

SLEEP IN PRADER-WILLI SYNDROME

September 27, 2022

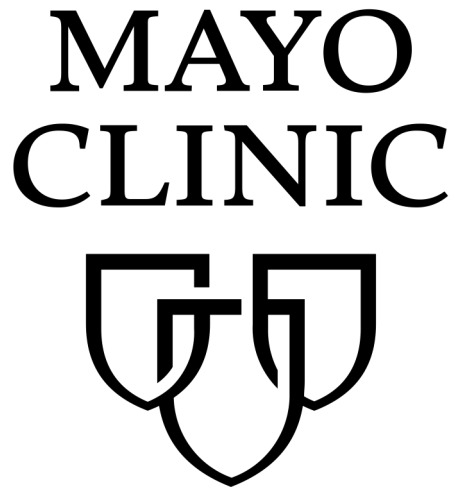


TREND CommunityTM
Turning Anecdotes Into EvidenceTM



WHAT IS PRADER-WILLI SYNDROME?

TRUSTED SOURCES MAY NOT HAVE CURRENT INFORMATION



Prader-Willi (PRAH-dur VIL-e) syndrome is a rare genetic disorder that results in a number of physical, mental and behavioral problems. A key feature of Prader-Willi syndrome is a constant sense of hunger that usually begins at about 2 years of age.

People with Prader-Willi syndrome want to eat constantly because they never feel full (hyperphagia), and they usually have trouble controlling their weight. Many complications of Prader-Willi syndrome are due to obesity.

“Phase 3 is characterized by hyperphagia, typically accompanied by food-seeking and lack of satiety (median age of onset: 8 years; quartiles 5-13 years).”

- Miller et al., 2011

<https://doi.org/10.1002/ajmg.a.33951>

LIMITED DISEASE UNDERSTANDING

CONSIDER THE CONSEQUENCES

- Social stigma
- Self-fulfilling prophecy
- Failed clinical trials

“Science is a bit like the joke about the drunk who is looking under a lamppost for a key that he has lost on the other side of the street, because that’s where the light is. It has no other choice.” – Noam Chomsky

THE STREETLIGHT EFFECT

OBSERVATIONAL BIAS

One night a policeman found a man searching for his keys under a streetlight. He joined to help, only to realize after hours of searching, that the man had lost his keys in the park.

“Then why are you searching here?” asked the policeman.

“Because this is where the light is,” replied the man.



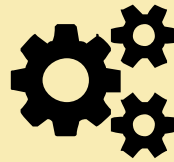
TURNING ON THE LIGHTS

A PARADIGM SHIFT



Ethical Framework

- Trusted relationships built
- Social data sources identified
- Consensus reached/Data Access Agreement signed



Conversation Analysis

- TREND engine analyzes anonymized co-social data
- Conversations categorized using TREND's lexical knowledge-base



Evidence Accelerator

- Community stakeholders convene
- 6 to 12 months
- 2-4 workshops
- Define needs and priorities
- Data Exploration



Real-World Evidence

- Publish in peer-reviewed journals
- Present at conferences and scientific meetings
- Data used for medical product development

Gout

REAL-WORLD EVIDENCE ACCELERATOR



TREND Community harnesses machine learning and natural language processing techniques to capture the perspective and experiences of people living with rare and chronic conditions. In January 2022, we launched the Gout Real-World Evidence Accelerator to bring together sponsors, thought leaders, and online support groups to turn the gout community's conversations on social media into actionable insights.

“Living with rare diseases can feel dark and lonely. It's an honor to join TREND Community's efforts bringing light and acceptance.”
— Dr. Christopher Parker
Gout Support Group of America



July 2022

16,904

POSTS
SHARED

210,544

COMMENTS
ELICITED

JUN 2004 - NOV 2018

DATE RANGE

Facebook Group: The Gout Support Group of America (12.4k members)
Subreddit: r/Gout (12.7k members)

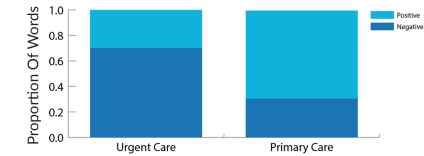
PATIENT MENTAL HEALTH OUTCOMES
IN THE MANAGEMENT OF GOUT

FOCUS SELECTED

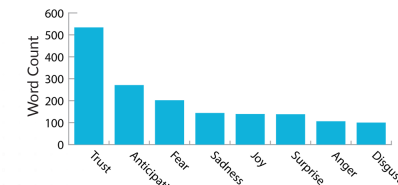
MANAGEMENT STRATEGIES

THEMES EMERGED

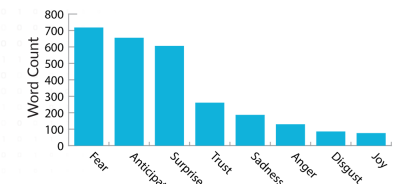
REAL-WORLD EVIDENCE



Care Type Distributions



Primary Care Emotions



Urgent Care Emotions

Digital Strategy & Innovation for Medical Affairs Summit
Expand Patient Advocacy Through Peer-to-Peer Online Support Group Partnerships

Maria Picone, TREND & Josie Cooper, AFPA

Leveraging Social Media to Capture Real-World Patient Insights

Maria Picone, TREND, Dr. Bob Wassman, TREND,
Gary Ho, GSGA, Dr. Christopher Parker, GSGA

Abstract Submitted to ACR Convergence 2022

RWE From Social Media Provides Insights Into Patient MH Outcomes in the Management of Gout
TREND, GHILF, Horizon Therapeutics



"SLEEP IN RARE" EA



Harmony Initiates Trial of Pitolisant for PWS
(June 2020)



Harmony completes enrollment
(June 2022)

SLEEP

The Utilization of Social Media to Identify Sleep Problems Associated with Prader-Willi Syndrome

Apr 2019

02

A Pioneering Treatment for Uncontrollable Hunger – nytimes.com (Jun 2019)

A Search for Answers – Global Genes NEXT Report (Jun 2019)

Bringing social media listening into R&D - Pharma Phorum Deep Dive Digital Magazine (Feb 2020)

