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Making Pain Research More Inclusive: Why and How

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Abstract

Current knowledge about mechanisms and interventions for pain has largely been derived from samples that are healthier, wealthier, younger, and more likely to be White than the general population. Failure to conduct inclusive pain research not only restricts generalizability and application of findings, but also hampers the discovery of mechanisms and the development of measures and interventions that are valid across population subgroups. Most of all, inclusive practices are critical to ensure that underrepresented groups derive equitable benefit from pain research. Here, we provide guidance for the pain research community on how to adopt inclusive research practices. We define “inclusion” to encompass a range of identities and characteristics, including racialized group/ethnicity, disability status, gender identity, sexual orientation, and age.

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We first describe principles relevant to promoting inclusion in pain research, including attention to: 1) stakeholder engagement; 2) structural factors underlying inequities; 3) the limitations of “disparity” research; 4) intersectionality; and 5) universal design. Next, we provide checklists with practical strategies for making studies more inclusive at each stage of the research process. We conclude by calling for system-level changes to ensure that the future of pain research is socially just, scientifically productive, and responsive to the needs of all people.

Perspective: This paper offers guidance on promoting inclusion of underrepresented groups in pain research. We describe principles relevant to conducting more inclusive research; e.g., attention to stakeholder engagement, structural factors, and universal design. We provide checklists with practical strategies for inclusion at each stage of the research process.

Introduction

An extensive body of research documents inequities in pain outcomes and the quality of pain care by sociodemographic and health characteristics. These include, but are not limited to, racialized group/ethnicity, age, sex and gender identity, disability status and socioeconomic position.^{11,34,43,59,61–63} These same characteristics affect inclusion in pain research, such that the minoritized and marginalized groups who already receive inferior pain care and are the most burdened by pain are underrepresented in studies which ultimately seek to alleviate pain. Much of what we currently know about mechanisms and interventions for pain comes from study samples that are healthier, wealthier, younger, less affected by disability, and more likely to be White than the general population. For example, most evidence that informs clinical practice guidelines and policy comes from randomized controlled trials (RCTs); yet RCT samples tend to be more homogeneous than real-world populations, limiting their external validity.^{47,95}

Failure to engage diverse participants in pain research not only restricts generalizability and real-world application of findings, but also diminishes the impact of pain research in other ways. For example, it hampers the discovery of relevant mechanisms that create and perpetuate pain inequities, and leads to the development of measures and interventions that lack suitability across population subgroups.¹¹ Precision medicine, in which prevention and treatment are tailored based on individual genetics, environments, and lifestyles, depends on heterogeneous samples to inform the evidence base.^{56,80,85} This is also true of samples used to build machine learning algorithms that are increasingly being implemented in clinical care; for example, an algorithm for grading knee osteoarthritis severity had a better predictive performance when trained on a racially and socioeconomically diverse dataset.⁷⁷ Thus, inclusive research practices--from study design through implementation and dissemination-- are critical to ensure that marginalized groups experience equitable benefit from pain research, and that the resulting treatments, recommendations, and guidelines meet the needs of society broadly rather than select groups.

The goal of this paper is to provide guidance for the pain research community on why and how to increase diversity in human-subjects research. A major focus of the paper is inclusion of underrepresented racialized groups. However, we define inclusion and diversity broadly to encompass a range of identities and characteristics, such as disability status,

sexual and gender identity, health literacy, lived experiences, socioeconomic status, and age (for examples of additional marginalized identities relevant to pain research, see Craig and colleagues).¹⁶ In this paper, we first synthesize cross-cutting themes relevant to promoting *diversity* (the immediate goal), *inclusion* (the process of achieving diversity) and *equity* (the ultimate goal) in pain research. (See other usage notes in Table 1.) Next, via a series of checklists, we provide practical strategies for pain researchers to attend to these themes at each stage of the research process, resulting in more inclusive research practices that will promote pain equity.

Cross-Cutting Themes for Inclusive Pain Research

When designing more inclusive pain studies, it is helpful to be familiar with current thinking from various disciplines about how and why to do this. In this section we describe five cross-cutting themes that provide context for the practical recommendations in the subsequent section: 1) stakeholder and community engagement; 2) appreciation for structural factors as an underlying cause of racialized and other inequities in pain care; 3) uses and limitations of research focused on between-group differences; 4) an intersectional approach to pain research; and 5) principles of universal design (i.e., designing materials and processes to be accessible to people with a range of abilities and characteristics). These five themes were agreed upon by the authors, a multidisciplinary group of pain equity researchers, as being especially salient. However, we acknowledge that this is not an exhaustive list of principles relevant to inclusive research, and our discussion of each is necessarily brief. We encourage readers to turn to the cited literature for more in-depth treatments of these topics.

1) Stakeholder and community engagement represent an overarching strategy for increasing the relevance and validity of pain research.

Traditionally, broad areas of inquiry as well as specific research questions have been determined solely by investigators and/or funders, who are in positions of relative power and privilege. Greater involvement of patients/participants, family members, community members, and providers (referred to collectively as “stakeholders”) in the research process will lead to questions, approaches, and interventions that are more relevant to groups that have been underrepresented in pain research. This also means that researchers should engage members of, and/or advocates for, populations labeled as “vulnerable” (e.g., people with diminished cognitive capacity, or limited education) to ensure they are not simply paternalistically protected *from* research but rather can reap the benefits of research *through* their meaningful input into shaping the research process.^{92,101} On scientific grounds, non-tokenistic inclusion of patients in the research process improves its acceptability, feasibility, rigor and potential for translation.²⁵ It also improves recruitment and retention rates in clinical trials, increasing their efficiency.¹⁸

The culture of health research has shifted to recognize the scientific, ethical, and practical value of expanded roles for stakeholders across all stages of the research process. The 2010 launching of the Patient-Centered Outcomes Research Institute (PCORI) in the United States pushed stakeholder-engaged research into the mainstream. PCORI-funded studies require stakeholder engagement in study design, conduct, and dissemination. A similar initiative

in the United Kingdom has promoted patient and public involvement (PPI) in research.¹⁸ The degree of participant engagement in research can be placed on a continuum, from *participant input* (a unidirectional process; e.g. focus groups) to *consultation* (bidirectional communication; e.g., advisory panels) to *collaboration/shared leadership* (joint decision making; e.g., steering committees, patients as co-investigators).²⁵ This menu provides researchers with options for developing a feasible engagement plan, and there are an increasing number of innovative approaches to engaging a broad range of stakeholders in research.

While the PCORI framework focuses on engaging individuals to represent stakeholder groups, the community based participatory research (CBPR) approach is a longer-standing tradition that emphasizes collaborations between researchers and communities.^{39–41,102} In the CBPR model, academic and community knowledge are combined, in a process of shared decision-making, to bring about social change to reduce health inequities. As in the PCORI model, such partnerships lead to more effective study processes and greater relevance of research findings. CBPR emphasizes selection of research questions that align with community-identified needs, leverage community strengths and resources, and yield mutual benefit; for example, through capacity-building among community partners. CBPR can help to address the “understandable distrust of academic research” common in communities of color (p. 2094)⁴⁰ and “counters the historical, geographical and conceptual boundaries that distance underserved communities from the process and products of research” (pp. 904–905).³⁹

In CBPR, mutual trust is built on durable relationships between academic researchers and communities. Accordingly, so-called “drive by” research-- in which a researcher collects data with no feedback loop and no ongoing relationship with the community of interest-- is discouraged. To date, there are few examples of pain research using CBPR or related community-engaged approaches; yet as communities confront deeply entrenched, multi-level, pain-related problems (e.g., the opioid and overdose crisis), such approaches can generate evidence for solutions that are feasible and grounded in community values and specific needs. Fortunately, this focus has been increasingly promoted by major funders of pain research in the U.S. For example, patient and community engagement is a high priority for studies funded under the HEAL (Helping to End Addiction Long-term) initiative, a trans-agency effort by the National Institutes of Health to accelerate scientific solutions to curb the national opioid public health crisis. (<https://heal.nih.gov/about/director/patient-engagement>)

2) Structural factors are an underlying cause of inequities in pain care and outcomes.

Research has consistently revealed disparities in pain treatment and outcomes disadvantaging minoritized populations, particularly African Americans. These disparities have been observed across levels of inquiry, from acute pain sensitivity in controlled laboratory settings, to clinical pain treatment, to pain-related outcomes including disability.^{35,63,64,86} As many pain care disparities researchers have noted, imposing factors such as unequal treatment, provider implicit bias, and limited healthcare access contribute to these disparities.^{62,64} It is important for pain researchers to recognize that the root cause of pain inequities is not “race”, a “biological fiction”⁴, but rather racism^{6,23,46,110}, which

is deeply embedded within our societal structures in the form of residential segregation, economic deprivation, and inferior access to medical care and quality education.^{3,29,48,57,75} These structures reflect ideologies of inferiority of minoritized groups, normalize unjust treatment based on group membership, and permit interpersonal discrimination.¹⁰⁷ In addition to racism, structural discrimination in the form of sexism, classism, ageism, homophobia, transphobia, and ableism are also powerful cultural forces that influence pain and pain treatment. For example, compared to men, women are perceived as more emotional, and are not taken as seriously for their pain, with some studies showing that they are less likely to receive treatment despite higher reports of pain.^{38,88}

The assumption that observed between-group differences are rooted in biology, and/or individual-level behavior and preferences, molds interpersonal, clinical, and societal responses to disparities.^{36,37,50,73} Research outside of the pain field has shown that when disparities are attributed to behaviors or preferences, people are less supportive of large-scale social intervention.³² In health services research, attributions of observed disparities to medical mistrust, preference to avoid or delay care, or preference for non-traditional medicine,^{7,78} as well as a focus on interventions aimed at individual coping,⁷⁶ may serve to perpetuate disparities if the need for broader systemic change is not recognized.

