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PERSPECTIVES

Operationalizing Trauma-Informed Principles to Build Safe, Inclusive, and Equitable Patient Partnerships in Pediatric Pain Research

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Abstract: Advancing inclusion in pediatric pain research requires approaches that move beyond recruitment diversity toward authentic partnerships with youth and families whose lived experience can inform scientific rigor, relevance, and ethical integrity. Although patient engagement is widely endorsed, practical guidance for implementing partnerships that are safe, equitable, and sustainable remains limited, especially when working with populations exposed to intersectional marginalization and stigma. In this perspective, we argue that trauma-informed principles provide a critical framework for structuring meaningful patient partnerships in pediatric pain science. In collaboration with our patient partner (co-author, SS), we situate contemporary partnership approaches within their historical foundations in the justice-oriented movements that first recognized lived experience as a form of expertise. We then synthesize evidence describing benefits of patient engagement for research quality, feasibility, and translation, alongside emerging data on benefits for patient partners themselves. We use a case example from our lab to illustrate how patient partners can shape study design, language, recruitment, and ethical safeguards in ways that strengthen methodological and contextual validity. We also examine structural, relational, and emotional barriers that may limit equitable, rewarding participation if not intentionally addressed. In response to these barriers, we propose a partnership framework that links core trauma-informed care (TIC) principles (eg, safety, transparency/trustworthiness, peer support, collaboration, empowerment, cultural responsiveness) to actionable strategies and underlying mechanisms toward authentic engagement. We conclude inclusive partnership practices can help pediatric pain researchers to build collaborations that are ethically grounded, methodologically robust, and amplify the voices and priorities of youth living with pain.

Plain Language Summary: Young people living with chronic pain have valuable ideas that can improve research about pain when they are included as partners, not just participants. Working with patient partners can make research studies more useful, relevant, and respectful. However, many researchers are unsure how to build partnerships that feel safe, fair, and supportive, especially for youth who have had negative healthcare experiences. In this perspective, we explain why it is crucial for pediatric pain researchers to ensure their partnerships include diverse perspectives and treat partners as true equals. We describe how patient partners can improve how researchers design their studies, connect with participants, and interpret the information they gather in their studies, and help the findings to be used in patient care. We also talk about how patients benefit from these partnerships, by helping them feel heard, connected, and able to make a difference. Using an example from one of our studies, we show how patient partners help improve study materials, questions asked, and overarching research plans, as well as avoid unintended harm. We review common challenges with partnerships (eg, limited time, unclear roles, burden) and offer practical suggestions for addressing them. These suggestions focus on safety, trust, respect, and making decisions together – all approaches that acknowledge that patients may have had difficult experiences. In sum, thoughtful and inclusive partnerships help make sure that pediatric pain research reflects the real needs and priorities of the young people it aims to serve.

Keywords: pediatric pain, patient partnerships, lived experience, trauma-informed care, inclusivity, equity

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Introduction

Patient-oriented health research has shifted the field beyond viewing patients solely as research subjects toward their integration as key interest-holders and genuine collaborators across the research lifecycle.[1,2] Patient partnership, the meaningful and active collaboration with people with lived experience (and their families and caregivers, as appropriate), in the priority-setting, study design, conduct, and dissemination of research, strengthens rigor, feasibility, and translation, while advancing inclusion.[3,4] With care and strong guiding principles, patient partnerships, particularly with historically marginalized communities, serve as both methodologically innovative and a necessary act of social justice.[5] In pediatric pain, the case for patient partnership is especially compelling: youth experience and express pain in developmentally distinct ways,[6,7] youth and caregiver priorities often diverge from clinician assumptions,[8,9] and longstanding sampling homogeneity has constrained generalizability and perpetuated inequities in prior pain research.[10] In this perspective, we argue that pediatric pain research can fulfill its scientific and ethical obligations only when partnerships are intentionally designed to be safe, inclusive, and equitable.

We offer our perspective in several parts: (1) situating contemporary patient partnerships within their historical and ethical foundations, (2) synthesizing existing evidence on the bidirectional benefits of partnerships for teams and patients, (3) illustrating the impact of partnership through a study of gender identity and chronic pain among transgender and gender diverse adolescents and young adults, and (4) delineating the structural, relational, and emotional barriers that often undermine safe and equitable partnership for teams and partners. We then offer a trauma-informed, equity-centered operational framework for patient partnership in pediatric pain research. Drawing on the key principles of trauma-informed care, we translate values into concrete, actionable strategies that redistribute decision-making power, enhance psychological safety, and prevent tokenism across all study phases. In each component of this perspective, we include reflections and direct quotations from our patient partner (co-author, SS). Our goal is to offer researchers, patient partners, and institutions a pragmatic, ethically grounded, theoretically driven framework for cultivating partnerships that are not only meaningful but also safe, inclusive, and enduring. While prior scholarship documents the value of both patient engagement and trauma-informed principles individually, existing patient engagement frameworks rarely operationalize principles into behavioral guidance or integrate trauma-informed theory with equity-centered partnership design. Our framework addresses this translational gap by linking principles, mechanisms, and actionable strategies.

