Social Listening for Patient Perspectives on Chronic Pain

FDA Office of Minority Health and Health Equity

FDA Center for Devices and Radiological Health

Inspire

Virtual ISPOR 2020

May 20, 2020

FDA U.S. FOOD & DRUG ADMINISTRATION
OFFICE OF MINORITY HEALTH AND HEALTH EQUITY

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CENTER FOR DEVICES AND RADIOLOGICAL HEALTH

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- This presentation represents the personal opinions of the speakers and does not necessarily represent the views or policies of FDA

- No conflicts of interest to declare

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FDA and Understanding Chronic Pain From a Regulatory Perspective

CDR Christine Merenda

Office of Minority Health and Health Equity

Food and Drug Administration (FDA)

Mission

FDA is responsible for protecting the public health by assuring the safety, efficacy and security of human and veterinary drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation.

FDA also regulates the manufacturing, marketing, and distribution of tobacco products to protect the public health and to reduce tobacco use by minors.

Consumer Protection Agency

Provide information on regulated products to ensure safe and effective use to consumers/patients/health care providers

Regulatory Agency

Intersection of commerce, laws and public health

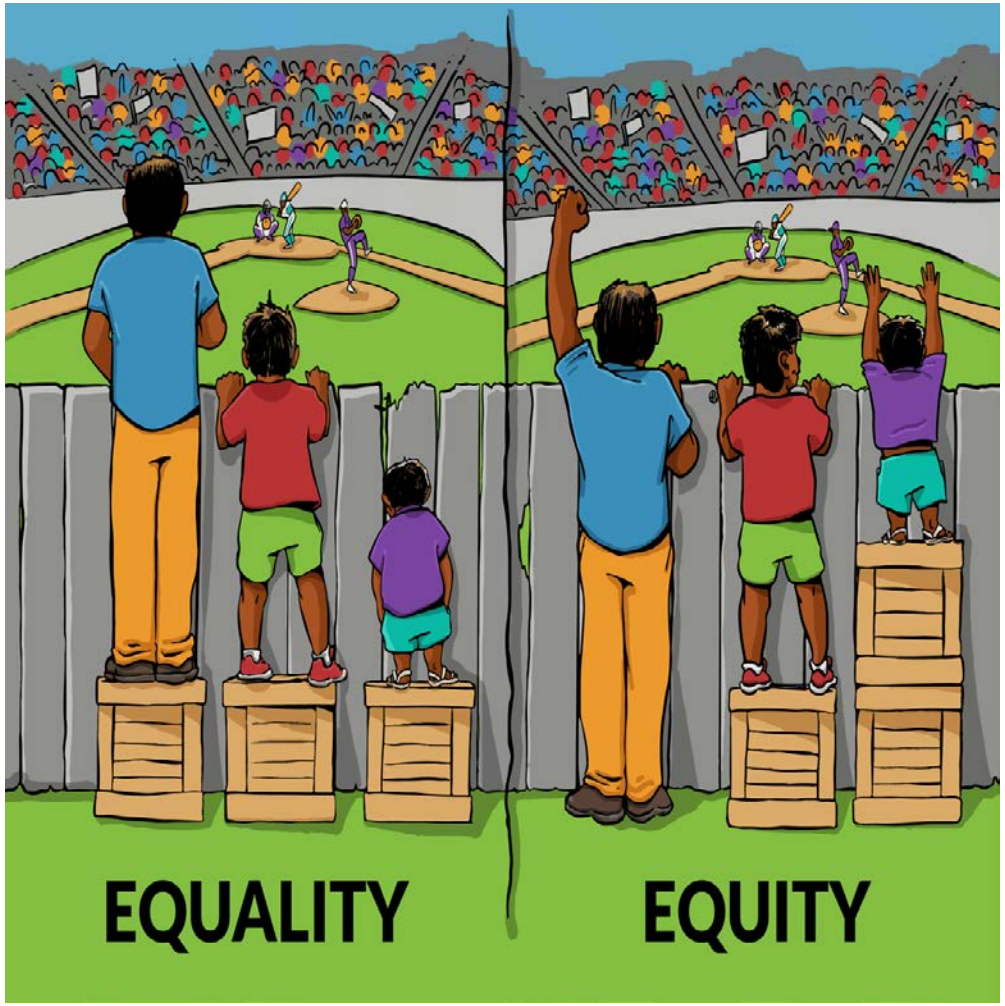
FDA Office of Minority Health and Health Equity (OMHHE)

Mission

To promote and protect the health of diverse populations through research and communication that addresses health disparities.

Vision

To create a world where health equity is a reality for all.



Center for Devices and Radiological Health (CDRH)

Mission

To assure that patients and providers have timely and continued access to safe, effective, and high-quality medical devices and safe radiation-emitting products.

Vision

Patients in the U.S. have access to high-quality, safe, and effective medical devices of public health importance first in the world.