Attribution to individual-level factors can also lead to victim blaming, which is prevalent in cultural and medical discourse and can take subtle forms.⁶ For instance, a group may be labeled “non-adherent” when the underlying cause is a lack of resources and support for adherence. Another example is the often-cited mistrust of medical research on the part of the African American community when the fundamental problem is a lack of *trustworthiness* on the part of the health research establishment.¹⁰³ Communities of color have tended to be either (1) excluded from research altogether or (2) coerced or invited into research studies but then unethically treated. Infamous examples include the dehumanizing treatment of African American men in the Tuskegee Syphilis Study and surgical experimentation without anesthesia on enslaved persons by J.M. Sims, the so-called “father of modern gynecology;”⁵² yet there are countless less well-known instances of cruel and unethical treatment by researchers.

This history of abuse is particularly salient when it comes to research involving evoked pain, or stigmatized conditions such as opioid use disorder. In such cases, close collaboration with stakeholders and communities is required to design investigations in a way that builds trust and fosters safe research environments –particularly for communities that have experienced trauma and systemic interpersonal and structural violence.¹⁶ In sum, rather than placing the location of the problem or vulnerability within individuals, researchers must strive to identify the social, structural, and environmental determinants of inequities so that their effects can be better understood.^{2,110}

3) Research on between-group pain disparities can illuminate inequities, but researchers should be aware of limitations and potential pitfalls.

A long tradition of pain disparities research has summoned attention to inequities between groups as defined by gender, racialized group membership, and socioeconomic status.^{2,11,59,63} This body of literature forms a strong foundation for continued research

that can contribute to eliminating these inequities. Recent (and long overdue) strategic attention across sectors and funding agencies to social and health disparities is anticipated to create a new cadre of researchers interested in investigating pain inequities. It is critical for new investigations to build on the first generation of pain disparities research to not only identify how and why group differences emerge, but also to test solutions for their amelioration. To that end, it is important to be aware of potential pitfalls in conducting studies where the primary research question is assessing between-group differences in pain-related phenomena.

Documenting between-group differences can shine a light on injustices, can track progress (or lack thereof) in reducing inequities over time, and can inform allocation of health resources.⁴⁶ Yet reporting group differences without discussion of deeper causal factors opens the door to interpretations that normalize or legitimize disparities, leading to misplaced targets for intervention or decreased perception of need for intervention at all.^{53,100} For example, racialized disparities in pain coping and pain catastrophizing -- psychosocial constructs known to impact pain outcomes -- are well documented.⁶⁵ However, a lack of understanding of the mechanisms driving these differences not only limits development of targeted interventions but also perpetuates a mentality that blames patients rather than systemic factors.⁶ While many scholars reporting on pain treatment disparities have contextualized why these disparities occur, including provider bias, and structural and access barriers,^{2,34,59,60,63,97} and while some epidemiological studies on disparities in pain prevalence have included at least limited discussion of social and structural factors underlying observed differences,^{43,54,81} contextualization is also needed at earlier stages of the research process. Research questions themselves should be formulated within a structural framework, and measurement of potentially causal factors built into study designs.

Two additional caveats are advised when conducting between-group analysis. First, the assumption should be avoided that one group (often, people from racialized or otherwise minoritized groups) is deviant relative to the presumed reference group (often, White or otherwise privileged groups).⁶ This common framing leads to a deficit-oriented understanding of observed differences, such that deviations from the dominant majority are viewed as vulnerabilities.⁹ Even when investigating the presence of clinician bias, where differences in treatment confer poorer pain outcomes for minoritized patients, researchers should still be careful not to “deficit frame”. In these cases, differences are not related to differential vulnerabilities originating within patients, but rather structural factors that lead to biases within physicians.

Second, researchers should take care that a focus on between-group differences does not reinforce perceptions of the fixedness of between-group boundaries or ignore intragroup variability. Group boundaries are socio-culturally determined and shift over time, and there is vast heterogeneity in cultural, linguistic, educational, and environmental exposures within racialized and ethnic groups as they are commonly defined.⁵⁵ Many pain studies categorize participants based on one dimension (e.g., racialized group), with other important dimensions unmeasured (e.g., intersectional identities; sociopolitical and historical context; structural realities, country/region of origin, acculturation). Similarly, gender is now recognized as existing along a spectrum, yet virtually all pain research continues to

operationalize gender as binary, and gender identity as a determinant of health has seldom been examined⁵⁶ (but see two recent studies examining pain among transgender individuals).^{68,96} Between-group analysis risks obscuring the diversity that exists within most research samples, and meaningful information is lost that could help identify accurate targets for interventions.

4) An intersectional approach to pain research reflects real-world complexity.

The concept of intersectionality highlights that a person's lived experience differs at the juncture of multiple dimensions of identity and societal position.¹⁷ Hence, a focus on broadly-labeled groups (e.g., defined by racialized group, gender identity, or disability status) reduces people to a single dimension, ignoring their real-world experiences where these identities converge.⁴ The National Institutes of Health have recently called for greater attention to intersectionality in research questions, designs, and data analysis.¹ Pain researchers who wish to use an intersectional lens should identify the important dimensions of the experience of their sample relevant to the pain experience (typically, by engaging stakeholders and using qualitative methods of inquiry), measure these dimensions where possible, and incorporate multiple indicators of identity and position into analyses. In health research, intersectionality research has traditionally employed qualitative methods, but there is movement toward greater use of quantitative as well as mixed-methods that can accommodate complexity.^{1,4}

According to Newman and Thorn⁷⁰, examining intersections of multiple identities provides a more accurate image of pain disparities. It may also shed light on causation of inequities, point to intervention strategies, and enhance the relevance of research in specific communities.⁴ A small but growing body of pain research takes an intersectional approach. For example, findings from a qualitative study of women with fibromyalgia show that all respondents perceived gender-based stigma (e.g., were made to feel neurotic), but Black women in the sample additionally reported navigating racialized stereotypes around drug-seeking.⁸³ In a study using quantitative methods, information on poverty and urban settings examined two, three, and four-way interactions of racialized group, poverty status, sex, and age on the likelihood of pain presence in at least one body site, revealing complex patterns and helping to shed light on racialized group differences.⁸⁴ Another study used multilevel models to assess the risk of prescription opioid misuse within strata made up of the intersections of gender, racialized group/ethnicity, income and age, and found that certain groups—e.g., young, high-income African American women—are at elevated risk for misuse but have been overlooked in the dominant narrative in the U.S. of opioid misuse as a “White problem”.⁷⁴

Examining intersectionality and inter-individual differences can also aid in identifying pain mechanisms within context. This is essential for phenotyping, which allows us to move toward a personalized medicine approach. Historically, phenotyping has relied heavily on biomarkers including genetics and epigenetics; more recently, however, there has been a push to include psychosocial, cultural, and environmental factors in phenotyping.³⁰ This will build an evidence base for a more precise understanding of pain mechanisms in context

and one that is inclusive of people that have been un- or under-represented in the current literature.

5) Applying “universal design” thinking to study processes will optimize accessibility, inclusion, and equity in pain research.

A disability-rights perspective views disabilities as stemming largely from inadequate physical and social environments.¹⁰⁶ The concept of universal design calls for products and features that can, to the greatest degree possible, be used by everyone.⁴² When applied to research, the concept of universal design means that “all people can be included as potential participants... without the need for adaptation or specialized design”.¹⁰⁶ Much of health research has traditionally been inaccessible to individuals living with disabilities; therefore, their experiences are under-represented in findings and their application to policy and practice.⁶⁶ Given that people with disabilities and older adults (who are more likely to have impaired functioning) are disproportionately affected by chronic pain, it is particularly critical to ensure their representation in all types of pain research, from lab-based experimental studies to intervention trials. A universal design approach should inform each stage of the research process, starting with designing studies to be able to accommodate participants with any disability who otherwise meet eligibility criteria, and eliminating any exclusion criteria (e.g., visual impairments) that do not have a compelling scientific rationale. Multisensory, flexible options and accommodations should be available for all study materials and interactions with the research team.

As the term suggests, universal design is an efficient way of accommodating the needs of many different groups simultaneously. As it is not possible to design for *everyone* who could potentially take part in a study, the notion underlying universal design is instead to design for *anyone*. Mapes and colleagues⁵⁶ note that a variety of historically underrepresented groups experience similar barriers to research; e.g., financial, cognitive, language, communication and cultural factors, structural (including transportation and geographic accessibility), discrimination, and study design (restrictive eligibility criteria). A universal design approach suggests that the solutions to addressing these barriers can also overlap. Universal design notions can be applied to many aspects of study planning; for example, using plain language geared toward a low health literacy level makes study processes more accessible to those with limited educational attainment, cognitive impairments, or limited English proficiency. Having remote options or home visits for data collection enables the participation of rural individuals as well as those with transportation challenges due to poverty or disability.

Practical Strategies for Designing Inclusive Pain Research

Many pain researchers appreciate the need for more inclusive research practices, but confront barriers such as a lack of experience, resources, or connections with diverse communities. In recognition of these challenges, we offer a series of checklists associated with each major phase of the research process (*Study Planning and Design; Recruitment, Consent, and Retention; Measure Selection; Data Collection Procedures; Data Analysis; and Reporting and Dissemination*). These enumerate practical strategies for bridging the divide

between researchers/clinician scientists and more diverse and representative populations of interest, as well as relevant references and resources that provide further guidance. We also note the most pertinent cross cutting-themes at each phase, as presented above, though all themes should be considered throughout the research process.

