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IMPROVING HEALTH CARE FOR THE FUTURE UNINSURED IN LOS ANGELES COUNTY: A COMMUNITY-PARTNERED DIALOGUE

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Objectives: To understand the health care access issues faced by Los Angeles (LA) County's uninsured and residually uninsured after implementation of the Affordable Care Act (ACA) and to identify potential solutions using a community-partnered dialogue.

Design: Qualitative study using a community-partnered participatory research framework.

Setting: Community forum breakout discussion.

Discussants: Representatives from LA County health care agencies, community health care provider organizations, local community advocacy and service organizations including uninsured individuals, and the county school district.

Main Outcome Measures: Key structural and overarching value themes identified through community-partnered pile sort, c-coefficients measuring overlap between themes.

Results: Five overarching value themes were identified – knowledge, trust, quality, partnership, and solutions. Lack of knowledge and misinformation were identified as barriers to successful enrollment of the eligible uninsured and providing health care to undocumented individuals. Discussants noted dissatisfaction with the quality of traditional sources of health care and a broken cycle of trust and disengagement. They also described inherent trust by the uninsured in “outsider” community-based providers not related to quality.

Conclusions: Improving health care for the residually uninsured after ACA implementation will require addressing dissatisfaction in

INTRODUCTION

In March 2010, the Patient Protection and Affordable Care Act (ACA) became law, increasing access to health insurance through the expansion of Medicaid and the establishment of statewide insurance exchanges. Although this legislation is providing coverage to millions of uninsured Americans, approximately 30 million individuals will remain uninsured.¹ The number of residually uninsured is particularly high

in California, where approximately 3.1 million Californians (8.15% of the state population) and 1.27 million residents of Los Angeles (LA) County (12.7% of the county population) have been predicted to remain uninsured despite health care reform efforts.^{2,3} Undocumented immigrants, who are ineligible for ACA coverage, and low-wage workers, who may have difficulty affording health insurance from the exchange, contribute to these high estimates.² Moreover, the ethnic, linguistic and

safety-net providers, disseminating knowledge and providing health care through trusted nontraditional sources, and using effective and trusted partnerships between community and health care agencies with mutual respect. Community-academic partnerships can be a trusted conduit to discuss issues related to the health care of vulnerable populations. *Ethn Dis.* 2015; 25(4):487-494; doi:10.18865/ed.25.4.487

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cultural diversity of urban counties in California such as LA County may be an obstacle to effective enrollment, in part due to mistrust of the health care system among racial minorities.⁴ Initial ACA enrollment period survey results show California's remaining nonelderly uninsured are 76% minorities and 30% undocumented.⁵

A survey of uninsured individuals in California demonstrated public confusion about the implementation of the ACA.⁶ Of those eligible for health insurance subsidies, three quarters did not believe they would receive financial assistance. Of those eligible for expanded Medicaid benefits, only half were aware of their eligibility. Ongoing efforts seek to educate the public regarding the opportunities for expanded access to health insurance, though outreach to vulnerable populations may be insufficient. Covered California, the California state health insurance exchange, awarded \$36.3 million in grants to support outreach and education during the first ACA enrollment period, with an emphasis on under-resourced communities, though the outcomes remain to be formally assessed.⁷

Academic researchers can help improve outreach and care for marginalized populations through community-partnered participatory research (CPPR).⁸ The CPPR approach has facilitated improvement for conditions such as depression, asthma, and obesity, and has proved successful in LA County.^{9,10} While the development of effective academic-community partnerships in CPPR takes a significant amount of time and trust, existing trusted partnerships can be used to achieve new goals.

In this study, we used existing trusted partnerships and a CPPR framework to bring together community members, health care providers, academic researchers, and policymakers in an open forum about the residually uninsured in LA County. The goals of our study were to understand community perspectives on health care access issues faced by the uninsured,

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and to use this understanding and the open dialogue between the community and policymakers to identify potential solutions to the problem of the residually uninsured after implementation of the Affordable Care Act.