Knowledge of Chronic Pain Management in Diverse Communities

- Research shows that minorities or persons of color are sometimes stigmatized in the healthcare system and may not receive appropriate pain therapies for chronic diseases like sickle cell disease or hepatitis.
  - Key challenges and barriers faced by patients?
- Over the past three years opioid-involved overdose deaths have steadily increased for all racial and ethnic minority groups, with some of the largest increases seen among African-Americans.
  - How do patients mitigate and/or treat chronic pain medication dependence/addiction?
- FDA can not underestimate the importance of understanding patients' experience with device treatments for chronic pain
  - What do patients share about their pain and treatment?
- OMHHE and CDRH are committed to continue to implement multifaceted, culturally tailored interventions to appropriately respond to this crisis that will meet the needs of our diverse consumers (e.g., Opioid Challenge).
  - How do chronic pain patients describe their pain and its treatment and management?
  - What are patients' goals and measures of success?

FDA - Inspire Chronic Pain Study Objectives

- Better understand the patient perspective on chronic pain, their treatment and pain management with medications and devices
- Gain insights into patients' barriers to treatment
- Identify major issues driving discussion around chronic pain and treatment among patients and caregivers
- Are there differences by race/ethnicity, gender, age or disease condition for the questions above?
- Build a topic model based on a dataset of chronic pain-related text from Inspire and open social media data

Case Study Findings: Social Listening for Patient Perspectives on Chronic Pain

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May 20, 2020

PREPARED FOR:

ISPOR 2020 VIRTUAL EVENT

What is Inspire?

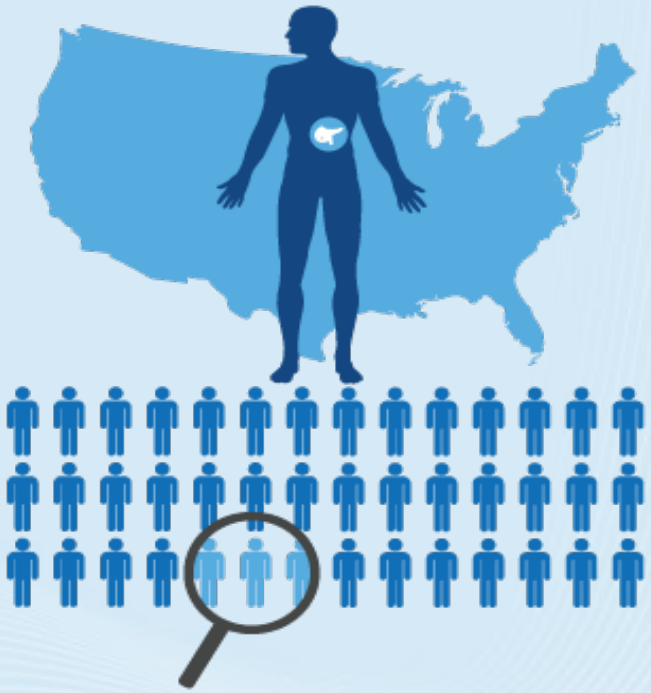
Inspire is the largest and most trusted health support community, where patients and caregivers connect with others who understand what they're going through.

10M
Annual Visitors
(1.2M MAU)

250
Communities

2M
Members
(+25K/month)

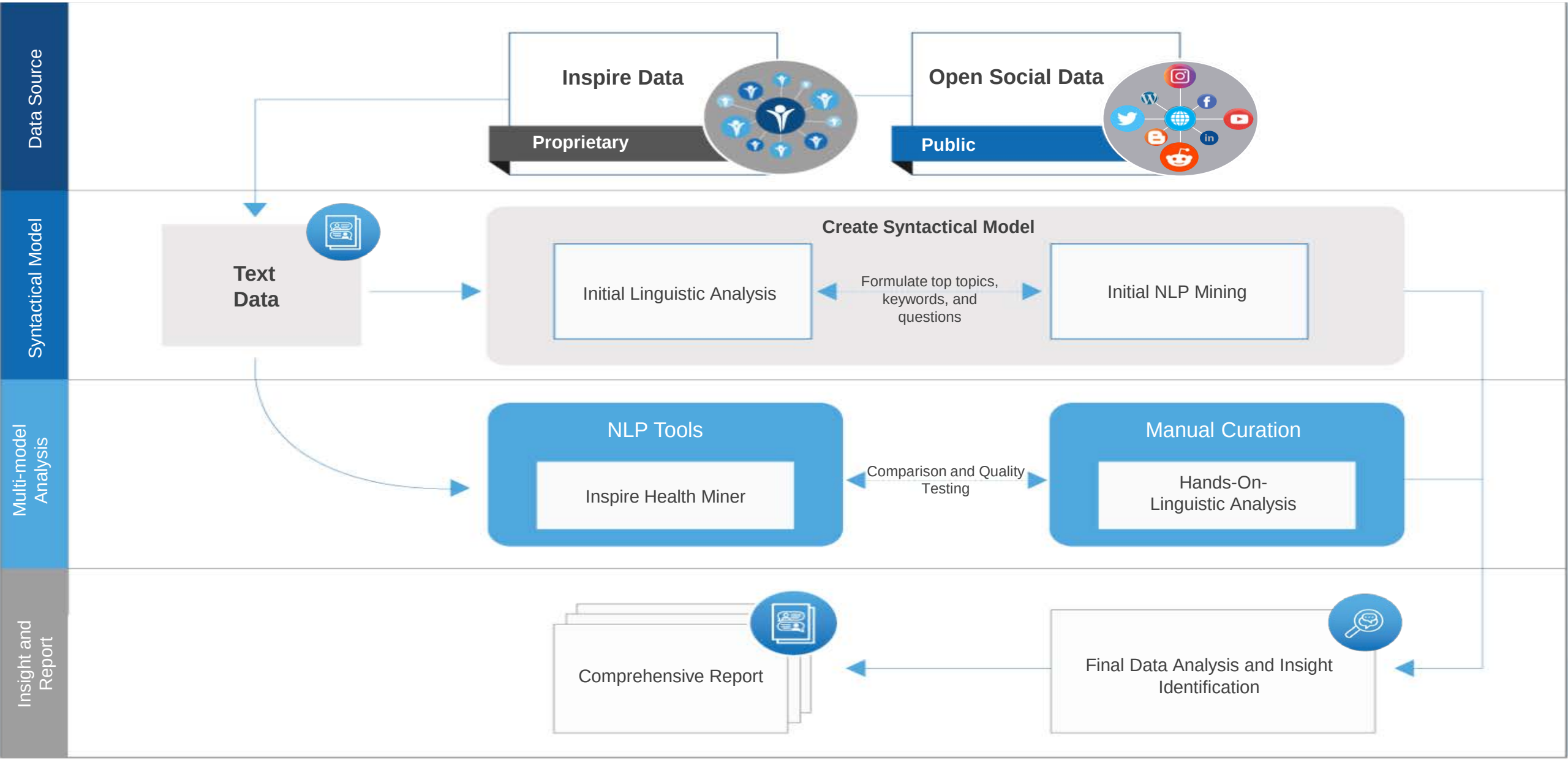
10M
Posts
(+4K/day)