In compiling these strategies, we drew on best practices from a variety of disciplines as well as from our own collective research experiences. Many of the strategies can be used across the spectrum of human-subjects pain research; from experimental, laboratory-based studies to translational and community-based research. However, we caution that not every strategy can or should be used in every investigation. Rather, researchers are encouraged to select strategies based on relevance and feasibility.

Study Planning and Design Checklist (Table 2)

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design

Overview: This checklist addresses issues in the pre-study phase, when decisions are made about study design (including research questions) and funding applications are being developed. Here, we address the need to engage relevant stakeholders and budget appropriately for ongoing engagement; select a diverse research team and provide team training; and make study design choices to maximize inclusion.

Checklist examples: Researchers should engage stakeholders (potentially including patients, family members, providers and others) at this early stage, which often takes the form of an advisory board. This board can shape the study's overall direction and specific research questions, the nature of comparison conditions, and outcomes. It is also necessary to plan for ongoing stakeholder engagement, in terms of both time and budget, ensuring that stakeholder partners will be adequately compensated as true members of the study team. Budgeting should also support strategies for ensuring a diverse sample such as those outlined below in *Recruitment, Consent, and Retention* and *Data Collection Procedures* and to make procedures maximally accessible, per universal design principles. To ensure that the advisory body itself is inclusive, potential barriers such as transportation should be anticipated and accessible virtual options made available. Training board members in research fundamentals can facilitate their role as study advisors/partners.²¹

Researchers can consider applying principles of community-based participatory research (CBPR) to inform their approach; for example, by convening meetings with community representatives to determine their most pressing needs and goals, designing research projects to support advocacy efforts and planning for involvement of community members in research activities like data collection.^{41,102} Researchers developing behavioral interventions for underserved populations can apply the Transcreation Framework for Community-engaged Behavioral Interventions to Reduce Health Disparities. Blending an implementation science framework with CBPR principles, the Transcreation Framework provides specific steps for the design, delivery, and evaluation of interventions to ensure their fit and sustainability in community settings.⁶⁹

Eligibility criteria should be scrutinized for being overly restrictive and for potential unintended effects, with attention to balancing the internal and external validity of an investigation. For example, exclusions based on comorbidities may disproportionately prohibit the participation of minoritized groups and older adults. Persons with cognitive impairment should not automatically be excluded but rather assessed for their ability to make decisions about their participation in research.⁴⁴ Study protocols should include screening for accessibility needs and variations for people with disabilities.⁸⁷

Researchers should plan for the hiring of staff who speak any non-English languages common in a given community so that non-English speakers are not automatically excluded from participation. Identifying a process for team training in cultural humility¹⁰⁹ is recommended so that values can be shared and skills developed. Training all team members including principal investigators, research coordinators, interviewers, research assistants and community advisors can contribute to team cohesiveness and productivity. Fryer and colleagues²⁷ note the limits of “racial concordance” of study team members as a sole strategy for recruiting in minoritized communities and emphasize the need for research teams to also understand historical context; to apply humility, transparency, and reciprocity to build relationships with communities; and to engage in self-reflection as a means to connect with other human beings.¹⁰⁹

Recruitment, Consent, and Retention Checklist (Table 3)

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design

Overview: This checklist covers issues related to identifying and engaging diverse samples, how to make the informed consent process as accessible and patient-centered as possible, and tips for retaining diverse participants given the greater barriers minoritized and marginalized groups face to ongoing study participation.

Checklist examples: Stakeholder advisors can provide input into all aspects of the recruitment process, including the design of materials and recruitment strategies. They can offer guidance on messaging; for example, crafting an appeal to altruism that is rooted in cultural and community priorities.³¹ Abundant online resources are available to ensure that all recruitment and other study materials are written at an appropriate health literacy level. Yet to be fully inclusive of individuals with sensory or cognitive impairments, or very low literacy levels, it is important to consider additional ways of making the consent process accessible. These include using “teach back” informed consent –that is, asking the participant to explain, in their own words, key elements of the consent form to verify comprehension. Multimedia consent processes, most easily done on tablets, can include videos explaining and illustrating aspects of the study; other digital tools can also be useful to support decision-making around informed consent.²⁸

Family members often play a significant role in decision making about participation in research, and they should be given the opportunity to express concerns and ask questions. Community town halls or forums can help ensure transparency and allay the concerns of community gatekeepers. Cultivating strong partnerships with community-based

organizations and institutions, such as faith-based communities, can also boost acceptability and trust within a given community.²⁶

Disabilities, including cognitive, sensory, and mobility impairments, should be accommodated by conducting recruitment activities through a variety of media and having multiple ways to respond to recruitment notices, including video relay service for deaf participants. Websites and other electronic materials used for recruiting should be accessible to screen readers and compliant with federal Americans with Disability Act guidelines.¹⁰⁶

Other considerations at this phase include ensuring that common logistic barriers for study participants are addressed (dependent care, transportation, accommodating work hours) and that adequate resources are allocated for recruitment in community-based sites such as clinics, which are likely to be understaffed.²⁰ Electronic cash transfers should be an option for receiving financial incentives, given that checks, mailed gift cards, and store-specific gift cards may not be usable by participants who don't have a bank account, reliable transportation, or secure location to receive mail. Finally, special issues that arise for undocumented people should be accommodated; for example, allowing the use of pseudonyms, offering verbal consent that does not require a written signature, and offering incentives that do not require a social security number for payment or confirmation of citizenship in other ways.

Many of the same strategies that facilitate inclusive recruitment and data collection (see below) will also enhance study retention. Other recommended retention strategies include regular outreach with newsletters (which can include interim findings, profiles of advisory board members, or educational material), birthday cards, or postcards; and providing “value added” to study participation (e.g. personalized health information such as assessment results). Least tangibly but most importantly, researchers should provide a clear explanation of the vision/purpose of the study, and ensure that every interaction between study staff and participants conveys genuine respect and caring so that participants understand that they are valued members of the research process. Navigation upon request to other studies for chronic pain or common comorbidities can be another “value-add” for participants. As researchers experienced in recruiting diverse samples, we have learned that such non-monetary factors are critically important.

Measure Selection Checklist (Table 4)

Relevant cross-cutting themes: Structural Factors, Intersectionality

Overview: This checklist covers the selection of measures for a given study, highlighting the need to choose measures that are valid across subgroups and capture relevant structural and sociocultural factors that can help to explain outcomes.

Checklist examples: Ideally, measures should be selected with input from patient/stakeholder advisors, who can help prioritize outcomes and also give input on what is important to measure and the appropriateness of existing measures for a given population. Demographic data should be as inclusive as possible, expanding upon the U.S. Census categories of racialized group and ethnicity (the reductionist “Hispanic or non-Hispanic”,

and lack of option for Middle Eastern/North African ethnicity) to encompass relevant dimensions within and beyond these groups, as identified by group members themselves. Data on racialized group membership should be collected by self-report rather than medical records to guarantee accuracy. Indicators of root causes of inequities such as experiences of individual-level discrimination or racism at the neighborhood or community level (e.g., segregation) should be considered for inclusion, as well as indicators of community and individual strengths and assets and protective sociocultural factors.

Many common pain-related measures were developed in convenience samples lacking in diversity. Thus, for latent or abstract psychological constructs, a given scale may not adequately reflect the experiences of minoritized and marginalized populations and items might have different meanings.⁹⁴ Psychometric properties of proposed measures should be considered; in particular, whether they have been validated across the groups represented in the study sample. Techniques for testing measurement invariance include qualitative inquiry (such as cognitive interviewing) and psychometric tests such as confirmatory factor analysis. This is particularly important when comparing groups on a given measure, given that differences in outcomes could be due to lack of measurement invariance. For example, Joyce, Harris and Ellis⁴⁵ confirmed that the Pain Catastrophizing Scale performed similarly in male and female-gendered individuals, adding evidence that observed gender differences were real and not an artifact of measurement. Measure content should also be assessed for its appropriateness to individuals with disabilities; for example, items measuring function that assume the ability to ambulate.⁶⁶

Measures in non-English languages needed for a given study sample should be obtained or created. PROMIS measures, which include a number of pain-related scales, are in the public domain, have all been validated in Spanish, and some are available in other languages.⁸² For measures for which no validated translation exists, Sousa and Rojjanasrirat⁹¹ delineate practical steps for translating, adapting and validating instruments cross-culturally. Researchers can also ask investigators who have research experience with a given community (e.g., to see if they have already translated the measure or what kind of adaptations they have made) via professional listservs or social media. Using measures in other languages generally requires the availability of bilingual study staff to help with data collection. Per CBPR principles, researchers can also consider training community members for these roles, which has the dual benefit of capacity-building.

Finally, integrating qualitative data collection into the study can enrich data consistent with diversity of samples.^{10,33} Focus groups, in-depth interviews, photovoice and related approaches can help elucidate contextual factors that might be missed or are difficult to assess in quantitative methods. For example, barriers and facilitators to study participation, pain management challenges, as well as motives for enduring pain, are qualitative investigations focused on the experience of pain from an individual's perspective.^{19,51,72,98}

Data Collection Procedures Checklist (Table 5)

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design

Overview: Reducing data collection burden is crucial for making studies feasible for underrepresented groups and is also a major factor in study retention. This checklist addresses the process of data collection, with special attention to making procedures accessible and reducing barriers across groups.

Checklist examples: Logistic barriers to data collection should be anticipated and accommodated. Providing on-site child care and elder care is essential, and may be needed even during home visits, in the form of an additional staff member present to provide this care. Travel should be reimbursed and/or transportation provided; e.g., through a partnership with ride-sharing/ride-hailing companies. There are an increasing number of options for remote data collection, which are more feasible and familiar than ever before, due to their increased use during the Covid-19 pandemic, including for pain treatment.¹⁵ Going well beyond electronic (or mailed) surveys, these now include smart devices, sensors, and video assessments. In order to not exclude individuals by age, socioeconomic status, or rural location, special attention may be needed to provide training and internet access (e.g., providing wireless hotspots).