Consistent with reflexive approaches to conceptual scholarship, we (AS, HR, JC) acknowledge that our multidisciplinary training, clinical and research experience in pediatric pain settings, and commitments to equity-centered and trauma-informed care shape the lens through which we interpret the role of patient partnership. Collaboration with patients with lived experience, our local Patient-Family Advisory Committee, and our patient partner (co-author, SS) informed our understanding of the interpersonal and systemic dimensions of patient partnership. We offer this perspective and framework transparently as one viewpoint, intended to advance dialogue about inclusive partnership practices.

Historical and Ethical Foundations

Participatory action and community-engaged research have long been established as effective methodologies and as drivers of change in health research. Their origins are deeply rooted in advocacy movements and embody principles of health equity and social justice. Patient partnerships were predicated on social movements that challenged who is permitted to speak, decide, and lead, within knowledge-producing institutions such as healthcare and research. Within the disability rights movement, activists rejected the notion that medical professionals were the sole experts on disability and advanced a social model that located disability within socially driven barriers and policies, rather than bodies alone.[11,12] From this movement, the principle “Nothing About Us Without Us” re-emerged to demand that individuals with disabilities be directly involved in policymaking, research priority-setting, determining clinical standards, and care delivery design.[13] The recognition of lived experience as expertise, a concept previously absent from healthcare, is widely understood to stem from this movement and simultaneous activism within the LGBTQ+ community during the HIV/AIDS crisis. LGBTQ+ activists demonstrated that excluding lived experience leads to harm, whereas inclusion improves relevance, ethics, and trust.[14,15] These ethical movements led to the recognition that health research questions often fail to reflect patient priorities, study outcomes are misaligned with lived experience, and marginalized communities were being systematically excluded.[16,17] Similarly, Indigenous sovereignty movements, feminist health movements, and mental health consumer and survivor movements asserted the rights of impacted communities to be heard, credited, and centered.[18–20] This laid the intellectual groundwork for intersectionality theory[21,22] and emphasized that health experiences are shaped by interacting social identities and systems of power. More recently, the Patient-Centered Outcomes Research Institute (PCORI) institutionalized a response to these very concerns, embedding patient engagement into the infrastructure of health research in the United States by resourcing patient engagement and evaluating it as expected practice.[4,16,17]

Consistent with these justice-oriented foundations, patient engagement has often been conceptualized along a continuum of involvement, defined by the degree of influence patients hold over decision-making processes, ranging from informing and consulting to involving, collaborating, and empowering partners to share knowledge and decision-making authority.[23] This continuum underscores that engagement varies not only in presence, but in the extent to which lived experience meaningfully shapes research priorities, processes, and interpretation.

These foundations of patient partnership are particularly salient in pain research, where lived experience is central to understanding discomfort, suffering, disability, and engagement in care, yet pain itself is often been marginalized in research and clinical care. Given the subjective nature of pain and the many biopsychosocial factors contributing to its development and maintenance, the experience of chronic pain cannot be fully characterized through biomedical metrics alone. Patient partnership offers a mechanism to align research priorities, methods, and outcomes with what matters to those living with pain. Importantly, the rationale for patient partnership is not solely instrumental. Even in the absence of measurable improvements in study outcomes, inclusion remains an imperative grounded in principles of justice, representation, and respect for experiential knowledge. Thus, patient partnership should be understood not only as a strategy for improving research, but as a standard for conducting it responsibly.