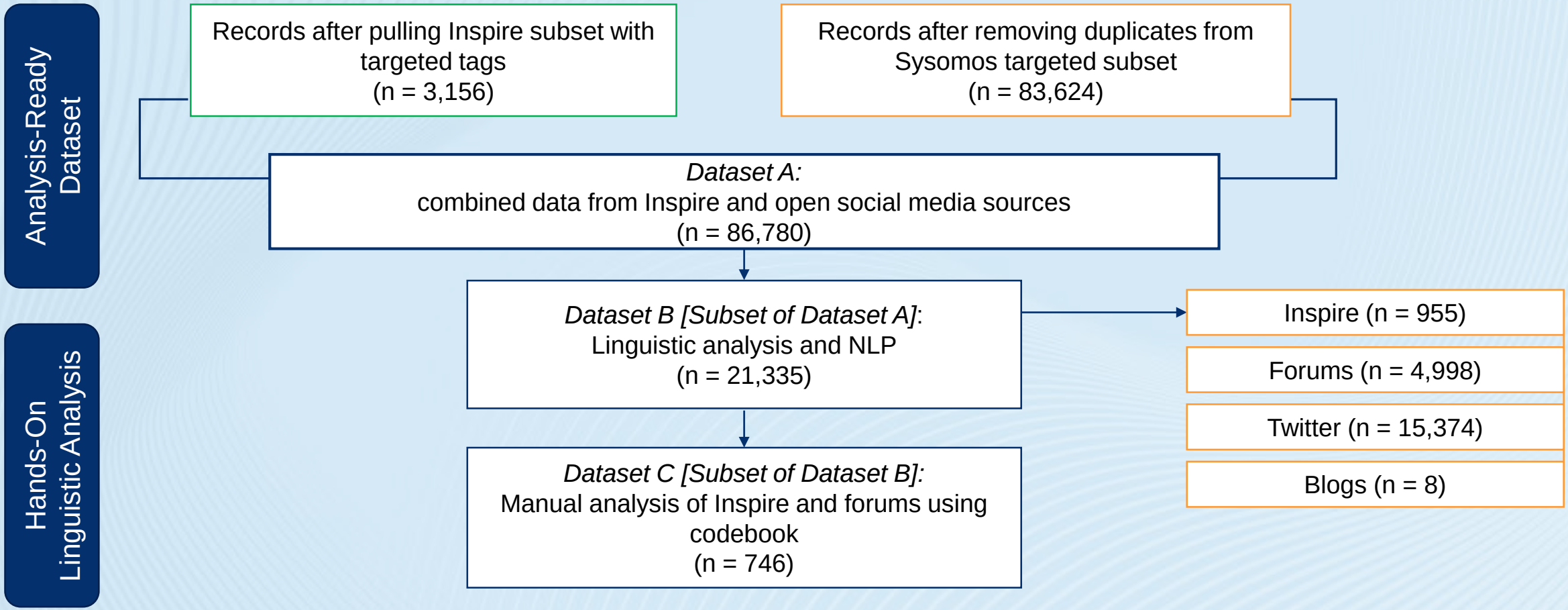
As the leading healthcare social network, Inspire's research and engagement platform delivers permission-based access to the most valuable patient populations across the healthcare value chain.