TREND Report

Narcolepsy Community Voice Report

Sep 2021

04

JCSM

Diagnosis and Management of Sleep Disorders in Prader-Willi Syndrome

June 2022

07



2018/2019

2020

2021

2022

Q4

Q1

Q2

Q3

Q4

Q1

Q2

Q3

Q4

Q1

Q2

Q3

Q4

Q1

Q2

Q3

Q4

01

TREND Report

Exploring Disordered Sleep in PWS TREND Data Exploration Report

Sep 2018

03

JPPT

Cognitive Improvements in Children with Prader-Willi Syndrome Following Pitolisant Treatment

Apr 2019

04

NIH

Insights From Closed Social Networks Advance the Understanding of Commonalities Between Rare Diseases

Feb 2020

The Wildness of Rare Genetic Diseases and the Parents Navigating It – nytimes.com (Jun 2020)

05

FDA

Critical Path Innovation Meeting: Symptom-Focused Basket Trials in Rare Disease

Nov 2021

06

World Sleep

Extracting Real-World Insights From Social Media to Understand Narcolepsy and the Impact of Brain Fog

March 2022

In Progress

Underrecognized Sleep Disorders Across Rare Diseases: Real-world Insights from a Patient and Caregiver Summit (Under review @ Frontiers in Neurology)

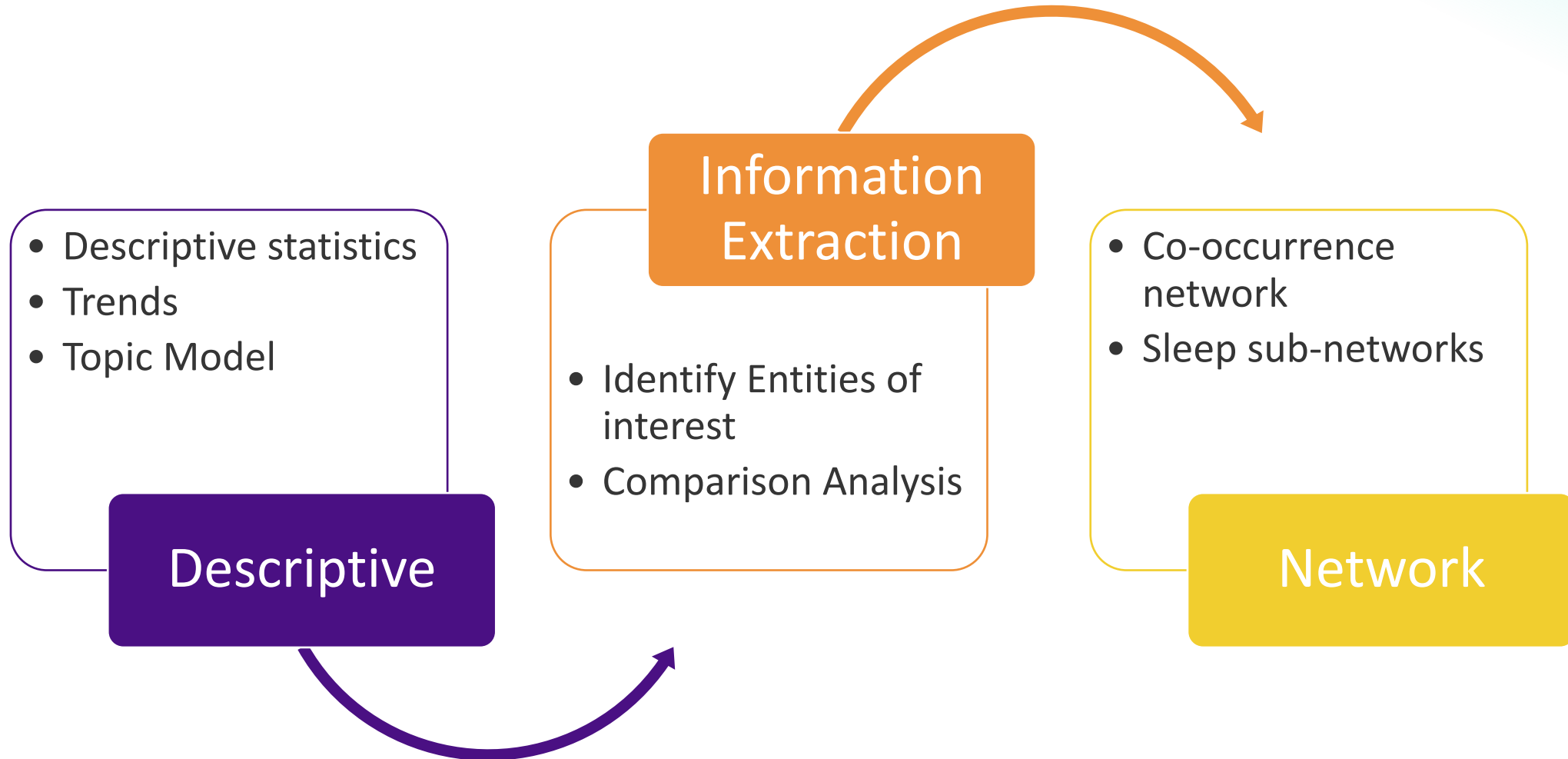
Refining Clinician Perception of Unmet Medical Needs in Prader-Willi Syndrome: Sleep Disorders (Under review @ JCSM)