Bidirectional Benefits of Partnership

For Research Teams

Beyond its ethical imperative, patient partnership offers practical advantages for research teams. A growing body of qualitative and mixed methods evidence demonstrate that patient partnerships can improve the overarching quality of empirical research, which, through direct improvements on methodological design and generalizability, also hold indirect benefits for the population being studied. First, patient partners bring unique insights from their lived experiences navigating their health conditions and participating in healthcare systems that are difficult for research teams to intuit or access independently.[16,17,24] Second, patient partnerships may improve participant engagement in research and, in turn, support more inclusive and applicable findings for dissemination and implementation. This promotes research that is likely to be adopted in clinical settings.[25] For instance, during study design, patient partners help teams to ensure the relevance and quality of research questions, that research participation is not burdensome to patients, that measurement tools are accessible and appropriate, and that interventions align with patient preferences and daily realities.[24,25] Third, patient partnerships can improve the quality and efficiency of healthcare research. Studies that involve patient partners have been associated with improvements in rigor, feasibility, quality, and relevance,[26] fewer endeavors that fail to result in meaningful benefit, better translation of findings into clinical practice,[27,28] and increased transparency and accountability.[29] Moreover, research teams may experience intrapersonal and intellectual benefits, including novel learning opportunities, personal growth in understanding and humility, and meaningful insights that shape future projects and professional development.[30,31] Researchers also benefit from strengthened confidence, authenticity, and legitimacy, knowing they have taken critical steps to reduce personal biases and assumptions in data interpretation,[31,32] a dimension of partnership impact that remains underexamined in engagement scholarship. While much of this evidence derives from qualitative or observational designs rather than trials determining causation, convergence across methodologies suggests consistent perceived and practice-level benefits for research teams.

For Patient Partners

The body of literature exploring and measuring the benefits of partnership for patients remains comparatively small, relative to that which has been conducted with research teams.[33] While often motivated primarily by altruism (eg., the desire to improve the health system and benefit other patients),[34,35] patients may also experience substantial personal benefits from engaging as research partners. Our patient partner (co-author, SS), collaborated with our team on a literature review to generate a list of commonly cited benefits for patient partners. SS then reflected upon their experiences as a partner and offered quotations in direct response to the comprehensive list. SS agreed to quote placement and context below; no quotes were omitted from their contributions to the text below.

SS first reflected on their motivations for engaging in partnership with our team:

> I wanted to give back and help ensure that future patients would be able to receive the same amazing care that I did. It has been incredibly meaningful to be able to pay it forward by helping to influence a research study and help others receive improved care. I know that the work I am doing will have a direct impact on improving the care that other young people with chronic pain will receive.

More personal benefits for patient partners include: having their voice heard, feeling valued by and connected to the healthcare system, maintaining and developing new relationships, distress relief and self-improvement, and softening power imbalances between researchers, clinicians, and patients.[34–38] As SS notes, this can include building confidence and trust in the research process as a whole:

> Seeing how pain research is conducted has been an incredibly eye-opening experience for me. I am someone who always loves to understand how things work and why things are the way they are, so being able to go behind the curtain and see how the research is done, knowing that similar research helped to inform the care I received, has been valuable. To see all the different hurdles that the team has to jump through and the care with which the [research is] being conducted brings not only confidence, but trust in how medical research is done.

Participation can also help patient partners to clarify their own perspectives and promote their own personal growth through experiential knowledge:

> Being a part of this research team [exploring the intersection of pain and gender identity] helped me to think about and clarify how I feel and think about these topics. I have independently explored how my experience with chronic pain has influenced and changed how I think about my gender identity and body. It also helped me to learn how to work with people coming from a very different set of experiences. As someone whose work outside of the study revolves around collaboration, this experience will help me in my career.

Partnership can also offer a unique form of support and emotional connection, which SS notes experiencing during a key healthcare transition:

> I had just finished my time [in pain rehabilitation] and knew I was going to be losing some of the direct contact with medical professionals I had loved and made me feel safe. Joining this team of people who have studied chronic pain and continue to work with other adolescents and young adults with chronic pain lessened some of that separation anxiety.

Perhaps most pertinent to equity, patient partnerships allow those with lived experience to fundamentally shape research that reflects real-world needs, instead of exclusively academic, institutional, or political interests, thus democratizing the research agenda.[16,17]

A Case Example

The following case example illustrates how meaningful collaboration with our patient partner (co-author, SS) has served not only as a methodological strength but also an ethical safeguard for study participants, supporting sound pain science and inclusivity. As youth with historically marginalized social identities are at heightened risk for poorer pain outcomes, in our recent study, we examined how transgender and gender-diverse adolescents and young adults (TGD-AYA) living with chronic pain and multidisciplinary pain providers understand the intersections of gender identity and pain, as well as the barriers and facilitators to affirming pain care, using a mixed-methods approach. Because this work sits at the complex juncture of two marginalized, frequently misunderstood, and clinically contested identities, as patient partner, SS helped to ensure that our inquiries and interpretations reflected and respected the realities of TGD-AYA living with pain. This was accomplished through their integration as a valued and compensated member of the research team from the inception of the study, via regular attendance at study meetings, preparatory review and editing of materials between meetings, and informal updates and check-ins (eg, via email, text) between work sessions Importantly, while the TGD-AYA study began with two patient partners, our second partner stepped away from the project unexpectedly due to worsening health. At this time, SS had established rapport with the team, had built confidence as a valued contributor, and expressed comfort continuing in their role independently. In fact, they highlighted that bringing a partner in mid-study could be inadvertently more challenging for the new member to feel integrated and informed.