Objectives, Methodology, and Executive Summary

Chronic Pain Study Methodology Overview



Data Curation Workflow

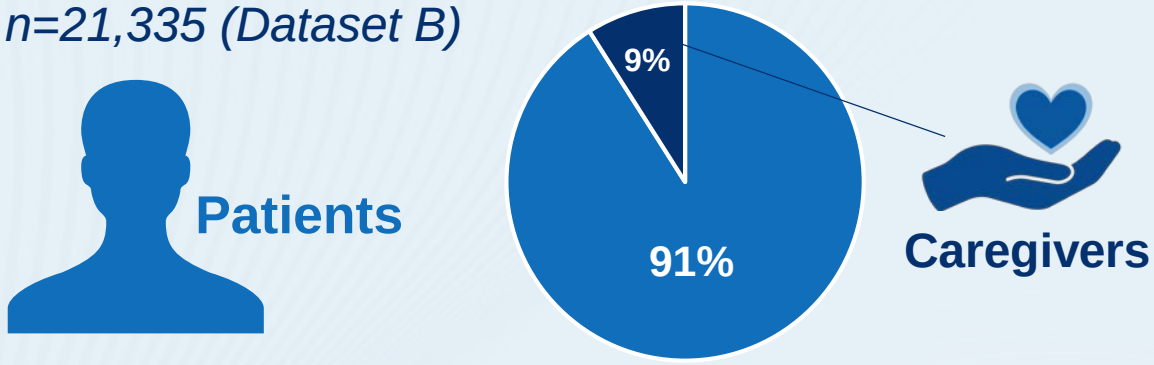


Demographics and Identity

Demographics and Identity

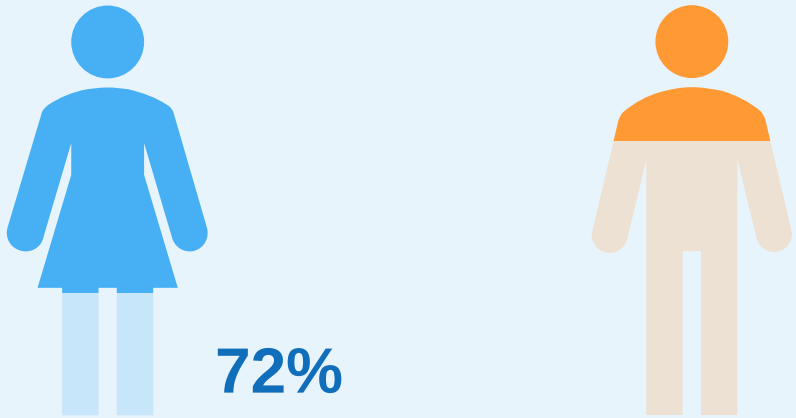
Patient/Caregiver Status

n=21,335 (Dataset B)



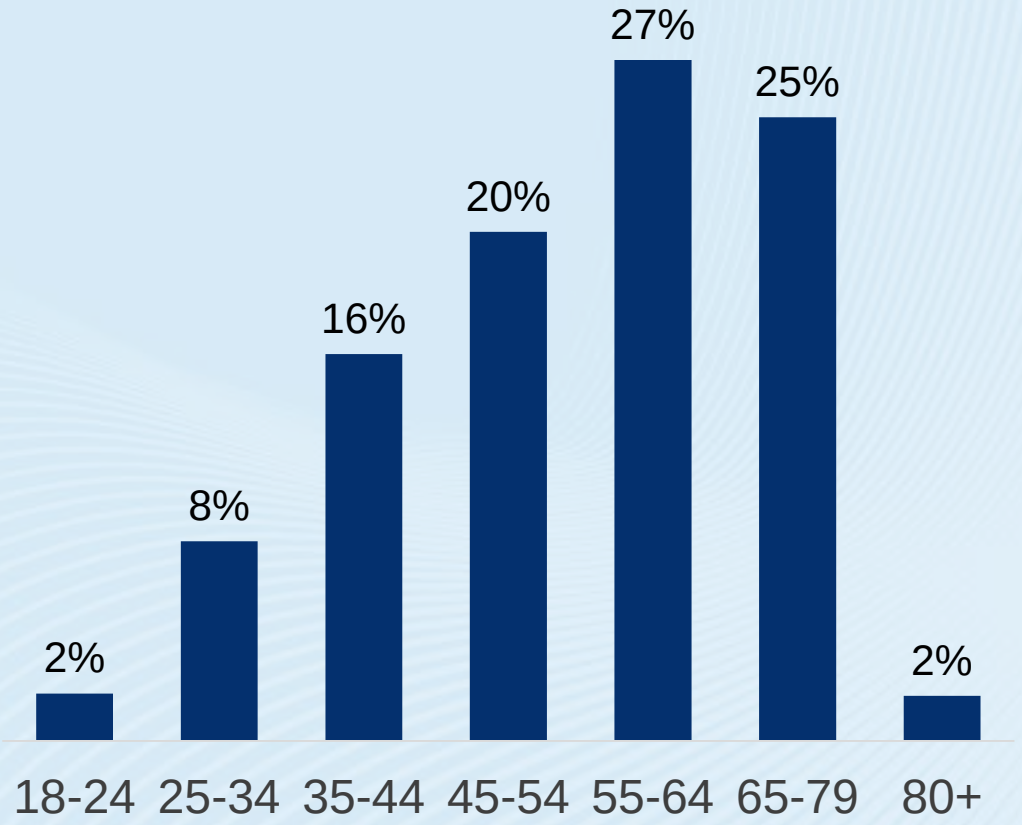
Self-Identified Gender

n=43,584 (Dataset A)