Principles of universal design should be applied to data collection. Consider options for non-drivers, a plan for orienting people with visual impairments to surroundings, and offering frequent rest or stretch breaks¹⁰⁶—which are also welcomed by anyone experiencing pain. A comprehensive list of strategies for conducting accessible research can be found in Rios and colleagues;⁸⁷ many of these same strategies can also accommodate normal age-related changes in physical and cognitive functioning.²²

Data Analysis Checklist (Table 6)

Relevant cross-cutting themes: Stakeholder Engagement, Structural Factors, Limitations of Disparity Analysis, Intersectionality

Overview: This checklist discusses steps that can be taken to ensure that data analysis accommodates complexity and intersectionality, and incorporates root causes of disparities.

Checklist content and examples: As in other phases, collaboration with participants and other stakeholders can strengthen the data analysis phase, particularly in interpretation of findings. For example, the RADaR approach to qualitative data analysis¹⁰⁴ is a simple, practical approach that allows multiple stakeholders to play a role in identifying and prioritizing qualitative themes. Analytic methods and models should be selected that can accommodate heterogeneity and intersectionality. As it may not be feasible to account for all levels of intersectionality, the focus should be on identities most relevant to the research question and/or most salient to the participants.⁵ Intersectionality is not an additive phenomenon; therefore, it is critical to not “control out” one group when looking at another. Rather, quantitative analysis of diversity requires alternative data analytic methods. A caveat is that these analytic techniques tend to require a large sample size which may not always be feasible. This is not a reason not to examine complexity, however. Given the dearth of research in this area, exploratory research is needed to start documenting patterns and inform future research. Using mixed quantitative and qualitative methods may help with identifying

intra group diversity, relevant dimensions of identity, and subjective mechanisms of effect with smaller samples.

Steps should be taken to ensure that interpretations of between-group differences are both accurate and socially just. For instance, because of the effects of structural racism in both creating conceptions of racialized groups and patterning of social disadvantages (e.g., socioeconomic status), rather than considering either variable as primary or confounding, researchers should consider the social construction and impact of racism on both of these proximal measures to pathways to health.^{60,108} Further, in place of a disparities framework, researchers can adopt a diversity framework that interprets inequity as the creation of dynamic sociocultural processes--and seeks to identify and measure those processes.⁷⁹ Within this perspective, researchers may shift away from data analytic plans focused on group comparisons, toward exploration of how sociohistorical, cultural, societal, and structural contexts impact pain.

Steps toward leveraging sample diversity can also be taken when working with existing datasets. For example, researchers can take care to report measures of participant identity in all reports, and assess diversity within existing samples. In some cases, samples may be combined from extant data sets to increase sample size, allowing for a finer-grained assessment of diversity. A caution, however, is that secondary analysis of existing datasets or administrative datasets that were collected with a biased lens can further perpetuate disparities. The accuracy and representativeness of these samples depends on those qualities in the original studies. Biases in data collection can lead to inequity in big data.⁷¹ Further, some large datasets that may be used for research, such as medical records, may include inaccurate demographic labels imposed by clinical staff rather than reported by patients.

Reporting and Dissemination Checklist (Table 7)

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design

Overview: This checklist provides ideas for reporting and dissemination that ensure that study findings are shared with (or co-owned) by diverse stakeholders and communities and can be used to address the pressing needs identified by these groups.

Checklist examples: The reporting and dissemination phase is one of the most critical for ensuring that research is responsive to the needs of stakeholders, for maintaining relationships that have been cultivated with communities and stakeholder groups, and, where relevant, for using findings to enable advocacy and policy change. There is growing recognition of the ethical responsibility of researchers to report findings beyond peer-reviewed scientific journals, so that it is accessible to those it ultimately aims to benefit, including the public.¹⁴ Both community and academic dissemination plans should be formulated.

There are numerous options for community-based dissemination sharing via social media (including those commonly used outside of the academy, like Reddit and TikTok) and traditional media outlets, to community-based events and/or community-focused webinars where findings are presented and time allocated for discussion. Universal design principles

should inform the manner and format in which results are reported. Further, it is useful to report (in both academic publications and public-facing materials) on the process of stakeholder/community engagement. This helps make it clear how engagement shaped the investigation and interpretation of results. Moreover, since the pain research literature has relatively few examples of engaged research, this will contribute to a knowledge base from which others can draw. Researchers writing for peer-reviewed journals should consider following the GRIPP2 guidelines for the reporting of patient and public involvement.⁹³ Guidance is also available for use of language and terminology to refer to racialized groups/ethnicity in medical and science journals,²⁴ including guidelines specific to the field of pain⁶ (Hood et al, in revision).

Discussion

It is time for the pain research community to adopt practices that reflect a commitment to greater diversity in our studies, and to the promotion of equity in pain care and outcomes. Pain prevalence continues to rise steadily, with causes not fully understood,¹¹¹ and minoritized and marginalized groups continue to be disproportionately affected by pain and its effects.^{11,34,43,59,61–63} A recent study indicates that younger generations will bear a greater burden of pain than their parents' generation, and that this increase is tied to increasing inequity in the conditions of life for working-class Americans.¹³ Researchers are also seeking effective ways to address the epidemic of opioid-related harms, which is disproportionately affecting minoritized communities.⁴⁹ The information presented in this article is designed to provide a framework and toolkit for changing research practices to be more inclusive and improve generalizability of findings to reflect the diverse needs of people affected by pain.

To continue making progress in this area, increased attention and effort are needed in a number of areas. More research is needed to understand the perspectives of underrepresented groups specifically toward pain research, which has unique features such as the potential to experience intentional discomfort in certain studies; the assessment of a subjective experience that has often been stigmatized or discounted; and a topic that may evoke historical trauma in groups that have suffered systematic abuse and violence including physical pain. These perspectives must be recognized, respected, and accommodated.

Changing entrenched practice is difficult, and pain investigators cannot make substantial progress toward more inclusive studies without sustained support from institutions and funding agencies. Many of the strategies presented in the checklists-- including meaningful involvement of stakeholders, accommodation of those with disabilities or other participation barriers, and larger sample sizes required for intersectionality research--demand additional time and money relative to traditional research. Funders should support building and sustaining academic-community partnerships (including *between* studies; e.g., for collaborative study planning). Funding agencies should consider making inclusivity along one or more dimensions part of scored review criteria; e.g., using the definition of historically underrepresented groups identified in the All of Us initiative.⁵⁶ Institutional Review Boards could take inclusivity into consideration when reviewing studies for ethics and safety. Finally, as CBPR researchers have noted for decades,⁴¹ academic promotion

systems tend not to reward aspects of engaged research; for instance, the community- or public-facing communications that are essential for transparency, trust, and amplifying the impact of findings do not “count” as much as peer-reviewed articles in tenure and promotion decisions.

Other addressable barriers include researcher knowledge about how to leverage stakeholder and community expertise and how to engage in genuinely equitable decision-making. Training will be needed for both senior and junior pain investigators on many of the techniques presented here, as well as for research staff. NIH has recently taken steps in this direction (e.g., a Virtual Workshop on Achieving Health Equity in the NIH HEAL Initiative in February 2021); more such trainings are needed across institutes and by other funders.

An even more fundamental step is to ensure that our pain research workforce reflects the diversity in our society⁶ (Hood, Booker, et al., under revision). The voices, beliefs, and ideologies of researchers are embedded in outcomes and processes of research.⁶⁷ When there is a homogeneous workforce, inherent biases-- in how science is conducted, what research questions are asked, and how we frame disparities-- are not visible. In other words, there are bias blind spots in the norms of the scientific community. Our extant knowledge, the research questions with a rich history and amassed scientific premise, are shaped by privileged groups (and serve those groups).⁵⁸

At present, certain racialized/ethnic groups, economically disadvantaged individuals, people with disabilities, and women are all underrepresented in the biomedical research workforce.^{89,99} There is thus an enormous need to bolster efforts to promote career entry, retention and advancement in underrepresented groups, as representation diminishes at higher levels of the career ladder. Increased diversity in the research workforce will result in higher-quality and more generalizable science, and is needed to broaden the pain research agenda and enhance its cultural relevance.^{12,99} As an exemplar, Booker and colleagues describe the multi-pronged approach taken by the University of Florida Pain Research & Intervention Center of Excellence (PRICE), including “reverse mentoring” in which early career researchers help educate senior leadership, fostering enduring connections with the local community, and leveraging training grants to build a more diverse workforce.⁶

Shifting to more inclusive research practices undeniably presents challenges, but one has only to look at the troubled history of medical research to see that positive change is indeed possible. We underscore that some progress toward more inclusive pain research is better than none; and our checklists provide researchers in a wide variety of situations with numerous options to consider. Ultimately, making changes both large and small in the way pain research is conducted will enable more socially just ways of learning about pain, while helping to reduce the pervasive, persistent inequities in pain care and outcomes that stand in the way of a healthier society.

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Highlights

Marginalized and minoritized groups remain underrepresented in pain research.

- Benefits of adopting principles and practices of inclusive research are discussed.
- Key concepts are structural causes of pain disparities, intersectionality, and universal design.
- Numerous strategies for promoting inclusion are presented, with a focus on stakeholder engagement.
- Training, resources for engagement and a diverse workforce will advance inclusive pain research.