Table 1 details SS' contributions to the TGD-AYA study's language, recruitment processes, interview protocols, and risk-mitigation plans from the perspective of the researchers (AS, HR, JC), as well as the ways in which engaging in

Table 1 Bidirectional Benefits of Patient Partnership by TGD-AYA Study Stage

Study Stage	Researchers' (AS, HR, JC) Description of How Patient Partnership was Helpful to Each Project Stage:	Patient Partner's (SS) Description of How Their Engagement in Each Project Stage was Impactful:
Study design	"SS identified terminology and protocol pain points prior to study initiation by providing insight into how aspects of the protocol would be perceived by participants (eg, protecting patient safety, establishing researchers as 'safe,' reducing burden) This resulted in a deliberate, community-centered study design that reflected the priorities of the TGD-AYA community. SS bridged the gap between medical jargon and accessible language (eg, on consent forms). This facilitated the integration of important messaging while maintaining transparency and conveying safety." (JC)	"Coming into the project at the start, a time when I could have influence, was crucial to my feeling of ownership and ability to contribute freely. I was able to think about ways in which the design and protocol would be most inclusive. Being able to offer suggestions of language and other ways of engaging to help make the study a place where everyone could be heard, and to have those suggestions considered seriously and implemented, helped me to feel confident in being a valued member of the team. I also had worries about needing to speak for an entire identity group and learn lots of new medical terms and concepts. At this early stage, I was able to talk through these concerns and understand the new language. This gave me the space to ask questions because I did not feel like I was behind." (SS)
Recruitment	"SS' input on study materials and recruitment methods helped to design and refine solid recruitment processes. Their input ranged from community norms (eg, text vs. Email use among AYAs) to diversifying recruitment methods (eg, considerations of online access, privilege of affirming homes) to improve inclusivity and reach. They constructively challenged recruitment plans, resulting in materials that reflect community values through inclusive images and language. They encouraged the team to pause and reflect on the reasons for recruitment challenges, before generating solutions." (HR)	"This was a part of the project where I struggled at first. I needed to constantly remind myself not to feel compelled to speak for entire identity groups. I did not know how different people might react or respond to the recruitment methods we were exploring. The team's willingness to explore different options helped me to gain confidence… I was surprised by the questions I was able to answer, just with the knowledge of the tendencies of people my age. Being able to ensure that all potential study participants would be able to understand the terms and processes being thrown at them was important to me, since I was always in a position to ask questions and clarify when they were unclear for me… I also enjoyed the opportunity to improve on how we recruit participants, as it is important to me that those who take part in the study represent as wide a range of experiences as possible." (SS)

(*Continued*)

Table 1 (Continued).

Study Stage	Researchers' (AS, HR, JC) Description of How Patient Partnership was Helpful to Each Project Stage:	Patient Partner's (SS) Description of How Their Engagement in Each Project Stage was Impactful:
Qualitative Interview Development	"When designing the interview, SS ensured that questions were asked in an affirming manner, with sensitivity to the emotion they might evoke. Their input reduced risk (eg, not asking questions that did not further the study's aims, adding a discussion of strengths), incorporated expressions of safety and empowerment, and reduced burdens of participating (eg, shortening length, appropriate remuneration). This helped to increase interview efficiency and clarity (eg, refining when a question was about pain, gender identity, or both)." (HR)	"It has personally heavily interested me to think about how you can ask a question in a way that provides the most space for an answer while also being respectful of the patient. As someone careful not to speak for an entire identity group, it was additionally important to me that the questions were framed in a way that did not ask the participants to feel that way." (SS)
Mock interviews	"Practicing the interview with SS created a safe place for us to make and learn from mistakes and highlighted what felt most genuine, given our relationship with SS. They facilitated consideration of how questions, tone, and approach landed when posed directly to a person with lived experience (vs. on paper), which positively shifted the interview feel. SS also identified non-verbal opportunities for us to convey safety and inclusivity to participants (eg, wearing rainbow lanyards/pride pins)." (AS)	"The mock interview helped me to personally explore how my experience with chronic pain has influenced and changed how I think about my gender identity. As someone who struggles to feel comfortable in the body they are in, the added layer of sometimes debilitating chronic pain further amplifies a desire for change and feelings of sadness for the body I am in. It also further brought to light for me how each of these two identities can feed on the other to make pain, dysphoria, sadness, and anxiety more prevalent… I spent a lot of time thinking about the questions we would ask and how the interview would work. Being able to experience firsthand what it would be like for participants gave me a better understanding of how we might be able to make the study more inclusive to everyone." (SS)