Self-Identified Age

n=32,381 (Dataset A)



Top Self-Identified Disease/Condition

% of Dataset B (n=23,536)	Disease/Condition	% of Dataset C (n=746)
5.3%	fibromyalgia	11.9%
11.1%	cancer (most common: bladder)	5.0%
5.0%	Ehlers-Danlos syndrome (EDS)	9.1%
4.9%	chronic migraine	4.9%
2.2%	mood disorder (most common: depression)	5.8%
4.7%	scleroderma	3.3%
0.4%	Complex Regional Pain Syndrome (CRPS)	5.2%

Detailed Analysis of Patient Perspectives

Chronic Pain Dialect

Lexicon

- **Top adjectives:** “severe,” “constant,” “intractable,” “extreme,” “crushing”
- **Subjective scales and levels** provide a range for patients to share how they feel at a given time: “new level of pain,” “very severe,” “unbearable”
- **QOL impact**: “disruptive,” “disabling,” “struggle,” “debilitating”
- **Frequency and length**: “daily,” “intermittent,” “unceasing,” “progressive”
- **Pain sensations**: “burning,” “throbbing,” “radiating,” “sharp,” “stinging”
- **Justification against stigma**: “legitimate,” “actual,” “real,” “serious”

Imagery and Metaphors

- Pain is commonly discussed as a **prison sentence, an invading monster, a plague, a battle, or hell**
- Pain is compared to specific sensations or objects such as **razors, broken glass, electric shocks, hot coals, a swarm of bees, and bricks**
- Some patients discuss their increased chronic pain as **“flares”** or **“flare-ups”** but this often includes other increased symptoms such as fatigue and inflammation
- CPPs often self-identify as **“spoonies”** on social media as a reference to a widely shared metaphor on the Internet to help explain **how chronic fatigue and chronic pain impact daily life** for patients

Key Disease Challenges

Disease Burden

- CPPs discuss chronic pain as having a significant negative effect on: **emotions** (19.5% of QOL discussion), **ability to exercise and play sports** (12.4%), **work and school** (9.7%), sleep (9.2%), **social life** (8.1%), **general function** (7.7%), **getting out of bed**, (7.6%), and **performing daily activities** such as bathing and completing chores (6.5%)
- **Physical debilitation** caused by chronic pain can lead to **emotional challenges**, including depression, anxiety, and even suicidal ideation
- CPPs often **lament the loss of ability** to participate in hobbies, previously active lives, and even simple activities, such as playing with pets or children

Support & Advocacy

- CPPs discuss **support as extremely meaningful** on their chronic pain journey
- **Personal support** often comes from family, friends, and significant others
- In many cases, patients express **appreciation at being in digital communities** such as Inspire, where their experiences are shared and understood by fellow CPPs
- In some instances, patients explicitly express **frustration at not being surrounded by a supportive social network**

Proper Diagnosis

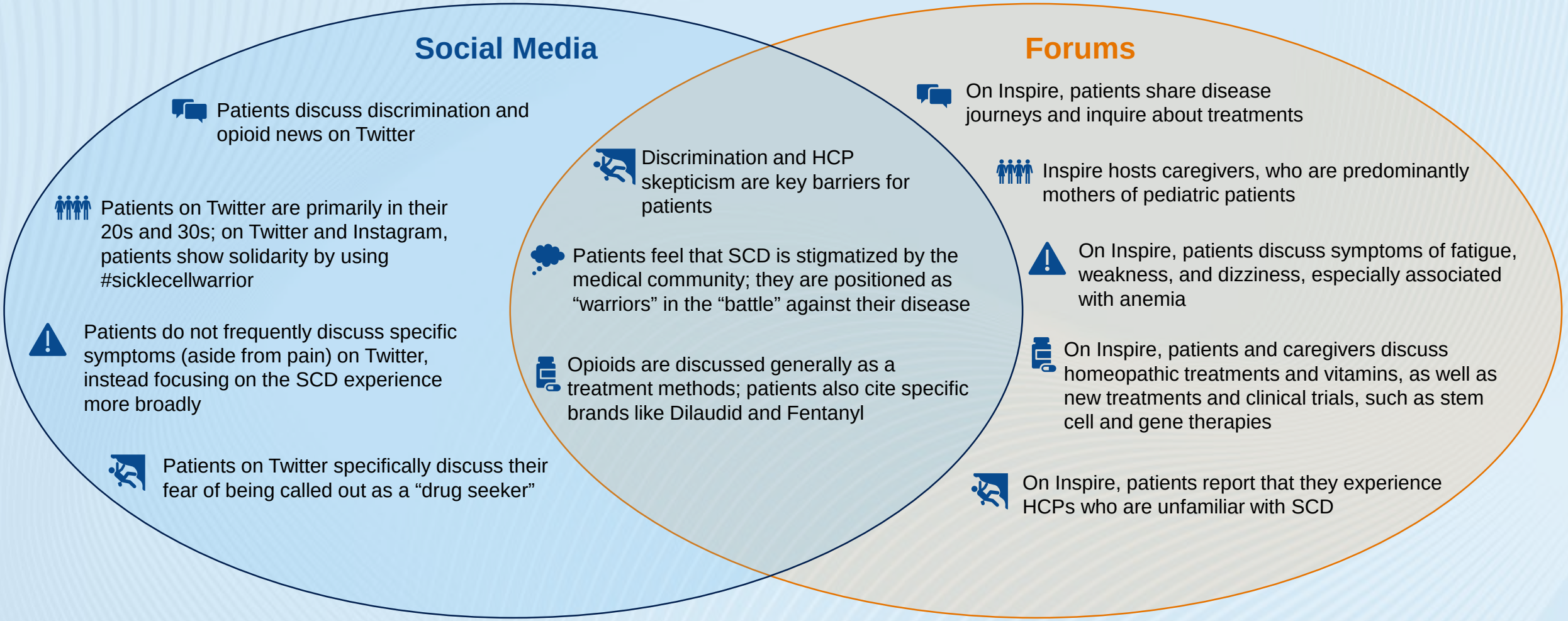
- Numerous patients report going **undiagnosed or misdiagnosed** and being **improperly treated** for years or even decades
- Further, many patients active in the online chronic pain discussion report remaining undiagnosed at the time of posting
- Patients **face doubt over the legitimacy of their pain from their HCPs**, leading to **mismanaged pain** and neglected lifelong **disease**
    - Often, HCPs **lack literacy** about rare diseases and therefore **do not recognize symptomatology**

