

Comparing Sampling Methods to Engage Residents of Underrepresented Communities to Identify Research Priorities

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SECTION B. ABSTRACT

Background: For patient-centered outcomes research to improve health care decision making and ultimately health status, patients and caregivers need to serve as research partners. Yet evidence-based community engagement methods are lacking, especially with hard-to-reach populations. This study evaluated sampling methods to recruit and engage residents of rural, Hispanic-majority communities to identify research priorities.

Objectives: (Aim 1) To compare purposive sampling (PS) and respondent-driven sampling (RDS) to recruit patients and caregivers to serve as research participants (RPs) who then brainstormed and prioritized ideas about services, programs, and research to improve outcomes for persons with chronic noncancer pain (CNCP); and (Aim 2) to publish a practical guide to start and sustain hard-to-reach community partnerships.

Methods: Two county-based community advisory boards (cCABs) in 2 similar rural, Hispanic-majority counties with poor health outcomes directed implementation of PS and RDS. We predicted that PS would yield greater recruitment and retention and more research ideas. However, low recruitment using PS led the cCAB in one county to add purposive sampling plus convenience sampling (P + C) using a local recruiter. In the other county, the cCAB preferred a different chain-referral method—snowball sampling (SS)—to RDS because it was less complex and demanding for participants. In each county, 3 groups of consenting RPs, both caregivers and people with CNCP, attended 3 structured meetings to generate and rate ideas for research (total 12 meetings). Thematic analysis was used to categorize ideas. In a mixed methods analysis, RPs recruited by P + C versus SS were compared on demographics; participation (number consenting, number attending); number of ideas; and Likert scale ratings of ideas on importance to improve living with chronic pain and feasibility to implement. For external validity, a representative sample of Hispanic adults from 5 southwestern states was surveyed online to evaluate the RPs' ideas.

Results: Using P + C, 62 RPs were recruited; 36 (58%) attended the first meeting and 26 (42%) attended all 3 meetings. XXXX RPs were recruited using SS; 52 (95%) attended the first meeting and 36 (65%) attended all 3. SS yielded more Hispanic RPs than P + C (87% versus 73%; $P = 0.049$) and more disabled recruits (47% versus 10%; $P < 0.001$). SS RPs generated 115 ideas

versus 101 ideas for P + C RPs. For 7 of 8 categories of ideas, ratings on importance and feasibility did not differ between SS and P + C RPs ($P > 0.05$). The 5-state online sample represented 10.5 million primarily urban Hispanics. Ratings on importance to improve living with chronic pain by this sample were all lower than the RPs' ratings ($P < 0.002$), but the order of relative ranking on the Likert scale and in a MaxDiff preference analysis was similar to that of the RPs. To fulfill Aim 2, the *UP AHEAD Research Handbook* was produced as a guide for investigators seeking to partner with hard-to-reach communities.

Conclusions: Snowball sampling yielded greater and more sustained study participation—especially by Hispanics—than P + C sampling, but the SS method recruited more disabled RPs. RPs from both groups had similar ideas and ratings. A largely urban 5-state online Hispanic sample rated the rural RPs' ideas lower but, again, the highest priority ideas were similar. The advisory boards from hard-to-reach communities served a vital role in directing engagement.

Limitations and subpopulations: The project's methods were adjusted to align with real-world circumstances. Lessons learned may be most relevant to rural, Hispanic-majority communities.

SECTION C: BACKGROUND

Development, evaluation, and sustainable implementation of evidence-based health care advances must utilize productive partnerships between community stakeholders and investigators. A seminal Institute of Medicine white paper cited several-year delays in adoption of effective advances into real-world medical practice, supporting the need for community–researcher collaborations to speed implementation.¹ The Centers for Disease Control and Prevention endorsed community–researcher partnerships to address “differences in health outcomes and their determinants . . . as defined by social, demographic, environmental, and geographic attributes.”² These partnerships must involve stakeholders from vulnerable, underserved communities to inform patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) to develop evidence about the value of health care options and to improve patient health care decision making.³ For the Patient-Centered Outcomes Research Institute (PCORI), stakeholder engagement achieves multiple objectives: (1) to show respect for patients and vulnerable populations; (2) to select research questions that matter most to stakeholders; (3) to enhance study design with outcome selection and methodologies that matter to community members; and (4) to increase community buy-in and dissemination.³

Our project responded to the PCORI Methodology Committee’s call to advance methods of engaging patients and caregivers in the continuum of PCOR,⁴ especially those who are “hard to reach because of socioeconomic, geographic, racial, or ethnic barriers or due to physical or cognitive impairments.”⁴ Here the term *hard-to-reach* encompasses a broad array of barriers and should not be construed as the fault of the community. Rather, it is a descriptor reflecting the fact that many communities have not benefited from research due to barriers such as distance from academic centers. These communities generally have a disproportionate burden of health care needs and shorter life expectancy.⁵ A systematic review for the Agency for Healthcare Research and Quality (AHRQ) synthesized valuable recommendations for stakeholder engagement to develop research priorities; however, AHRQ did not specifically address engaging hard-to-reach communities.⁶

An essential component of community-based participatory research (CBPR) is the community advisory board (CAB), a group with deep understanding of the community that serves as a “steering committee.”⁵ But the CAB’s role in collaborating on research projects is distinct from having CAB members serve as stakeholders who generate research priorities. The latter approach has been criticized because CABs are usually composed of “prominent stakeholders who are connected to or comfortable with research and academia, and thus may not accurately represent the perspectives of underrepresented groups who have been labeled hard-to-reach, including racial minorities and low-income or low-literacy populations.”⁵

This project responds to a gap in evidence regarding methods to engage community members from hard-to-reach communities by testing 2 sampling strategies for recruitment of research participants (RPs), who then participated in structured group meetings to generate priorities for future research on chronic pain. The study was conducted in 2 similar Health Resources and Services Administration–designated⁵ rural counties with majority Hispanic populations. This project drew on the long-term community relationships through the South Central Area Health Education Center (AHEC); however, there was no previous research project under way in these counties. In partnership with the AHEC’s connections, we were able to engage residents from these counties to serve on a county-based CAB (cCAB). These individuals were *not* RPs; rather, they served as the project’s steering committee and directed our implementation of the sampling methods to recruit RPs.

We tested 2 commonly used nonprobability sampling strategies (1 per county) to recruit RPs for CBPR and PCOR. Nonprobability sampling is defined as a frame of subjects who are identified by specific strategies that do not involve random selection, so not all eligible persons have an equal opportunity to participate. However, for the purposes of identifying broadly held community beliefs and ideas, nonprobability sampling has been shown to be effective and consumes fewer resources than probability sampling.⁶

In 1 county, we proposed to employ respondent-driven sampling (RDS), a chain-referral method often used in hard-to-reach populations.^{7,8} In RDS, eligible individuals, called seeds, are purposefully selected to initiate recruitment of a limited number of other eligible persons from their social networks.⁹ Seeds’ recruits then recruit others, and so on.

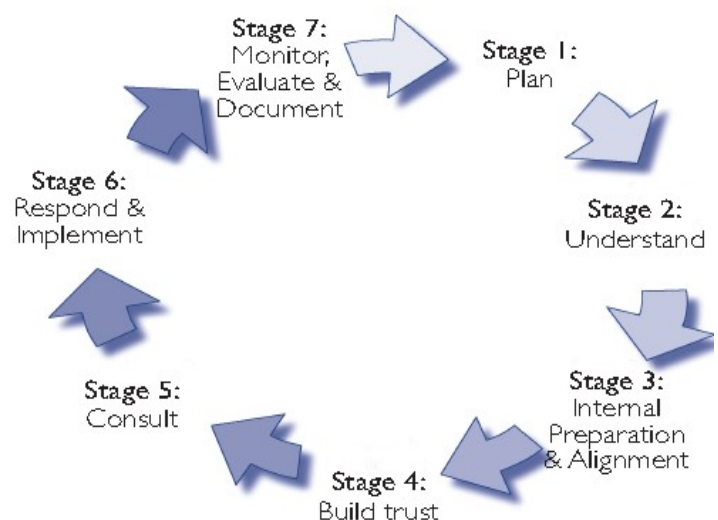
Throughout the process, data about recruits' characteristics are analyzed; recruitment stops when characteristics of the RPs resemble those of the target population. RDS is more rigorous than snowball sampling (SS), the other widely used chain-referral method (in fact, it is sometimes called semiprobability sampling), but it is also more demanding of community members.¹⁰ SS does not require the same systematic analyses of recruits as RDS, but it can be prone to bias.^{11,12,15}

In a second rural county, we proposed to use purposive sampling (PS) or judgmental sampling, which targets recruitment on the basis of an understanding of a community's constituencies and assets as related to the study goals^{12,13} Methods for PS depend on the objective: to achieve representativeness, to examine comparability, to evaluate unique cases, or to define or elaborate on certain features of a condition.¹² We sought representativeness using a heterogeneous sampling strategy¹² to select RPs across broad community constituencies with the guidance of a local cCAB. The advantages of well-conducted PS include preventing undersampling, targeting only suitable candidates, avoiding too many RPs from 1 social network, relatively low cost, and usefulness for hard-to-reach populations.¹³ Representativeness is another strength of PS: The sampling frame adequately characterizes the target population for the research and invited subjects agree to participate, which enables generalization of results to

other groups.¹³ When the PS sample is selected on the basis of very specific characteristics, it could restrict generalization to a limited, well-defined group, but it likely bolsters community engagement and partnership-building.

For this PCORI project, we originally hypothesized that by studying the community's diverse constituencies with the cCAB's direction PS could achieve a larger, more representative sample of patients and caregivers than RDS. Our rationale for

Figure 1. Road Map to Meaningful Engagement

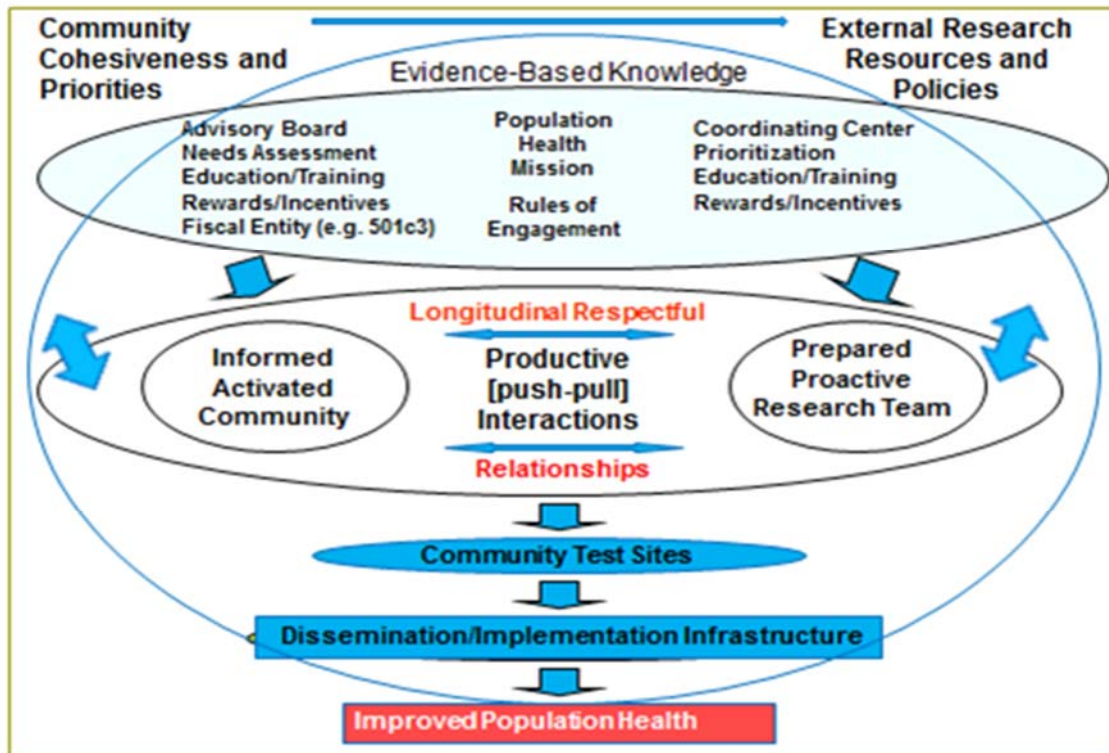


this hypothesis was that PS would offer a greater diversity of community constituencies that would be engaged to serve as RPs. We also predicted that PS recruits would produce more research ideas with higher ratings on importance (see Methods).

The study's conduct was informed by 2 CBPR frameworks. The first was the Road Map to Meaningful Engagement (Figure 1).¹⁴ Developed at the Doughty Centre, Cranfield School of Management of Cranfield University, United Kingdom, the Road Map includes 7 components: (1) *Plan* for engagement by developing a research team with appropriate skills to engage a specific community; (2) *learn* about a community from primary and secondary sources; (3) ensure *internal preparation/alignment* to recruit a CAB; (4) *build trust* with multiple planning meetings and responsiveness to the CAB's guidance; (5) *consult* by recruiting community stakeholders using a sampling approach under the guidance of the CAB and using structured group processes for meetings; (6) *respond and implement* by analyzing community ideas and meeting with local leaders to operationalize; and (7) *conduct a study of plans to monitor, evaluate and document* the process to inform future initiatives.

Because the Road Map does not define specific relationships and partnerships for sustainable, effective community engagement, our second CBPR framework was a model developed by James Mold, a national leader in this field (Figure 2).¹⁵ As in the Road Map, an initial step involves learning about the community from diverse sources such as the internet, key informant interviews, a windshield survey (i.e., a process in which the research team drives or walks through a community, making notes about its features, resources, and assets),¹⁶ and local news sources. The Mold model emphasizes the key role of a CAB to guide research, compensation (not just for researchers), and rules of engagement.

