# The Community and Patient Partnered Research Network (CPPRN): Application of Patient-Centered Outcomes Research to Promote Behavioral Health Equity

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**Objective:** We describe the rationale, development, and progress on the Community and Patient Partnered Research Network (CPPRN). The CPPRN builds on more than a decade of partnered work and is designed to promote health equity by developing partnered research on behavioral health and social risk factors in Los Angeles and New Orleans.

**Methods:** Review of rationale, history, structure, activities and progress in applying community partnered participatory research (CPPR) to CPPRN.

**Setting:** A community-academic partnership across Los Angeles County and New Orleans.

**Design:** Descriptive report.

**Findings:** Patient and community stakeholders participated in all phases of development, including local and national activities. Key developments include partnered planning efforts, progress on aggregating a large, de-identified dataset across county agencies, and development of an information technology-supported screening approach for behavioral and social determinants in health care, social, and community-based settings.

**Conclusion:** The CPPRN represents a promising approach for research data

## Introduction

The Institute of Medicine's 2001 landmark report, *Crossing the Quality Chasm*, outlined a strategic plan to make American health care more safe, effective, patient-centered, timely, efficient, and equitable. Although there have been documented improvements in US population health since then,[1] significant racial/ethnic disparities persist in behavioral health due to variations in access to, as well as the quality

networks, balancing the potential benefit of information technology and data analytic approaches while addressing potential risks and priorities of relevant stakeholders. *Ethn Dis.* 2018;28(Suppl 2):295-302; doi:10.18865/ed.28.S2.295.

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and outcomes of, care.[2-5] A growing literature demonstrates how marked differences in social determinants of health[6] adversely affect minority and under-resourced communities.[7-10] To improve population health and address health disparities, the National Academy of Sciences recommends integrating three domains: 1) individual health care services; 2) efforts to address social determinants of health; and 3) public health programs to address individual health behaviors and exposures.[11] Yet, limited patient-centered, comparative effectiveness data exist to guide systems in integrating social and clinical services for people with behavioral health conditions and social risk factors for such conditions in under-resourced communities.[12]

One emerging approach to accelerate progress in comparative effectiveness research is the use of large, integrated data systems. Yet, such systems rarely integrate data on health and social factors and typically lack the input of patients or community members in under-resourced communities. For example, the collection of sensitive health information across large groups of individuals and application of statistical and machine learning techniques to guide service decisions can raise significant issues for stakeholders, including sensitivity of data, privacy, and potential impact of analytic approaches.[13] In relation to social determinants of health, it is important to ensure that the benefit of the analytic approaches reach those contributing data, a potential challenge especially in under-resourced communities.[14]

To develop opportunities for data driven, analytic approaches to health improvement while bal-

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ancing patient-centered priorities, the Patient-Centered Outcomes Research Institute (PCORI) supported the formation of the Pa-

tient-Centered Outcomes Research Network (PCORnet).[15] PCORI is an independent, nongovernmental, nonprofit agency authorized by the Patient Protection and Affordable Care Act. PCORnet focuses on improving the effectiveness and efficiency of patient-centered outcomes research by supporting the creation of large datasets and networks of patients to serve as resources for patients, caregivers, researchers, and other stakeholders. PCORnet's emphasis on impactful, scalable research aligned with patient priorities has potential to enhance health equity if diverse and under-resourced communities are included equitably in generating research priorities and conducting rigorous research that informs stakeholders' health-related decisions. Data presently exist for more than 80 million individuals aggregated through 33 national and regional subnetworks.[16] PCORnet supports health-condition or community-specific issues through Patient-Powered Research Networks (PPRNs) focused on the priorities of patients, family members and caregivers.

The known associations between behavioral health and social determinants of health in under-resourced communities, the potential for advancing community-partnered analytic approaches, and the need to address privacy, ethics, and relevance to vulnerable communities led us to create the Community and Patient Partnered Research Network (CPPRN) through the PCORnet PPRN funding mechanism. CPPRN emerged from a 12-year history of applying community

partnered participatory research (CPPR) for program development, implementation, and rigorous research on behavioral health and its social determinants in Los Angeles County and New Orleans, the two Centers or leadership hubs of the network. CPPRN was designed to promote health equity through equitable partnerships with patients, community members, and service providers in under-resourced communities, while developing datasets and approaches to patient centered outcomes research emphasizing social determinants of behavioral health among diverse, under-resourced populations.