Sickle Cell Disease Pain Discussion (n= 62)

Key Insights

- Unlike most CPPs, genetic testing as well as visual and microscopic assessment provides a definitive diagnosis of SCD, which often starts at or before birth
- SCD patients additionally **differentiate** themselves from CPPs in their **language around pain** in that they tend to mention their **“crises”** rather than their baseline, ongoing pain; they do not necessarily identify as CPPs
    - SCD patients discuss **hospitalization** as a normal part of their disease
- A shared experience for both SCD patients and other CPPs is **disease stigmatization**, which leads to **distrust of HCPs and hospitals**
- Structural barriers and systemic disease bias **hinder** treatment access; many SCD patients perceive their **struggle** in obtaining opioids and other crucial pain medication as tied to **racial bias in the healthcare system**
- SCD patients report being given OTC medications instead of stronger opioids to combat their pain, due to **perceived discrimination** stemming from **racial stereotypes** about drug-seeking behavior

Sickle Cell Disease Source Analysis



Treatment Dialect

Lexicon

- **Top Terms:** “pain meds,” “pain medication,” “pain killers,” and “pain relief”
- **Top Descriptors:** “optimal,” “helpful,” “necessary”
- **Successful treatment** “masks pain” or makes it “bearable” or “manageable” and allows patients to be “functional”
- **Failed treatment** is described as “torture” or “ruining my life”
- **Devices** tend to be discussed generically rather than by specific brands, with terms such as “pain pump,” “implant,” or “internal stimulator”

Sentiment and Stigma Avoidance

- Emotions when treatments fail include **depression, frustration, and anger**; patient language is **fiercely negative**, reflecting **disappointment, dejection, and fear**
- CPPs often defend their usage of opioids by stating that they are on the **“lowest possible” or “weakest” dose**, or that it is the only treatment on which they have been successful, or that they only take it as needed
- CPPs reflect **discomfort** with requesting more or stronger pain medication from their HCPs, due to **worry** around sounding like an **“addict” or “pillhead”**
- Those who cannot compromise on their pain medication dub their regimen as “appropriate” and that a “smart” doctor is one who understands this

Treatment Successes & Challenges

Lack of Efficacy: CPPs struggle with weak or no efficacy as the treatment may prolong pain and exacerbate symptoms

HCP Relationship/Barriers to Access: CPPs suffer with virtually no pain control when HCPs withhold pain medication, largely due to opioid stigma and lack of health literacy around chronic pain

Fear of Addiction: Some CPPs feel cornered between desperately needing pain control and being frightened of strong medications due to possible addiction

Quality of Life: CPPs celebrate treatments that allow for physical independence, functionality, and a sense of normalcy, particularly with maintaining professional, social, and family life

Strong Efficacy: The reduction of pain is the most important measure of treatment success for CPPs and is particularly cherished if it's consistent and long-term for a year or more

Tolerability & Dose Adjustment: CPPs value the ability to remain on a treatment without experiencing intolerable side effects, and may adjust their dose for more control over efficacy or side effects