Table 1:

Definitions and Usage Notes

<i>Inequities</i>	Used to mean differences in health-related variables that are both avoidable and unjust. ¹⁰⁵
<i>Disparities</i>	Used descriptively, to denote difference, and also as a synonym to inequities, to refer to systematic, avoidable differences that adversely affect socially disadvantaged groups. ⁸
<i>Racialized group</i>	Used instead of <i>race</i> or <i>racial group</i> , in recognition that race is a socially imposed, rather than a natural or biological construct. ⁴⁸
<i>Minoritized group</i>	Used instead of <i>minority</i> , in recognition that systemic oppression and marginalization confer “minority” status on certain groups. ⁹⁰
<i>Underrepresented group</i>	Used per Mapes et al. ⁵⁶ to include a variety of groups defined by minoritized racialized/ethnicity status, low education or income, minoritized sexual or gender identity, disability, and/or other statuses known or presumed to be historically underrepresented in research.

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Table 2:

Study Planning and Design Checklist

<p>Relevant cross-cutting themes: Stakeholder Engagement, Universal Design</p>	
<p>Tips for pilot or other low-budget studies: Work with existing boards or panels, assemble a very small board, and/or hold one-on-one meetings with a community representative. Focus groups can also yield rich data and be time and resource-effective. Use free online trainings for cultural humility and implicit bias.</p>	
Item and Description	References and Resources (<i>pain-specific articles italicized</i>)
<p>• Identify and engage a Stakeholder/Community Advisory Board. Advisory boards that include diverse representatives from the priority population can define research questions, make key decisions about study design (e.g., comparator) and outcomes, or provide feedback on acceptability and feasibility of researcher-led design, including recruitment and retention activities. Engage a wide range of stakeholders where feasible: patients, family members, community members, representatives of professional organizations, advocacy groups, clinical staff including social workers and chaplains, and/or health department staff and representatives from insurance companies. Consider including an advisor with expertise on accommodations for disability. Develop roles, expectations, and accountability mechanisms for engaged stakeholders. Consider training advisors in the fundamentals of research. Allow advisors to participate by phone or video link to reduce transportation and mobility barriers and/or if social distancing is necessary. There may be existing boards or panels (e.g., Bureau of Sages, Community Engagement Studios) that can be accessed if it is not possible to convene a new one at the current phase.</p>	<p><i>Beneciuk, Jason M., et al. "Musculoskeletal pain stakeholder engagement and partnership development: determining patient-centered research priorities." Research Involvement and Engagement 6 (2020): 1–14.</i> <i>Bastian, L. A., Cohen, S. P., Katsoyich, L., Becker, W. C., Brummett, B. R., Burgess, D. J., ... & NIH-DOD-VA Pain Management Collaboratory. (2020). Stakeholder engagement in pragmatic clinical trials: Emphasizing relationships to improve pain management delivery and outcomes. Pain Medicine, 21(Supplement 2), S13-S20.</i> <i>Javaid, M. K., Forestier-Zhang, L., Watts, L., Turner, A., Ponte, C., Teare, H., ... & Kaye, J. (2016). The RUDY study platform—a novel approach to patient driven research in rare musculoskeletal diseases. Orphanet Journal of Rare Diseases, 11(1), 1–9.</i> <i>Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C., ... & Weiss, R. (2019). Patient stakeholder engagement in research: a narrative review to describe foundational principles and best practice activities. Health Expectations, 22(3), 307–316.</i> <i>Kim, K. K., Khodyakov, D., Marie, K., Taras, H., Meeker, D., Campos, H. O., & Ohno-Machado, L. (2018). A novel stakeholder engagement approach for patient-centered outcomes research. Medical care, 56(10 Suppl 1), S41.</i> <i>Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... & Murad, M. H. (2014). Patient engagement in research: a systematic review. BMC health services research, 14(1), 1–9.</i> <i>Joosten, Y. A., Israel, T. L., Williams, N. A., Boone, L. R., Schlundt, D. G., Mouton, C. P., ... & Wilkins, C. H. (2015). Community engagement studios: a structured approach to obtaining meaningful input from stakeholders to inform research. Academic Medicine, 90(12), 1646.</i> <i>Eisenstein, A. R., Milstein, L., Johnson, R., & Berman, R. (2020). The Bureau of Sages: Incorporating Older Adult Voice into Meaningful Research. Progress in Community Health Partnerships: Research, Education, and Action, 14(3), 359–370.</i></p>
<p>• Use principles of community-based participatory research (CBPR) in designing inclusive pain research. In CBPR, academic researchers and community members collaborate to conduct research that leads to community change, and improvement in health and quality of life. To ensure research is responsive to community-identified problems and priorities, some degree of CBPR principles can be used (e.g., a focus on community strengths, formation of long-term relationships, use of results for social change) even if the research is not "pure" CBPR.</p>	<p><i>Valerio, M. A., Rodriguez, N., Winkler, P., Lopez, J., Dennison, M., Liang, Y., & Turner, B. J. (2016). Comparing two sampling methods to engage hard-to-reach communities in research priority setting. BMC Medical Research Methodology, 16(1), 1–11</i> <i>Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health, 19(1), 173–202.</i> <i>Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. American Journal of Public Health, 100(S1), S40-S46.</i> <i>Newman, S. D., Andrews, J. O., Magwood, G. S., Jenkins, C., Cox, M. J., & Williamson, D. C. (2011). Peer reviewed: community advisory boards in community-based participatory research: a synthesis of best processes. Preventing Chronic Disease, 8(3).</i> Community Engaged Research Toolbox: https://prevention.ucsf.edu/resources/communityengaged-research-toolbox Community-Campus Partnerships for Health, Resource Library and CBPR curriculum: https://www.ccphealth.org/</p>
<p>• Allocate time and money in budget for meaningful engagement with stakeholders and to support inclusive recruitment and data collection practices. Budget items related to stakeholder engagement: payments for patient advisors/partners and other Advisory Board members time and input, funds to hold meetings in community locations. Budget items related to inclusive recruitment and data collection practices: materials for community-engaged dissemination, translation of research-related materials into other languages, tablets for multimedia informed consent, transportation and child/elder care</p>	<p><i>Hoefl, T. J., Burke, W., Hopkins, S. E., Charles, W., Trinidad, S. B., James, R. D., & Boyer, B. B. (2014). Building partnerships in community-based participatory research: budgetary and other cost considerations. Health Promotion Practice, 15(2), 263–270.</i> <i>Smith, E., Bélisle-Pipon, J. C., & Resnik, D. (2019). Patients as research partners; how to value their perceptions, contribution and labor?. Citizen Science: Theory and Practice, 4(1).</i> <i>De Alba, A., Schober, D., & Johansson, P. (2020). Examining Perceptions of Spanish Language Health Information Among Hispanics Living in the United States: A Qualitative Study Assessing Videos, Brochures, and Websites. Health Promotion Practice, 1524839920950029.</i> <i>Rhodes, S. D., Alonzo, J., Mann-Jackson, L., Tanner, A. E., Vissman, A. T., Martinez,</i></p>

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<p>costs, and snacks/refreshments. Budget additional resources for at-home data collection procedures for participants with barriers to on-site assessments. Build in time at the beginning of the study to identify patient and community stakeholders to engage in the research process. Consider the needs for community- and public-facing dissemination products; including graphic design, translation, event/hosting expenses, video production, etc.</p>	<p>O., ... & Reboussin, B. A. (2018). Selling the product: Strategies to increase recruitment and retention of Spanish-speaking Latinos in biomedical research. <i>Journal of Clinical and Translational Science</i>, 2(3), 147–155.</p>
<p>• Use principles of implementation science to design interventions (e.g., transcreation, which has a focus on developing interventions with and for disparity populations rather than adapting interventions developed elsewhere) and plan for translation of research findings into the community.</p>	<p>Nápoles, A. M., & Stewart, A. L. (2018). Transcreation: an implementation science framework for community-engaged behavioral interventions to reduce health disparities. <i>BMC Health Services Research</i>, 18(1), 1–15. Brewer, S. E., Simpson, M. J., Rice, J. D., Skendaore, A., & T O'Leary, S. (2020). Protocol: Engaging practices and communities in the development of interventions to promote HPV vaccine uptake: a protocol for implementing Boot Camp Translation in the private practice setting. <i>BMJ Open</i>, 1(12). Dissemination and Implementation Models In Health Research & Practice https://disseminationimplementation.org/</p>
<p>• Assess potential unintended effects of eligibility criteria and avoid overly restrictive criteria. Exclusion criteria based on health status (e.g., multimorbidity, cognitive impairment, opioid use) may disproportionately exclude underrepresented groups (by age, socioeconomic status, racialized group/ethnicity). Upper age limits should not be included without strong scientific rationale, per NIH Inclusion Across the Lifespan policy. Assess capacity to consent rather than screening out individuals with cognitive impairment.</p>	<p>Vaughan, C. P., Dale, W., Allore, H. G., Binder, E. F., Boyd, C. M., Bynum, J. P., ... & Colón-Emeric, C. (2019). AGS report on engagement related to the NIH inclusion across the lifespan policy. <i>Journal of the American Geriatrics Society</i>, 67(2), 211–217. Kim, E. S., Bruinooge, S. S., Roberts, S., Ison, G., Lin, N. U., Gore, L., ... & Schilsky, R. L. (2017). Broadening eligibility criteria to make clinical trials more representative: American Society of Clinical Oncology and Friends of Cancer Research joint research statement. <i>Journal of Clinical Oncology</i>, 35(33), 3737. Jeste, D. V., Palmer, B. W., Appelbaum, P. S., Golshan, S., Glorioso, D., Dunn, L. B., ... & Kraemer, H. C. (2007). A new brief instrument for assessing decisional capacity for clinical research. <i>Archives of General Psychiatry</i>, 64(8), 966–974. Gilbert, T., Bosquet, A., Thomas-Antérion, C., Bonnefoy, M., & Le Saux, O. (2017). Assessing capacity to consent for research in cognitively impaired older patients. <i>Clinical Interventions in Aging</i>, 12, 1553.</p>
<p>• Build cultural and language diversity on the research team. Build and retain a diverse team of researchers and staff to build trust and relationship with the community.</p>	<p>George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. <i>American Journal of Public Health</i>, 104(2), e16-e31. Fryer, C. S., Passmore, S. R., Maietta, R. C., Petruzzelli, J., Casper, E., Brown, N. A., ... & Quinn, S. C. (2016). The symbolic value and limitations of racial concordance in minority research engagement. <i>Qualitative Health Research</i>, 26(6), 830–841.</p>
<p>• Provide training for research team members in cultural humility, implicit bias, and communication strategies. This includes an examination of personal, professional, and research values that may guide actions. Include implicit bias training that helps researchers recognize how stereotypes and biases can be deeply embedded in their assumptions and cognitions and require ongoing examination to change these assumptions and related behaviors.</p>	<p>Yeager, K. A., & Bauer-Wu, S. (2013). Cultural humility: Essential foundation for clinical researchers. <i>Applied Nursing Research</i>, 26(4), 251–256. Eggy, S., Hamel, L. M., Heath, E., Manning, M. A., Albrecht, T. L., Barton, E., ... & Penner, L. A. (2017). Partnering around cancer clinical trials (PACCT): study protocol for a randomized trial of a patient and physician communication intervention to increase minority accrual to prostate cancer clinical trials. <i>BMC Cancer</i>, 17(1), 112. Parkin, R. T. (2004). Communications with research participants and communities: foundations for best practices. <i>Journal of Exposure Science & Environmental Epidemiology</i>, 14(7), 516–523. Online trainings in cultural humility and implicit bias available at Centers for Disease Control and Prevention: https://www.train.org/cdctrain/welcome</p>