Figure 2. Mold Model for Community Engagement



It also focuses on coordination, sharing knowledge, and developing priorities, which leads to an informed, activated community and a proactive, well-prepared research team.

To structure the project’s implementation and evaluation, we followed the RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) framework²⁷⁻³¹ Although RE-AIM is typically used to evaluate interventions, we adapted it to assess components of our engagement process. In our study, we operationalized *Reach* as the N (%) for each of the following: eligible RPs recruited, consenting, attending 1 meeting, attending all 3 meetings. *Adoption* was reflected by qualitative study of potential RPs who refused to participate and those who dropped out. We assessed *Implementation* by our responsiveness to the cCABs’ guidance based on qualitative data on study processes and procedures. *Effectiveness* typically represents the clinical impact of an intervention, but for our study we examined the productivity and quality (based on Likert scale ratings on importance and feasibility) of ideas generated by RPs in the 2 rural communities. In this study, we assessed *Maintenance* by the uptake and sustainment of RPs’ ideas from each community. A final innovative aspect of our evaluation plan was to conduct a 5-state survey of Hispanic members of the largest online

sample of adults in the United States to evaluate the external validity and potential generalizability of ideas generated by RPs from the 2 rural counties. This activity also provided insights into the potential value of using an existing online sample to evaluate community-identified research priorities.

We conducted the study in minority communities that typically feature barriers to research participation that include mistrust, competing demands, unintended outcomes, poor access to information, stigma of some topics, unawareness of health needs, and undocumented status in the United States.²² These concerns are relevant to the communities selected for this project: Frio and Karnes, Texas, which are 60 miles from San Antonio and equidistant from each other. These rural, Hispanic-majority communities have poor health outcomes (lowest quartile in Texas in the Robert Wood Johnson County Health Rankings).²³ They are far from academic centers and generally excluded from research collaborations.

For this project, the exemplar topic for our engagement activities was improving the lives of persons with chronic noncancer pain (CNCP), a topic with high public health significance due to the dire need to reduce non-evidence-based use of long-term opioid analgesics and increase adoption of nonpharmacologic approaches as endorsed by national agencies.^{24,25} This topic was initially identified by the local urban CAB for our research center and then assessed for interest by leaders of the target communities. All concurred that few accessible, affordable, evidence-based nondrug approaches exist to help persons with chronic low back pain and other forms of chronic pain.²⁶ Low-income communities such as those in this study have a higher prevalence of chronic pain,^{27,28} heightening interest this topic. Yet Hispanics and other underserved groups see chronic pain as stigmatizing,²⁹ which makes it more challenging to engage RPs. (Note: Persons with CNCP and their caregivers were RPs for this study, but these persons are often referred to as stakeholders and may guide the development of research priorities.⁸ The findings from this study may be relevant to engaging stakeholders to serve as RPs to generate research priorities for other stigmatizing conditions, such as hepatitis C³⁰ and postpartum depression.³¹)

SECTION D. PARTICIPATION OF PATIENTS AND OTHER STAKEHOLDERS IN THE DESIGN AND CONDUCT OF RESEARCH AND DISSEMINATION OF FINDINGS

D1: Types and number of stakeholders involved

Our project's developmental phase was conducted in partnership with an existing 15-member CAB, the Alliance, from urban Bexar County, Texas. The Alliance identified the topic of CNCP and guided development of materials to recruit and engage a lead partner and cCABs from 2 rural Texas communities. From the communities, we partnered with 3 categories of residents:

1. A **lead community partner** who recruited the cCAB and served as our main collaborator. In both counties, this individual worked for the Texas A&M AgriLife Extension³² service, a national, county-based network founded in 1871 to improve agricultural practices and to advance health and well-being. The 2 AgriLife partners (1 Hispanic, 1 non-Hispanic) used their extensive social networks to recruit the cCABs with a focus on diversity.
2. Two **country-based community advisory boards** composed of residents with an interest in chronic pain—personally, as a caregiver, or as a person who provides social support (e.g., a minister). In accordance with the Mold model, the cCAB guided implementation, evaluation, and dissemination for the project.
3. **Research participants:** In this project, community residents served as RPs, but for PCOR and other research they should be considered *stakeholders* who identified research priorities.⁴² As research subjects, their recruitment and engagement are described in the Methods section.

D2: How the balance of stakeholder perspectives was conceived and achieved

For this project, we followed core precepts of patient-engaged research defined by Guise et al. to establish trust, credibility, and equitable participation (Table 1) in our interactions with the lead community partners and the cCABs.⁸ We conducted monthly in-person and virtual meetings, initially focusing on shared learning and icebreaking activities. As in Road Map stages 1 to 3 and the Mold model, the research team featured a community

engagement expert and a Hispanic research team member with expertise in this process. The team learned about the community from primary and secondary data sources and reviewed

Table 1. Core Precepts of Patient-engaged Research⁸

✓	Early engagement of stakeholders
✓	Long-term partnerships, and building credibility
✓	High-quality dissemination during and after project period
✓	Multiple methods of engagement
✓	Time considerations for inclusion of all relevant stakeholders
✓	Documentation of all stakeholder input
✓	Skilled, neutral facilitators for group discussions
✓	Strategies for equitable group participation
✓	Complex research topics prioritized and distilled to focus stakeholder discussion
✓	Icebreaker activities to build rapport and familiarity
✓	Brief, understandable introduction for stakeholders to engagement process
✓	Continuous question-and-answer opportunities to provide clarification

these data with the cCABs, stimulating them to revise, correct, and contextualize the findings. The lead partner served as a facilitator to ensure that cCAB members participated meaningfully. We codeveloped rules of engagement, including time commitment, remuneration, and shared products. With both cCABs, we created and reviewed 2 videos of Hispanic patients and primary care providers dealing with CNCP. The videos encouraged cCAB members to openly discuss their experiences with chronic pain. Subsequent cCAB meetings summarized activities since the last meeting and undertook decision making about new issues. Plans were reviewed at the end of the meeting to ensure accuracy. One-hour meetings occurred during meals at convenient times for the cCABs.

D3: Methods used to identify and recruit stakeholder partners

The Alliance reviewed and revised plans to engage lead partners and cCABs, such as reframing the research question about CNCP and editing video testimonials about chronic pain. After this initial phase, our lead partners and cCABs guided all aspects of the project.

Table 2. Characteristics of County-based Community Advisory Board Members by County and Sampling Method

Characteristic	Total N (%)	Frio County Snowball Sampling N (%)	Karnes County Purposive + Convenience Sampling N (%)
Members	14 (100)	7 (50)	7 (50)
Age , mean [SD] (years)	49.8 [12.6]	53.4 [4.3]	46.1 [17.2]
Gender			
Female	9 (64)	4 (57)	5 (71)
Male	5 (36)	3 (43)	2 (29)
Race/ethnicity			
Hispanic	6 (43)	4 (57)	2 (29)
Non-Hispanic white	8 (57)	3 (43)	5 (71)
Education			
High school degree	3 (21)	2 (29)	1 (14)
Some college	2 (14)	0 (0)	2 (29)
College degree	5 (36)	1 (14)	4 (57)
Graduate degree	4 (29)	4 (57)	0 (0)
Employment status			
Employed	13 (93)	6 (86)	7 (100)
Unemployed (retired)	1 (7)	1 (14)	0 (0)
Occupation			
Administrative	1 (8)	1 (16.7)	0 (0)
Agriculture	2 (15)	1 (16.7)	1 (14.3)
Education	1 (8)	0 (0)	1 (14.3)
Government	2 (15)	1 (16.7)	1 (14.3)
Health care	5 (38)	2 (33.3)	3 (42.9)
Law enforcement	1 (8)	0 (0)	1 (14.3)
Clergy	1 (8)	1 (16.67)	0 (0)

We recruited lead partners through our collaboration with the South-Central Area Health Education Center, which is funded by the Health Resources and Services Administration

to promote health care workforce development and training. Following the Mold model, we aimed to partner with a respected, nonpolarizing community-oriented organization with an aligned mission to advance community health. AgriLife Extension office directors in each county met these criteria well. From their social networks, the lead AgriLife partners then recruited cCAB members from various community constituencies who were interested in or affected by CNCP. Initially, 18 cCAB members were recruited and attended an orientation (8 in Frio and 10 in Karnes); 7 cCAB members continued to serve in both communities (Table 2). Despite targeted efforts through the lead partners' outreach to include men and Hispanics, women comprised more than half the members in both cCABs, and the Karnes cCAB was not majority Hispanic. The educational level was generally high (college or graduate school) and most were employed in varied types of jobs.

D4: Methods, modes, and intensity of engagement

For monthly cCAB meetings, the research team traveled more than an hour each way. Frequency and timing of meetings were preplanned to avoid conflicts, such as the month-long San Antonio rodeo. Collaboration was sustained by phone/conference calls and emails to cCAB members to obtain regular guidance for the project; rarely, these were held on an emergency basis to address a challenge, such as poor recruitment. A PowerPoint presentation was created to review current activities and engagement methods concerning cultural competency, literacy level, and correct Spanish translation.

D5: Perceived or measured impact of engagement on

D5.a: Relevance of the research question

The cCABs guided implementation of the nonprobability sampling methods to recruit RPs to attend structured meetings aiming to generate research priorities for CNCP. The cCABs enthusiastically endorsed this research topic.

D5.b: Study design, processes, and outcomes

The cCABs directed the sampling methods, RP meeting conduct, and dissemination of results. We followed the Road Map (Figure 1) by *planning* recruitment materials and methods; *understanding* modifications to increase cultural competency and literacy appropriateness, and reduce stigma; *preparing internally* to identify seeds for SS (in Frio) and the PS frame (in

Karnes); *building trust* by responding to cCAB guidance and sharing resources; *consulting* with recruited RPs and reviewing results with the cCABs; *responding* to RPs' ideas in meetings led by a cCAB member with the broader community to develop a plan to operationalize; and *monitoring, evaluating, and documenting* subsequent initiatives reflecting the RPs' ideas.

D5.c: Study rigor and quality

Our study was informed by the Road Map, Mold model, and PCORI's principles for successful partnerships to (1) establish equitable allocation of control and resources, (2) remove power differentials and value community stakeholders as much as researchers, (3) promote a colearning environment, (4) establish a trusting relationship, and (5) be honest and transparent with each other³³These principles are critical in working with underserved racial-ethnic minority communities that are new to these types of partnerships. The cCABs were equal partners, offering invaluable expertise and connections in their communities. The cCAB and research team members learned from each other while addressing challenges and celebrating successes. The research team nurtured a trusting relationship by following the cCABs' direction and developing initiatives and projects that were responsive to prioritized needs. To ensure transparency and honesty in financial arrangements, we provided mutually agreed-on compensation to partners. We could not pay government employees (AgriLife Extension leaders), but we covered their costs for supplies (e.g., trophies and food). Reflecting the strength of our academic–cCAB partnership, collaboration has continued on projects and a practical handbook for Aim 2 (Results).

D5.d: Transparency of the research process

We maintained open, frequent communication with community partners to foster a trusting collaboration. cCABs reviewed methods and materials and, after the project, shared results with RPs, community leaders, and other interested community residents. We also emphasized shared decision making on how to expand research monies.

D5.e: Adoption of research findings into practice

In collaboration with the cCABs and other community leaders, we initiated research projects and other initiatives after the engagement process to address RPs' priorities through ongoing meetings to develop multimodality, evidence-based treatment of chronic pain and to

support caregivers in these resource-limited settings. Subsequently, the Frio cCAB has merged with an existing translational advisory board (TAB) in the University of Texas Clinical and Translational Science Award (CTSA) program to continue this work. Dissemination activities included an all-CAB symposium, community-based presentations, bimonthly newsletters, health fair demonstrations (yoga and massage), and webinars with clinicians to discuss pain. Our partners at the AgriLife Extension office have hosted initiatives such as Walk Across Texas and encouraged residents with pain to join others in tracking steps and attending Zumba or cooking classes. We received CTSA small-grant funding to offer a community program that reflects our Living Better Beyond Pain program (Section G2) to support self-management of pain.

The Karnes CAB has recently formed a TAB, supported by the CTSA program, to maintain momentum for project development. One project incorporates the Substance Abuse and Mental Health Services Administration's model for Screening, Brief Intervention, and Referral to Treatment intervention for residents who are dependent on opioids. The TAB also initiated a counseling project for caregivers of persons with chronic pain through psychiatry telecommunication services from University of Texas Health San Antonio. Additional webinars and teleconferences are currently offered in partnership with University of Texas Health School of Nursing.

SECTION E: METHODS

E1: Research design

This project's primary aim was to compare and contrast results from 2 commonly used nonprobability sampling methods to recruit research participants to brainstorm and prioritize ideas about services, programs, and research to improve outcomes for persons with CNCP. We conducted the study in 2 rural, majority-Hispanic South Texas counties. In this exploratory methods project, we hypothesized that PS would result in greater RP engagement and retention than RDS and would produce more highly rated ideas. Based on the 2 engagement frameworks, our lead community partners and cCABs directed the implementation of both sampling methods, evaluated them, and disseminated the results. We structured mixed

methods analyses by RE-AIM to evaluate RP recruitment and retention and to examine the results of group meetings. Without a gold standard to compare outcomes of these 2 sampling methods, we examined the external validity of the RPs' ideas in an online survey of a representative sample of Hispanics from 5 southwestern states, including persons with chronic pain, caregivers, and persons without chronic pain. Figure 3 shows the sequence of activities for each aim as well as initiatives external to the scope of this project but stemming from its findings.