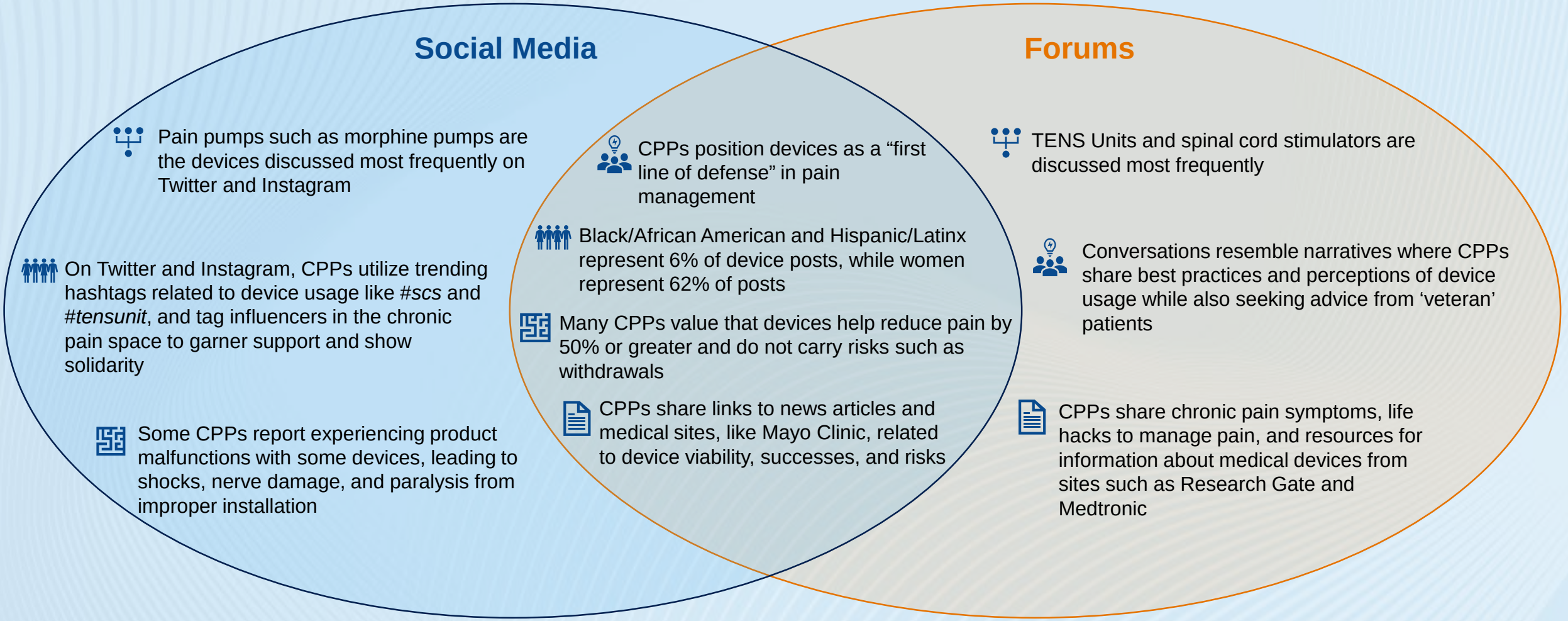
Chronic Pain Medical Devices

- Approximately **22%** of treatment-related posts in the dataset mention **pain relief devices**
- **Access to wearable devices is portrayed as easier**, simply because they are available for purchase online and patients can use them without the assistance of a medical professional
- Patients interchangeably use “pain stimulator,” “pain pump,” and “spinal cord stimulator,” often abbreviating to “SCS”
- Patients define **success for pain relief devices primarily on their ability to improve QOL,** measured as being “pain-free,” regaining realistic functionality for activities of daily life, and decreasing dependence on oral pain medication
- CPPs perceive **neurostimulation to be thoroughly tested and safe**
- CPPs with negative experiences or who have decided against using pain relief devices cite their **greatest challenges as lack of efficacy, surgical complications from device implantation, and increased pain medication necessity** and tolerance

Chronic Pain Medical Devices, con't

Top Medical Devices	Mentions	% of Total
spinal cord stimulator	24	42.9%
TENS machine/unit	11	19.6%
pain pump	6	10.7%
Quell	4	7.1%
Medtronic neurostimulation trial	4	7.1%
biofeedback	2	3.6%
unspecified implant	2	3.6%

Medical Devices Source Analysis



Patient Resources & Information Sharing

Treatment Information

- If CPPs are not receiving satisfactory pain management advice and resources from their HCPs, they turn to their fellow CPPs online
- Patients often share links to medications and pain relief products on online retailers, such as Amazon, or pharmacy websites
- Product recommendations range from OTC medications to TENS machines to homeopathic or other non-pharmaceutical solutions, such as curcumin or ice packs

Clinical Research & News

- Patients link to clinical trial research, often via the PubMed Central database
- CPPs discuss policy news from sources such as STAT, Reason, and Pain News Network covering the repercussions of the opioid epidemic and CDC restrictions on opioid prescriptions
- House and Senate press releases are shared, along with petitions seeking to change legislation, stigmatization, or public education around opioids for chronic pain
- National news sources such as the *New York Times*, the *Washington Post, NPR,* and *USA Today,* as well as medical and scientific news, such as *Science Daily* and *MedPage Today,* are particularly trusted for opioid-related information

Advocacy & Support

- Online CPPs share hundreds of links to finding a local HCP or support group, particularly in response to patients who are newly diagnosed or in crisis
- The most shared advocacy groups are the Ehlers-Danlos Society, Pain News Network, and Thyroid Cancer Survivors' Association
- Messages of patient empowerment and self-advocacy are prolific on patient accounts and advocacy group accounts, particularly on Twitter