DATA SOURCES & METHODS

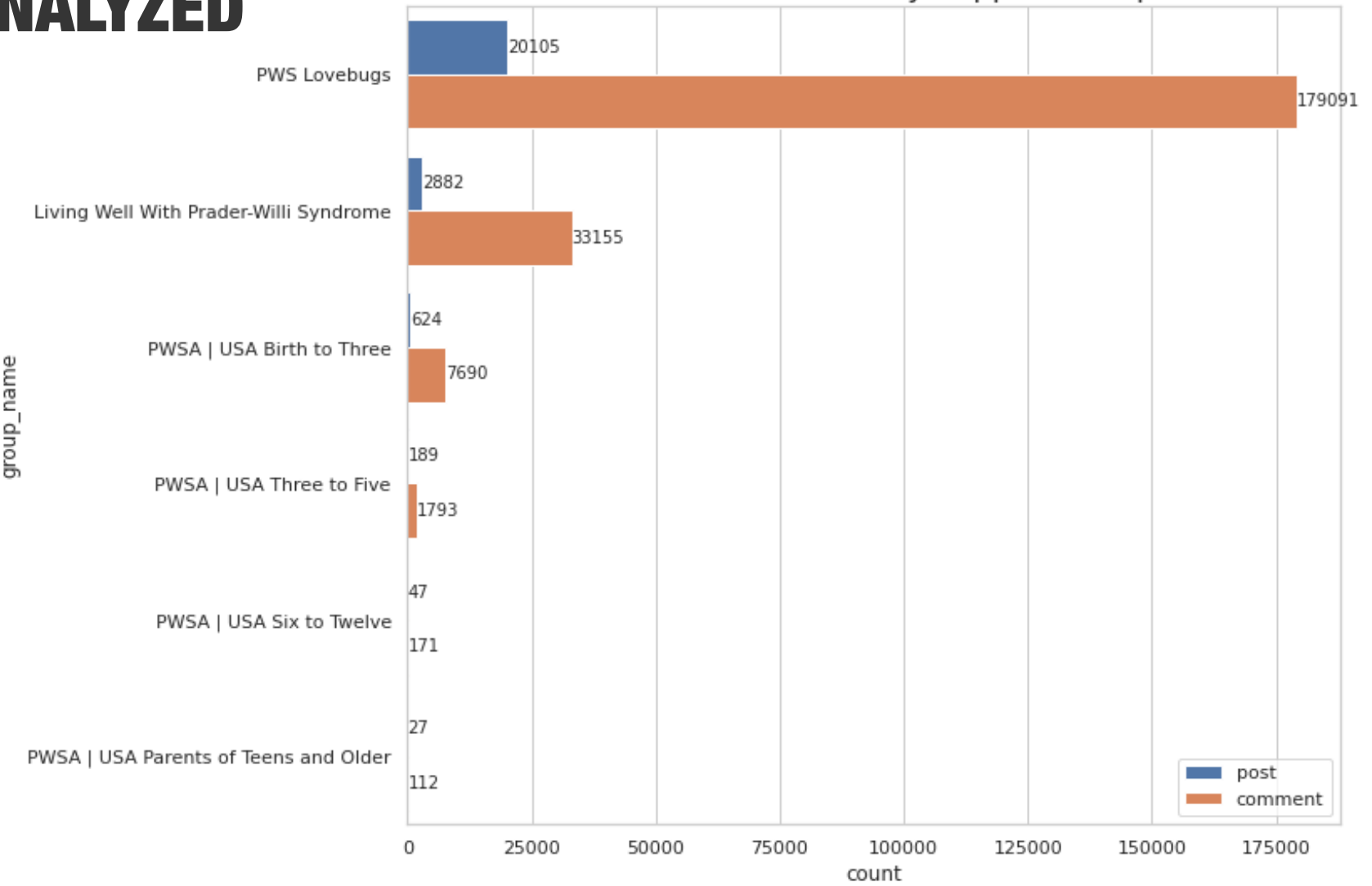


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METHODS: HARNESSING THE POWER OF AI