these study elements personally impacted SS. To create Table 1, SS collaborated with our team to determine the core domains of their contributions to the study. To describe the benefits of partnership for the research team/study itself, the researchers reviewed meeting agendas/summaries, as well as tracked changes and comments on study documents. It is also our team's general process to note team members' contributions to study, to support accurate acknowledgement and authorship equity. Simultaneously, SS reflected on their experience with each study domain and offered direct quotations on their experience, all of which are included in Table 1. The TGD-AYA study case example illustrates mechanisms through which our patient partnership influences research integrity: ethical and equity calibration, linguistic accessibility optimization, and contextual validity checking. Such mechanisms help explain how true partnership affects methodological rigor beyond that which may be offered by surface-level engagement.

Barriers to Safe, Inclusive, Equitable Collaboration

While invaluable, patient partners in pediatric pain research can face unique vulnerabilities due to their lived experiences as individuals with pain, potentially holding other marginalized social identities, and serving as consultants on those experiences. Their engagement in research may entail disclosure of deeply personal material, exposure to invalidating narratives, and pressures to best represent broader communities. Pediatric contexts must also account for evolving developmental capacity, family dynamics, and protections for vulnerable groups as well. Thus, awareness of structural, relational, and emotional barriers to safe and equitable partnership (and in turn, efforts to ameliorate them) are essential not only to successful collaborations but also to preventing harm. Without this, tokenism remains a central risk in patient engagement work.[39] Various frameworks for patient engagement (eg, INVOLVE, GRIPP2) warn that patient involvement can quickly become merely symbolic rather than substantive,[40,41] particularly at less involved levels of the engagement continuum[23] (eg, informing or consulting) At these levels, lived experience perspectives may be solicited but they are often not substantively integrated into research processes and decision-making.

Below, we begin with an overview of various structural barriers, as these can shape and constrain relational dynamics. Then, we review potential interpersonal and emotional barriers to successful partnerships, with these sections primarily written by our patient partner, SS.

Structural Barriers

- Funding: Equitable partnerships require sufficient funding to compensate patients for their time and effort, funding that, if not budgeted for,[42,43] can pose challenges to successful and fair patient engagement. Resource constraints may limit the number and diversity of patient partners with whom teams are able to engage, which can result in increased workload and emotional burden for existing partners. These challenges highlight the importance of designing partnership frameworks that remain feasible across resource-diverse research contexts.
- Institutional policy gaps: While review boards and funding sources often inquire about involvement of communities in research design, this has not yet been mandated universally. Consequently, many institutions lack guidance on creating and sustaining patient partnerships, resulting in no clear workflow, policies, or guidance on patient engagement processes.[43–45] The resulting confusion can open the door to inadvertent missteps that jeopardize the safety and equity of the partnership.
- Training gaps: Without sufficient orientation and training, patient partners may struggle with research processes and terminology, while researchers may lack skills in facilitating meaningful collaboration.[43–45] Without addressing these foundational needs, teams risk a disconnect between key interest-holders, where both parties remain siloed from the lived experience and professional background of the other.
- Regulatory constraints: Empirical analyses demonstrate that institutional review board (IRB) structures and regulatory priorities can conflict with the relational and iterative practices that equitable patient partnerships require, undermining shared decision-making and negatively affecting partners' experience.[46,47] Dense language and multi-step procedures can feel inaccessible and daunting to partners, failing to demystify the research process. Other bureaucratic hurdles slow the implementation of rapid, iterative feedback from patient partners, fostering feelings of disappointment or mistrust if not acknowledged in earnest.

Importantly, each of these structural barriers may also hold consequential influence upon the level of patient engagement along the continuum that is feasible within a given research context.