E1a: Research participants

Eligible RPs in the 2 rural counties were aged 35-75 and responded to 3 questions consistent with the diagnosis of chronic pain³⁴:

1. Do you have chronic pain or care for someone with pain? (yes)
2. Does this pain affect daily activities or sleep on most days? (yes)
3. How long have you (person who you care for) had pain? (3+ months)

To be inclusive, the cCABs recommended that RP eligibility should include persons with all types of musculoskeletal chronic noncancer pain, not just those with chronic lower back pain. Exclusions included cancer-related pain (due to unique care needs), planned operation (due to lack of availability), and health care providers (their priorities for addressing chronic pain differ from those of patients).³⁵ People who were not actively receiving care for CNCP were also eligible, as their needs are important to consider for research priorities.

E1b: Sampling methods

Engagement of cCABs was guided by the Alliance, an urban CAB of community partners (Road Map stages 3-4) and the AHEC. In conducting the RP sampling and engagement (Road Map stages 5-7) the research team relied on cCAB leadership for direction, including in the recruitment methods and implementation of the engagement methods. We proposed to recruit 130 consenting RPs, consistent with the 40 to 100+ persons recommended by a review of structured group meetings for stakeholder engagement.³⁶ Both cCABs reviewed our proposed sampling strategies for recruiting 65 consenting RPs per county. The Frio cCAB reviewed 2 chain-referral methods—respondent-driven sampling and snowball sampling; members

preferred SS to RDS (as proposed) to reduce data collection demands and restrictions on the number of persons each RP could recruit. The Frio cCAB initiated SS by identifying initial RP recruits (*seeds*) who met the eligibility criteria and introducing them to the project. A bilingual research coordinator then contacted the potential recruits to describe the project and obtain initial consent. Consenting seeds were asked to recruit other eligible persons from their social networks; this process was repeated over 4 months. RPs were paid \$5 for each person they recruited, with a maximum of \$10 for 2 people. To reduce bias, we did not reward the recruitment of many persons from 1 individual's social network.

The Karnes cCAB directed the purposive sampling frame after reviewing data collected by the research team about county demographics, businesses, and organizations. The cCAB introduced the project to 15 key community constituencies with whom they had a personal contact. For groups without a contact (e.g., large companies), the research team sent a letter cosigned by the lead partner, followed by up to 5 attempts to engage a company representative. However, large employers generally refused to participate, citing company policy. Slow recruitment with PS prompted the cCAB to recommend adding P + C by a local businesswoman, the owner of a Sno-Cone stand, who interacted daily with many different community residents. This woman was hired part time and trained to screen and recruit eligible community members with CNCP to serve as RPs.

E1c: Research participant (community stakeholder) meetings

We originally proposed to ask RPs to generate ideas in response to a question about potential research initiatives: *“What programs can health care providers develop and test to improve coping strategies and promote useful activities to improve outcomes of patients with chronic pain?”* The cCABs revised this to *“What types of services and programs can the community develop to improve the lives and daily activities of people with chronic pain?”* This version emphasized the community's role in leading initiatives to address priorities and revised vague wording to be more understandable (e.g., changing “improve outcomes” to “improve the lives”).

Table 3. PCORI Research Participant Meeting Schedule

Karnes County		
Group #1	Group #2	Group #3
Orientation: April 21, 2014 5:30-7:00 PM	Orientation: June 2, 2014 5:30-7:00 PM	Orientation: June 23, 2014 5:30-7:00 PM
Brainstorming: May 27, 2014 5:30-7:00 PM	Brainstorming: June 16, 2014 5:30-7:00 PM	Brainstorming: July 14 5:30-7:00 PM
Rating & Sorting: June 18, 2014 12:00-1:30 PM	Rating & Sorting: July 9, 2014 5:30-7:00 PM	Rating & Sorting: August 11, 2014 12:00-1:30 PM
Follow-up: Evaluation Meeting: August 20, 2014 5:30-7:00 PM		
Community Report: December 9, 2014 6:00-7:00 PM		
Frio County		
Group #1	Group #2	Group #3
Orientation: April 22, 2014 5:30-7:00 PM	Orientation: June 3, 2014 5:30-7:00 PM	Orientation: June 24, 2014 5:30-7:00 PM
Brainstorming: May 13, 2014 5:30-7:00 PM	Brainstorming: June 17, 2014 5:30-7:00 PM	Brainstorming: July 22, 2014 5:30-7:00 PM
Rating & Sorting: June 19, 2014 5:30-7:00 PM	Rating & Sorting: July 10, 2014 12:00-1:30 PM	Rating & Sorting: August 12, 2014 12:00-1:30 PM
Follow-up: Evaluation Meeting: August 20, 2014 5:30-7:00 PM		
Community Report: December 11, 2014 6:30-7:30 PM		

Table 4. Research Participant Engagement Meeting Agenda

Content and Activities

Meeting 1. Orientation

- Introduced project team and participants to each other
- Overview of project aims, rules of engagement, schedule, and participant roles
- Presented an orientation slideshow on the chronic pain problem in the community
- Asked participants for reactions to presentation
- Presented a video of a Hispanic patient and physician discussing their experiences with pain
- Participants shared personal experiences with pain and challenges with obtaining support
- Introduced research question to participants (needed services and programs to improve living with chronic pain)
- Asked participants to consider answers to question for next meeting
- Collected presurvey and postsurvey data on chronic pain knowledge

Meeting 2. Brainstorming (Bilingual Professional Facilitator)

- Reviewed first meeting with participants
- Each participant asked to write ideas in response to the research question
- Ideas posted on white board in round robin manner and discussed by the group
- Facilitated group process to start to review ideas and remove duplicates
- Areas of disagreement reviewed
- Charge for the next meeting: consider ideas and priorities

Meeting 3. Rating & Sorting

- Review of brainstorming process about the research question
- Participants given index cards with ideas from brainstorming and asked to place similar ideas into categories and name each category
- Asked participants to rate all ideas on both importance and feasibility (5-point Likert scales)

Follow up: Evaluation (optional)

- Presented data and preliminary findings
- Asked stakeholders for opinions and comments about initial findings and feasible services
- Discussed 6 questions about expectations, interests, concerns, and suggestions for meetings

In each county, we conducted 3 recruitment waves to (1) accommodate RP schedules, (2) ensure a more manageable group size, and (3) offer more time to achieve recruitment goals (4 months). Each wave of RPs was asked to attend a series of 3 meetings (6 in each county; Table

3) to orient to CNCP and project activities, brainstorm ideas in response to the research question, and rate/sort ideas. We followed the nominal group technique (NGT) to generate, combine, and prioritize ideas because it can yield many ideas within a short timeframe and allows all individuals to be heard rather than just the most outspoken.^{37,38} Two bilingual meeting facilitators who were highly experienced with NGT directed each session (Table 4). All RP meetings started with a review of rules for courteous discussion. We offered simultaneous Spanish translation and individualized assistance for persons with limited reading skills.

The cCABs reviewed all recruitment and orientation materials for comprehension (sixth grade reading level in both Spanish and English) and inappropriate medical terminology. For the orientation, the cCAB helped our team summarize the epidemiology and management of CNCP while avoiding excessive details that could bias participant opinions (Appendix 1). We showed video testimonials of Hispanic patients living with CNCP, which stimulated reflections about unmet needs. The brainstorming meeting started with RPs generating ideas separately and then reviewing their collective ideas on a whiteboard (listed round robin). For the final subsequent rating/sorting meeting, individual ideas were recorded on a card so that each RP could categorize them into groups individually and collectively. The RPs then rated each category on a 5-point Likert scale of importance for improving life with CNCP and on feasibility of implementation. RPs received \$50 for each meeting they attended.

E2: Data sources and data sets

We studied primary and secondary data to learn about the 2 counties (Background, Road Map stage 2). We collected descriptive data about cCAB members and qualitative interviews conducted with lead partners after the project's completion to derive insights for future application and for the handbook developed for Aim 2 (Results). We collected qualitative and quantitative data about RPs at all levels of engagement (Table 5). The first RP meeting yielded quantitative data from pre–post responses to questions about knowledge, attitudes, and intentions (Table 6). From the second meeting, brainstorming ideas to address chronic pain produced qualitative data. From the third meeting, qualitative data included the categories of ideas and quantitative data from the importance and feasibility ratings. To gain insight into the

reasons people did or did not participate, we conducted phone interviews of a convenience sample of persons from each of 3 groups: consented, refused, and dropped out.

Table 5. RE-AIM Measures and External Validation of Research Participants' Ideas

Framework	Measure	Source
Reach	<ul style="list-style-type: none"> • Descriptive data about two communities • Participants: N (%) eligible, N (%) consent, N (%) attend first meeting, N(%) attend 3 meetings; demographic characteristics (esp Hispanic) 	Primary and secondary data about communities, contact records and primary data from participants
Effectiveness	<ul style="list-style-type: none"> • N of ideas generated • Importance ratings for each idea* • Feasibility ratings for each idea* • Categories of ratings and average of mean ratings of ideas within each category 	Lists from participants' brainstorming activities Ratings by each participant of each idea Concept mapping data Thematic analysis to categorize ideas
Adoption	<ul style="list-style-type: none"> • Research participants' reasons for participating or refusal • Lead partners ideas about methods and outcomes 	Interviews of research participants (consenting and refusers) Interviews of lead partners from each county
Implementation	<ul style="list-style-type: none"> • County Community Advisory Board (cCAB) members' demographics • Qualitative data about modifications based on cCAB guidance • Change in research participants' knowledge, attitudes, and intentions after first meeting • Description of activities, resources/time involved, community outreach logs 	Primary data from cCAB members, Records of cCAB recommendations, Pre-post survey after first meeting Logs of activities
Maintenance	<ul style="list-style-type: none"> • Meeting with community leaders • New initiatives in communities based on participants' ideas • dissemination to researchers and community-research partners 	Record of meetings with cCABs leaders Data from research team and cCABs about ongoing initiatives Publication of results of project, publication of handbook

*Ratings on five point Likert Scale (1=not at all important, 2=somewhat important, 3=important, 4=very important, 5=extremely important)

† Ratings on four point Likert Scale (1=not important, 2=somewhat important, 3=important, 4=extremely important)

Table 6. Responses to Knowledge, Attitudes, and Intentions Survey, Before and After

Question ⁺	N = 74 [*]		P Value [‡]
	Before N (%)	After N (%)	
My community has few services and programs for people with chronic pain.	63 (85)	66 (89)	0.46
Pain is the most serious public health problems in the US.	68 (92)	72 (97)	0.15
Most people with chronic pain need only medications to make their pain better.	32 (43)	28 (38)	0.50
People with chronic pain have to stretch and exercise every day.	54 (73)	61 (82)	0.17
People with chronic pain and who are heavy should lose weight to help their pain.	60 (81)	63 (85)	0.51
People with chronic pain need counseling to help them deal with pain.	60 (81)	68 (92)	0.054
Most people with chronic pain get depressed.	65 (88)	68 (92)	0.41
Stronger pain medication can cure pain.	37 (50)	23 (31)	0.019
The videos helped me learn about how patients and doctors are dealing with chronic pain.	-	64 (86)	-
The presentation helped me understand more about chronic pain and its care.	-	67 (91)	-
I already knew most of the information that was presented.	-	56 (76)	-
I trust the information that was presented.	-	69 (93)	-
I need more information from studies about how to help people with chronic pain.	-	72 (97)	-
I plan on coming to the ideas meeting.	-	71 (96)	-

^{*} Data missing for 14 participants

⁺ Respondents agreed with all listed statements

[‡] General McNemar Test

External validation

We used an online survey of a 5-state representative sample to provide an external validation of ideas generated by rural RPs. Because ideas from RPs who are residents of 2 rural, Hispanic-majority counties may not be broadly generalizable, we elected to conduct a survey of a population-based sample of Hispanics with chronic pain to determine the generalizability and

usefulness of these ideas within a broader Hispanic sampling frame. This type of external validation exercise is consistent with Road Map stage 7. For this aspect of the project, we collaborated with marketing research firm GfK Custom Research to survey their KnowledgePanel®—a probability-based online panel representative of community-based adults in the United States. Panel members are recruited using random digit dialing and address-based sampling from the US Postal Service’s Delivery Sequence File.³⁹To promote participation of low-income and minority US residents, GfK provides computer hardware and internet service to households without access and oversamples Census Block Groups with high-density minority communities. The sample continues to recruit new members to maintain about 55 000 active panel members for survey participation.

GfK generates general population samples using an equal probability selection method (EPSEM).⁴⁹ First, the entire KnowledgePanel® is weighted to detailed geodemographic benchmarks of US adults from the latest supplement of the Current Population Survey (CPS⁴⁰). This ensures that the weighted distribution matches that of US adults. Second, GfK uses a probability-proportional-to-size (PPS) procedure to select study-specific samples reflecting the measure of size (MOS) for each panel member.⁴⁹ The PPS methodology applied to the MOS values produces fully self-weighting samples, for which each sample member can carry a design weight of unity. Where oversampling of specific subgroups is required, departures from EPSEM are corrected by adjusting the corresponding design weights using the CPS benchmarks as reference distributions.

Survey development: The web-based survey had 4 sections: (1) chronic pain characteristics; (2) approaches to manage chronic pain; (3) evaluation of chronic pain treatment options; and (4) knowledge, attitudes, and beliefs (KAB) about chronic pain (Appendix 2). Pilot testing was completed by 38 Hispanic KnowledgePanel® members; it led to abbreviating the survey and reframing some questions. The survey was translated into Spanish and back-translated. Median survey completion time was 24 minutes.