GROUPS ANALYZED

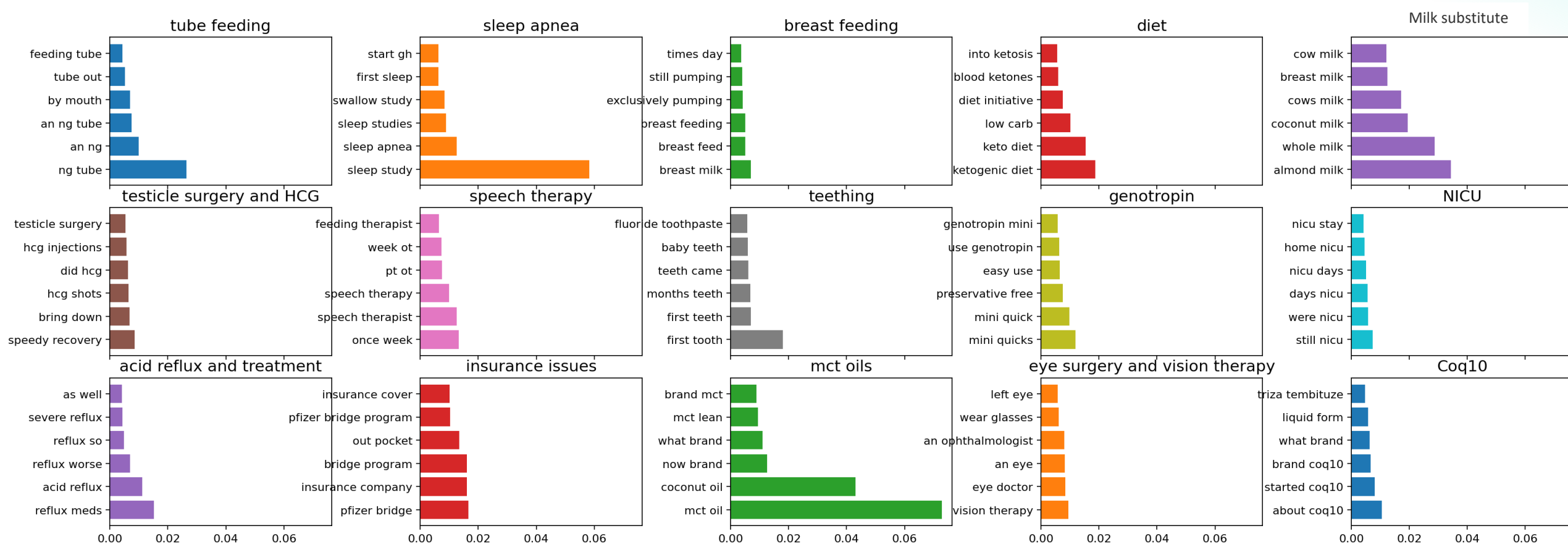


DATA REVIEW: TRENDS AND TOPICS

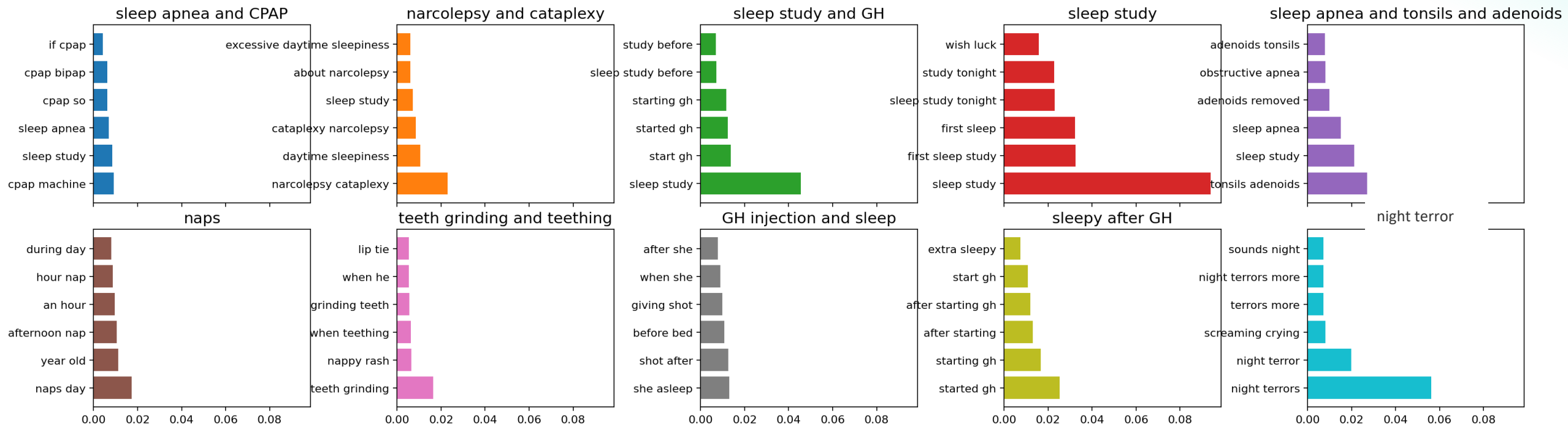


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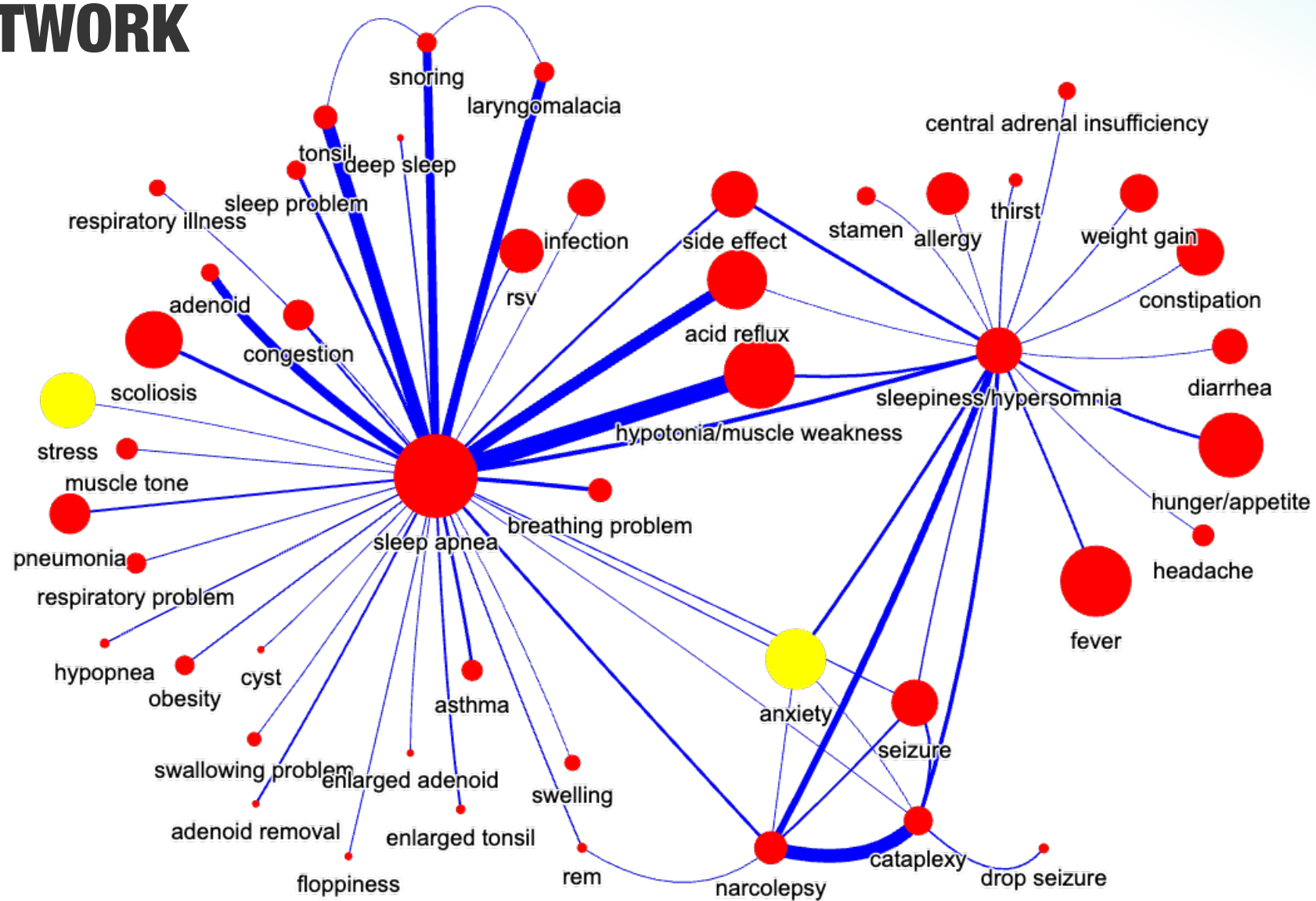
TOP 10 ALL TOPICS DISCUSSED