METHODS

Context

The impetus for this project originated in the Robert Wood Johnson Foundation (RWJF) Clinical Scholars program at the University of California, Los Angeles (UCLA) along with other affiliated health services research programs at UCLA. Over the last decade, multiple RWJF Clinical Scholars at UCLA have built effective and trusted partnerships across LA County and have used CPPR framework principles to address health is-

sues in vulnerable populations.¹¹⁻¹³ Representatives from LA County health care agencies and from Healthy African American Families, an LA County community service agency, noted that the RWJF Clinical Scholars program at UCLA could serve as a "safe space" for discussions between county agencies and the community about sensitive topics, such as health care for the residually uninsured. Thus, the UCLA research fellows and representatives from these community partners collaboratively planned a community forum to address this issue, recruiting existing partners and key community representatives to participate. The community partners recruited community representatives, including uninsured individuals who did not hold leadership positions. Partners included LA County health care agencies, various community health care provider organizations, local community advocacy and service organizations, and the LA Unified School District. The team also collaboratively designed a qualitative study to accompany the forum discussion.

Data Collection

Data collection occurred in February 2013 at the community forum event with our partners. The event had three components. During the first component, a panel of community representatives, including the uninsured, described experiences with accessing and receiving services from safety net health care agencies, and identified the need for community input. During the second component, a panel of representatives from LA County health care provider agencies discussed the impending

implementation of the ACA, avenues being explored to expand access to care, and potential opportunities for partnership with the community.

The third component of the forum was a one-hour breakout discussion during which data collection occurred. Thirty-nine individuals from LA County community organizations, community health care provider organizations, the LA Unified School District, and county health care agencies participated. Community organization representatives included uninsured and undocumented individuals. Discussant characteristics are provided in Table 1. We did not collect additional demographic information from discussants in order to respect potentially vulnerable community members, such as those who were undocumented, and to preserve a “safe space” for open discussion. We divided discussants into seven tables, attempting to ensure representation of community organizations, county agencies, researchers, and provider organizations in each group. Each table had about six discussants, a research team member who served as a facilitator, and a trained scribe taking paraphrased notes. Discussants were asked to answer three open-ended questions in a conversational format about the uninsured in LA County, as collaboratively determined by the academic and community partners: 1) What needs to be done to address the residually uninsured in LA County?; 2) What partnerships are needed?; and 3) What next steps do you recommend?

Discussants were informed that de-identified notes would be taken for research purposes, and IRB exemption was obtained from the RAND Corpo-

Table 1. Characteristics of discussants in the breakout discussions

Discussant characteristics (N=39)	n	%
Community organizations	17	44
County agencies	9	23
Researchers	9	23
Health care providers	4	10

ration. The RAND Corporation had previously provided IRB review and exemption for the evaluation of community-partnered projects at UCLA.

Pile Sorting and Codebook Creation

To identify key themes from the discussion, we used a community-partnered pile sorting activity. We began by dividing notes from the discussion into individual quotations that represented single ideas. A team of three community members and six researchers then met and the quotes were randomly distributed across the meeting table. County health agency representatives did not participate in this activity due to scheduling. Team members read the quotes and independently sorted them into thematic piles. Once the piles were complete, each member described their piles to the larger group. These descriptions served as input into a larger group discussion about which themes were most important to examine.

The group collaboratively identified two types of themes: structural themes describing the logical structure of health care, and overarching value themes representing subjective themes expressed by the community forum discussants about health care. The broader structural theme, participants, included quotations about any person, group or organization connected to

health care. We subdivided this theme into patients and providers. The theme of patients was further subdivided into the two main groups of the residually uninsured, those who are documented and potentially eligible for enrollment in insurance through the Affordable Care Act’s provisions, and those who are undocumented and ineligible for these opportunities. The theme of providers was further subdivided into two subthemes. “Insider” providers represented systems or organizations that are traditionally associated with the provision of health care (eg, county health agencies and medical clinics). “Outsider” providers represented community-based groups, organizations, or providers not traditionally associated with health care but that serve the community (eg, barbershops, school systems, and advocacy groups).

The pile sort also identified subjective overarching value themes that categorized the statements made about the structural elements of the health care system – knowledge, trust, quality, and partnership. These themes were defined broadly in order to universalize the experience of community members within the health care system and to facilitate coding. They were defined to include statements in both the positive and negative for each theme (eg, trust and mistrust, knowledge and lack of knowledge). The members of the pile sorting activity also collaboratively

Table 2. Codebook derived from the pile sort activity

Structural Codes Codes that define the structure of the health care system		
Participants People, groups and organizations connected to the health care system	Patients People who access or want to access care	Documented uninsured
		Undocumented uninsured
	Providers	"Insider" Groups or organizations within the traditional health care system
		"Outsider" Groups or organizations not traditionally in the health care system
Processes Obtaining health care, including getting in the door and how and where to go		
Roles The roles, behaviors, and activities of the participants involved		
Overarching Values Codes Codes reflecting themes from the discussion around health care for the uninsured		
<ul style="list-style-type: none"> - Knowledge - Trust - Quality - Partnership - Solutions 		

included solutions as an overarching theme, in order to help identify means to address the problems faced by the uninsured. We compiled these themes into a general codebook, where each thematic code had a mnemonic, a short and long description, and typical and atypical examples, as seen in Table 2.

