

Advancing the
health & human rights
of people in pain.



Kate Nicholson, JD

- Executive Director, National Pain Advocacy Center, <http://nationalpain.org>
- NPAC takes no industry funding.
- 30-year career in health-related human rights/policy, previously at U.S. Department of Justice's Civil Rights Division.



Framing: Trust

Thomas Friedman

The increasingly important role that trust, and its absence, plays in international relations, now that so many goods and services that the United States and China sell to one another are digital, and therefore dual use – meaning they can be both a weapon and a tool. (emphasis added)”

Opinion: America, China and a Crisis of Trust, Friedman, 4.14. 2023, New York Times

Trust & Pain

- Well-established biases in terms of whose pain is credited or believed (Fricker’s idea of testimonial injustice: testimony discredited on basis of identity).
- Oversight and fear of oversight due to the specter of opioids (regardless of whether they are used).

*Nicholson, Hellman Opioid Prescribing and the Ethical Duty to *Do No Harm*. Am J Law Med. 2020.*

Inequity, Bias, Disparities

- **Racialized persons**: providers rate Black and Brown people's pain as less severe than white people's, resulting in systematic undertreatment, even though studies suggest BIPOC people have more pain (false ideas about biology and race)
- **Women**: are more likely to have their pain discounted though studies show they experience more pain, more comorbid conditions causing pain (wandering uterus, hysteria)
- **Disability**: people with disabilities face heightened barriers to care and providers who substitute their judgment for that of the individuals (paternalism; takers & fakers)
- **LGBTQIA+** esp. trans persons face heightened barriers & more severe pain

See, e.g., Hoffman K, *Poc Natl Acad Sci U S A*. 2016 Apr 19;113(16); Losin, Woo, et al. *Nature Hum Beh* 4 (2020); Samulowitz A, *Pain Res. Manag.* (2018).

Oversight

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(Lagisetty, PAIN 2021; Lagisetty, JAMA Open Netw. 2019. 5-8 M Americans.)

Black and Hispanic patients are less likely to receive pain medication for acute pain in the ER (Lee et al, Am J Emerg. Med, 2019)

Black patients report higher average levels of pain but, in 90% of US healthcare systems, **receive significantly lower doses** (Morden et al, N Engl. J Med, 2021)

This inequity exists in end-of-life pain care in **Black older patients with cancer** (Enzinger et al, J Clin Oncol., 2023)

Access: Benefits

- In the pandemic experiment, remote care improved patient health, provided good quality care, and increased access to vulnerable populations. [Hollander, Sharma, NEJM Catalyst, 2022/06/15](#)
- Enormous potential for bridging care deserts (100 M in areas of health care shortage; 130 M in behavioral health shortages; the dearth of pain clinicians). [Health Resources and Services Administration, 2022 report.](#)
- Examples: EMPOWER; clinician consults.
- Remote care bridges transportation barriers and offers safer care options for immune-compromised people.
- People with disabilities were the most likely cohort to use remote care. [2022 Medicare fee-for-service Part B claims data and Medicare enrollment information.](#)

Access/Equity: Concerns

- Broadband and infrastructure divide: may compound existing disadvantages. Facility with technology (older patients).
- Rural areas are some of the worst care deserts. A systemic review of barriers to pain care in rural older patients found transportation the largest barrier. [Suntai et al, Am J Hosp Palliat Care \(2021\)](#). Will remote care help?
- Accessibility/translation: Example: National Academy of Medicine's digital & web-based tool. Very patient-centered and culturally competent but initially not accessible.
- When treating people in their homes, issues such as children overhearing sensitive medical information; potential bias in perception of living conditions; domestic violence considerations.

Regulatory

- Overall, remote care improves care access.
- Congress & CMS have moved quickly to expand it after the PHE ends on May 11.
- But DEA proposed rollback for telemedicine prescribing compounds existing disadvantages & risks lives.



Apps/Devices: Privacy & Security

- **Great for education and self-care** putting patients in the driver's seat to manage their care & providing input to clinicians where person-centered care and shared-decision making is embraced.
- **Potential biases** i.e., culturally-specific diets being blamed for diabetes. Does recording this data to share with providers risk compounding bias/inequity issues?
- **Privacy/Security** concerns emerge when intimate details become data.
 - Classic example: period trackers not intended for contraception (pre- and post-*Dobbs*).
 - Devices that help people manage a disease but don't offer medical advice are in a nebulous regulatory zone: areas where the FDA simply "exercises discretion." & FTC does after-the-fact enforcement (Flo Health).