For KnowledgePanel® members with chronic pain and caregivers, the survey asked about pain characteristics (e.g., location, duration, impact on work or quality of life, intensity)⁴¹; pain treatments in the past 12 months, with ratings on helpfulness (4-point Likert-type scale);

and importance and feasibility of implementing 13 categories of ideas generated by RPs from Frio and Karnes (Results). All respondents, including caregivers and those with or without chronic pain, were asked to choose the most and least preferred of 13 categories of ideas developed by the RPs from the 2 counties, based on maximum difference (MaxDiff) scaling.⁴² This choice-based modeling technique (also known as best–worst scaling) ranks the importance (preference) for a group of items/concepts and has been widely used to avoid rating concepts in one direction.⁴³ For MaxDiff, respondents were presented with items in sets of 3 to 5 and asked to pick the item they preferred most and the item they preferred least. The questions were then shuffled and re-presented for 12 iterations. The last section of the survey addressed KAB about chronic pain and was completed only by persons without chronic pain⁴⁴ These KAB statements were adapted from the Survey of Pain Attitudes-Brief to be appropriate for administering to persons without chronic pain⁴⁵

Survey administration: We originally proposed to survey Hispanic KnowledgePanel® members aged 35-75 from Texas (estimated N = 400), without focusing on CNCP. After reviewing with GfK, we expanded the sample to KnowledgePanel® members from 5 states to increase the sample of persons with CNCP, caregivers, and the general public. The sampling frame totaled 1007 members who were Hispanic; aged 35-75; and living in California, Texas, Arizona, Nevada, or New Mexico. The survey was first opened to members with a history of (but not necessarily current) chronic pain from their GfK profile. Among this group, members with current CNCP were identified by the same screening questions described above for RPs (Section E1). Caregivers were also identified from the general population. Exclusions included cancer pain, disability, and inability to speak either Spanish or English. After 1 week, the survey was opened to the remainder of the 1007 adults in the sampling frame. After 18 days, responses dwindled, so the survey was closed. We aimed for at least 500 completed responses. No secondary data analyses were completed.

E3: Evaluative framework

We designed the study to compare 2 nonprobability sampling methods for recruitment of RPs from 2 rural, Hispanic-majority counties. In alignment with Road Map stage 7, evaluative metrics included RP recruitment and retention rates at meetings, RP demographics, and

number/quality of ideas generated. We followed the RE-AIM framework, which has been described as applicable to a broad array of research³¹ (Section C, Table 5).

E4: Study outcomes

A primary outcome was *reach* based on the number of eligible and consenting RPs recruited using each sampling method. We also compared attendance to the first orientation meeting and to all 3 meetings (*retention*). We compared demographics of RPs from the 2 communities. A second set of outcomes included the number of unique categories of ideas generated by RPs from 1 county (and recruited by 1 sampling strategy) and ratings by the community RPs of these ideas based on importance (5-point Likert scale: 1 = not at all important, 2 = somewhat important, 3 = important, 4 = very important, 5 = extremely important) and on a similarly structured 5-point scale for feasibility. The 5-state representative sample of persons with chronic pain from GfK's KnowledgePanel[®] also evaluated these ideas (Section E5).

For Aim 2, we created an 80-page document, *Underserved Populations: Advancing Health, Engaging, And Developing (UP AHEAD) Research Handbook*, that was written by our team, informed by community-based stakeholders, and reviewed by a national board of community and academic experts in PCOR/CER. This handbook offers a synthesis of relevant approaches and literature on steps to develop a productive longitudinal partnership for research with a hard-to-reach, underserved community, as well as real-world lessons from our project, including quotes from lead partners and participants.

E5. Analytical and statistical approaches

We had originally hypothesized that PS would yield more consenting, engaged, and ethnically diverse RPs. We also expected that the PS sample would generate more highly rated ideas. For the first set of outcomes, RPs recruited by the 2 sampling methods were compared using the chi-square test or Fisher exact test for categorical variables and 2 independent sample *t* tests with the unequal variances assumption used for continuous variables (i.e., the unequal variance was assumed to be conservative). We also compared their responses to a pre–post survey from the first meeting using the McNemar test.

The second outcome was the number of ideas generated by the PRs from the 2 communities and their mean ratings of the importance and feasibility of the categories of ideas. Data on the categories of ideas and ratings from the last meeting of 6 groups (3 in each county; Table 3) were first analyzed using *Concept Systems* software[®], which created clusters using nonmetric multidimensional scaling and provides a visual display of the relative relationships of elicited concepts.^{46,47} Cluster concept maps from each community display ranked the importance of overall categories based on distance of similarly and dissimilarly sorted statements.

Due to the variety of ways the RPs from these 6 groups categorized similar ideas, concept mapping could not combine them into more uniform categories. To address this, 3 research team members conducted a thematic analysis, beginning with a review of categories of ideas created by the *Concept Systems* software for 6 maps. Because many of the 20 concept mapping categories were similar, the team and the cCABs were able to reduce the number to 13 distinct categories. Then the team recategorized all 216 RP ideas and reviewed them again to resolve the remaining differences.

For each RP, the team calculated the mean ratings on a 5-point Likert scale for importance for all ideas in each category and calculated a mean for the feasibility ratings. These participant-specific mean ratings for each category were averaged for all RPs who had been recruited by either P + C or SS sampling. The team compared the mean ratings of the 2 RP groups for each category (on importance or feasibility) using 2-sample *t* test with the unequal variances assumption as a conservative approach.

A third analysis involved surveying a 5-state representative sample of Hispanic KnowledgePanel[®] members. The team compared characteristics of RPs attending all meetings (both communities combined) with characteristics of KnowledgePanel[®] respondents grouped as (1) CNCP/caregivers and (2) persons without CNCP. For RPs, these data included means (SD) for continuous variables and counts and proportions for categorical variables. For the 5-state representative sample, weighted means and corresponding standard errors (SEs) as well as weighted proportions and corresponding SEs were computed for continuous variables and categorical variables, respectively. Sampling design weights were provided by GfK based on its

iterative proportional fitting (ranking) procedure, ensuring that final weights were aligned on all study benchmark distributions and adjusted for survey nonresponse as well as requirements of the study-specific sample design.⁴⁹ We used the adjusted Wald test to compare the weighted mean/proportion from the GfK sample with the unweighted mean/proportion from the community sample.

The team compared RP ratings on importance and feasibility with ratings on similar metrics by GfK respondents who had CNCP and caregivers of individuals with CNCP. Based on a GfK recommendation, the survey used a 4-point rating scale (i.e., 1 = not important, 2 = somewhat important, 3 = important, 4 = extremely important) to avoid a noninformative neutral option. To allow comparison, we created a single category for an “important” rating by combining response options 3 to 5 on the community sample’s scale and response options 3 and 4 on the 5-state sample’s scale. For the recoded importance ratings (i.e., 1 = not important, 2 = somewhat important, 3 = important), we computed the mean (SD) for each category for the RPs and weighted means (SE) for the GfK sample. The original feasibility ratings were similarly recoded. The adjusted Wald test was used to compare differences in importance ratings between the 2 samples. In a sensitivity analysis using the original scales for comparison, we found similar patterns of results.

In a sensitivity analysis, we examined whether specific demographic subgroups of the 5-state sample were more likely to endorse a certain category of ideas generated by the rural RPs as being important to implement for CNCP. In weighted logistic regression, we examined associations of participants’ demographic characteristics (i.e., age, gender, language preference, employment status, and annual household income) with a high importance rating (i.e., 3 or 4 on the original scale) for each research initiative.

All GfK respondents completed the MaxDiff exercise to elicit their preferences among the RPs’ categories of ideas.^{52,48,49} We used hierarchical Bayes estimation modeling to derive useful scores at the individual level under the multinomial logit rule. We converted the scores to ratio-scaled probabilities that sum to 100. A higher score indicates that a specific category of ideas is more important or strongly preferred. GfK Custom Research completed MaxDiff analyses using the *Sawtooth* software (Appendix 3).

E6. Conduct of the study

The UT Health San Antonio Institutional Review Board examined protocols and judged our project to be nonregulated (exempt) research (IRB # HSC20140064N). In accordance with the responsive design of this project, the lead community partners and cCABs guided all modifications, such as reframing our primary question to be more understandable and culturally appropriate. Additionally, in response to challenges in conducting PS in Karnes, the cCAB directed the addition of convenience sampling. For the 5-state KnowledgePanel[®] survey, we benefited from the expertise of GfK in survey development, administration, and analysis.

SECTION F. RESULTS

The 2 Texas counties where this project was conducted were quite comparable. Frio County's population in 2015 totaled 18 793 residents: 70% aged 19-64 years, 41% women, and 78% Hispanic ethnicity (13% of these foreign born⁵⁰ The median household income was \$35 681, with 26% of residents living in poverty and 23% uninsured. In Karnes County, there were 14 975 residents in 2015: 70% aged 19-64, 41% women, and 52% Hispanic ethnicity (6% of these foreign born⁵¹ The median household income was \$44 650, with 22.3% of residents living in poverty and 19% uninsured. Among residents of Frio and Karnes, 12% and 15%, respectively, were disabled. Of all ranked Texas counties (N = 243), the Robert Wood Johnson County Health Rankings placed Frio at 236 and Karnes at 217 (both lowest quartile) in health outcomes.⁵²

Table 7. Research Participants by Sampling Method^a

	Snowball Sampling Research Participants (Frio County)				Purposive Plus Convenience Sampling Research Participants (Karnes County)				P Value [†]
	Group 1	Group 2	Group 3	TOTAL	Group 1	Group 2	Group 3	TOTAL	
	N			N (%)	N			N (%)	
Contacted	4	6	2	67 (100)	9	0	0	71 (100)	
Consented to Participate	17	20	18	55 (82)	21	23	18	62 (87)	0.392
Orientation	17	19	16	52 (95)	12	12	12	36 (58)	<0.0001
Brainstorming	16	16	10	42 (76)	10	9	10	29 (47)	0.001
Rating/Sorting	11	15	10	36 (65)	8	8	12	28 (45)	0.028
Participated in all meetings[‡]	11	15	10	36 (65)	8	8	10	26 (42)	0.011

^a In each county, three groups of participants met and each group attended a series of three meetings
[†] Chi-Square test for comparison of participation for each sampling method
[‡] Calculated by dividing the number of participants attending the first meeting who attended all three meetings

RPs were recruited using different nonprobability methods in each community (these were the *study interventions*, in PICOT terms). The primary results comparing sampling methods have been published⁵³; we offer the following summary with the publisher’s permission. In terms of **Reach** (Table 7), 67 potential participants in Frio were identified using snowball sampling, of whom 65 (97%) were eligible and 55 (85%) consented. Of these, 52 (95%) RPs attended orientation (7 were caregivers) and 36 (65%) attended all 3 meetings. In Karnes, P + C resulted in 71 potential participants who were contacted (21 purposive and 50 convenience). Of these, 69 (97%) were eligible, 62 (90%) consented, 36 (58%) attended orientation (4 were caregivers), and 26 (42%) attended all 3 meetings. As noted, SS yielded higher participation rates for meetings (Table 8).

Table 8. Ethnicity and Gender of Research Participants by Sampling Method

Characteristic	Snowball Sampling N (%)			Purposive Plus Convenience Sampling N (%)		
	Total	Hispanic ^a	Men ^b	Total	Hispanic ^a	Men ^b
Contacted	67	60 (90)	16 (27)	71	50 (70)	19 (38)
Consented to participate	55	48 (87)	12 (25)	62	45 (73)	17 (38)
Orientation	52	47 (90)	12 (26)	36	27 (75)	7 (26)
Brainstorming	42	37 (88)	11 (30)	29	21 (72)	7 (33)
Rating/sorting	36	32 (89)	7 (22)	28	21 (75)	4 (19)
Participated in all meetings	36	32 (89)	7 (22)	26	19 (73)	4 (21)

^aPercentages reflect the number of Hispanic participants divided by the total sample.

^bPercentages reflect the number of Hispanic male participants divided by the Hispanic sample.

Consenting RPs recruited using SS (Frio) and P + C (Karnes) were similar in age and gender (Table 9). Compared with P + C, SS resulted in greater Hispanic representation (73% versus 87%, respectively; $p = 0.049$) and trended toward more Spanish-speaking participants ($P = 0.089$) and a higher proportion who were disabled (10% versus 47%, respectively; $p < 0.001$). Occupations did not differ ($p = 0.47$). Characteristics of RPs recruited by P (N = 21) and C (N = 41) sampling were similar (Table 10) except that P recruited slightly more Spanish-speaking RPs (19% versus 9%, respectively; $P = 0.17$). In support of reach to Hispanic residents, the proportions of Hispanic RPs exceeded those of all Hispanics in each county (87% versus 78% in Frio; 73% versus 52% in Karnes).

Table 9. Characteristics of Research Participants Recruited by Sampling Method

Characteristic	Snowball Sampling N (%)	Purposive Plus Convenience Sampling Stakeholders N (%)	<i>P</i> Value ^a
Stakeholders	55 (100%)	62 (100%)	-
Age , mean ± SD (years)	58 ± 11.97	57 ± 9.77	0.624 ^b
Gender			
Female	38 (69)	40 (65)	0.60
Male	17 (31)	22 (35)	
Race/ethnicity			
Hispanic	48 (87)	45 (73)	0.049
Non-Hispanic white	7 (13)	17 (27)	
Employment status			
Employed	17 (31)	38 (61)	< 0.001
Disability	26 (47)	6 (10)	
Retired	8 (15)	16 (26)	
Unemployed	4 (7)	2 (3)	
Occupation	17 (100%)	38 (100%)	0.474 ^c
Administrative	1 (6.25)	6 (16)	
Agriculture	2 (6.25)	3 (8)	
Business	2 (12.5)	8 (21)	
Domestic labor	3 (18.75)	7 (18)	
Education	2 (12.5)	2 (5)	
Government	3 (18.75)	1 (3)	
Health care	2 (12.5)	2 (5)	
Manual labor	2 (12.5)	6 (16)	
Self-employed	0 (0)	3 (8)	
Primary language			
English	46 (84)	55 (89)	0.089
Spanish	9 (16)	7 (11)	

^aChi-square test.^bTwo-independent-sample *t* test with unequal variances assumption.^cFisher exact test.