Coding and Analysis

In order to describe more completely the overarching value themes and to explore how these overlapped with the structural themes, we entered the forum discussion notes into Atlas.ti 7, a text management software package. Two researchers and a community member, all of whom participated in the pile sort, used the developed codebook to code all the quotations from the forum discussion notes. Since codes were not mutually exclusive, multiple structural and value codes could be applied to the same set of quotations. We used Atlas.ti’s c-coeffi-

cient to calculate how often different codes were applied to the same quotations. The c-coefficient is calculated as $c = n12 / (n1 + n2) - n12$, where n12 is co-occurrence frequency of two codes c1 and c2, and n1 and n2 are their individual occurrence frequency. The c-coefficient varies between 0 (these codes never co-occur) and 1 (these two codes co-occur wherever they are used), where higher values represent higher co-occurrence. We used the results from the calculated c-coefficients to identify structural and value codes with high or low amounts of overlap, and re-analyzed quotations relating to overlapping codes to better understand the reasons for co-occurrence.

RESULTS

Analysis of Themes

Below, we describe in more detail the overarching value themes

identified in the pile sort, including their overlap with structural themes.

Knowledge

The code of knowledge was defined as any participant having or not having information about the health care system or health care reform. The definition of this code also included quotations about providing or failing to provide knowledge about the health care system or about health care reform. Quotations about knowledge most frequently included statements about patients’ lack of knowledge about available resources, sources of care, and means to navigate the health care system. Quotations about documented patients noted the uninsured were often unaware of their eligibility for Medicaid or their existing coverage through California’s pre-ACA Medicaid expansion. Barriers to knowledge included lack of resources, language discordance, and

skepticism about providers wanting to divulge information about effective use of the health care system. Concerns about misinformation involved fears of losing insurance, Social Security, citizenship, housing, money, or work. A discussant reported that some uninsured fear their children will be required to serve in the military if they request Medicare. Trusted or effective sources of information included community partners, fliers, rallies and fairs, kiosks at public arenas, barbershops, beauty salons, bus ads and school newsletters. Educating children was seen as a potentially effective means of educating adults about health care coverage options. Ineffective sources included billboards, brochures, and “street talk.”

Trust

The code of trust was defined as trust, or mistrust, of any part of the system, including individuals or groups “outside” the system. Discussants described trusted sources as being comfortable, natural, and familiar. Quotations with overlapping codes for both trust and “outsider” providers were universally positive about outsider providers, including barbershops, beauty salons, and the school system in particular. Discussants attributed a lack of trust in “insider” provider organizations to racism, sexism, a history of abuse, and a lack of cultural sensitivity or social justice. Discussants identified a cycle of broken trust, where failures in the health care system lead to a lack of trust, leading to decreased engagement that perpetuates failures in the system. For the undocumented, discussants described safety and con-

fidentiality as critical elements of trust, especially regarding immigration status and fears of deportation. Means for the health care system to improve trust included improving communication of accurate information, using celebrities to disseminate information, providing resources to the community, and partnering with “outsider” community-based agencies that already engender trust.

Quality

The code of quality was defined as the quality of care provided by providers. It also included perceptions about high or poor quality care delivery. Quotations coded for both quality and “insider” providers were almost universally negative, centering on dissatisfaction with accessible sources of health care services including county-run facilities, federally qualified health centers (FQHCs), mental health centers, and other community clinic providers. Discussants’ descriptions of poor quality focused on employee attitudes, poor interpersonal treatment of patients, long wait times for services, and poor care coordination. These included descriptions of patients “falling through the cracks” or not getting clear instructions from county agencies or providers, and providers limiting access to health care because of patients not meeting financial or insurance qualifications. Other discussants stated that quality problems stemmed from insufficient funding and infrastructure problems, and not from providers. The few quotations coded for both “outsider” providers and quality did not include satisfaction or dissatisfaction with the services received.

Means to improve quality included reducing fragmentation, increasing community input, introducing a “corporate culture”, having surprise auditing visits to clinics by community members, and using technology, such as automated systems and social media, to improve care.