This article describes the formation and progress of the CPPRN. We review the network's focus on equity, partnership histories, theoretical underpinnings, goals, approaches, and examples of research initiatives.

## FORMING OF THE CPPRN

The CPPRN's guiding principles stem from CPPR,[17] a form of community-based participatory research that emphasizes capacity building, promotion of respect, and equal authority among partners through power-sharing and two-way knowledge exchange.[17-19] The model applies these principles through a leadership council that supports working groups and community engagement activities through three stages: Vision (developing goals), Valley (doing the main work), and Victory (products and dissemination).

This partnered model has been applied in multiple projects that have informed the CPPRN's approach. Starting with Witness for Wellness in Los Angeles,[20] a community council and multiple workgroups identified local priorities including addressing stigma around depression, enhancing the quality of health services, and supporting policy to increase behavioral health equity.[21-23] A subsequent study was Community Partners in Care (CPIC), a group-randomized trial of a coalition approach to implementing an expanded version of collaborative care for depression.[24] A Cochrane Collaborative Review identified CPIC as the only rigorous evidence for a coalition approach over an alternative to improve health of minority communities.[12] Partnerships expanded to the New Orleans area, adapting the CPPR model for depression to support recovery after Hurricane Katrina through the REACH NOLA Mental Health Infrastructure and Training (MHIT) Project.[25] Importantly, because of the two-way learning in CPPR between community partners and academics, "victories" were experienced as joint accomplishments. For example, when CPIC received the Association of Clinical and Translational Science's 2014 Team Science Award and the 2015 Campus-Community Partnerships for Health Annual Award, the recipients included community and academic investigators from CPIC and MHIT.[24]

Key lessons from the partnered work in both cities that shape the CPPRN include: 1) behavioral health, while often stigmatized especially in under-resourced communities, is a common interest to be approached in a manner that respects community assets and history; 2) underlying social determinants of health and risk events are highly salient to behavioral health interventions; and 3) data on program effectiveness in under-resourced communities is a valuable asset to intervention implementation and sustainability. For example, in Louisiana, lessons from MHIT and CPIC guided responses to subsequent disaster events, such as floods in Baton Rouge, Louisiana.

To inform priorities for the CPPRN proposal, investigators held four meetings in 2012-2014 with relevant community, academic and health system stakeholders to elicit stakeholder perceptions on priorities. Community stakeholders emphasized the importance of addressing depression and social factors to achieve improvements in client-centered services and improvements in health. For example, participants noted that addressing depression is "fundamental" to healthful functioning and goes "hand-in-hand" with factors such as poor housing, school drop-out, and violence. Stakeholders also prioritized the need to include adolescents in the project ("we need to invest in our young people") and underscored an ambition to "help communities bring resources together." They highlighted the interdependency of social factors such as housing and education in addressing health equity (it "may not make sense to take on one problem without others") as well as the importance of being "focused…(and) doing

something feasible." They identified that patient and client leadership is key to "solutions based on lived experience" and "being treated with respect." Health system leaders prioritized understanding models of intervention that influence entire neighborhoods and address social determinants as part of the mission of improving behavioral health services.

## CPPRN Overview

### Aims

The aims of CPPRN are: 1) to develop a sustainable infrastructure for community and patient partnered, participatory research, anchored by hubs in Los Angeles and New Orleans; 2) to develop a data-driven approach for comparative effectiveness research on patient, system, and community priorities in behavioral health and social risk factors, including aggregation of large, linked, de-identified, datasets on county services and a screening approach for behavioral health and social risk factors; 3) to explore uses of these data to inform patient, provider and policy decisions to advance health equity; and 4) to partner on initiatives that build on and utilize these datasets and infrastructure to advance knowledge and health equity.

