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EDITORIAL

Pain Medicine Needs an Open-Access Data Revolution

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In oncology, open-access data has reshaped both research and patient care. Large, centralized repositories—such as The Cancer Genome Atlas—have created a "rising tide lifts all boats" effect. By sharing data, competing institutions and companies gain deeper insights, and the field benefits from faster innovation in diagnostics, therapeutics, and personalized care.[1] Centralized datasets also enable artificial intelligence (AI) to perform at its best—identifying complex patterns, uncovering mechanism-based insights, and detecting subtle signals that smaller datasets miss.[2] For example, AI trained on these repositories has predicted tumor drug responses and identified novel genetic subtypes, helping clinicians tailor treatments to individual patients.[3] The lesson is clear: when data are pooled and made accessible, progress toward precision medicine accelerates for everyone.

Per a 2023 study, chronic pain affects over 51.6 million Americans[4] and carries an economic burden exceeding $722.8 billion (in 2021 USD) annually,[5] yet pain medicine lacks a data infrastructure comparable to oncology. National Institutes of Health (NIH) has made notable strides: federally funded studies must share raw individual-level clinical trial data, and the NIH Toolbox[6] has demonstrated how validated, standardized measures can be implemented across institutions to improve comparability. Within pain research, the NIH Helping to End Addiction Long Term (HEAL) Initiative's Common Data Elements (CDE) Program[7] provides standardized measures to harmonize studies and facilitate cross-study comparisons. Supporting multisite trials, the EPPIC-Net Data Coordinating Center (DCC)[8] manages data collection, ensures quality, and enables harmonization across sites. Together, these efforts establish an important foundation for a more coordinated and accessible pain data ecosystem.

However, pain medicine operates with a stark disadvantage: what oncology has that pain medicine currently lacks is an abundance of public funding. Cancer research benefits from a dedicated National Cancer Institute, with stable and expansive investment in large-scale infrastructure. Pain medicine, by contrast, has no institute of its own—and, with the dismantling of the NIH Office of Pain Policy and Planning this year, it has lost even the limited coordinating presence it once had. This lack of sustained, dedicated funding explains why pain lags far behind oncology in data infrastructure, despite the scope of its burden.

Cardiology offers another instructive contrast. The American College of Cardiology's National Cardiovascular Data Registry (ACC-NCDR),[9] launched in 1997, has impressively grown into a global standard for cardiovascular outcomes. While initially supported by professional societies and industry, government involvement solidified its longevity and tenure. Centers for Medicare & Medicaid Services (CMS) mandated standardized reporting and quality improvement across several domains – requiring reporting for Medicare coverage. The NCDR now includes at least ten registries that cover a broad range of areas: percutaneous coronary interventions, myocardial infarction, atrial fibrillation, valve therapies, and more. Its standardized data dictionaries, risk-adjustment tools, and integration with electronic medical record (EMR) systems have enabled benchmarking across thousands of institutions, informed ACC and American Heart Association guidelines, shaped payer policy, and guided legislation. Ultimately, cardiology leveraged professional leadership, payer incentives, and government requirements to build a sustained infrastructure that continuously and transparently drives quality and innovation. Pain medicine has had neither oncology's federal investment nor cardiology's profession-led registry model. Thus, the field remains fragmented and underpowered to deliver the data revolution patients need.

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Responsibility for building a comprehensive, open-access repository cannot fall on NIH alone. Industry, health systems, and insurers hold enormous amounts of valuable data: clinical trial outcomes, electronic health records, claims, and treatment utilization. Much of this—particularly non-proprietary elements—could be shared without threatening competitive advantage or shareholder responsibilities. Additionally, CMS possesses institutional experience creating and maintaining high-quality, accessible data that assist researchers across many different types of organizations, and they may be able to help integrate patient-level pain management data into the larger data ecosystem. By contributing to a centralized resource, these stakeholders could accelerate discovery, improve understanding of treatment outcomes, and support evidence-based policy and clinical decision-making.