CPP Perceptions of Discrimination

Racial Discrimination and Stereotypes

- Some CPPs experience “intersectional health-related stigma” in chronic pain, undergoing **discrimination based on multiple factors at once** and facing **layered treatment barriers** and disease challenges
- **Women of color** are particularly active online in the discussion of **racial bias** in chronic pain
- Black/African-American CPPs report **neglectful and even harmful treatments** because of HCP stereotypes around racial differences in **pain sensitivity**
- CPPs of color report that HCPs prescribe **lower doses of opioids during hospitalization** despite experiencing similar levels of pain as white CPPs

Health Outcomes for People of Color

According to online discussions, the most frequently reported health outcomes for CPPs of color, in contrast with white CPPs, are:

1. People of color are ***more likely*** **to be misdiagnosed** multiple times and take longer to be accurately diagnosed for diseases that do not have a genetic or blood test
2. People of color are ***less likely*** **to seek ongoing pain management** from HCPs, including pain specialists, rheumatologists, and other specialists
3. HCPs are ***more likely*** **to undertreat** symptoms and **underprescribe** opioids, and to overcompensate with NSAIDs, acetaminophen, and other OTC medications

CPP Perceptions of Discrimination, cont'd

Disease Stigmatization

- As discussed by CPPs, the general public tends to discount or dismiss diseases without visible symptoms or definitive tests, which is often the case with diagnoses such as EDS, chronic migraine, and fibromyalgia
- Public skepticism and lack of empathy can critically impact QOL for CPPs, including physically, emotionally, and socially
- Some CPPs report encounters with family, friends, and acquaintances in which their chronic pain is framed as over-exaggerated or fabricated
- Many patients express frustration with HCPs who do not believe the extent of their chronic pain and withhold proper treatment
  - Desperation for treatment leaves a small but vocal minority (8%) of posters noting that they obtain their pain medications via illegal means or from family members

Gender and Age Discrimination

- CPPs experiencing discrimination often need to see multiple HCPs before receiving meaningful diagnoses and proper treatment
- Age discrimination is reported most notably at both ends of the spectrum: by teens who are told "you're too young to be sick" and by patients in their early 60s who are told "this is normal pain for someone your age"
- Female CPPs consistently post on social media that both male and female HCPs delay diagnosis and proper management of their chronic pain, deeming CPPs "melodramatic"
  - Female CPPs rally against the notion of chronic pain, particularly menstrual pain, as a gendered performance for attention
- Male patients are occasionally undertreated due to stereotypes around masculinity and higher pain tolerance

Study Summary

The top unmet needs and challenges that affect CPPs discussing chronic pain online:

- Patient centricity in the healthcare space
- Barriers to treatment access
- Systemic healthcare discrimination based on race, gender, and age

More research is needed to develop strategies to address unmet needs faced by CPPs regarding:

- Experiences with pain relief devices and opioid-based treatments
- Chronic pain experience in the context of race/ethnicity and gender and for CPPs of rare or stigmatized conditions

Social Listening for the Patient Perspective

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Office of Strategic Partnerships and Technology Innovation (OST)

Benefits of Social Listening

- Unlike traditional studies, social listening data can offer insights into the performance of medical products in a short time frame
- May supplement traditional surveillance for adverse events which are less frequently reported in traditional systems
- Data is readily available to researchers

Social Listening: Considerations

Standardization of Data

Generalizability

Data Duplication

Data Integrity and Verifiability

Social Listening: Considerations

Standardization of Data

Terminology may vary due to multiple factors, making analysis difficult:

- Socioeconomic status
- Culture
- Ethnicity
- Geography
- Medical condition

Social Listening: Considerations

Generalizability

Barriers to platform participation, limiting inferences:

- Socioeconomic factors (e.g., cost of devices)
- Internet availability (e.g., geographic area)
- Cultural factors
- Trust issues (e.g., government collection of data)
- Privacy concerns
- Awareness

Social Listening: Considerations

Data Duplication

Tracking uniqueness of users can be an issue:

- Weighting may be applied disproportionately based on multiple factors:
  - Duplicative posts
  - Participation in multiple platforms

Social Listening: Considerations

Data Integrity and Verifiability

Data may not be authentic:

- Bot reporting
- Sponsored groups or individuals may try to sway opinion
- No validation of diagnosis or treatment
- Absence of certain descriptive data (e.g., age, race, gender, region)

Key Takeaways

- Social listening data can provide insights and context around:
  - Overall patient experience
  - Patient perceptions regarding diagnosis and treatment
  - Patient preferences
  - Quality of life

- Some insights gathered may impact patient outcomes and willingness to use medical treatment
  - Patients of color may potentially under-report chronic pain to avoid stigmatization which could impact diagnosis or participation in trials
  - CPPs often take advice from fellow CPPs online

Social Listening in Summary

- Relays information about patients' perceptions and preferences with respect to medical products
- Describes patients' experience according to their own perspective, in their own words
- Is useful for discovering current topics of concern or interest
- Is useful for identifying concepts and wording to be used in Patient-Reported Outcome instruments and other survey tools
- More research is required to determine under which conditions and device areas social listening can be leveraged for insights on medical device performance
- Ongoing consideration must be given to challenge areas (generalizability, verifiability, etc.)
- May help identify relevant patient populations appropriate for clinical trials and frame presentation of clinical trials to different patient populations

Thank You!

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