Table 10. Characteristics of Research Participants Recruited by Purposive or Convenience Sampling

Characteristic	Purposive Sampling N (%)	Convenience Sampling N (%)	P Value*
Stakeholders	21 (100%)	41 (100%)	-
Age, mean ± SD (years)	58 ± 9.72	57 ± 8.53	0.69 [†]
Gender			
Female	14 (67)	26 (63)	0.80
Male	7 (33)	15 (37)	
Race/ethnicity			
Hispanic	16 (76)	29 (71)	0.65
Non-Hispanic white	5 (24)	12 (29)	
Education			
Less than high school	5 (24)	7 (17)	0.79
High school or GED	9 (43)	16 (39)	
Post high school	3 (14)	10 (24)	
College graduate	4 (19)	8 (20)	
Employment status			
Employed	12 (57)	26 (63)	0.67 [‡]
Disability	3 (14)	3 (7)	
Retired	6 (29)	10 (24)	
Unemployed	0 (0)	2 (5)	
Occupation	14 (100%)	24 (100%)	0.49 [‡]
Administrative	2 (14)	4 (17)	
Agriculture	1 (7)	2 (8)	
Business	1 (7)	7 (29)	
Domestic labor	3 (21)	4 (17)	
Education	2 (14)	0 (0)	
Government	0 (0)	1 (4)	
Health care	1 (7)	1 (4)	
Manual labor	2 (14)	4 (17)	
Self-employed	2 (14)	1 (4)	
Primary Language			
English	17 (81)	38 (93)	0.17
Spanish	4 (19)	3 (7)	

*Chi-square test.

[†]Two-independent-sample *t* test with unequal variances assumption.[‡]Fisher exact test.

Adoption was first assessed by qualitative data regarding participation. For 10 out of 117 (8.5%) persons selected for an interview, interest in chronic pain and ways to reduce pain were the primary reasons for participating. In Karnes (P + C sampling), 3 persons cited inconvenient meeting times and 2 had no interest. In Frio (SS sampling), persons who did not

participate cited not needing treatment of pain (3) and no transportation (2). Interviews of all persons who dropped out after the first meeting (24/88; 27%) found that 8 individuals recruited by P + C cited summer vacation and other obligations while 16 individuals recruited using SS cited vacation, other obligations, no interest, and too sick. We offer descriptive data for the RPs who attended all 3 meetings and those who attended fewer meetings (Table 11).

Qualitative data on **implementation** reflect modification in the study design by both cCABs (Table 12). Eligibility criteria were revised to include all persons with CNCP, not just low-back pain; in addition, sampling methods were revised, the question for brainstorming reframed, and meeting schedules revised. Other changes focused on cultural competency, understandability, and language (i.e., nontechnical, Spanish). A quantitative analysis was conducted of RPs' knowledge, attitudes, and intentions before and after the first meeting (Table 6). Among 74 of 88 RPs (81%) who completed this survey, at least 85% agreed that the community had few resources to manage pain and that pain was a serious a public health problem. More than 75% agreed with using various nonpharmacologic approaches, but roughly 40% responded that medications alone were needed for chronic pain (Table 6). After the presentation, fewer respondents agreed that increasing the strength of medication could cure pain (50% versus 31%; $P = 0.019$). Statements about the value of the presentation were largely endorsed.

In each county, 3 different groups of RPs brainstormed initiatives to improve living with chronic pain (Table 7). In Frio County (SS sampling), these groups totaled 16, 16, and 10 RPs (total 42), and they generated 115 ideas ($N = 38, 37, \text{ and } 40$, respectively). In Karnes (P + C sampling), there were 10, 9, and 10 participants at the meetings (total 29), and they generated 101 ideas ($N = 33, 31, \text{ and } 37$, respectively). Overall, 216 ideas were generated. These ideas were rated and sorted in the last meeting, attended by 36 persons in Frio and 28 in Karnes.

Table 11. Characteristics of Participants Attending All Meetings and Dropouts by Sampling Strategy*

Characteristic	Snowball Sampling Research Participants N (%)			Purposive Plus Convenience Sampling Research Participants N (%)		
	Participants	Dropped Out	<i>P</i> Value [†]	Participants	Dropped Out	<i>P</i> Value [†]
Age , mean ± SD (years)	36 (100)	16 (100)		28 (100)	8 (100)	
	59 ± 10.27	56 ± 14.37	0.46 [‡]	59 ± 8.73	57 ± 11.64	0.63 [‡]
Gender						
Female	27 (75)	10 (63)	0.36	22 (79)	4 (50)	0.13
Male	9 (25)	6 (38)		6 (21)	4 (50)	
Race/ethnicity						
Hispanic	32 (89)	15 (94)	0.51	21 (75)	6 (75)	0.66
Non-Hispanic	4 (11)	1 (6)		7 (25)	2 (25)	
Education						
Less than high school	12 (33)	4 (25)	0.65	5 (18)	0 (0)	0.73
High school or GED	18 (50)	7 (44)		12 (43)	4 (50)	
Post high school	3 (8)	3 (19)		6 (21)	2 (25)	
College graduate	3 (8)	2 (13)		5 (18)	2 (25)	
Employment status						
Employed	10 (28)	6 (38)	0.41	16 (57)	5 (63)	1.00
Disability	16 (44)	9 (56)		2 (7)	0 (0)	
Retired	6 (17)	1 (6)		8 (29)	3 (38)	
Unemployed	4 (11)	0 (0)		2 (7)	0 (0)	
Occupation	10 (100)	6 (100)	0.060	16 (100)	5 (100)	0.35
Administrative	0 (0)	1 (17)		1 (6)	0 (0)	
Agriculture	1 (10)	0 (0)		1 (6)	1 (20)	
Business	1 (10)	1 (17)		6 (38)	1 (20)	
Domestic labor	0 (0)	3 (50)		2 (13)	1 (20)	
Education	2 (20)	0 (0)		2 (13)	0 (0)	
Government	3 (30)	0 (0)		1 (6)	0 (0)	
Health care	2 (20)	0 (0)		1 (6)	0 (0)	
Manual labor	1 (10)	1 (17)		2 (13)	0 (0)	
Self-employed	0 (0)	0 (0)		0 (0)	2 (40)	
Primary language						
English	34 (94)	9 (56)	0.002	27 (96)	5 (63)	0.028
Spanish	2 (6)	7 (44)		1 (4)	3 (38)	

* Participants are those who completed the program (3 sessions), while nonparticipants are those who completed at least 1 session.

[†]Fisher exact test or chi-square test as appropriate.

[‡]Two-independent-sample *t* test with unequal variances assumption.

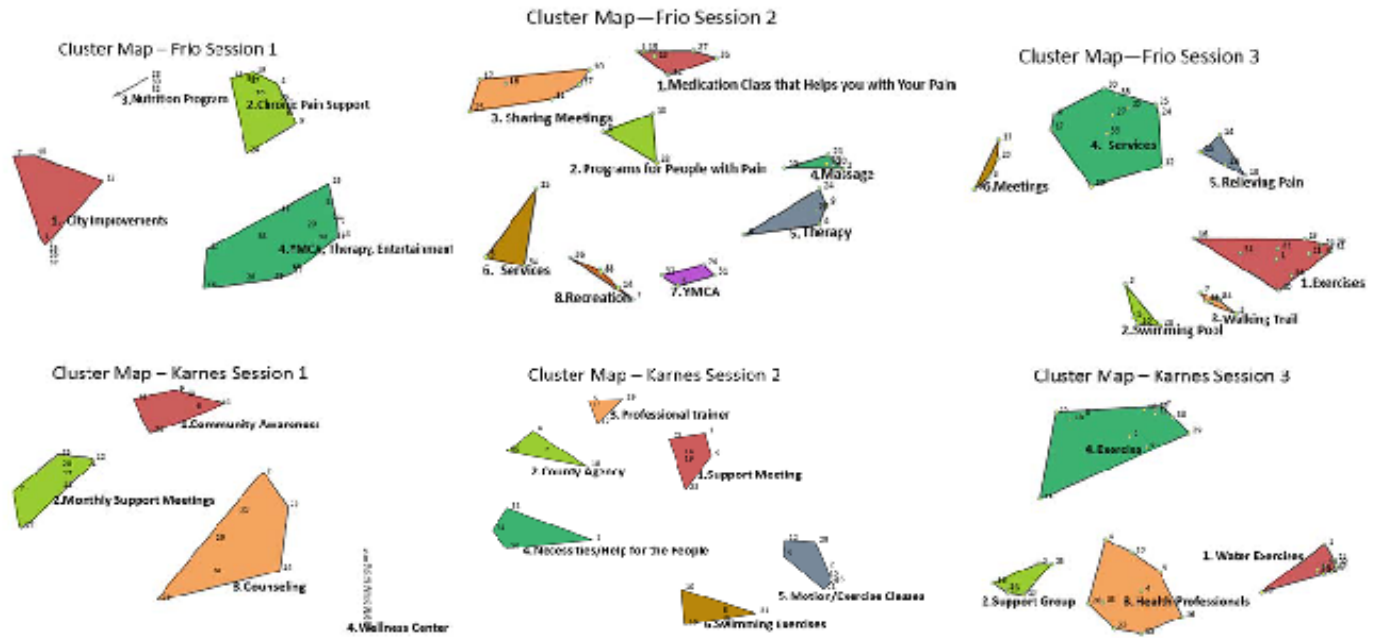
Table 12. Examples of Design Modifications Under Guidance of cCAB Members in Both Counties

Original Research Plan	cCAB Modifications
Conceptual model Jeffrey’s Road Map to Meaningful Engagement Model	Add Mold’s model for community engagement.
Project question Focus research question on health care research to improve outcomes for chronic low back to improve function: <i>“What programs can health care providers develop and test to improve coping strategies and promote useful activities to improve outcomes of patients with chronic pain?”</i>	Rearrange question to put community as lead in conducting research and be more specific about outcomes: <i>“What types of services and programs can the community develop to improve the lives and daily activities of people with chronic pain?”</i>
Eligibility criteria Chronic low-back pain	Include other forms of musculoskeletal chronic pain.
Recruitment methods Use respondent-driven sampling to recruit research participants in Frio County Use purposive sampling to recruit research participants in Karnes County	Use snowball sampling to reduce recruitment demands. Supplement purposive sampling with convenience sampling to improve recruitment.
Meetings and materials Introduction about chronic pain Develop and show a video of a primary care doctor and Hispanic persons living with chronic pain Meals Scheduling of meetings	Offer data about the health impact of chronic pain but describe in low-literacy terms. Directly address the stigma of chronic pain to reduce shame of participants. Meals from a San Antonio restaurant preferred by rural residents. Change schedule to keep the meetings of each group closely timed.
Analytic methods Conduct mixed methods analysis using concept mapping software	Conduct secondary thematic analysis of concepts in order to compare 6 groups.

Concept Mapping[®] software sorted categories, rankings, and content into 6 maps that offered a visual display of similar ideas (Table 13). This produced 18 categories for the SS group and 14 for the P + C group, based on RP sorting and rating (Appendix 4). Additional thematic analysis performed by our research team with the cCABs identified 20 categories of ideas.

Recategorization and team consensus reduced this to 13 unique categories of ideas. For the **methods** publication, we selected the top 8 categories for analysis (see Table 14).

Table 13. Concept mapping statement clusters from Frio and Karnes county sessions*



*See Table 12 for grouped statements and ratings

† This type of map shows where the boundaries are drawn around the points to create categories. Each shape represents a category of ideas brainstormed by research participants. Larger headings across each shape represent the category name for all services within the shape. Ideas that are closer to each other on this map have generally been grouped together more frequently by the participants. The small number represent each individual idea. Larger shapes contain ideas that have greater distances between them.

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	House duty, moving, sweeping, mopping, washing clothes, dusting	3.7	3	Community to help people with medicine for pain when they can't afford them	2.88	3
	Bus with assistance for shopping in San Antonio	3.36	3.6	Provide transportation to and from meetings or pool	3	3.1
	A way or someone to do yard work-start machine	3.45	3.4	Try to get volunteers to visit with you. Just because	3.13	3
	Transportation for those who need it	4.60	4.2	Building where group gathers to do exercise	3.75	3.83
	Sidewalks	4.60	3.9	Place to find help	4.13	3.6
	Full service gas stations for pumping gas	2.6	2.67	Provide transportation	4	3.9
	Curb cuts	4	3.7	Hippo therapy center, horses	2.38	2.3
	Equipment rental service to patients with chronic pain	3.70	3	Senior center for people with disabilities	4.38	3.6
	Flat sidewalks	4	3.6	Garden activities	2.58	2.92
	Day care for pain patients	4.07	3.6	Equine center, trails and no broncos	2.25	2.1
	A planting garden, seasonally	3.4	3.07	Transportation	3.13	3.5
	Walking area for disabled, very well lit	4.2	3.79	Thrift center for equipment for handicapped (people with disabilities)	3.13	3
	In-home care programs, driving, errands, deliveries	3.6	3.93			
	A well-lit movie theater for disabled	3.13	3.15			
	Leash laws enforced so we can walk on streets	4.00	3.4			
	Services to assist people in getting therapy	4.1	3.6			
	Free medical transportation to appointments and doctors	4.22	3.4			