The need for collaboration is urgent. Chronic pain patients face long waits, geographic disparities, and insurance hurdles, worsened by a shrinking workforce—15.5% of fellowship positions went unfilled in 2023–2024.[10] Open-access data can extend the reach of specialists, helping health systems target effective treatments and allocate resources efficiently. Combined with AI, harmonized datasets can reveal treatment-response patterns, predict who will benefit from specific therapies, guide precision care pathways, and support Advanced Practice Providers with decision tools—allowing more patients to receive timely, personalized care.[11]

Pain medicine stands at a critical juncture. What it lacks is not just standardized measures, but a centralized, NIH-led repository to bring those measures together at scale. To achieve this, NIH should convene a working group of data managers and curators from academia, industry, health systems, insurers, and patient groups to design and launch such a repository. This group would define the technical and governance details—metadata standards, documentation practices, privacy and consent frameworks, and mechanisms for continuous updating. Drawing on best practices for responsible dataset creation,[12] it would ensure that the repository is high-quality, transparent about limitations, and sustainable over time.

By pairing the standards already in place (CDEs, Toolbox, DCC) with a federated, open-access repository built under NIH leadership, pain medicine can finally realize the same acceleration that oncology and cardiology have achieved. The field does not need more isolated datasets; it needs a coordinated home. NIH is uniquely positioned to build it—and the time to act is now.

Disclosure

Dr Shravani Durbhakula reports personal fees from Averitas Pharma, outside the submitted work. Dr Michael Schatman is a senior medical advisor for Apurano Pharma, outside the submitted work. Dr Stephen Bruehl reports personal fees from Akigai and Ambros, during the conduct of the study. The authors report no other conflicts of interest in this work.

References

1. Hulsen T. Sharing is caring-data sharing initiatives in healthcare. *Int J Environ Res Public Health*. 2020;17(9):3046. doi:10.3390/ijerph17093046
2. Bhattacharya S, Saleem SM, Singh A, Singh S, Tripathi S. Empowering precision medicine: regenerative AI in breast cancer. *Front Oncol*. 2024;14:1465720. doi:10.3389/fonc.2024.1465720
3. Chiu YC, Chen HH, Zhang T, et al. Predicting drug response of tumors from integrated genomic profiles by deep neural networks. *BMC Med Genomics*. 2019;12(Suppl 1):18. doi:10.1186/s12920-018-0460-9
4. Rikard SM, Strahan AE, Schmit KM, Guy Jr GP. Chronic pain among adults - United States, 2019–2021. *Morb Mortal Wkly Rep*. 2023;72(15):379–385. doi:10.15585/mmwr.mm7215a1
5. Guy Jr GP, Miller GF, Legha JK, et al. Economic costs of chronic pain-United States, 2021. *Med Care*. 2025;63(9):679–685. doi:10.1097/MLR.0000000000002181
6. United States Department of Health and Human Services. NIH Toolbox. Available from: https://nihtoolbox.org/. Accessed August 20, 2025.
7. United States Department of Health and Human Services. Common Data Elements (CDEs) Repository. Available from: https://heal.nih.gov/data/common-data-elements-repository. Accessed August 20, 2025.
8. USNIoNDaSEPPICNE-NAa. Available from: https://www.ninds.nih.gov/current-research/trans-agency-activities/ninds-role-heal-initiative/early-phase-pain-investigation-clinical-network-eppic-net. Accessed August 20, 2025.
9. American College of Cardiology. National Cardiovascular Data Registry. Available from: https://cvquality.acc.org/NCDR-Home. Accessed August 22, 2025.
10. Jueng J, Pritzlaff SG, Mehta N, et al. Analyzing trends in the pain fellowship match - A survey of program directors. *J Pain Res*. 2025;18:2335–2341. doi:10.2147/JPR.S496104
11. Malaguti MC, Gios L, Giometto B, et al. Artificial intelligence of imaging and clinical neurological data for predictive, preventive and personalized (P3) medicine for Parkinson Disease: the NeuroArtP3 protocol for a multi-center research study. *PLoS One*. 2024;19(3):e0300127. doi:10.1371/journal.pone.0300127
12. Orr W, Crawford K. Building better datasets: seven recommendations for responsible design from dataset creators. *arXiv:2409.00252*. 2024. doi:10.48550/arXiv.2409.00252