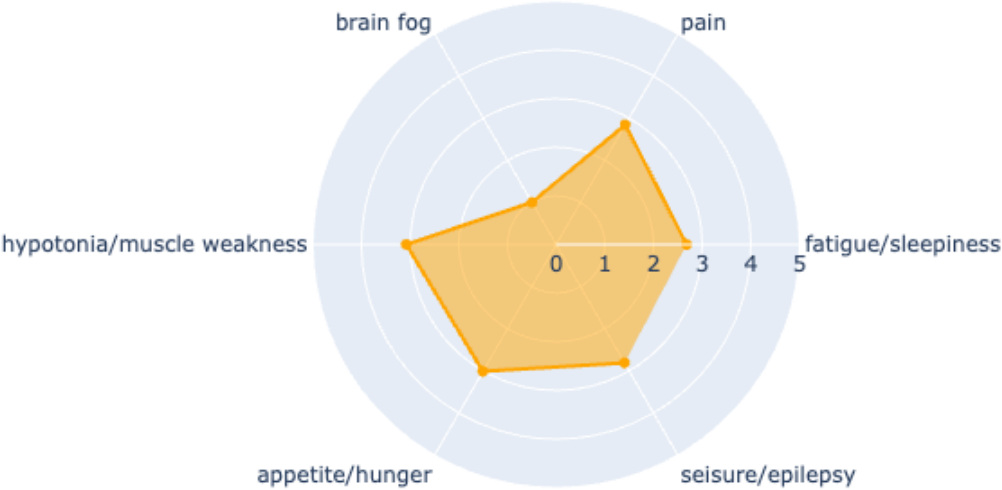
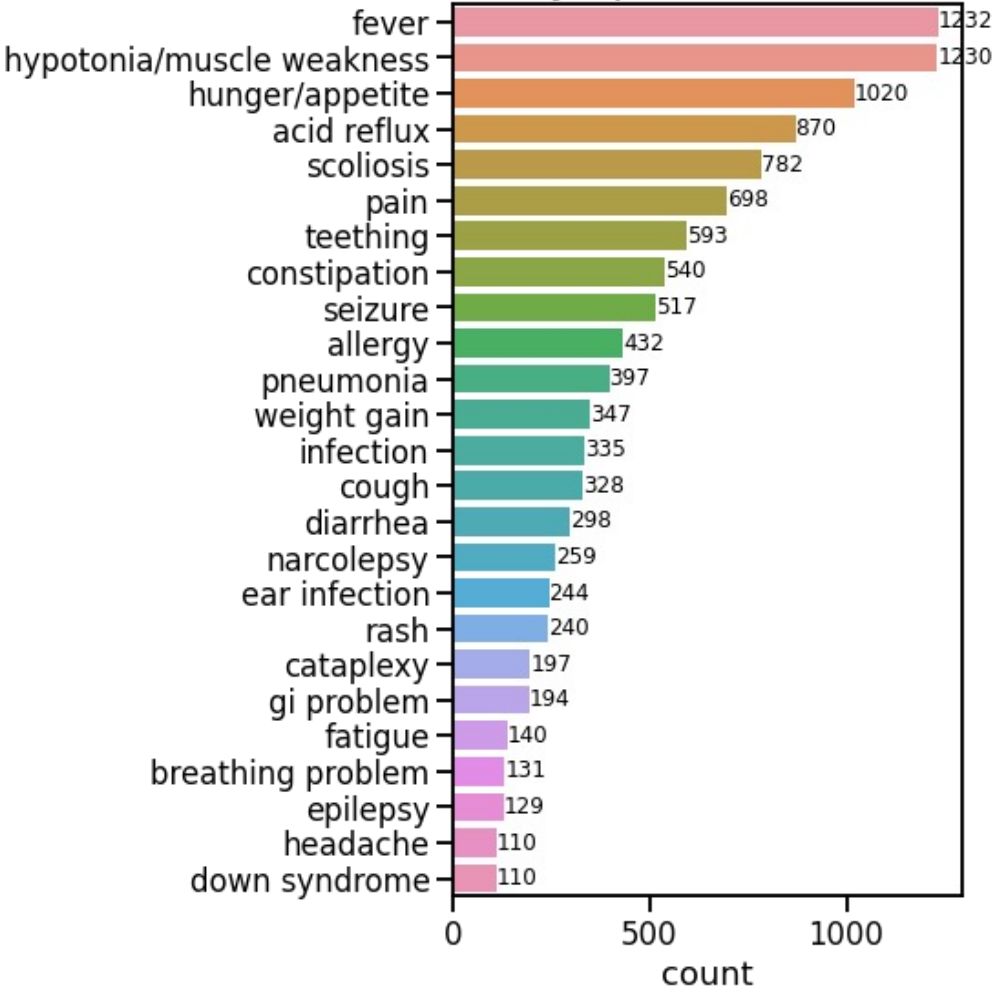
TOP 10 SLEEP TOPICS DISCUSSED