Table 3:

Recruitment, Consent and Retention Checklist

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design	
Tips for pilot or other low-budget studies: Work with 1–2 members of the priority population and involve them in the recruitment materials design process. “Piggyback” on existing advisory boards or meetings of relevant organizations for input on processes and materials.	
Item and Description	References and Resources (<i>pain-specific articles italicized</i>)
<p>• Work with Stakeholder/ Community Advisory Board to develop recruitment strategies. Have the board review materials and design recruitment strategies and messages. Board engagement maximizes the effectiveness of recruitment strategies, minimizes the burden to patients and communities, and addresses relevant concerns about the trustworthiness of the research team and safety concerns.</p>	<p><i>Beneciuk, Jason M., et al. “Musculoskeletal pain stakeholder engagement and partnership development: determining patient-centered research priorities.” Research Involvement and Engagement 6 (2020): 1–14.</i></p>
<p>• Conduct a health literacy check on consent and other recruitment materials. A lack of informational access about research opportunities and low health literacy limits participation, therefore efforts should be made to create patient-friendly materials and use of a universal design that maximizes understanding for everyone.</p>	<p><i>Thorn, B. E., Campbell, L. C., Van Dyke, B. P., Newman, A. K., & Torres, C. A. (2018). Literacy-Adapted Cognitive Behavioral Therapy Versus Education for Chronic Pain. Annals of Internal Medicine, 169(6), 422–423.</i> PRISM Readability Toolkit (editing checklist, template consent forms, list of plain-language alternatives to scientific terms): https://www.nhlbi.nih.gov/files/docs/ghchs_readability_toolkit.pdf PRISM free online training: https://prism.kpashingtonresearch.org/course_introduction/splash_page_before_registration.html CDC Health Literacy resource hub: https://www.cdc.gov/healthliteracy/ AHRQ Health Literacy Universal Precautions Toolkit: https://www.ahrq.gov/health-literacy/qualityresources/tools/literacy-toolkit/index.html</p>
<p>• Consider specific barriers faced by undocumented individuals. Undocumented individuals may have concerns about the legal consequences of participation. Anticipate potential sources of harm and mitigate them appropriately. Use pseudonyms and consider obtaining verbal consent to minimize the risk of a breach of anonymity. Offer incentives that do not require social security numbers for payment.</p>	<p>Olukotun, O., & Mkandawire-Valhmu, L. (2020). Lessons Learned From the Recruitment of Undocumented African Immigrant Women for a Qualitative Study. <i>International Journal of Qualitative Methods, 19</i>, 1609406920904575. Burke, N. J. (2016). Contextualizing “Choice” for Undocumented Immigrants in US Clinical Trials Research. <i>The American Journal of Bioethics, 16</i>(10), 7274.</p>
<p>• Ensure that compensation and incentives are appropriate and accessible. Compensation should adequately reflect time investment and disruption to daily life. If it is not possible to offer cash, consider electronic cash transfers, as checks and gift cards may present barriers to individuals without bank accounts or transportation. Incentives should not require a social security number or other proof of citizenship.</p>	<p>Galán, C.A., Bekele, B., Boness, C. L., Bowdring, M. A., Call, C., Hails, K., ... Yilmaz, B. (2021) Editorial: A Call to Action for an Antiracist Clinical Science, <i>Journal of Clinical Child & Adolescent Psychology, 50</i>:1, 1257, DOI: 10.1080/15374416.2020.1860066</p>
<p>• In addition to plain language, consider ways to make the consent process inclusive and accessible. “Teach back” informed consent and/or multimedia consent forms can enhance comprehension among individuals with low health literacy and/or cognitive impairment. The informed consent process should not be a single point in time but rather participants should be encouraged to consider and ask questions frequently throughout the study. Address transportation and time barriers more common in underrepresented groups by having a remote option for informed consent, or a home visit option.</p>	<p>Hughson, J. A., Woodward-Kron, R., Parker, A., Hajek, J., Bresin, A., Knoch, U., ... & Story, D. (2016). A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials. <i>Trials, 17</i>(1), 1–10. Furberg, R. D., Ortiz, A. M., Moultrie, R. R., Raspa, M., Wheeler, A. C., McCormack, L. A., & Bailey Jr, D. B. (2018). A digital decision support tool to enhance decisional capacity for clinical trial consent: design and development. <i>JMIR Research Protocols, 7</i>(6), e10525. Kripalani, S., Bengtzen, R., Henderson, L. E., & Jacobson, T. A. (2008). Clinical research in low-literacy populations: using teach-back to assess comprehension of informed consent and privacy information. <i>IRB: Ethics & Human Research, 30</i>(2), 13–19. Beattie, E., O’Reilly, M., Fetherstonhaugh, D., McMaster, M., Moyle, W., & Fielding, E. (2019). Supporting autonomy of nursing home residents with dementia in the informed consent process. <i>Dementia, 18</i>(7–8), 2821–2835.</p>
<p>• Make clear in the consent form that accommodations are available for participants with disabilities. Both recruitment materials and consent forms should state that accommodations are available for people with</p>	<p>Williams, A.S., & Moore, S.M. (2011). Universal design of research: Inclusion of persons with disabilities in mainstream biomedical studies. <i>Science Translational Medicine, 3</i>(82), 8212. Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting accessible research: including people with disabilities in public health, epidemiological, and outcomes studies. <i>American Journal of Public Health, 106</i>(12), 2137–2144.</p>

disabilities, offering the name of a contact person with whom they can discuss their participation.	
<p>• Allow opting in or out of specific study procedures on the consent form. This may be helpful where some components of the study might be culturally non-congruent, invasive or painful procedures, or particularly time-consuming elements.</p>	
<p>• Ensure images in recruitment materials mirror diversity in priority population(s). This can include members of the study team. It is important to ensure that graphics and images represent the priority population but are also sensitive and not stereotypical.</p>	<p>Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. <i>Health Literacy: A Prescription to End Confusion</i>. Washington: National Academies Press; 2004. Harrigan, R., Perez, M. H., Beaudry, S., Johnson, C., Sil, P., & Apau-Ludlum, N. (2014). Recruitment and retention of under-represented groups with health disparities into clinical trials: A formative approach. <i>Journal of Immigrant and Minority Health</i>, 16(5), 898903.</p>
<p>• Use recruitment videos to explain the study. This can offset potential in-person bias such as spending less time with patients from minoritized groups during recruitment.</p>	<p>Eggly, S., Barton, E., Winckles, A., Penner, L. A., & Albrecht, T. L. (2015). A disparity of words: Racial differences in oncologist–patient communication about clinical trials. <i>Health Expectations</i>, 18(5), 1316–1326. Free video stock footage: https://www.videvo.net/, YouTube Creative Commons: https://www.youtube.com/user/creativecommons</p>
<p>• Consider engaging a trial navigator. For outreach to marginalized populations, lay navigators can help address participants' practical and logistical barriers to clinical trial recruitment and retention.</p>	<p>Cartmell, K. B., Bonilha, H. S., Matson, T., Bryant, D. C., Zapka, J., Bentz, T. A., ... & Alberg, A. J. (2016). Patient participation in cancer clinical trials: a pilot test of lay navigation. <i>Contemporary Clinical Trials Communications</i>, 3, 86–93.</p>
<p>• Ensure adequate support for recruitment in community clinics. Community clinics that serve underrepresented groups are likely to be understaffed. The Assessment of Infrastructure Matrix is a tool that can be used by organizations to conduct a selfassessment of their clinical trial infrastructure and performance.</p>	<p>Dimond, E. P., Zon, R. T., Weiner, B. J., St. Germain, D., Denicoff, A. M., Dempsey, K., ... & Grubbs, S. S. (2016). Recap: Clinical trial assessment of infrastructure matrix tool to improve the quality of research conduct in the community. <i>Journal of Oncology Practice</i>, 12(1), 63–64.</p>
<p>• Have a plan for working with community or family gatekeepers. Decisions about participation are often linked to family and community involvement and costs. Partner with institutions that have a historical bond with community. These might include local physicians, businesses, advocacy groups, and/or faith-based communities. Accommodate understandably protective attitudes of family members/community leaders. Invite family members to information sessions/screenings so that they can also ask questions and express concerns. Hold townhall meetings or newsletters to ensure transparency and allay fears. Consider providing incentives to family caregivers of research participants (e.g., compensated for time off work).</p>	<p>George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. <i>American Journal of Public Health</i>, 104(2), e16-e31. Linnan, L. A., D'Angelo, H., & Harrington, C. B. (2014). A literature synthesis of health promotion research in salons and barbershops. <i>American Journal of Preventive Medicine</i>, 47(1), 77–85.</p>
<p>• Use mHealth and social media channels for recruiting geographically dispersed groups. These methods can help reach dispersed and invisible communities; e.g., sexual and gender minorities.</p>	<p>Lunn, M. R., Capriotti, M. R., Flentje, A., Bibbins-Domingo, K., Pletcher, M. J., Triano, A. J., ... & Obedin-Maliver, J. (2019). Using mobile technology to engage sexual and gender minorities in clinical research. <i>PLoS One</i>, 14(5), e0216282. Russomanno, J., Patterson, J. G., & Tree, J. M. J. (2019). Social media recruitment of marginalized, hard-to-reach populations: development of recruitment and monitoring guidelines. <i>JMIR Public Health and Surveillance</i>, 5(4), e14886.</p>
<p>• Develop retention strategies that enhance transparency, build trust, and convey value of participants. Examples: Newsletters, birthday cards, incentives, and sharing interim study findings in plain language.</p>	<p>Abshire, M., Dinglas, V. D., Cajita, M. I., Eakin, M. N., Needham, D. M., & Himmelfarb, C. D. (2017). Participant retention practices in longitudinal clinical research studies with high retention rates. <i>BMC Medical Research Methodology</i>, 17(1), 30. https://doi.org/10.1186/s12874-017-0310-z Otado, J., Kwagyan, J., Edwards, D., Ukaegbu, A., Rockcliffe, F., & Osafo, N. (2015). Culturally competent strategies for recruitment and retention of African American populations into clinical trials. <i>Clinical and Translational Science</i>, 8(5), 460–466.</p>