Interpersonal/Relational Barriers

- Power dynamics: The historical lack of patient inclusion in research has perpetuated a hierarchical dynamic between researchers and patients.[42,48] This dynamic again echoes Arnstein's Ladder of Citizen Participation[49] and Etchegary's engagement continuum,[23] where less involvement (eg, informing, consulting) preserves institutional authority, while more involved partnership allows for shared decision-making and genuine power redistribution Lingering effects of these hierarchies may contribute to partners feeling that their experiential knowledge is undervalued or not being utilized effectively.[28] Importantly, patient partners may also be accustomed to the idea of medical professionals as authority figures. Without efforts to shift this dynamic in partnerships, researchers may be unable to access their partner's full potential.
- Role ambiguity: Joining an established group of research professionals who have gone through intense schooling and may even be viewed as experts in their field can make a patient partner feel unsure of their role on the team. Additionally, patients who are unfamiliar with the concept and value of lived experience partnerships may be unaware of the scope and cadence of their involvement. Absent or vague discussions about these key details can result in a nebulous and dissatisfying experience for patient partners.[50]
- Mismatched expectations: Differing views about what meaningful engagement in research will look like for patient partners can create tension and damage trust between team members.[42,43,48] For example, fragmented engagement

in the research lifecycle (eg, involvement in study design but not grant writing, data analysis, or dissemination) can lead to confusion and invalidation At the same time, pre-determining specific expectations for patient partner involvement without consideration of the partner's interests, capability, and perspective is likely to result in mismatched expectations,[48] which can adversely affect the partner and the work overall.

Emotional/Identity-Related Barriers

- Representation Pressures: It can be difficult for individuals with historically marginalized identities and diverse lived experiences to feel that they must represent their identity or experience in day to day life and in advocacy efforts.[34] This pressure will only be magnified for patient partners, if they perceive they are being asked to do so in the context of a formal research study. This immense pressure to be "the voice" of an entire group can escalate intensely, with the knowledge that their perspective can influence the nature of the study and in turn have lasting impact in medical practice through its outcomes.
- Emotional Burden & Distress: When asking a patient partner to dig deep into identities and experiences that may be uncomfortable, painful, anxiety-provoking, and traumatic, there is a real possibility of experiencing emotional distress. This distress adds to the overarching burden associated with serving in this role, as patient partners are often juggling their research commitments to the research team alongside health management and other life responsibilities,[48] thus increasing the risk of burnout.[51] Questions about privacy and confidentiality (for the partner's lived experience and the study details), when not discussed explicitly, can create apprehension, confusion, and distress.
- "Feeling Out of My Depths": As patient partners may have limited or no experience in the practice of science or medicine, or in conducting research, they may feel intimidated or hesitant to speak up to contribute.[52] They may feel that they are not the most knowledgeable team members and so may naturally worry about overstepping their role. Bringing in related but novel ideas that are not explicitly tied to a question asked of them can be challenging, creating missed opportunities for valued expertise and result in the partner feeling ineffective or isolated.

Collectively, these barriers and challenges rarely appear in isolation. Attempting to address these challenges one by one misses how risk and burden compound, especially for youth and families living with chronic pain. In practice, the accumulation of compounded risks is most often what derails successful partnerships and unintentionally reproduces inequity. These layered complexities require a justice-oriented approach that intentionally designs patient partnerships with safety, inclusion, and accountability built in from the start, rather than as an afterthought or course correction. Inviting patient engagement in research is a vital first step, but pediatric pain researchers must move beyond good intentions to be impactful.

A Framework for Creating Safe, Inclusive, and Equitable Partnerships

There is a critical need for an accessible, feasible, and effective framework to support cultivating and sustaining inclusive and equitable patient partnerships from their inception. We argue that a trauma-informed approach offers robust guidance, ensuring research teams recognize the lived experiences of our patient partners and reduce the likelihood of re-evoking prior harm,[53] instead creating safe, empowering environments for collaboration. Using the six principles that guide Trauma-Informed Care[54] (developed by Substance Abuse and Mental Health Services Administration and detailed in Table 2), we specify concrete, evidence-based strategies[34,38,44,55] to redistribute decision-making power and enhance psychological safety, accompanied by reflections from our patient partner (co-author, SS), on why these choices matter in practice. This trauma-informed approach views patient partnership as an iterative system in which our overarching ways of relating (eg, cultural humility, respect, accountability) mutually reinforce specific strategies to support meaningful engagement We conceptualize trauma-informed partnership as operating through three reinforcing mechanisms: reduction of perceived interpersonal threat, redistribution of epistemic authority, and enhancement of patient partner self-efficacy.