### Structure

CPPRN's organizational structure integrates distinct but collaborating Centers of Excellence (ie, leadership hubs for partnered research) in New Orleans and Los Angeles. Each collaborates with lo-

cal community, patient, and health care system partners and convenes local stakeholder meetings to gather input on priorities for research and programs to promote health equity. Each Center's priorities are aligned with other PCORI, NIH, and foundation initiatives on behavioral health and social risk factors. The combined infrastructure consists of an Executive Council and a Data Infrastructure Working Group that meet weekly. In addition, focused working groups meet as needed for issues such as engagement of special populations and community research infrastructure for each site. CPPRN includes academic, patient and community stakeholders in each component to preserve equal power sharing and ensure that community and patient input is represented throughout the research process.

## Activities and Future Directions

### Infrastructure: Leadership Development and Activities

A core goal of CPPRN is to ensure that community stakeholders are equally involved and invested in all research phases including formulating questions, study design, as well as collecting, interpreting, and reporting data. This includes involving CPPRN community and patient stakeholders in PCORnet's national network governance and local leadership opportunities. At least one academic or community CPPRN investigator participates in each national PCORnet Council Meeting to represent concerns of CPPRN's

community and patient partners. CPPRN engages regularly with Los Angeles and New Orleans county-level and state-level, community, patient and policy stakeholders. For example, we meet with agency leaders, health care supervisors/administrators, consumer representatives, and coalition groups such as the Los Angeles County's Health Neighborhood Initiative councils and Resilient Baton Rouge. In addition, CPPRN partners present at stakeholder meetings and community events, such as the Martin Luther King Day Parade in South Los Angeles, and the NOLA Partnership for Mental Health's community-policy forums.

### Large, Linked, De-Identified Datasets

CPPRN leaders explored options for developing a linked services dataset that could facilitate research on behavioral health risk factors, safety net services access, and disparities in Los Angeles. Leveraging existing county-wide data integration initiatives, CPPRN negotiated a plan to aggregate a large, geocoded, de-identified dataset, linked at the individual client level, of all safety net services delivered over a 4-year period (2013-2016) by the Departments of Health Services, Mental Health, Public Health's Substance Abuse Prevention and Control, Public Social Services, and Children and Family Services and the LAC Sheriff's Department, Probation Department, and Los Angeles Homeless Services Authority. Linkage at the client level was done through a probabilistic matching algorithm, given no com-

mon unique identifier across datasets. The dataset to date includes more than 1 million Department of Health Services clients, 500,000 Department of Mental Health clients, and 133,000 Substance Abuse Prevention and Control clients. The total number of unique clients across the eight agencies is yet to be determined. The elements include: demographic (gender, race/ethnicity, year of birth) and location data for geocoding and, depending on the agency, includes Veteran, disability, and homelessness status; diagnoses, primary substance of abuse, and criminal offense codes; information on participation in specific programs; data on behavioral health, physical health, social, and criminal justice services utilization; and mortality data.

This dataset is intended for both research and quality improvement efforts through partnerships between CPPRN and local agencies, including to evaluate impact of innovative services and policy initiatives and to examine relationships between individual behavioral and general health indicators, social risk factors, neighborhood variations in risk, need, utilization, and services program coordination and outcomes. The data use will be guided by the UCLA Institutional Review Board, the LA County Data Use Agreement, and a CPPRN data sharing agreement that emphasizes applying the CPPR principles for partnered research and building community capacity while generating rigorous science. A limitation of this dataset is that it is restricted to publicly funded services.

## Screening

A workgroup of academic and community CPPRN partners convened weekly to develop a screening approach to identify community members with behavioral health conditions and/or with social risk factor(s) for behavioral health problems, who are therefore eligible to enroll in CPPRN and PCORnet research registries.