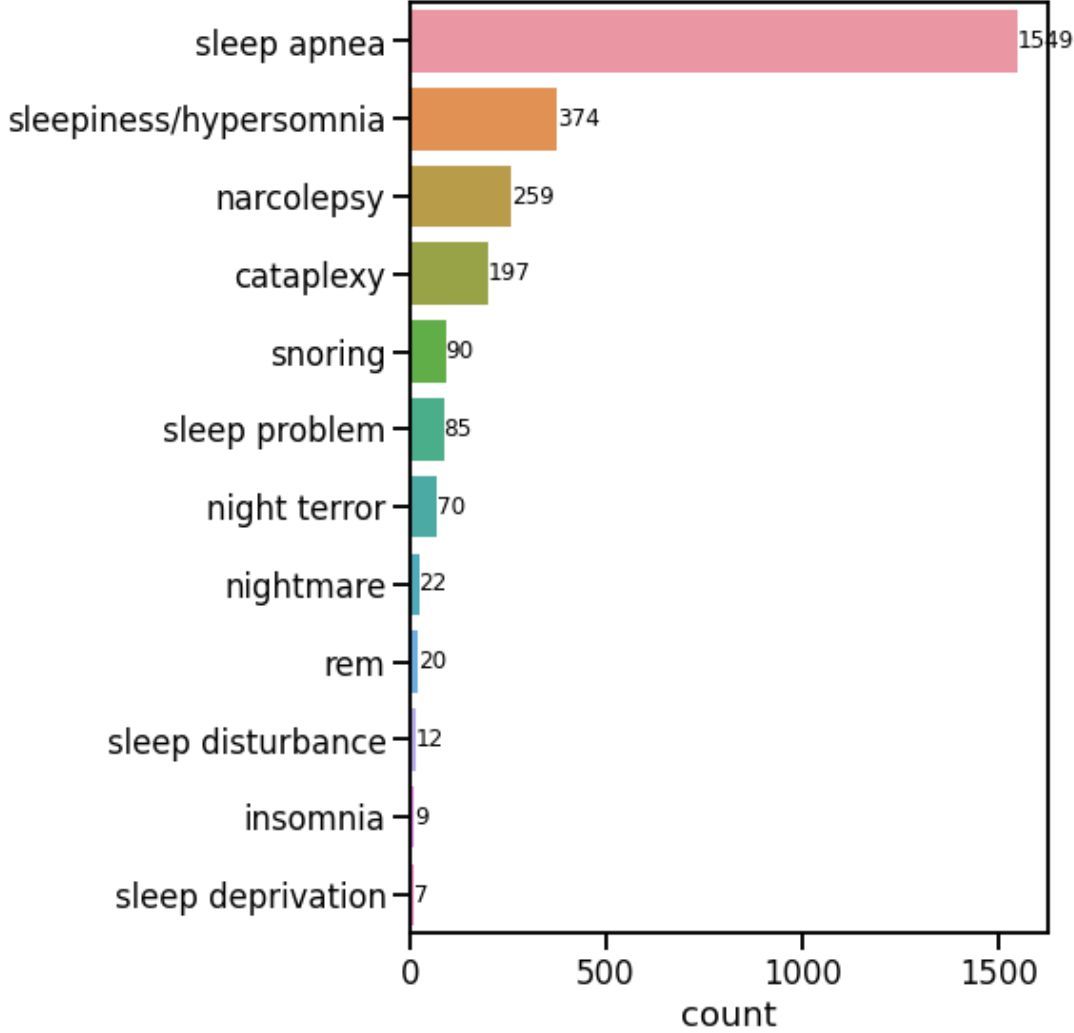
SLEEP NETWORK



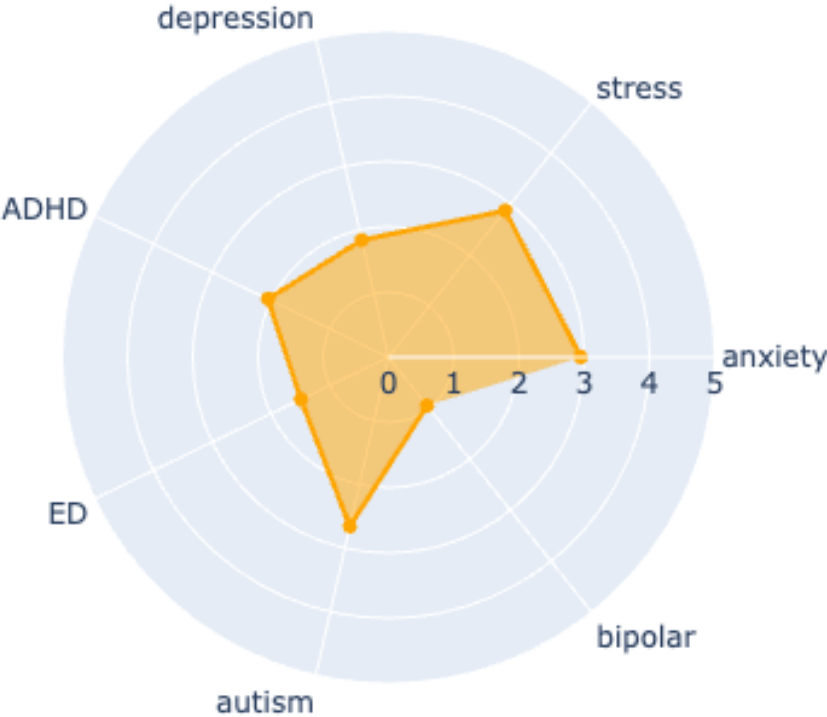
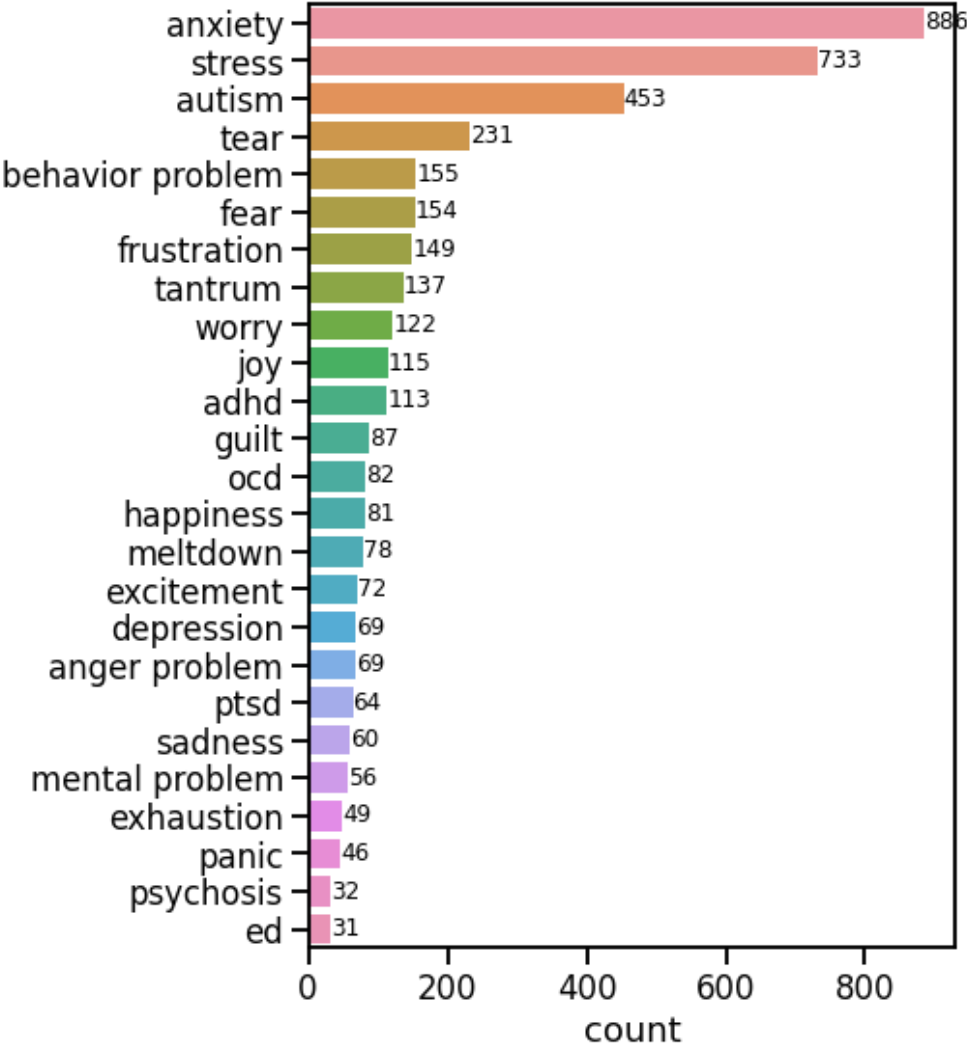
SYMPTOMS DISCUSSED