In practice, trauma-informed principles are not intended to be implemented as isolated techniques, but as coordinated design decisions made across the research lifecycle. Early engagement and shared agenda-setting may enhance epistemic

Table 2 Trauma-Informed Model for Patient Partnership: Principles Translated into Implementation Strategies

Principle	Partnership Strategies	Mechanisms Addressed	Why This Matters to Patient Partners
Safety: Creating physical and emotional environments where people feel protected and supported, ensuring that spaces are free from harm, and fostering a sense of safety through their interactions and practices	● Training and orientation to research processes and terminology ● Ongoing emotional support and readily accessible resources ● Check-in opportunities between meetings ● Trigger warnings for sensitive subjects ● Confidentiality regarding study involvement ● Private channels for providing feedback	● Reducing anticipatory threat, emotional risk, and uncertainty ● Increasing psychological safety ● Ensuring autonomy over participation	"Stepping into a world that, for most of us patient partners, is unknown, having resources and opportunities to speak with team members who can help us through potential emotional distress (and understand the medical world we are stepping into) are vital to feeling safe, in addition to any research background, terms, and procedures we may be provided." (SS)
Trustworthiness & Transparency: Building trust through transparency, having open and honest communication, and providing clear and consistent information.	● Clearly articulated, co-defined role definitions ● Transparent compensation structures ● Clearly articulated, co-defined expectations for scope and cadence of participation ● Shared decision-making processes ● Continuous, bidirectional feedback ● Continued offline discussion and check-ins between meetings	● Building epistemic trust and role clarity ● Enabling partners to invest cognitively and emotionally in the work ● Reducing burden ● Allowing the role to evolve over time	"Clear role definitions and expectations, of which we, as patient partners, are a part in creating, are critical to our success as a team because they allow us to trust each other. It is vital that there is room for feedback and flexibility for the role to grow and change as the study and team progress." (SS)
Peer Support: Connecting people with others who have had similar experiences, promoting shared understanding, reducing feelings of isolation, and offering practical advice and support.	● Early and sustained engagement to foster and maintain connections ● Co-patient partner models ● Structured peer mentorship	● Normalizing experience ● Building trust and respect ● Distributing emotional labor ● Reducing feelings of isolation ● Fostering confidence and comfort in sharing perspectives ● Making efforts feel valued and sustaining engagement	"When relationships are established and maintained, we, as patient partners, are more likely to open up about our own experiences and feel comfortable sharing perspectives of often marginalized groups."(SS)
Collaboration: Working together by involving those affected by trauma in decisions about their care, encouraging teamwork, and ensuring that everyone's voice is heard and valued	● Early, ongoing engagement across all phases ● Shared agenda-setting ● Collaborative decision-making ● Co-creation of protocols and materials ● Matching partner to tasks by preference and capacity	● Redistributing decision-making authority ● Shifting partners from consultants to co-producers, ● Promoting ownership of the work ● Fueling engagement and preventing tokenism	"Integrating with the team and engaging with the project early in the research process helped me to feel a sense of ownership. Being seen as a collaborator raises my level of investment and increases the care with which we approach the work." (SS)
Empowerment, Voice, and Choice: Giving people control over their care, respecting their decisions, and fostering resilience.	● Shared power and authority ● Addressing power differentials ● Appropriate, adequate compensation for time and contributions to enable participation ● Flexibility in participation format, communication style, and timelines ● Appropriate recognition ● Sufficient time to review, reflect, and prepare	● Increasing perceived agency and self-efficacy ● Promoting sustained engagement and authentic input ● Conveying that the partner's voice is central ● Making participation worthwhile and feasible	"Compensation, recognition, allowing for flexibility in our participation, and addressing potential power imbalances help us, as patient partners, to feel empowered to contribute as we purposefully take time out of our busy lives to be part of a study." (SS)
Cultural, Historical, and Gender Awareness: Understanding and respecting diverse backgrounds and experiences, being sensitive to cultural differences, recognizing the impact of historical and gender-related trauma.	● Intentional trust-building with historically marginalized communities as first step ● Structural equity in recruitment, authorship, and compensation practices ● Use of inclusive language ● Flexibility, respect for, and tailoring to individual preferences	● Signaling safety ● Reducing identity threat and anticipatory marginalization ● Allowing partners to participate without self-monitoring ● Showing willingness to meet people where they are	"The team's awareness of our being a part of marginalized groups and that, as patients, we have often viewed medical professionals as authority figures, is vital to our successful engagement with the team. It ensures that they truly listen to our ongoing needs as a part of building trust and respect." (SS)

authority by positioning patient partners as contributors to research priorities, while flexible communication structures and transparent expectations may reduce perceived interpersonal threat and support sustained participation. Across the research lifecycle, these trauma-informed strategies function cumulatively, shaping how partners interpret their role, the degree to which their perspectives influence decisions, and whether partnership feels meaningful, feasible, and safe. Rather than prescribing a fixed model of engagement, the framework is intended to support dynamic, context-sensitive decisions that aligns partnership structures with study goals, partner preferences, and available resources. As illustrated in our case example and SS's contributions throughout this perspective, these principles operate iteratively, with our patient partner influencing not only study focus, design, and decisions, but also the nature of partnership itself.