The workgroup defined individuals as eligible for CPPRN if they: 1) have mental health[26,27] or substance use symptoms[28,29]; 2) indicate that they had a social risk factor(s) such as housing or food insecurity, violence exposure, unemployment/underemployment, disaster exposure, or receipt of government financial assistance[30]; and/or 3) have accessed behavioral health care in their lifetime. In addition to screening for an individual having depression symptoms, alcohol and drug use, and psychological distress, recognizing the risk for emotional stress in caregivers, we also screen for caregiver involvement. Community partners emphasized strength-based measures so we included a brief wellness measure.[31] Items assessing health services utilization[24] and satisfaction[24] were included to describe services used and assess unmet needs.

We are currently recruiting individuals in under-resourced communities in Los Angeles and New Orleans at clinics, social service agencies, churches, and community centers. Our goal is to enroll 1,575 participants, one-third adolescents (aged 13-17 years) and two-thirds adults (≥18 years). Those who enroll into CPPRN will be invited to participate in future research projects and will have access to resources, information, and opportunities to give input on research priorities through CPPRN's website (http://www.cpprn.org) and social media groups. All procedures have been approved by the University of California Los Angeles, Tulane

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University, and Louisiana State University Institutional Review Boards and the Los Angeles County Department of Mental Health Human Subjects Research Committee.

## Affiliated Studies/Projects

CPPRN's infrastructure and ongoing PCORnet activities have led

to new partnered initiatives, including: 1) a PCORnet demonstration of comparative effectiveness of a group psychoeducation class on Cognitive Behavioral Therapy for depression (B-RICH) relative to time-limited case management for LGBTQ adults with depression in Los Angeles and New Orleans; 2) a partner site in a PCORnet demonstration for comparative effectiveness of an Internet-based mindfulness meditation intervention compared with usual care; 3) a Robert Wood Johnson Foundation/Baton Rouge Area Foundation-funded program using MHIT/CPIC models to provide mental health recovery using a community resilience framework in Baton Rouge following the 2016 floods; 4) three PCORI Pipeline to Proposal projects focused on developing patient centered comparative effectiveness research partnerships and funding proposals; 5) participation as co-leaders in a behavioral health interest group under PCORnet; and 6) a National Academies of Sciences-funded community partnered, controlled comparative effectiveness trial. Randomization will occur at two levels: 1) coalitions vs technical assistance at the community-level; and 2) use of a community-developed, resiliency-based mobile app vs resources at the individual level.

## DISCUSSION

Building on more than a decade of work across Los Angeles and New Orleans in applying CPPR to behavioral health issues, disasters,

and other social determinants of health and behavioral health, we formed the PCORnet-funded Community and Patient Partnered Research Network. The CPPRN represents a unique opportunity to combine large research data networks with partnered approaches to facilitate stakeholder-driven comparative effectiveness research aimed at reducing inequities in behavioral health and social risk factors. The long-term goal is to develop a sustainable infrastructure for such research. Progress to date includes partnered leadership development, creation of a large, de-identified dataset that integrates data across diverse Los Angeles County health, social service, and criminal justice agencies, as well as creation of a screening approach for social determinants and other behavioral health outcomes and risk factors. The CPPRN has also supported several new research initiatives on behavioral health and social determinant issues in vulnerable populations.

Our approach is relatively unique among PPRNs in the level of inclusion of participatory methods to building trust, transparency and equal power sharing among stakeholders and communities, while addressing underlying causes of inequities in behavioral health and social determinants. This is broadly consistent with efforts such as the accountable community model.[32] Consideration of health equity and social risk factors is particularly important with respect to large data analytic approaches in under-resourced com-

munities, given the need to build trust and ensure benefit for communities.[13,14] We hope that the CPPRN may serve as a model for addressing these concerns as information technology and large-scale data analytic approaches continue to expand. We attribute our progress to longstanding, cross-site community-academic partnerships that have employed CPPR. Such a model may be replicated elsewhere, but feasibility under less-established partnerships could be lower, require longer engagement periods, or necessitate more resources.

## CONCLUSION

This report describes the history, planning process, aims and initial experiences in creating the Community and Patient Partnered Research Network. The CPPRN may represent a promising approach for research data networks that balance the potential benefit of information technology and data analytic approaches while using community engagement to address priorities of stakeholders. Together, through achieving this balance, we may be better positioned to address health disparities.

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