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	Getting different types of help to assist the elderly at home	4	3.7			
	Services that help people get to the places they need to go	4.7	3.6			
Chronic Pain Support: Professional	Statements (13)		Statements (22)			
	Some nurse that will explain the good and bad of some medications – belongs in meds	4.73	4.6	Educational health center nutrition, coping skills, mental health support	4.13	4.4
	Personal care training to train family members who care for terminally ill family members or for the sick	4	4	Help with counseling when you need someone at no expense	3.88	3.3
	Pain management program; to discuss progress, ideas and suggestions	4.2	3.8	Monthly support group featuring health consultants	4.25	4.1
	Medication class that helps you with your pain	4.43	4.07	Therapy service, program with therapist	3.88	3.9
	Monthly counseling sessions	4.13	4.21	Local therapy	4	3.3
	Doctors who are pain specialists	4.53	4.14	Group facility to talk to doctors about medications	4	3.1
	Physical Therapy	4.4	3.8	Physical therapist	4.3	3
	Counseling program to help relieve pain	4.27	4	County nurse to coordinate health related programs that are available	4.3	3.3
	Meditation class	3.3	2.7	Behavior program	3.38	3
	Nurse hot line for general info and advice	4.2	3	Chiropractor, massage, acupuncture center	3.63	3
	Pain management programs for specific illnesses	4.29	3.87	Doctors that deal with holistic approach and osteopathic doctor	3.88	2.9

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	Physical and occupational therapists	4	3.93	Counselor services for depression and anxiety	4.17	3.83
	Counseling for pain	4.5	3.3	Counseling	3.5	3.92
				Rehab center for those with pain	4.38	3
				Physical therapy	4.33	4.33
				Therapy center	4.30	4
				Better doctors offices	4.58	4.33
				Clinics	4.25	4.42
				A center for chronic pain	4.33	3.5
				Group therapy	3.67	3.83
				Therapy workshop	3.75	3.5
				County sponsored agency that specializes in pain and movement disorders	3.88	3.4
Chronic Pain Support: Non-Professional	Statements (9)		Statements (10)			
	Support groups for homebound	4.09	3.9	Meetings continue to discuss pain	4.75	4.5
	A place to play bingo	2.87	3.33	Meetings and support groups	4.25	4.5
	Programs, discussion groups for those with chronic pain	4.09	3.6	To have a place to share your emotional pain	3.5	3.4
	Place where we can meet indoors to play bingo	3.18	3.6	Chronic pain support groups, regular meetings	4	3.4
	Arts and crafts	3.1	3.1	Getting back to work club	3.63	3.3
	Social support to relieve pain	4	4	Talking with others	3.92	3.67
	Pain support group	4.33	4.13	Fun day to get together and vent	3.75	3.3
	Support group for people in pain	4.4	4.1	Group sharing	3.42	3.25
	Art & crafts activities for movement and to take mind off pain	4	3.4	Continue meetings among ourselves	3.5	3.33

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
			Monthly support meeting	3.88	3.5	
Exercise/Fitness Facility	Statements (38)		Statements (27)			
	Walking and biking trail indoors or around city pond	2.73	4	Wellness center indoor walking, swimming, staffed	4.25	3.3
	Obstacle course for physically impaired & patient with chronic pain	4.09	3.9	Yoga classes with a trained instructor knowledgeable about pain	3	2.3
	Exercise programs geared at those with pain at a facility	4	3.1	Appropriate equipment for exercising	4.5	3.9
	Weekly dancing lessons	4.33	2.93	Donate exercise equipment	3.25	3.6
	Parks for walking	4.07	4.2	Inside walking path	4.13	3.5
	Curves for women	3.27	3.3	Accessible exercise facility	4.38	3.8
	A place we can go to exercise	3.43	3.73	Make a jogging or walking area	4.1	3.6
	YMCA to do exercise	4.1	3.9	Weights	3.13	3.1
	Park to walk	3.2	4.5	Dance exercise classes low impact	3.75	3.1
	Indoor walking track to walk in cool place without heat exhaustion	3.87	3.3	Exercise center with classes that target pain-level walking track-sports courts	3.88	3
	To have a place to play tennis	3.64	3.07	Exercise at our speed	4.25	4.5
	Indoor walking lot of bathrooms available	4	3.3	Exercise classes for dealing with pain or lack of function	3.75	3.9
	Provide exercise programs for homebound	3.93	3.73	Gym trainer for flexibility and stretching exercises	3.5	2.8
	Year around exercise classes	3.9	3.6	Yoga and dance and games	3	2.9
	Gym	3.6	3.1	Walking path for exercise	3.75	3.5
	Exercise classes	4.22	4.1	Exercise places	4.17	4.25
	Fitness classes	4.1	3.6	Some easy exercise places	3.55	3.92
	YMCA	4.3	3.8	Group exercise	4	4
	YMCA needed for exercise	4	4.21	Walking trail	3.67	3.67

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	Move every day	2.79	4.29	Exercise programs	4.08	3.67
	Walking groups	3.3	3.5	Exercises	3.75	3.92
	Bike exercise	3.7	3.3	Exercise for adults	4.33	3.75
	Walking Park	3.9	3.7	Sidewalk around the park	3.75	3.58
	Exercise gym	3.9	3.5	Wellness center	3.83	3.75
	A walking trail	3.6	3.9	Exercise bikes	3.38	3.8
	A gym to get therapy	3.8	3.4	Exercise center	4.25	3.83
	Sports Court	3	3.2	Tai Chi classes	2.38	2
	Exercise classes for relieving pain	4	3.8			
	Machine workouts, bike or treadmill	3.8	3.5			
	Exercise management with supervision	4.29	3.6			
	A facility to meet all wants and needs	3.55	3.3			
	Therapist to teach how to stretch	4	3.6			
	Yoga classes to assist with stretching	3	3.2			
	Running track	2.6	3.3			
	A place to get therapy	4.6	3.5			
	Electronic machine for easy body movements	3.8	3.2			
	Professional therapist instruction for exercise	4.22	3.9			
Education/Outreach	Statements (10)		Statements (9)			
	Make video of group with the same situation and the result of the outcome of the individual	3.00	3.9	Let's just see how the community can help and what way they can help when we ask them	3.63	3.4

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	Therapy training for family members-therapy from family would help everyone	4.09	3.4	Awareness, promote through local schools and businesses	3.63	3.5
	Program that familiarizes you with your condition	4.13	4.07	County agency to educate people on programs	4.38	3.8
	Fellowship, sharing meetings	3.87	3.8	Talking about chronic pain	3.91	3.67
	Weekly newsletter about pain management	4.07	4	Health fair events sponsoring chronic pain and other illnesses	4.63	4
	Information related to financial concerns	3.5	3.07	Have program service available at work, at company	3	3.5
	People don't obey the disabled signs	4.64	3.7	Annual event promotion, recognition, funding	4	3.9
	Programs	3.9	3.4	Workshops	3.33	3.75
	Information meetings	3.9	3.7	Program availability, after work or on my time	3.88	3.4
	Meetings like this to learn	3.9	3.5			
Massage Therapy	Statements (8)		Statements (1)			
	Massage center	4.15	3.87	Massage therapy	4.42	4
	To have a place for massage therapy	4.27	3.53			
	Massage therapy that focuses on specific illnesses	3.93	3.8			
	Massage therapy for face neck and body	4.33	3.2			
	Massage class	4	3.3			
	Place to get a massage	3.5	3			
	Acupuncture therapy	3.64	3.13			

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	Massage therapist home visit to patient with chronic pain. Might not have transportation	4.27	4.4			
Nutrition Program	Statements (7)		Statements (3)			
	Dietician program	4.6	4	Dietician	3.83	3.5
	Weekly visits with a nutritionist	3.57	3.53	Nutrition and pain education classes	4	3.3
	Dietician to help with healthy eating recipes	4.80	4.3	Agency to teach people about food	3.25	2.9
	Nutritional cooking classes used to have them	4.64	4.6			
	Nutrition, what to eat and not to eat	3.53	3.87			
	Nutrition classes tailored for weight loss and pain reduction	4	3.5			
	Some kind of nutrition program for people that are diabetic	4.89	4.1			
Water Therapy	Statements (11)		Statements (16)			
	Hot tubs for soaking	4.3	3.6	Swimming pool	3.88	3.6
	Swimming and sauna facility for the elderly women only	3.7	3.6	Community pool for swimming lessons	3.75	3
	A place for swimming classes	3.43	3.53	Aquatic center with water aerobics	3.63	2.8
	Availability of water therapy in the community	3.86	3.73	Health Pool for adults with chronic pain	4.25	3.67
	Pool for therapy	3.53	3.2	Warm Springs Rehab Center	4.08	3.33
	Swimming	4.2	3.3	Community pool for therapy	4.17	4.08

Table 14. Thematic Analysis: Concept Mapping Statements by Sampling Strategy

Statement Categories	Snowball Sampling Research Participants		Purposive + Convenience Sampling Research Participants			
	Importance Means [†]	Feasibility Means [†]	Statements (12)	Importance Means [†]	Feasibility Means [†]	
City Improvements/ Transportation/Services	Statements (19)					
	Indoor swimming pool for water exercise	3.9	3.3	Hot tub, muscle relaxer	4.25	3.75
	Inside pool	3.8	3.5	Community Hot Tub	4	3.25
	Whirlpool to ease the pain	4.1	3.22	Heated exercise pool	3.75	3.3
	Swimming pool, hot tub, exercise equipment, etc. all in one place	4.18	3.90	Swimming pool	3.92	4
	Water aerobics at pool with a way to get in and out of the pool	3.8	3.4	Pool for exercise	4.25	3.3
				Hot Tub	4.08	3.4
				Sauna	3.58	3.27
				Hot tub	3.38	3.42
				Spa	3.92	3.5
				Water aerobics	3.42	3.17

[†] Rating on 5 point Likert type scale (1=not at all important, 2=somewhat important, 3=important, 4=very important, 5=extremely important)

Resources required for **implementation** included time and travel costs to sites, meals, cCAB/stakeholder payment, and communication (e.g., telephone, webinars). During the planning stage, approximately 360 research team hours were devoted to training, travel, meetings with CABs and other community groups, and recruitment activities. Twelve stakeholder engagement meetings and related activities required roughly 150 hours of preparation, organization, travel, and intensive contact to keep RPs engaged. Analysis and dissemination involved roughly 100 hours of staff time. Lead partners and their staff devoted an estimated 30 hours to cCAB recruitment, meeting preparation, and meetings. The cCABs spent an average of 3 hours monthly over 1 year to oversee implementation and dissemination.

Table 15 demonstrates the **effectiveness** of these 2 sampling methods based on a comparison of mean RP importance and feasibility ratings for categories of ideas using a 5-point Likert scale. These categories were generated by both communities. Ratings on importance did not differ for 7 of 8 categories of ideas between the RPs recruited by the 2 sampling methods. Only “city (town) improvements/transportation services for persons with chronic pain” was rated more highly by the SS (Frio) group than the P + C group (Karnes) (diff = 0.62 [95% CI, 0.18-1.06]; $p = 0.007$). Mean importance ratings were largely higher than those on feasibility. Ratings on feasibility did not differ significantly between the groups.

To evaluate the external validity of RPs’ ideas, we conducted a survey of KnowledgePanel® members who were Hispanic, aged 35-75, residing in 5 states (N = 1007). We achieved a 51% overall survey response rate (N = 516); of these, 484 responses were valid for inclusion (exclusions due to speeding through or skipping more than one-fourth of the questions). With sampling weights, the 486 GfK members represent more than 10 million Hispanics in 5 states (102 respondents with CNCP represented 1 772 496 persons⁵⁴; 34 caregivers represented 632 326 persons; the 349 respondents without CNCP represented 8 810 704 persons⁵⁴).

The RPs differed ($P < 0.001$) from the 5-state sample on all characteristics (Table 11): They were older, more were women, fewer were Hispanic, all lived in nonmetropolitan (i.e.,

rural) service areas, fewer had higher education, and more were disabled. Annual household income (for the 5-state sample only) showed that 44% earned less than \$35 000.

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Table 15. Importance and Feasibility of Categories of Brainstormed Ideas by Research Participants Recruited by Two Nonprobability Sampling Methods in Two Rural Texas Counties *

Category of Ideas	Importance Rating				Feasibility Rating			
	Snowball Sampling Mean (SD) N=36	Purposive + Convenience Sampling Mean (SD) N=28	Difference (95% CI)	P Value [†]	Snowball Sampling Mean (SD) N=36	Purposive + Convenience Sampling Mean (SD) N=28	Difference (95% CI)	P Value [†]
Professional Chronic Pain Support	4.26 (0.62)	4.04 (0.76)	0.21 (-0.14, 0.57)	0.23	3.89 (1.02)	3.66 (0.94)	0.22 (-0.27, 0.71)	0.37
Nutrition Program	4.16 (0.96) [‡]	3.75 (1.14) [‡]	0.41 (-0.20, 1.03)	0.18	3.83 (0.86)	3.33 (1.22) [§]	0.51 (-0.12, 1.13)	0.11
Massage Therapy	4.07 (0.78)	4.42 (0.51) [†]	-0.35 (-0.75, 0.05)	0.087	3.73 (1.07)	4.00 (0.95) [†]	-0.27 (-0.95, 0.42)	0.43
Education/Outreach	3.90 (0.71)	3.87 (0.93)	0.03 (-0.40, 0.46)	0.89	3.71 (0.82)	3.73 (0.97)	-0.01 (-0.47, 0.44)	0.95
City Improvements/ Transportation	3.83 (0.71)	3.21 (0.97)	0.62 (0.18, 1.06)	0.007	3.50 (0.83)	3.23 (1.09)	0.28 (-0.22, 0.78)	0.27
Non-Professional Chronic Pain Support	3.81 (0.76)	3.83 (0.85)	-0.02 (-0.43, 0.39)	0.94	3.71 (0.96)	3.60 (1.00)	0.12 (-0.38, 0.61)	0.64
Water Therapy	3.78 (0.80)	3.86 (1.08)	-0.08 (-0.57, 0.41)	0.75	3.54 (0.91)	3.35 (1.30)	0.19 (-0.40, 0.76)	0.53
Exercise/Fitness Facility	3.70 (0.59)	3.77 (0.86)	-0.07 (-0.45, 0.31)	0.72	3.66 (0.64)	3.54 (0.96)	0.12 (-0.30, 0.55)	0.56