From a trauma-informed lens, the ideal level of patient engagement in each partnership is not determined by how far along the engagement continuum it is, but rather by the extent to which the partnership structures support safety, autonomy, voice, and meaningful influence. Naturally, higher levels of engagement, such as collaboration, often increase opportunities for lived experience to shape research in ways that enhance relevance and equity, provided adequate relational and structural supports are in place. At the same time, trauma-informed principles also emphasize respect for partner readiness, preferences, and capacity, recognizing that meaningful engagement can occur at any level, so long as participation is voluntary, valued, and free from undue burden. Above all, trauma-informed partnership is an evolving process, not a specific set of techniques; it requires ongoing care, reflexivity, institutional support, and cultural change.

Limitations and Future Directions

This perspective should be considered in light of several limitations. First, in keeping with trauma-informed principles of transparency and humility, we again acknowledge that this framework reflects our specific clinical, research, and lived-experience perspectives and represents one contribution to an evolving conversation about equitable patient partnership. The framework is intended to provide a foundation for partnerships that hold space for the lived experiences and epistemic authority that patients bring to pain care and research. Additionally, although we identified structural influences on safe and equitable partnerships (eg, funding constraints, institutional policies, regulatory processes), our operational framework focuses primarily on relational, interpersonal, and emotional principles, mechanisms, and strategies. It does not yet fully specify approaches for addressing the structural determinants of partnership equity. Taken together, these limitations highlight the need for continued refinement, empirical testing, and structural support to advance equitable, trauma-informed partnership practices in pediatric pain research.

Second, the case example and reflections included here draw from our collaboration with one lived-experience patient partner (our co-author, SS), who has reported generally positive experiences with navigating the healthcare system and with their role as partner. Thus, while this collaboration provided meaningful insight into partnership processes and potential benefits, no individual can represent the full diversity of experiences among those whose voices they seek to amplify (for SS, this was gender-diverse AYA living with chronic pain in our study and patient partners in this perspective). Engagement with multiple patient partners across varied social positions is important to ensure that partnership on both research studies and framework development remain responsive to heterogeneity in needs, preferences, and risks. Third, as a conceptual perspective, our framework, while grounded in existing literature, theory, and clinical experience, has not yet been empirically evaluated.

Future research may refine and extend this framework in several directions. Integrating structural and institutional determinants of partnership equity into the trauma-informed framework represents a critical next step toward supporting routine implementation. Future work should examine how macro-level factors such as reimbursement structures, institutional review board processes, and sociopolitical contexts shape the feasibility and sustainability of equitable partnership. Still, the current trauma-informed partnership framework can serve as a strong rationale for advocacy around systemic conditions that support meaningful, adequately resourced, and sustainable patient engagement.

Empirical work is also needed to evaluate the feasibility, acceptability, and impact of trauma-informed partnership across diverse research contexts, including community-based and resource-constrained settings. Additional work may also examine how trauma-informed partnership influences research processes, partner experiences, and study outcomes across methodological approaches and populations. Development of practical implementation guidance, training resources, and evaluation tools may support broader uptake of equitable partnership practices across pediatric pain research settings. Continued collaboration with patient partners across diverse lived experiences will be essential to iteratively strengthen this framework and ensure responsiveness to evolving needs and priorities.

Conclusion

By intentionally enacting the trauma-informed strategies described here, pediatric pain researchers are positioned to build partnerships that are meaningful and emotionally safe, better align pain science with lived patient realities, and ultimately reduce pain disparities. Ensuring that patient voices are valued and amplified advances inclusion not only in pediatric pain research, but in improving understanding, prevention, and management of pain more broadly. The question is no longer whether patient partners belong in pediatric pain research, but whether research can be considered rigorous, equitable, or inclusive without them.

Data Sharing Statement

Not applicable; no datasets were generated or analyzed during the current study.

Ethics Approval and Informed Consent

Our patient partner and co-author, SS, provided informed consent for their direct quotes to be published.

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Author Contributions

AS and SS drafted and edited the manuscript. HR helped draft and edited the manuscript. JC helped edit the manuscript. All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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