CHRONIC PAIN RESEARCH PARTICIPATION: GAPS, BARRIERS, & OPPORTUNITIES

Chronic pain affects nearly one in four Americans. But the research enterprise meant to serve those most affected often excludes their voices, with clinical trials failing to reflect the real-world complexity of pain.

To shed light on the issue, the U.S. Pain Foundation surveyed over 2,400 people nationwide in May 2025. Following are insights from 2,098 adults with chronic pain, and 87 parents and guardians of children with pain, regarding research access, participation, and unmet needs.

ADULTS WITH CHRONIC PAIN

Involvement in Research

- 89%: Never participated in a study
- 70%: Unaware of chronic pain research opportunities
- 85%: Would consider joining in the right circumstances
- Among the 11% who had participated, areas included:
  - 39%: Non-pharmacological (e.g., physical therapy, mindfulness)
  - 34%: New medications
  - 21%: Device or implant trials
  - 13%: Biomarker or diagnostic tools

Barriers to Participation

- 59%: Lack of knowledge
- 46%: Reservations about stopping current treatments
- 42%: Worries about safety or side effects
- 38%: Concerns about receiving placebo
- 28%: Transportation or access limitations

Other reported barriers:
→Disqualification due to comorbidities or complex diagnoses
→Being homebound or financially unable to participate

Discovering Research Opportunities

- 38%: Health care provider
- 13%: ClinicalTrials.gov or registries
- 9% each: Online searches; advocacy organizations; social media

Paths to Participation

- 71%: Virtual or remote access
- 65%: Clear communication
- 63%: Flexible scheduling
- 60%: Travel reimbursement

Patients' Research Priorities

- 70%: New medications
- 62%: Mental health and pain
- 58%: Alternative therapies
- 52%: Non-invasive treatments

U.S. PAIN FOUNDATION

PARENTS OF CHILDREN & TEENS WITH CHRONIC PAIN

Child Research Participation

- 84%: Their child had never participated in a study
- 15%: Their child had participated once or multiple times
- 91%: Would consider participating in future trials with the right support
- 68%: Not enough available information about pediatric pain research
- **Only 26%**: Approached by child's provider about research participation

Parental Concerns About Participation

- 56%: Long-term effects on child
- 56%: Physical discomfort or side effects
- 45%: Disruption to child's schedule
- 39%: Safety concerns about research protocol
- 35%: Worry about receiving placebo

Facilitating Involvement

- 78%: Travel reimbursement or assistance
- 74%: Clear communication
- 72%: Flexible scheduling
- 66%: Remote or virtual access
- 54%: Financial support (e.g., lost wages, childcare)

Pediatric Research Priorities

- 77%: Impact of chronic pain on development and quality of life
- 75%: Improved provider training
- 69%: Psychological impacts of pain
- 62%: Pain and co-occurring conditions (e.g., anxiety, depression)

Addressing barriers to research participation is vital to ensure standards of care are grounded in diverse experiences and effective for everyone living with chronic pain.

To learn more, visit uspainfoundation.org.

References can be located at uspainfoundation.org/surveyreports.