* 5 point Likert scale (1=not at all important, 2=somewhat important, 3=important, 4=very important, 5=extremely important) with similar scale for feasibility

[†] Two-sample t test with unequal variances assumption

[‡] N=20 for purposive+convenience sampling group and N=35 for snowball sampling group

[§] N=20 for purposive+convenience sampling group

[†] N=12 for purposive+convenience sampling group for both importance and feasibility ratings

Table 16. Ratings on Importance of Categories of Ideas to Improve Living With Chronic Pain: Rural Research Participants With Chronic Pain/Caregivers Versus 5-state Hispanic Sample With Chronic Pain

Category of Ideas	Rural Research Participants Sample	5-state Hispanic Sample With Chronic Pain (Weighted)* (N = 1 772 496)
	Mean Rating (SD)‡	Mean Rating (SE)‡
Massage therapy services (N = 48) [†]	2.96 (0.12)	2.56 (0.09)
More physical therapy visits (N = 44)	2.95 (0.21)	2.60 (0.07)
Specialized pain care center (N = 64)	2.89 (0.26)	2.52 (0.08)
Chiropractic services (N = 8)	2.88 (0.35)	2.46 (0.08)
Acupuncture (N = 14)	2.86 (0.36)	2.05 (0.11)
Safe, well-lit places to walk (N = 64)	2.85 (0.35)	2.39 (0.08)
Exercise/fitness classes for persons with chronic pain (N = 63)	2.85 (0.30)	2.25 (0.09)
Community weight loss program (N = 55)	2.85 (0.36)	1.95 (0.10)
Water therapy (N = 64)	2.84 (0.38)	2.63 (0.07)
Individual counseling about chronic pain by a professional (N = 64)	2.84 (0.34)	2.53 (0.08)
Support groups or group counseling to share successes and ideas (N = 64)	2.81 (0.36)	2.23 (0.09)
Gym/facility with exercise equipment (N = 64)	2.80 (0.31)	2.17 (0.09)
Meditation and mindfulness training (N = 10)	2.70 (0.67)	2.04 (0.11)

* *P* value < 0.002 for all comparisons using the adjusted Wald test.

[†] Sample size shown in parentheses next to each category of service.

‡ On 3-point Likert scale (1 = not important, 2 = somewhat important, 3 = important).

To evaluate RPs' ideas, ratings on importance and feasibility were completed only by KnowledgePanel® members who were caregivers and those who had chronic pain (Table 16). For all categories of ideas, the 5-state sample gave lower ratings than did RPs (all *p* < 0.002); however, for 5 categories (physical therapy, massage therapy, a pain care center, water therapy, and professional counseling about pain), both groups gave mean ratings of at least 2.5

on a 3-point Likert scale, signifying that they were important. The 5-state sample gave low ratings (2.25 or lower) to exercise classes, gym facilities, acupuncture, support group meetings, city improvements, meditation/mindfulness training, and weight loss programs. Although the 5-state sample gave lower feasibility ratings to all categories than the RPs (Table 17), the higher ratings (more than 2) were assigned to improving walking locations, exercise classes, making a gym available, chiropractic services, massage services, and water therapy.

Table 17. Ratings on Feasibility to Implement Services and Interventions to Improve Outcomes of Persons With Chronic Pain by South Texas Rural Community Sample Versus a 5-state Hispanic Sample

Service/Intervention	Rural Community Sample [†]	5-state Hispanic Sample (Weighted) [*] (N = 1 772 496)
	Mean Rating (SD)	Mean Rating (SE)
Massage therapy services (N = 48)	2.83 (0.40)	2.08 (0.10)
Safe, well-lit places to walk (N = 63)	2.81 (0.37)	2.26 (0.10)
More physical therapy visits (N = 44)	2.80 (0.51)	1.98 (0.10)
Community weight loss program (N = 56)	2.80 (0.43)	1.89 (0.10)
Specialized pain care center (N = 64)	2.80 (0.31)	1.83 (0.10)
Individual counseling about chronic pain by a professional (N = 64)	2.77 (0.43)	1.94 (0.09)
Support groups or group counseling to share successes and ideas (N = 64)	2.76 (0.45)	1.92 (0.10)
Exercise/fitness classes for persons with chronic pain (N = 64)	2.73 (0.41)	2.18 (0.10)
Gym/facility with exercise equipment (N = 64)	2.71 (0.44)	2.27 (0.10)
Water therapy (N = 64)	2.67 (0.53)	2.03 (0.10)
Chiropractor services (N = 8)	2.63 (0.52)	2.18 (0.10)
Acupuncture services (N = 15)	2.60 (0.63)	1.77 (0.09)
Meditation and mindfulness training (N = 10)	2.20 (0.92)	1.78 (0.10)

[†] Community sample size shown in parentheses next to each service.

^{*} *P* value < 0.001 for all comparisons using the adjusted Wald test.

Table 18. MaxDiff Analysis of Rural Research Participants’ Categories of Ideas to Improve Living With Chronic Pain by KnowledgePanel® Respondent Type

	Total Score (Reference Order)	Respondents With Chronic Pain	Respondents Without Chronic Pain	Caregivers
Sample Size	483	102	347	34
Categories of Ideas	MaxDiff Index			
A center for people with chronic pain, such as for education and exercise	194 (1)	176 (2)	199 (1)	163 (2)
Water-based classes and therapy	154 (2)	189 (1)	151 (2)	121 (6)
Massage therapy services	141 (3)	146 (3)	136 (3)	195 (1)
More visits with a physical therapist	130 (4)	119 (4)	129 (4)	159 (3)
Professional individual counseling about chronic pain	119 (5)	102 (6)	120 (5)	125 (5)
Chiropractor services	108 (6)	103 (5)	106 (6)	144 (4)
Acupuncture services	87 (7)	75 (9)	90 (7)	64 (9)
Gym/facility with exercise equipment (weights, treadmills, stationary bikes, etc)	83 (8)	91 (7)	85 (8)	45 (12)
Support groups or group counseling to share successes and ideas with others with chronic pain	81 (9)	70 (10)	84 (9)	67 (7)
Exercise/fitness classes that anyone can take	78 (10)	89 (8)	79 (10)	46 (11)
Meditation and mindfulness training	54 (11)	53 (11)	53 (11)	59 (10)
Community weight loss program	37 (12)	38 (13)	37 (12)	44 (13)
City improvements such as well-lit places for walking	34 (13)	48 (12)	30 (13)	67 (8)

^a Ordered by priority rating.

The MaxDiff analysis (best–worst choice) was completed by all 3 GfK survey respondent groups (CNCP, non-CNCP, and caregivers). Table 18 shows preferences from highest to lowest. The data are weighted so the average is 100; thus, the index of 194 for a center with specialized programs signifies that respondents were 1.94 times more likely to prefer this idea than the average of all ideas. The top 6 choices among persons with and without chronic pain were largely similar, but caregivers rated a center for chronic pain lower (1.63) and massage therapy higher (1.95). Among the lowest rated choices, respondents with CNCP rated exercise facilities and city improvements higher than the other groups, and caregivers rated acupuncture higher.

In the 5-state sample, a multivariate analysis was conducted to identify demographic characteristics associated with rating specific ideas as important (3 or 4 on the scale). Older age was negatively associated with lower adjusted odds ratios (AORs) for rating chiropractic services and water therapy as important to improve the lives of persons with chronic pain (all $P < 0.05$) (Table 19). Women were more likely than men to rate a specialized pain center, mindfulness/meditation training, and weight loss programs as important (all $P < 0.05$). Respondents who preferred English had more than 3-fold higher AORs of water therapy as important versus those who preferred Spanish ($p = 0.03$). Unemployment was associated with lower AORs of rating the following as important: a specialized pain care center ($p = 0.03$), gym access ($p = 0.05$), and professional counseling ($p = 0.06$). Poverty (less than \$10 000 annual household income) was also associated with lower AORs of rating a specialized pain care center and chiropractic services as important versus incomes of \$35 000 or more (all $p \leq 0.05$).

Finally, to promote broad uptake of project learnings for Aim 2, we developed *Underserved Populations: Advancing Health, Engaging and Developing (UP AHEAD) Research Handbook*, which is being e-published with the Society for Public Health Education (SOPHE). The handbook provides a summary of evidence and practical insights from this project to help investigators who seek to initiate partnerships for research that addresses community priorities. Chapter headings are listed in Table 20. Development of the *UP AHEAD Research Handbook* involved 7 phases: (1) outline topics with cCABs and CBPR experts; (2) literature review prioritizing systematic reviews; (3) interviews with lead partners and RPs regarding the engagement process; (4) drafting evidence reviews and practical insights; (5) draft review by national CBPR leaders; (6) revisions and publication submission; and (7) revisions in collaboration with SOPHE for e-publication.

Table 19. Adjusted Associations of Respondent Characteristics with Importance Rating of Rural Research Participants' Categories of Ideas by KnowledgePanel© Sample of Hispanics with Chronic Pain from 5 States*

Predictors in Model	Pain Center		Chiropractor		Gym		Water Therapy		Weight Loss	
	OR [95% CI]	P	OR [95% CI]	P	OR [95% CI]	P	OR [95% CI]	P	OR [95% CI]	P
Age	1 [0.94, 1.06]	0.99	0.91 [0.87, 0.96]	0.001	0.97 [0.93, 1.01]	0.25	0.95 [0.9, 0.99]	0.030	0.97 [0.92, 1.01]	0.15
Women	4.22 [1.43, 12.5]	0.009	1.04 [0.37, 2.88]	0.94	1.25 [0.5, 3.13]	0.64	0.78 [0.27, 2.28]	0.65	3.26 [1.18, 8.99]	0.023
English preference	0.5 [0.16, 1.54]	0.23	0.81 [0.28, 2.36]	0.70	1.08 [0.33, 3.6]	0.90	3.48 [1.1, 11]	0.034	1.22 [0.35, 4.26]	0.76
Employment										
Working	Reference									
Disabled	2.72 [0.6, 12.3]	0.20	0.65 [0.18, 2.36]	0.51	1.68 [0.44, 6.37]	0.45	3.17 [0.84, 12]	0.089	2.66 [0.8, 8.78]	0.11
Unemployed	0.27 [0.08, 0.9]	0.034	0.99 [0.31, 3.14]	0.99	0.32 [0.1, 1]	0.051	1.77 [0.59, 5.38]	0.31	1.13 [0.33, 3.85]	0.85
Annual income										
<\$10,000	Reference									
\$10,000- \$34,999	0.21 [0.03, 1.4]	0.11	0.08 [0.02, 0.42]	0.003	0.74 [0.18, 3.04]	0.67	0.22 [0.05, 0.89]	0.033	1.09 [0.24, 4.99]	0.91
\$35,000- \$74,999	0.06 [0.01, 0.45]	0.006	0.11 [0.02, 0.66]	0.016	0.67 [0.1, 4.64]	0.68	0.92 [0.17, 5.02]	0.92	0.79 [0.12, 5.35]	0.81
≥\$75,000	0.15 [0.02, 1.04]	0.054	0.07 [0.01, 0.47]	0.006	1.37 [0.24, 7.92]	0.73	0.71 [0.09, 5.48]	0.74	0.8 [0.13, 4.8]	0.80

* Data not shown for Acupuncture, Exercise, Safety, and Support as no significant associations (p<.07) were identified for these priorities.

Table 20. UP AHEAD Research Handbook—Table of Contents

The Purpose of This Handbook

Background. Lessons from research engaging vulnerable populations

Step 1. Understanding community-engaged research: resources and examples of conceptual models

Step 2. Establish a research team with complementary expertise and plan community partnership

Step 3. Learn about the partnering community

Step 4. Identify a lead community partner and establish a community advisory board

Step 5. Prepare for engaging community stakeholders, with a focus on vulnerable populations

Step 6. Recruit community stakeholders for group meetings

Step 7. Elicit ideas and priorities from stakeholders

Step 8. Concept mapping and similar methods for generation and analysis of stakeholder ideas

Step 9. Develop short- and long-term initiatives

Afterword. Future directions, limitations, and final thoughts

References

Appendix

Regarding *maintenance* of program activities, we have continued our collaboration and communication with both counties (Section D5.e) and have produced 3 publications and several presentations at national meetings.^{54,64-69} We independently supported and convened a national advisory board of academic and community-based experts in PCOR/CER for monthly webinars to discuss best practices in partnered research (Table 21).

Table 21. Members of the UP AHEAD Research National Advisory Board

Name	Role	Affiliation
Hayden Bosworth, PhD	Academic partner	Duke University, Durham North Carolina
Olivia Carter-Pokras, PhD	Academic partner	University of Maryland School of Public Health, College Park, Maryland
Myra Christopher, BA	Community partner	Center for Practical Bioethics, Kansas City, Missouri
Thomas Concannon, PhD	Academic partner	Tufts University, Boston, Massachusetts
Susan Goold, MD, MSHA	Academic partner	University of Michigan, Ann Arbor, Michigan
Miyong Kim, PhD, RN	Academic partner	University of Texas at Austin, Austin, Texas
Mary Olson, DMin	Community partner	Tri County Rural Health Network, Helena, Arkansas
Phyllis Rodgers	Community partner	Peer Plus Education and Training Advocates, Chicago, Illinois
Zachary Rowe, BBS	Community partner	Friends of Parkside, Detroit, Michigan
Myrl Weinberg, MA	Community partner	National Health Council (retired), Great Falls, Virginia

Finally, this study informed a pilot project, Living Better Beyond Pain, in which we developed a curriculum for chronic pain self-management that reflects the RPs' ideas (Table 22). We conducted a parallel, randomized trial of 2 methods to deliver this self-management curriculum over 6 months among low-income, primarily Hispanic primary care patients who were being treated with opioids for chronic pain.⁶⁰ One arm offered lectures in a local library by content experts while the other offered one-on-one clinic meetings with a trained community health worker. Both arms showed improvement (all $P < 0.05$) in physical and cognitive functional measures at 3 and 6 months, and depression and Brief Pain Inventory measures also improved at 6 months. Based on these results, our research team and the Frio translational advisory board received a community engagement grant from the CTSA program to replicate the pilot project in the Frio community.

