrom, Henderson, Martin, Kirkland, L Jones, Norris; Manuscript draft: Wennerstrom, Springgate, F Jones, Meyers, Brown, Niyogi, Norris; Statistical expertise: Martin; Acquisition of funding: Wennerstrom, Springgate, Martin; Administrative: Wennerstrom, Springgate, F Jones, Meyers, Henderson, Brown, Niyogi, Smith, Kirkland, L Jones, Norris; Supervision: Wennerstrom, Kirkland, L Jones, Norris

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