Partnership

The code of partnership was defined as existing partnerships, the need for partnership, desire for partnership, or lack of partnership. Partnerships were seen as a means to work together “with the systems that we have to make things better.” Partnerships focused on communication and coordination between community organizations and “insider” health care providers. Discussants also discussed the need for partnerships with the school system, mobile food services, managed care companies, private industry, legislators, and companies that pollute the community’s environment. Discussants identified fixed monthly meetings for community contact and collaboration on grants as means to incentivize partnership between county agencies and community organizations. Discussants also wanted to know what incentives or goals drove people to attend the forum. Several discussants also expressed concerns or skepticism about the limitations of partnerships between county agencies and community agencies. These discussants expressed concerns about whether the community was willing to work with county health care agencies, and concerns about the limitations in what community agencies can do. They were also concerned that county

agencies may ask community members and organizations to contribute more to partnerships while expressing their inability to contribute equally.

Solutions

The code of solutions was defined as solutions to the problems with health care access and health care reform, particularly for those who will remain uninsured despite reform efforts. Many solutions to improving knowledge, trust, and quality have been noted above. Additional solutions focused on means to provide health care for the uninsured, including health care access points in drug stores and other community locations, a community-run health system competing with the county system, immigration policy to facilitate health care access in Mexico, and dissemination of knowledge about access through FQHCs. Discussants identified additional means to educate community members about health care expansion, including holding resource fairs through either the school system or community agencies, training librarians to help people use the enrollment web site, and empowering adolescents through the school system to educate parents about health care insurance.

C-coefficient Analysis

A high degree of overlap between structural and value codes was seen between the codes of outsider providers and trust (c -coefficient=.39), undocumented patients and trust (c -coefficient=0.34), and insider providers and quality (c -coefficient=.32). Comparably, lower overlap in codes was seen between outsider providers and quality (c -coefficient=.06) and

insider providers and trust (c -coefficient=.21). High degrees of overlap were seen between both provider codes and the value codes of partnership and solutions, though there was greater overlap for outsider providers (c -coefficients=.32 and .48) than for insider providers (c -coefficients=.26 and .35). Analysis of the quotations with overlapping codes is included in the results presented above.

DISCUSSION

The community-partnered pile sort activity identified a set of five value themes, with two of the most salient themes being quality and trust. The c -coefficient analysis identified a close association between the themes of traditional “insider” providers and quality, and a similar association between community-based “outsider” providers and trust. Quotations associated with quality primarily focused on patient dissatisfaction with traditional sources of care. This dissatisfaction may cause the uninsured to be less willing to engage with these systems, which is compounded by the broken cycle of trust of “insider” providers. Thus, individuals eligible for health insurance through the ACA may not use or trust traditional sources of care as a route to enrollment, despite the fact that governments have placed significant investment in these systems to assist uninsured patients with the enrollment process. Furthermore, the eligible uninsured may be less likely to consider enrollment as beneficial if their only sources of care will be the same dissatisfying sources they have been accessing already.

Therefore, in order to facilitate health insurance enrollment associated with implementation of the ACA, issues of patient satisfaction with safety-net providers will need to be addressed, potentially through partnerships with community organizations and direct involvement of community representatives in quality improvement.

The theme of trust, however, was not directly related to satisfaction with services. Instead, it appears to represent more inherent values, such as comfort and familiarity. This may

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explain the closer association between the themes of trust and “outsider” community services, such as the school system, despite minimal discussion about the quality of these services. The inherent trust that eligible uninsured individuals have in these community settings can therefore be used to engage this population, to disseminate enrollment and health care access information, and to dispel misinformation about the ACA. This is particularly relevant to identifying solutions for the undocumented, for whom issues of trust with the traditional health care system were mainly related to issues of legality and fears

of deportation. Undocumented individuals may see outsider services as safer than traditional sources of care, which ask for details such as Social Security numbers. Since the ACA does not provide health care coverage or access for the undocumented, trusted sources will need to work on unique solutions to help identify safe sources of health care. Policymakers and partnerships seeking to provide services to this population can address the ideas noted by the discussants in this study, including establishing community-based health care access points, reforming immigration, and increasing use of FQHCs.