Pain Patients Who Take Opioids Can't Get in the Door at Half of Primary Care Clinics

"Secret shopper" study finds stigma is highest against those who say their last doctor stopped prescribing opioids to them.



AI/Algorithms



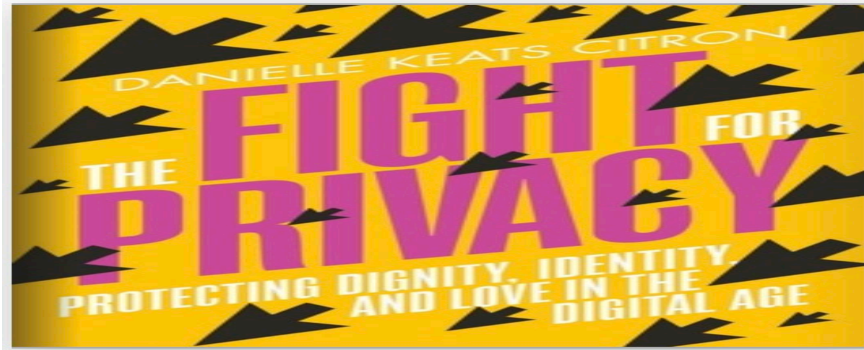
During the COVID-19 pandemic, many patients who had struggled to access care finally found a way, through video appointments with providers such as Dr. Vinit Rana of Doctor on Demand. (L.M. Glavin / Associated Press)

BY KATE M. NICHOLSON AND LEO BELETSKY

APRIL 15, 2020, 9 AM PT



The explosion of telemedicine during the COVID-19 pandemic has been transformative for countless patients who might otherwise be unable to access care.



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The Pain Was Unbearable. So Why Did Doctors Turn Her Away?

A sweeping drug addiction risk algorithm has become central to how the US handles the opioid crisis. It may only be making the crisis worse.

Bamboo Health's NarxCare. Proprietary AI ML-based algorithm used in 46 of the 51 PDMPs, issues scores re: risk for OUD.

Oliva: proxies likely artificially inflate scores for marginalized patients (women & racial minorities with complex, pain-related conditions; poor, un/underinsured & rural individuals; ppl with co-morbid conditions).

Bhagwat et al: Targets racialized populations & people w/ cancer & chronic disease.

Results in abrupt dismissal from clinics.

Recently-revised FDA guidance would allow **FDA regulation of Narxcare as a Medical Device.** Center for US Policy just filed a petition Friday.

Consequences: Abrupt Opioid Discontinuation

Abrupt cessation resulted in increased emergency care/hospitalization in half of cases (Mark, JSAT 2019)

Cessation is associated with 3x risk of OD
(James, J Gen Int Med 2019)

Cessation associated with 3-5x elevated risk of suicide
(Hallvik, PAIN 2021)

In VA data, increased overdose and suicide
(Oliva, BMJ 2020)

For Discussion: NIH/HEAL Devices

- A [trilingual telehealth pain coach mobile app](#) blends cognitive-behavioral therapy, physical therapy, mindfulness, and education about chronic pain management, and coordinates patient information with a health provider.
- Virtual reality devices are being tested for their ability to [reduce the sensation of chronic back pain](#) (which may lead to lower opioid use) and reduce pain by [immersing patients in three-dimensional immersive environments](#) like walking up waterfalls.
- An “[artificial muscle](#)” for people with back pain is a robotic device with built-in feedback that monitors how a person is moving and adjusts tension to encourage and allow safe movement.
- A [wearable monitor](#) measures and compares back and/or neck movement in people with low back pain disorders as well as in people with healthy spines, to identify predictive factors for low back pain.
- A [wrist-worn sensor](#) detects motion, heart rate, skin surface temperature, and skin conductivity to help rate functional impairment from chronic pain.
- A smartphone-based wireless device [monitors leg-abdominal muscle interactions](#) in real-time in women with chronic pelvic pain to guide home-based physical therapy.
- Decision-making tools embedded into electronic health records offer patients [complementary and integrative pain treatment options](#) after surgery or [advisories for providers](#) to identify people at high risk for developing opioid use disorder and offer treatment.