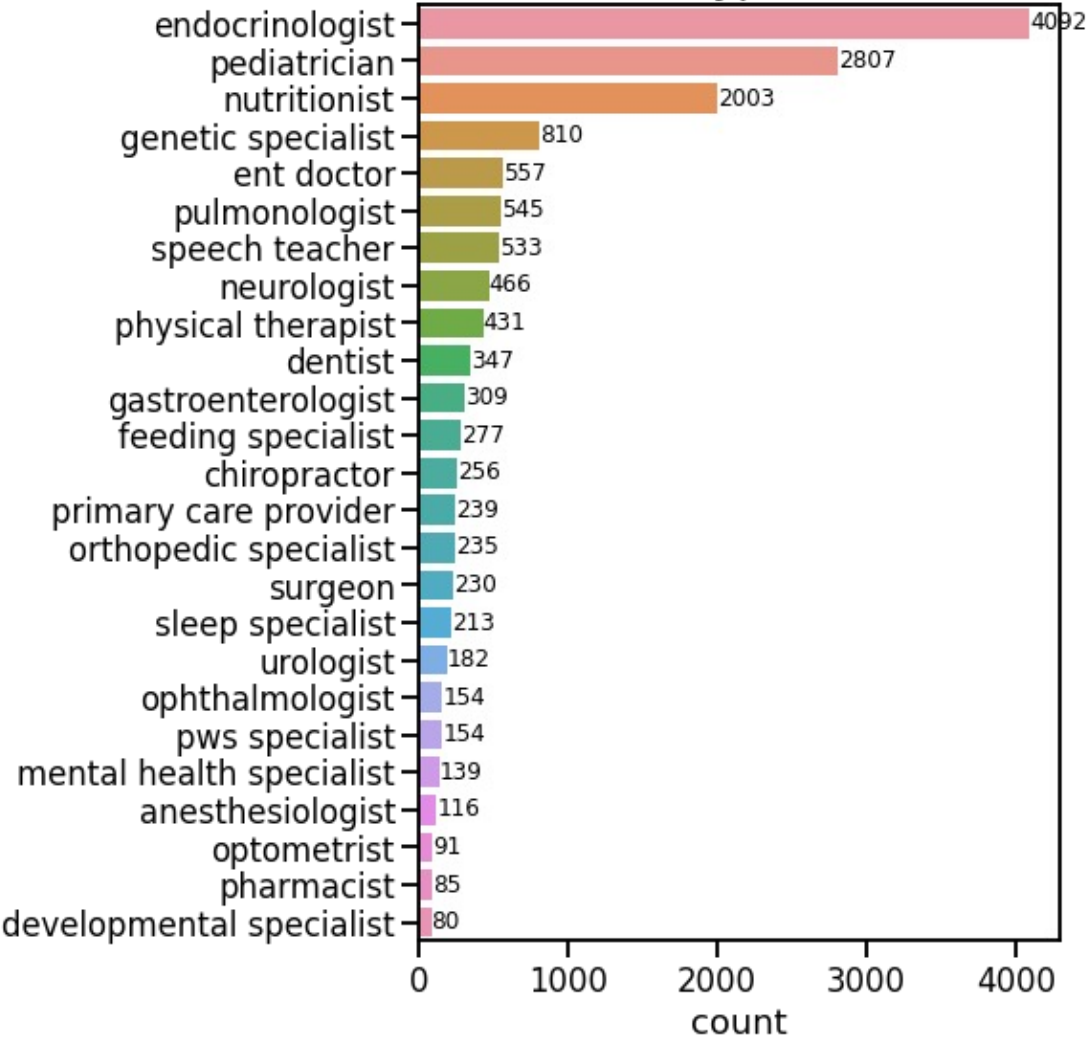
SLEEP CONDITIONS DISCUSSED



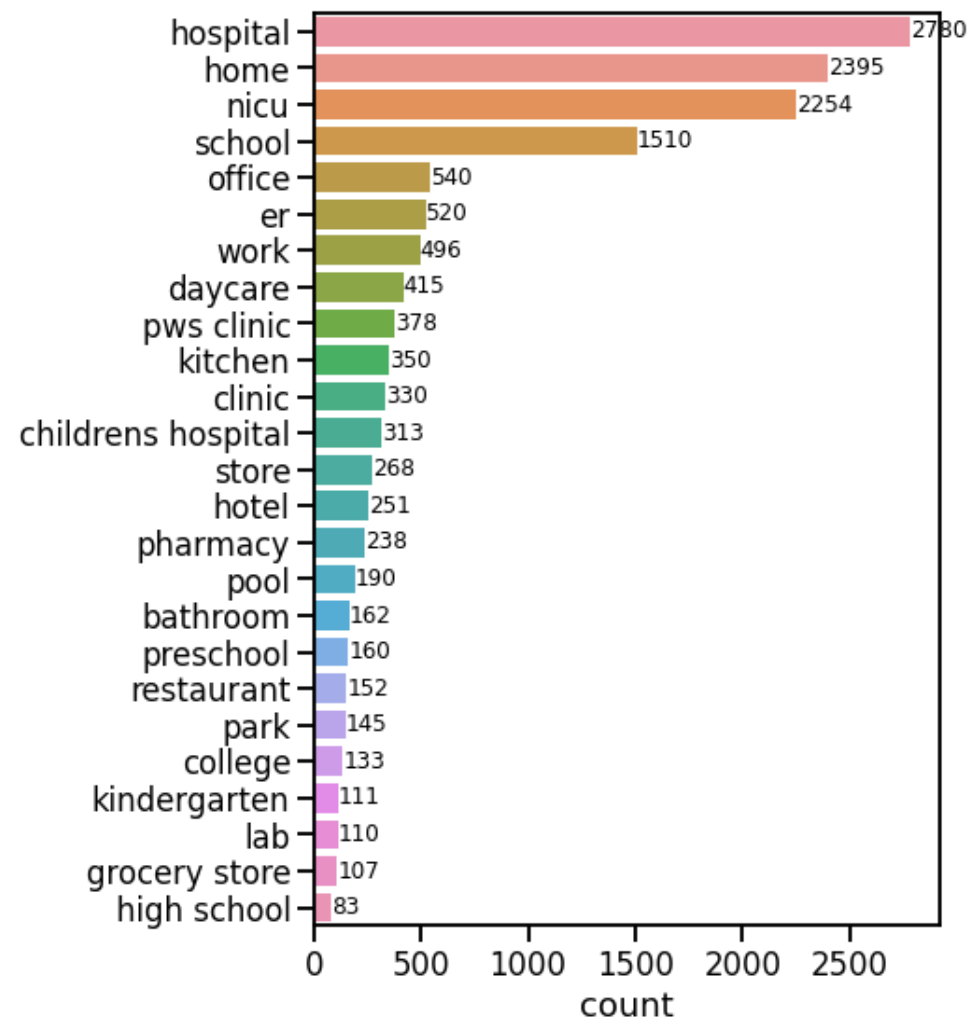
MENTAL HEALTH TOPICS DISCUSSED