In both of these situations, partnerships between “insider” and “outsider” organizations may be critical in addressing health care access for the residually uninsured. Discussants felt that these partnerships will be vital to address dissatisfaction with safety net care, and to direct the uninsured toward either ACA enrollment or other avenues for health care. In particular, discussants felt that partnerships should explore using the school system and educating adolescents to serve as conduits of trusted information about health care coverage eligibility or care access options for the undocumented. By incorporating these partnerships directly into policy-making and quality improvement procedures, community partners may be able to help traditional health care providers identify and execute processes to improve patient satisfaction and decrease care fragmentation. These partnerships can also help coordinate the dissemination of trusted information about insurance enrollment or safety net

health care. This dialogue will need to occur through the CPPR principles of mutual respect of experience and expertise and a promise of developing coordinated plans that ensure the goals of all partners are achieved.¹⁴ Further research will be needed to determine if these ideas can be successful in addressing health care access issues for the residually uninsured.

Our findings also highlight the need for further evaluation of existing community-partnered efforts at enrollment of under-resourced communities. As noted, the California health insurance exchange has provided community organizations with grants to support outreach and education.⁷ The grantees include the Los Angeles Unified School District and community organizations whose grant proposals sought to use “outsider” providers identified in the forum. At the end of the first ACA enrollment period, 29.6% of the subsidized enrollees in the California insurance marketplace identified themselves as Latino, and 2.8% identified as African American.¹⁵ While this is similar to the estimated proportion of 28.3% Latino projected to be eligible for subsidized insurance, this is lower than the projected 6.7% African American.¹⁶ This points to the need to assess closely how issues of trust and quality may be differentially affecting enrollment of vulnerable populations, especially for California’s second ACA enrollment period.

Our study had several important limitations, primarily due to the adherence to CPPR principles and the need to protect vulnerable community members. While our goal in this study was to provide an academic

analysis of the content of the forum discussion, the primary goal of the forum was to foster discussion and partnerships, a goal we achieved through the methods used. We limited the collection of identifiable information, allowed discussions to be open-ended without strict adherence to the provided structure, and used paraphrased notes rather than transcribed audio recordings. While this ensured our forum was a “safe space” for open discussion, it limited our ability to pursue a more in-depth analysis, including analysis of variations by discussant type, and may decrease the external validity of our findings. Additionally, the use of paraphrased notes rather than verbatim transcriptions may have prevented us from identifying key statements that went unrecorded, and may have led to missed or incompletely identified themes. The community partners, and the uninsured community representatives they recruited for participation, may not have been fully representative of all possible views on these topics, and thus key themes may have been underrepresented or omitted. However, our recruitment methods allowed for a frank and direct discussion between policymakers and community members that may not have otherwise been able to occur. The lack of county health agency representatives in the pile sort and coding analysis may have prevented us from identifying themes relevant to those stakeholders.

Overcoming the challenges of the residually uninsured in places such as LA County will require input from multiple stakeholders and partnership between providers, policymakers and community members. However,

having an open dialogue about these issues can be difficult, given the vulnerability of the population involved, the political sensitivity of the issue, and the issues of trust identified in the forum. Discussants described the community's mistrust of the health care system, and expressed their skepticism about health care agencies' reliability as sources of information or as effective partners. This forum can serve as a model for fostering dialogue and partnership between stakeholders, especially vulnerable populations like the uninsured, by building on trusted academic-public partnerships and by using CPPR-based principles. The RWJF Clinical Scholars have served as trusted partners for community members and for provider and county agencies in prior partnered research work. This trust allowed for a forum where community members' voices could be heard by local policymakers opening the door for new partnerships and solutions. Indeed, this forum may have served as a first step toward improving the engagement and enrollment of diverse populations in LA County going forward.

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AUTHOR CONTRIBUTIONS

Research concept and design: Iyer, A. Jones, Talamantes, Barnert, Kanzaria, Detz, Daskivich, L Jones, Ryan, Mahajan. Acquisition of data: Iyer, Talamantes, Barnert, Kanzaria, Daskivich, Ryan. Data analysis and interpretation: Iyer, A. Jones, Talamantes, Barnert, Kanzaria, Detz, L Jones, Ryan, Mahajan. Manuscript draft: Iyer, Talamantes, Barnert, Kanzaria, Ryan. Statistical expertise: Iyer, Kanzaria, Ryan. Acquisition of funding: Iyer, Talamantes, Kanzaria, Ryan. Administrative: Iyer, A. Jones, Talamantes, Barnert, Kanzaria, Detz, L Jones, Ryan, Mahajan. Supervision: Iyer, Talamantes, Detz, L Jones, Ryan, Mahajan.

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