Table 4:

Measure Selection Checklist

Relevant cross-cutting themes: Structural Factors, Intersectionality	
Tips for pilot or other low-budget studies: Use already-validated measures in different languages or for different groups. Pilot measures to assess their psychometrics for use in larger studies.	
Item and Description	References and Resources (<i>Pain-specific articles italicized</i>)
<p>• Seek input from Stakeholder/ Community Advisory Board on measure selection. The Board can help select meaningful and relevant outcomes and give feedback on other measures.</p>	<p><i>Hurtubise, K., Brousselle, A., Noel, M., & Camden, C. (2020). What really matters in pediatric chronic pain rehabilitation? Results of a multi-stakeholder nominal group technique study. Disability and Rehabilitation, 42(12), 1675–1686.</i></p>
<p>• Collect inclusive demographic data. More inclusive and comprehensive data will enable learning about the pain experience of marginalized or intersectional identities. Consider including: racialized group/ethnicity, sexuality, sex and gender identity (including trans and intersex individuals), and disability status. Enable self-identification of demographics and dimensions of identity through open-ended questions and “check all that apply” formats. Collect information about preferred pronouns and titles (Mr., Ms., Mx.) early in recruitment process, and do not assume the gender of spouses. Do not equate sex assigned at birth with gender.</p>	<p>Wadsworth, L. P., Morgan, L. P., Hayes-Skelton, S. A., Roemer, L., & Suyemoto, K. L. (2016). Ways to boost your research rigor through increasing your cultural competence (part 1 of 2). <i>The Behavior Therapist, 39(3), 76–82.</i> Mapes, B. M., Foster, C. S., Kusnoor, S. V., Epelbaum, M. I., AuYoung, M., Jenkins, G., ... & All of Us Research Program. (2020). Diversity and inclusion for the All of Us research program: A scoping review. <i>PLoS One, 15(7), e0234962.</i> Bauer, G. R., Braimoh, J., Scheim, A. I., & Dharma, C. (2017). Transgender-inclusive measures of sex/gender for population surveys: Mixed-methods evaluation and recommendations. <i>PLoS one, 12(5), e0178043.</i> Ready, Set, Go! Guidelines and Tips For Collecting Patient Data on Sexual Orientation and Gender Identity (SOGI): https://www.lgbtqihealtheducation.org/publication/ready-set-go-guidelines-tips-collecting-patient-data-sexualorientation-gender-identity/ Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys: https://williamsinstitute.law.ucla.edu/publications/geniuss-trans-pop-based-survey/</p>
<p>• Obtain or create measures in non-English languages. Common pain scales including the PROMIS measures, Pain Catastrophizing Scale, the Oswestry Disability Index and the Roland Morris disability questionnaire have been translated and validated in a variety of languages. Consult with colleagues who have worked with the priority population to find out if they have already translated/adapted measures. If creating a new translation, follow best practices for translating and validating measures.</p>	<p>Sousa, V. D., & Rojjanasrirat, W. (2011). Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. <i>Journal of Evaluation in Clinical Practice, 17(2), 268–274.</i> PROMIS scales (including pain-related measures) available in Spanish and other languages: https://www.healthmeasures.net/explore-measurementsystems/promis/intro-to-promis/available-translations Self-Management Resource Center: (Spanish and French versions of common scales for chronic disease studies): https://www.selfmanagementresource.com/resources/evaluation-tools/</p>
<p>• Collect qualitative data to enable in-depth and/or mixed-methods assessments of study processes and outcomes. Qualitative data collection (focus groups, in-depth interviews, open-ended responses, other textual data) can reveal nuances of patient experiences with pain or pain treatment, identify mechanisms of intervention effect, identify reasons for efficacy of lack of efficacy of an intervention or treatment, aid in discovery of mediators and moderators, and characterize intragroup diversity.</p>	<p><i>Luckett, T., Davidson, P. M., Green, A., Boyle, F., Stubbs, J., & Lovell, M. (2013). Assessment and management of adult cancer pain: a systematic review and synthesis of recent qualitative studies aimed at developing insights for managing barriers and optimizing facilitators within a comprehensive framework of patient care. Journal of Pain and Symptom Management, 46(2), 229–253.</i> <i>Torres, C. A., Thorn, B. E., Kapoor, S., & DeMonte, C. (2017). An examination of cultural values and pain management in foreign-born Spanish-speaking Hispanics seeking care at a federally qualified health center. Pain Medicine, 18(11), 2058–2069.</i> Calderon, J., Baker, R., & Wolf, K. (2000). Focus groups: a qualitative method complementing quantitative research for studying culturally diverse groups. <i>Education for Health, 13(1), 91–95.</i> Grace, D. (2014). Intersectionality-informed mixed methods research: A primer. <i>Health Sociology Review, 19(4), 478–490.</i></p>
<p>• Collect data on protective sociocultural factors. Understanding the role of protective factors can be helpful in identifying intervention targets. Examples are resilience, community cohesion, dimensions of ethnic identity, cultural pride, religiosity/spirituality, and social support.</p>	<p>Anderson, R. E., & Stevenson, H. C. (2019). RECASTing racial stress and trauma: Theorizing the healing potential of racial socialization in families. <i>American Psychologist, 74(1), 63.</i> Anderson, R. E., Jones, S. C., & Stevenson, H. C. (2020). The initial development and validation of the Racial Socialization Competency Scale: Quality and quantity. <i>Cultural Diversity and Ethnic Minority Psychology, 26(4), 426.</i> Resnicow, K., Patel, M. R., Green, M., Smith, A., Bacon, E., Goodell, S., ... & Stiffler, M. (2020). Development of an Ethnic Identity Measure for Americans of Middle Eastern and North African Descent: Initial Psychometric Properties, Sociodemographic, and Health Correlates. <i>Journal of Racial and Ethnic Health Disparities, 1–12.</i> PhenX Toolkit for collecting data on social determinants of health: https://www.phenxtoolkit.org/collections/view/6</p>

• Collect data on indicators of racism and structural inequities.

These can be at the individual level (e.g., experiences of discrimination) or at the community level (e.g., residential segregation).

Shariff-Marco, S., Breen, N., Landrine, H., Reeve, B. B., Krieger, N., Gee, G. C., ... & Johnson, T. P. (2011). Measuring everyday racial/ethnic discrimination in health surveys: how best to ask the questions, in one or two stages, across multiple racial/ethnic groups? 1. *Du Bois Review: Social Science Research on Race*, 8(1), 159.

Krieger, N., Waterman, P. D., Batra, N., Murphy, J. S., Dooley, D. P., & Shah, S. N. (2017). Measures of local segregation for monitoring health inequities by local health departments. *American Journal of Public Health*, 107(6), 903–906.