Table 22: Translation of priorities brainstormed by RPs into Living Better Beyond Chronic Pain content

Community-Identified Services or Support Needed to Improve Outcomes of Persons with Chronic Pain*	Content of Living Better Beyond Chronic Pain Curriculum
Professional Chronic Pain Support	<ul style="list-style-type: none"> • Multidisciplinary program developed by kinesiologist; general internist-pain specialist; psychologist, massage specialist; physical therapist-educator-researcher
Nutrition Program	<ul style="list-style-type: none"> • Healthy Plate and Affordable Health Choices
Massage Therapy	<ul style="list-style-type: none"> • Massage Techniques: using tools for self-massage as well as partnered
Education/Outreach	<ul style="list-style-type: none"> • Understanding Chronic Pain and Goal Setting: chronic pain physiology and management with drugs and other evidence based approaches • Meditation and Mindfulness • Prevention and Management of Set Backs • Sleep Hygiene
City Improvements/ Transportation	<ul style="list-style-type: none"> • Safer activities and using affordable facilities • Looking Back: review of approaches to take advantage of city resources and advocating for more
Non-Professional Chronic Pain Support	<ul style="list-style-type: none"> • Trained community health worker to deliver the program and offered videos of challenges of local Hispanics with chronic pain and their providers
Water Therapy	<ul style="list-style-type: none"> • Encouraged to use where available
Exercise/Fitness Facility	<ul style="list-style-type: none"> • Pain and Physical Activity Training: stretches, walking, and strength training

* Ordered by priority ranking on importance from the community participants with chronic pain

SECTION G: DISCUSSION

G1: Study results in context

Despite the obvious value of community–academic partnerships for research to reduce health disparities and improve health care decision making,^{4,61,62} recent reviews have reported that community stakeholder engagement is still not the norm for health system research and that many aspects of engagement have been poorly investigated.⁶³⁻⁶⁴ This project offered new evidence regarding the use of 2 nonprobability sampling methods to recruit RPs as stakeholders from hard-to-reach communities to inform research priorities.

We conducted the study in rural, majority-Hispanic counties typifying communities that need be engaged to reduce disparities in health outcomes.⁶² In this exploratory methods

project, we originally hypothesized that purposive sampling would produce higher recruitment rates. However, we found that PS was a challenging approach because of a lack of cooperation by large employers based outside the county. In retrospect, we lacked a resource noted in an AHRQ-sponsored review of sampling methods: a database of potential participants.¹² In hard-to-reach, vulnerable communities, these data are either not available or difficult to build. With cCAB guidance, we combined sampling strategies by adding P + C and hiring a community-based businesswoman for recruitment. P + C substantially increased enrollment from 21 to 62 eligible, consenting participants. Reviews of community-partnered research report that sampling methods are often combined to achieve recruitment goals.⁷⁵⁻⁷⁷ Meeting attendance was not ideal, with 36 RPs attending 1 meeting and 26 attending all 3. However, we found that these groups generated diverse and well-accepted ideas to improve living with chronic pain.

Respondent-driven sampling was our second proposed method. According to a systematic review, RDS and snowball sampling—both chain-referral methods—are the primary methods used to recruit hard-to-reach populations.¹⁶ The cCAB in the county slated to use RDS (Frio) was concerned about burdensome data collection and recruitment restrictions and therefore endorsed snowball sampling as a less complex method than chain referral. SS resulted in 55 consenting persons, of whom 52 attended any meetings and 36 performed rating activities. Compared with P + C, the proportion of consenting individuals did not differ, but attendance at the first meeting and retention were greater with SS than with P + C. Snowball sampling also engaged a higher proportion of Hispanic RPs. Other researchers have reported that SS performs better than direct recruitment in engaging potentially marginalized groups.⁷⁵ However, in a systematic review of sampling methods for hard-to-reach populations, Barros et al. raised concerns about biased recruitment with SS.¹⁶ Perhaps reflecting this concern, RPs recruited using SS were more likely to be disabled than those recruited by P + C.

We found that SS capitalizes on existing social networks of individuals while convenience sampling takes advantage of locations where it is easy to recruit or advertise for participation. We cannot say that either is superior; both resulted in relatively diverse groups of RPs who offered valuable input regarding CNCP.

Despite recruitment using different nonprobability sampling methods, RPs from these communities generated largely similar ideas and ratings of categories on importance and feasibility. This may reflect our adherence in meetings with RPs in both counties to the nominal group technique, a structured group process that promotes equitable participation.⁴⁸ To encourage participation, bilingual team members conducted meetings simultaneously in 2 languages and assisted low-literacy participants with reading. However, even with these efforts, Spanish-speaking RPs were more likely to drop out after the first meeting. We suggest that future meetings be held separately with persons speaking one language or the other, although this might prevent cross-fertilization of input.

Among the mixed methods to examine research participants' ideas, we used concept mapping software. With 3 groups of research participants in each community (total 6), 6 different maps were produced, which were difficult to combine because they classified similar ideas differently. To supplement this approach, we conducted a thematic analysis of all 216 ideas generated by the RPs using independent coding of identified themes.

To evaluate the external validity of the RPs' ideas, we employed the novel approach of conducting an online survey using GfK's KnowledgePanel,[®] which achieves a representative sample of community-dwelling adults in the United States, including people who are usually underrepresented, such as Spanish-speaking adults.⁶⁸ The KnowledgePanel[®] has been increasingly used for medical research in addition to its original use in marketing research.⁷⁹⁻⁸¹ We planned to survey only Hispanic KnowledgePanel[®] members from Texas but broadened the sampling frame to 5 southwestern states to ensure representation of caregivers and persons with CNCN. The 51% response rate is typical for KnowledgePanel[®] surveys, which, with weighting, represent more than 10.5 million adults.^{80,81} Categories of ideas from the 2 rural counties' RPs were examined 2 ways: Likert-type ratings of importance and feasibility completed by participants who were caregivers and those who had CNCN and a MaxDiff (best-worst) scaling offered to all respondents. Results of these approaches were consistent because the top 6 choices in MaxDiff also received the highest importance ratings. These ideas were similarly highly rated on importance by the RPs. This endorsement of the rural RPs' ideas by a largely urban sample of Hispanics reinforces the value of generating research priorities from a

nonprobability sample of community stakeholders affected by a health condition. As further validation, most of these highly valued categories of ideas have been espoused by the US Department of Health and Human Services' National Pain Strategy.³⁵ And finally, our multivariate analyses of the 5-state sample shows that certain demographic subgroups may be more or less receptive to specific ideas to improve living with CNCP, which may inform future research on this topic.

G2: Uptake of study results

This project's results informed our team's development of a CNCP self-management curriculum, Living Better Beyond Pain, which reflected the RPs' ideas, cCAB guidance, and other self-management curricula (Table 22) for nonpharmacologic interventions for chronic pain. We conducted a parallel-group, randomized trial of 2 approaches to deliver the curriculum over 6 months to low-income, primarily Hispanic primary care patients who were being treated with opioids for CNCP.⁷⁰ Both clinic- and community-based arms improved at 3 and 6 months (all $P < 0.05$) in physical and cognitive functional measures, and at 6 months in measures of depression and pain. Our research team and the Frio TAB received a community engagement grant from the CTSA program to replicate the pilot project in the Frio community.

G3: Study limitations

Various limitations should be noted. First, our study involved Hispanic-majority communities, but other underserved groups are a priority for PCOR/CER and for the National Pain Strategy.³⁵ Second, we modified several aspects of this project from the original proposal with the guidance of our CABs; however, this reflects the real-world experience of PCOR/CER investigators and community partners, as engagement methods may require adaptation to meet practical challenges. These challenges may reflect the way we implemented sampling and may not be generalizable to other settings. For example, differences such as more disabled persons being recruited using SS might be due less to the sampling method than to how we implemented it. Third, we aimed for 130 consenting RPs but recruited only 117, of whom 88 attended orientation and 64 attended all meetings. However, we exceeded our sample size goal of 60 RPs in the last rating step. Fourth, some of the RPs' ideas on unmet needs (e.g., city

improvements) may not be appropriate for research. Fifth, although we conducted a concept mapping analysis, the diversity of categories developed in each of the 6 RP groups made the resultant maps difficult to combine. Sixth, the GfK sample and the RPs from 2 rural counties differed in demographics; most notably, the GfK sample was entirely Hispanic, predominantly urban, and more likely to be men. We found recruitment of men to serve as RPs to be a challenge, even though we asked wives to bring their husbands if they had CNCP or served as caregivers, and we reached out to businesses where men were employed. Gender equity needs to be addressed in the future through innovative approaches. Finally, the Likert scales used by the RPs and 5-state sample differed, but results were comparable using both original and recoded ratings.

G4: Future research

Looking ahead, much research needs to be done to improve methods for stakeholder engagement with hard-to-reach populations due to the low rigor of most studies.⁷⁶ All too often, CABs that guide research projects are not typical of the communities they represent because they have a higher income or more education than most residents. Instead, our project design took advantage of a lead community partner and a CAB to guide the engagement of diverse RPs to inform research topics. This study offers support for using real-time online population-based samples to evaluate the external validity of community-generated ideas and research priorities.^{72,78,80}

Finally, this report focuses primarily on results related to our aim of evaluating nonprobability sampling methods rather than on findings related to improving the lives of persons with CNCP in vulnerable communities. However, the results have yielded multiple publications and presentations^{54,63,69} offering valuable community insights to address the major challenge of safely and effectively managing CNCP in the United States.

SECTION H: CONCLUSIONS

“Engage people representing the population of interest and other relevant stakeholders in ways that are appropriate and necessary in a given research context (PC-1).” This PCORI standard reflects a high priority cited by a systematic review of stakeholder engagement.⁷⁴ A

key lesson from this preliminary study of sampling methods is the critical contribution of a community advisory board to guide implementation. This approach contrasts with using CAB members themselves to inform research priorities, an approach that has been criticized because the CAB may not adequately represent the needs and interests of underserved community members.¹⁰

Secondly, we offer tempered endorsement of snowball sampling as a sampling method over P + C because of greater engagement in terms of RP numbers and Hispanic participation. However, as noted in a review of convenience versus purposive sampling, sampling methods should be selected based on the requirements of the project, so one approach would not always be superior to another.²¹ For example, respondent-driven sampling might be preferred for surveillance studies in hard-to-reach populations, where bias can lead to erroneous conclusions that have serious ramifications.¹⁷ For developing research priorities, we found that research participants recruited using either sampling method arrived at largely similar ideas, suggesting that different approaches can yield useful results.

Third, we endorse using structured group meetings to ensure that all RPs have an equal opportunity to contribute. This follows the recommendations of an Agency for Healthcare Research and Quality comparative effectiveness review to use structured group processes with stakeholders to define research needs.¹² We employed the nominal group technique and numerous approaches to meet the needs of Spanish speakers and RPs with limited reading skills. It is likely that these approaches can be further refined.

Fourth, we conducted a mixed methods analysis of the research ideas from our RPs. This approach offers diverse opportunities for analysis, including concept mapping (with the caveat of avoiding too many groups), thematic qualitative analysis, and quantitative analysis of Likert scale ratings on specific dimensions. In particular, thematic analysis has been employed to examine community members' deliberations to guide subsequent initiatives.⁷³

Finally, we produced the *UP AHEAD Research Handbook* based on a need expressed by our community partners and a national advisory board for a practical guide for investigators who wish to initiate a research partnership with hard-to-reach communities. The ultimate goal of this study is to highlight and advance methods to productively partner with communities that

have poor health outcomes and have much to gain from comparative effectiveness research and patient-centered outcomes research that addresses their priorities. Much work remains to be done to develop a rigorous methodology to partner with communities in developing priorities for relevant and valuable research projects.

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SECTION K: APPENDIX

Table 23. Rural Texas Research Participants With Chronic Pain or Caregivers Versus Representative Sample of Hispanic KnowledgePanel© Members From 5 Southwestern States*

Characteristic	Rural Community Stakeholders (N = 64) N (%)	5-state Sample (Chronic Pain or Caregiver) (N = 1 772 496) Weighted % (SE)	5-state Sample (No Chronic Pain) (N = 8 810 704) Weighted % (SE)
Age (years)†	59.3±9.25	52.6 (1.1)	49.7 (0.6)
Women	48 (75)	55.6 (5.9)	50.0 (3.2)
Hispanic ethnicity	53 (82.8)	100	100
Prefer English	57 (89.1)	53.5 (5.9)	43.6 (3.1)
Rural	64 (100)	10.7 (4.9)	5.8 (1.6)
Education			
Less than high school	18 (28.1)	43.3 (5.9)	38.7 (3.2)
High school graduate	30 (46.9)	19.2 (5.2)	28.9 (2.8)
Some college education	8 (12.5)	24.8 (5.2)	20.2 (2.5)
College graduate or higher	8 (12.5)	12.7 (3.5)	12.3 (1.7)
Employment			
Working	26 (40.6)	43.5 (6.0)	59.9 (3.1)
Disability	18 (28.1)	18.4 (3.8)	4.9 (1.3)
Not working	20 (31.3)	38.1 (5.8)	35.2 (3.0)
Annual household income (\$)			
Less than 9999		9.9 (2.9)	6.0 (1.2)
10 000 to 34 999		33.7 (5.2)	28.9 (2.7)
35 000 to 74 999		30.1 (6.1)	34.7 (3.1)
75 000 or greater		26.3 (5.4)	30.4 (3.0)

**P* < .01 for all comparisons from adjusted Wald test.

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