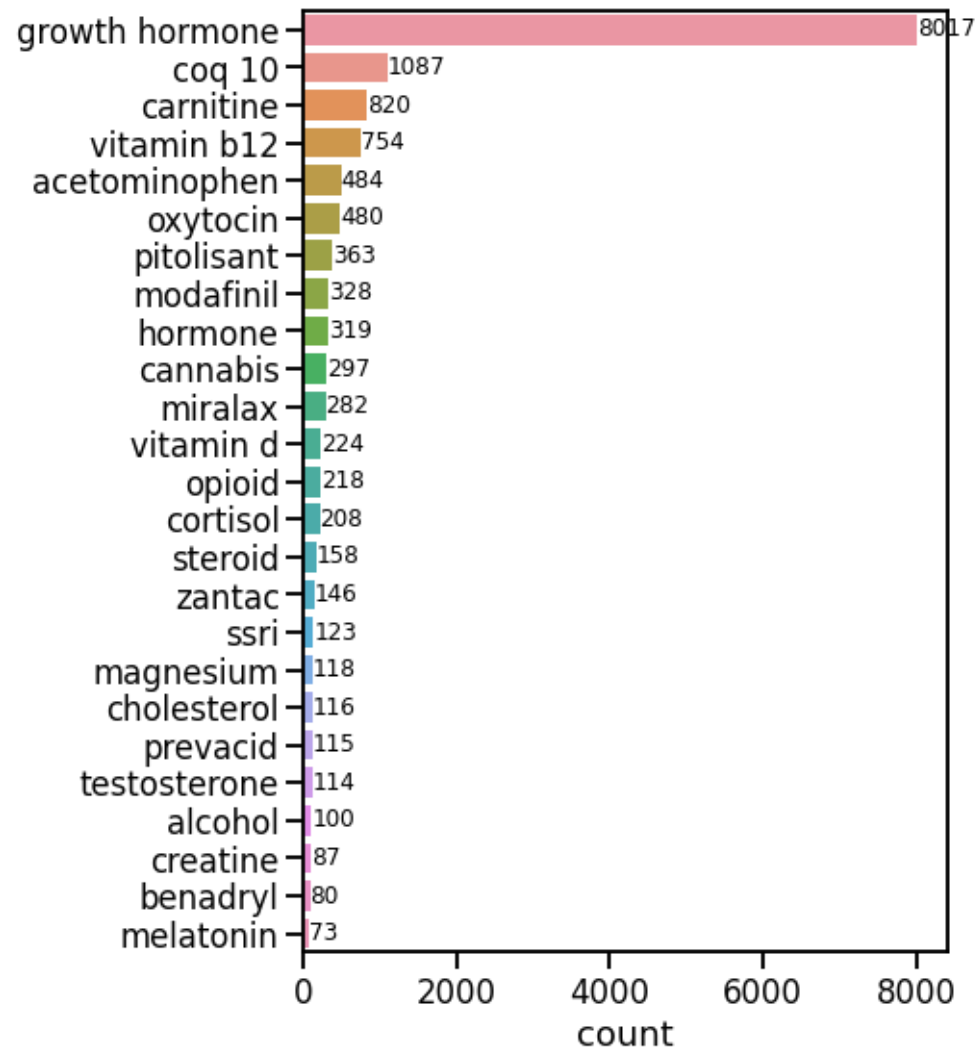
PROVIDER TYPES DISCUSSED



LOCATIONS DISCUSSED



SUBSTANCES DISCUSSED



THANK YOU!

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