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Table 5:

Data Collection Procedures Checklist

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design	
Tips for pilot or other low-budget studies: If there is not sufficient budget for transportation, dependent care or home travel, consider offering remote options.	
Item and Description	References and Resources (<i>pain-specific articles italicized</i>)
<p>• Consider ways to reduce/offset travel burden for data collection visits. Provide travel funds, transportation, and/or options to collect data remotely (including via sensors). Consider partnering with a ride-sharing service to provide transportation to clinical sites for research participation, and/or make home visits an option.</p>	<p>Leavens, E. L. S., Stevens, E. M., Brett, E. I., Molina, N., Leffingwell, T. R., & Wagener, T. L. (2019). Use of rideshare services to increase participant recruitment and retention in research: participant perspectives. <i>Journal of Medical Internet Research</i>, <i>21</i>(4), e11166</p> <p>Harkness, A., Gattamorta, K. A., Estrada, Y., Jimenez, D., Kanamori, M., Prado, G., & Behar-Zusman, V. (2020). Latinx health disparities research during COVID19: Challenges and innovations. <i>Annals of Behavioral Medicine</i>, <i>54</i>(8), 544–547.</p>
<p>• Accommodate other practical barriers to data collection visits. Participants lacking work flexibility and paid time off cannot attend data collection visits during business hours. Have flexible options including weekends. Dependent care is a major competing demand that is patterned by gender and age. For home visits, ensure that additional staff are available to help with child or elder care if needed.</p>	<p>Largent, E. A., & Lynch, H. F. (2018). Addressing financial barriers to enrollment in clinical trials. <i>JAMA Oncology</i>, <i>4</i>(7), 913–914.</p>
<p>• Make data collection accessible to people with disabilities. Technology: Use of smartphones or tablets for electronic magnification/contrast enhancement, or text-to-speech technology; in-room videoconferencing; handheld or smartphone amplification. Environment: Adequate lighting, reduce glare and noise. Communication: Speak slowly and in a low tone, rephrase rather than repeat, introduce yourself every time, do not rely on facial expressions, give context to the conversation. Online survey data collection tools often have accessibility options/tools, including reading questions out loud. For cognitively impaired individuals, proxies may be used. Allow long assessments to be completed over multiple occasions.</p>	<p><i>Monroe, T. B., Herr, K. A., Mion, L. C., & Cowan, R. L. (20 and legal issues in pain research in cognitively impaired of adults. International Journal of Nursing Studies, 50(9), 128</i></p> <p>Williams, A. S., & Moore, S. M. (2011). Universal design of research: Inclusion of persons with disabilities in mainstream biomedical studies. <i>Science Translational Medicine</i>, <i>3</i>(82), 82cm12–82cm12.</p> <p>Reed, N. S., Ferrante, L. E., & Oh, E. S. (2020). Addressing Hearing loss to Improve Communication during COVID-19 Pandemic. <i>Journal of the American Geriatrics Society</i>.</p> <p>Rios, D., Magasi, S., Novak, C., & Harmiss, M. (2016). Conducting accessible research: including people with disabilities in public health, epidemiological, and outcomes studies. <i>American Journal of Public Health</i>, <i>106</i>(12), 2137–2144.</p> <p>Web content accessibility guidelines: https://www.w3.org/WAI/standards-guidelines/wcag/</p>

Table 6:

Data Analysis Checklist

Cross-cutting themes: Stakeholder Engagement, Structural Factors, Limitations of Disparity Analysis, Intersectionality	
Tips for pilot or other low-budget studies: Focus on exploratory analysis and hypothesis generation.	
Item and Description	References and Resources (<i>pain-specific references are italicized</i>)
<p>• Involve Stakeholder/ Community Advisory Board in data interpretation. Board members can bring new perspectives to data interpretation, and the process of examining data can strengthen partnerships. Data can be presented in simplified or “dashboard” form, and reactions from Board members elicited. Board members can also help identify, validate, and explicate qualitative themes, or play a role in coding data. Consider training Board members in the basics of data analysis and interpretation. Data interpretation can take place on an ongoing basis by presenting Board members with interim results.</p>	<p>Hosting a “data party”: https://www.betterevaluation.org/en/evaluationoptions/data_party The Data Jam Initiative is a flexible curriculum designed to create spaces for teams to work together on real data analysis projects: https://fyi.extension.wisc.edu/datajams/ Presentation about training patient advisors to be engaged in data analysis and interpretation: https://www.pcori.org/sites/default/files/ACTIVATETraining-Patients-in-Data-Analysis.pdf Watkins, D. C. (2017). Rapid and rigorous qualitative data analysis: The “RADaR” technique for applied research. <i>International Journal of Qualitative Methods</i>, 16(1), 1609406917712131.</p>
<p>• Interpret data within the context of a diversity, rather than disparity, framework. Data do not speak for themselves; we must make meaning within a diversity framework including sociocultural and sociohistorical contexts. Null results may be misinterpreted.</p>	<p><i>Meghani, S. H., & Chittams, J. (2015). Controlling for Socioeconomic Status in Pain Disparities Research: AllElse-Equal Analysis When “All Else” Is Not Equal. Pain Medicine 16(12), 2222–2225. doi:10.1111/pme.12829.</i> Plaut, V. C. (2010). Diversity science: Why and how difference makes a difference. <i>Psychological Inquiry</i>, 21(2), 77–99. NIMHD Minority Health and Health Disparities Research Framework https://www.nimhd.nih.gov/about/overview/researchframework/</p>
<p>• Use analytic techniques that accommodate intersectionality. Analytic methods such as ANOVA, hierarchical class analysis, cross-tabulation, logistic regression, moderated mediation, multilevel modeling, latent class analysis, and moderation within metaanalysis can be used to assess intersectionality.</p>	<p>Else-Quest, Nicole M., and Janet Shibley Hyde. “Intersectionality in quantitative psychological research: II. Methods and techniques.” <i>Psychology of Women Quarterly</i> 40.3 (2016): 319–336. Bauer, G. R., & Scheim, A. I. (2019). Advancing quantitative intersectionality research methods: Intracategorical and intercategory approaches to shared and differential constructs. <i>Social Science & Medicine</i>, 226, 260–262.</p>
<p>• Leverage sample diversity in secondary data analysis. Combining samples for greater sample size allows for a broader conceptualization of diversity. Conduct and report exploratory analyses on existing datasets to examine the impact of diverse experiences and exposures on pain.</p>	

Table 7:

Reporting and Dissemination Checklist

Relevant cross-cutting themes: Stakeholder Engagement, Universal Design	
Tips for pilot or other low-budget studies: Use low-cost strategies, e.g., social media, newsletters of relevant organizations, university communications/public relations departments.	
Item and Description	References and Resources (<i>pain-specific references are italicized</i>)
<p>• Use a variety of channels to disseminate results to participants, communities, and the public. It is important to disseminate beyond scholarly publications; it is a way to give back and helps foster ongoing relationships between academic and community partners. Stakeholder/community advisory board should be involved in dissemination efforts and can help to identify appropriate channels. Examples include: social media, webinars, community talks, “research cafes”, and hosting events in accessible locations like faith communities, libraries or movie theaters.</p>	<p><i>Chambers, Christine T. “From evidence to influence: dissemination and implementation of scientific knowledge for improved pain research and management.” Pain 159 (2018): S56-S64.</i> <i>Vieira, A. C. G., Bueno, M., & Harrison, D. (2020). “Be sweet to babies”: Use of Facebook as a method of knowledge dissemination and data collection in the reduction of neonatal pain. Paediatric and Neonatal Pain, 2(3), 93–100.</i> Chen, P. G., Diaz, N., Lucas, G., & Rosenthal, M. S. (2010). Dissemination of results in community-based participatory research. <i>American Journal of Preventive Medicine, 39(4)</i>, 372–378. Ross-Hellauer T, Tennant JP, Banelyt V, Gorogh E, Luzi D, Kraker P, et al. (2020) Ten simple rules for innovative dissemination of research. <i>PLoS Computational Biology</i> 16(4): e1007704. https://doi.org/10.1371/journal.pcbi.1007704</p>
<p>• In publications, describe stakeholder engagement in detail. This adds validity to the study processes and will also promote the adoption of engagement strategies by other pain researchers. Consider use of GRIPP2 guidelines for the reporting of patient and public involvement in research.</p>	<p>Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., ... & Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. <i>BMJ, 358</i>.</p>
<p>• Refer to emerging guidance for how to report racialized group and ethnicity in academic journals. These guidelines—sometimes specific to journal or discipline-- include a process for choosing terminology, usage considerations, and what additional information should be included in reporting data by racialized group/ethnicity.</p>	<p><i>Booker, S. Q., Bartley, E. J., Powell-Roach, K., Palit, S., Morais, C., Thompson, O. J., ... & Fillingim, R. B. (2021). The Imperative for Racial Equality in Pain Science: A Way Forward. The Journal of Pain.</i> Flanagin, A., Frey, T., Christiansen, S. L., & Bauchner, H. (2021). The reporting of race and ethnicity in medical and science journals: comments invited. <i>JAMA, 325(11)</i>, 1049–1052. Palermo, T. M., Alderfer, M. A., Boerner, K. E., Hilliard, M. E., Hood, A. M., Modi, A. C., & Wu, Y. P. (2021). diversity, equity, and inclusion: reporting race and ethnicity in the Journal of Pediatric Psychology.</p>
<p>• Use reader-friendly data visualization to convey findings. Make sure that results are presented in plain language with the use of visuals; e.g., infographics.</p>	<p>Easy-to-use data visualization tips and techniques: https://stephanievergreen.com/blog/ For free photos: Unsplash: https://unsplash.com/, Flickr Creative Commons: https://www.flickr.com/creativecommons/, Google Creative Commons: https://search.creativecommons.org/ Free photos and icons: The Noun Project: https://thenounproject.com/, Iconfinder: https://www.iconfinder.com/free_icons</p>
<p>• Consider how results can be used for policy advocacy. Refine key messages from study that can be placed on public and policymakers’ agendas. Assess and understand policy environment and foster relationships with policy actors. Work with advocacy or professional organizations. Consider press releases or op-ed pieces. Per CBPR principles, consider training Board members or other community partners in advocacy techniques to address issues of concern to the community.</p>	<p><i>Wilson, M. G., Lavis, J. N., & Ellen, M. E. (2015). Supporting chronic pain management across provincial and territorial health systems in Canada: findings from two stakeholder dialogues. Pain Research and Management, 20(5), 269–279.</i> Ajayi, Ushie, & Kabiru (2021) Turning findings into policy: six tips for researchers. <i>The Conversation</i>. https://theconversation.com/turning-findings-into-policy-six-tips-for-researchers-157971</p>