

Covid-19 Positive Community Voice Report

VOLUME 1, ISSUE 1 - JULY 2020



DISEASE CATEGORY



RESPIRATORY



TREND Community[™]
Turning Anecdotes Into Evidence[™]

Capturing Patient Experience Data

The Problem

Capturing patient experience data and applying it to the drug development and regulatory process is often lengthy, laborious, and expensive. This can be further complicated for certain rare or emerging diseases.

The Solution

TREND analyzes years of real-world experience data shared within social networks to gain valuable insights into the community's perspective on living with rare disease. These data are de-identified and summarized into a Community Voice Report, which can then lead to Data Explorations and Health Initiatives.

Community Voice Report

The Community Voice Report follows the FDA's patient input Guidelines for Patient-Focused Drug Development meetings and aims to quantify disease burden, disease management strategies, and possible unmet needs.

Data Explorations

TREND Data Explorations further analyze existing social data to uncover deeper insights. Unlike the breadth of a Community Voice Report, Data Explorations examine a single topic and reanalyze the surrounding posts, comments, and feedback to better understand the community's interest.

Health Initiatives

TREND Community Health Initiatives bring community members together on the TREND Community™ platform to collectively track specific data and explore potential solutions to address an identified unmet need.

“The TREND report was invaluable in helping us define the questions and multiple-choice answers that should be included in our Externally Led Patient Focused Drug Development Meeting last June.”

*—Kyle Bryant, FARA, rideATAXIA Founder/
Program Director*



How It Works

All of our projects start with community engagement. Due to the unique difficulties of rare, chronic, and emerging diseases, many groups have created social networks online to support and validate each other. In these groups, community members are able to tell stories, promote advocacy, and share advice for managing symptoms, navigating the health care system, and living with the disease. We connect with individuals and leaders in these communities to learn about their illnesses, understand the current state of medical knowledge, and determine how our partnership can best address their unmet needs.

Once we have established a relationship with the community and gained consent, we download the de-identified data from these social media streams. These data are run through our analytics engine, named Krystie after the dear daughter of one of our community members. Krystie quickly analyzes vast amounts of data from years' worth of community discussion. Analysts manually code a sample of the data to validate the algorithms and train the engine to identify deeper insights (for example, to detect whether the speaker is a patient or a caregiver). This analysis culminates in a custom Community Voice Report.

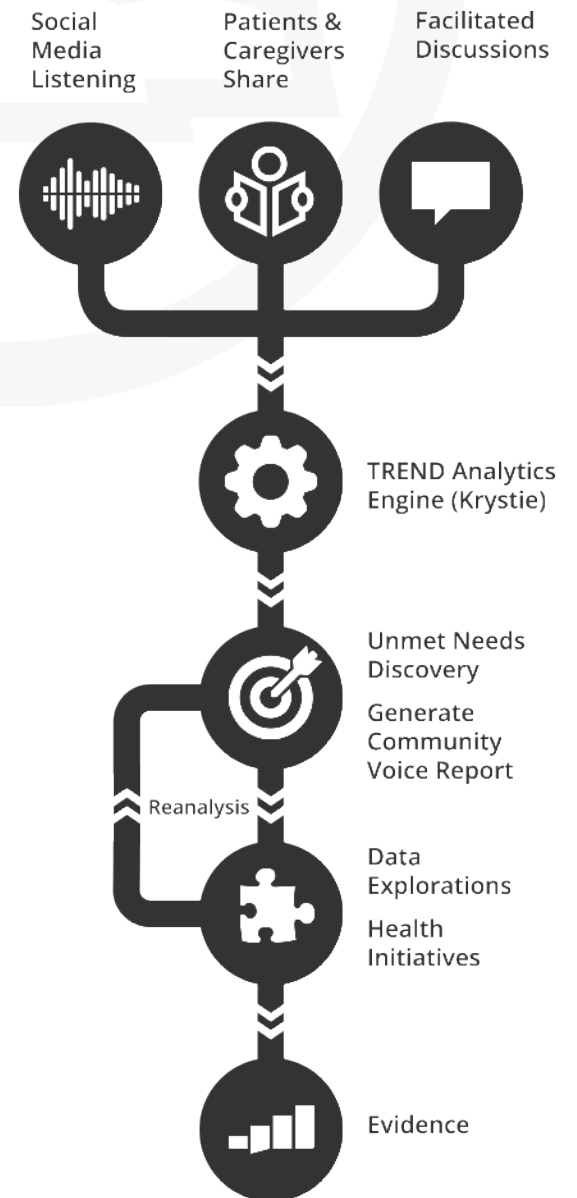
These Community Voice Reports are shared with the community free of charge, and our industry stakeholders have the opportunity to license the data for projects that address unmet needs and improve quality of life. These insights may be used to design Data Explorations or Health Initiatives.

Industry Stakeholders use TREND data to:

- Establish disease natural history
- Identify unmet therapeutic needs
- Understand quality of life issues
- Design better clinical trials
- Build a case for patient-centered regulatory approvals

Community Stakeholders use TREND data to:

- Inform medical and support teams
- Educate family members
- Catalyze research
- Spread awareness and advocacy



Analysis Background

COVID-19 is an illness that can affect many bodily systems and includes respiratory, immunological, gastrointestinal, ocular, urological, hepatic, dermatological, neurological, and psychiatric effects. Clinically recognized initial symptoms include fever, cough, shortness of breath, tiredness, and pneumonia. Associated symptoms were expanded to include aches and pains, sore throat, diarrhea, conjunctivitis, headache, loss of taste or smell, skin rash, and discoloration of fingers or toes. Serious symptoms include difficulty breathing, shortness of breath, chest pain or pressure, and loss of speech or movement. Mortality is associated with a massive immune response known as a cytokine storm as well as organ failure that may include one or more organs such as the heart, liver, and kidneys.¹

TREND analyzed the subreddit group, r/COVID-19positive. Most posts are from people who believe they have COVID-19 or have a loved one who does. They post or comment to share information on the issues of having the illness and possible treatments or management techniques. This overview looks at activity from the start of the group on March 14, 2020 until June 23, 2020, on which date, there were approximately 67,000 members of the group.



67,000
PEOPLE
PARTICIPATING

7,850
POSTS
SHARED

113,922
COMMENTS
ELICITED

MAR 2020 - JUN 2020
DATE RANGE



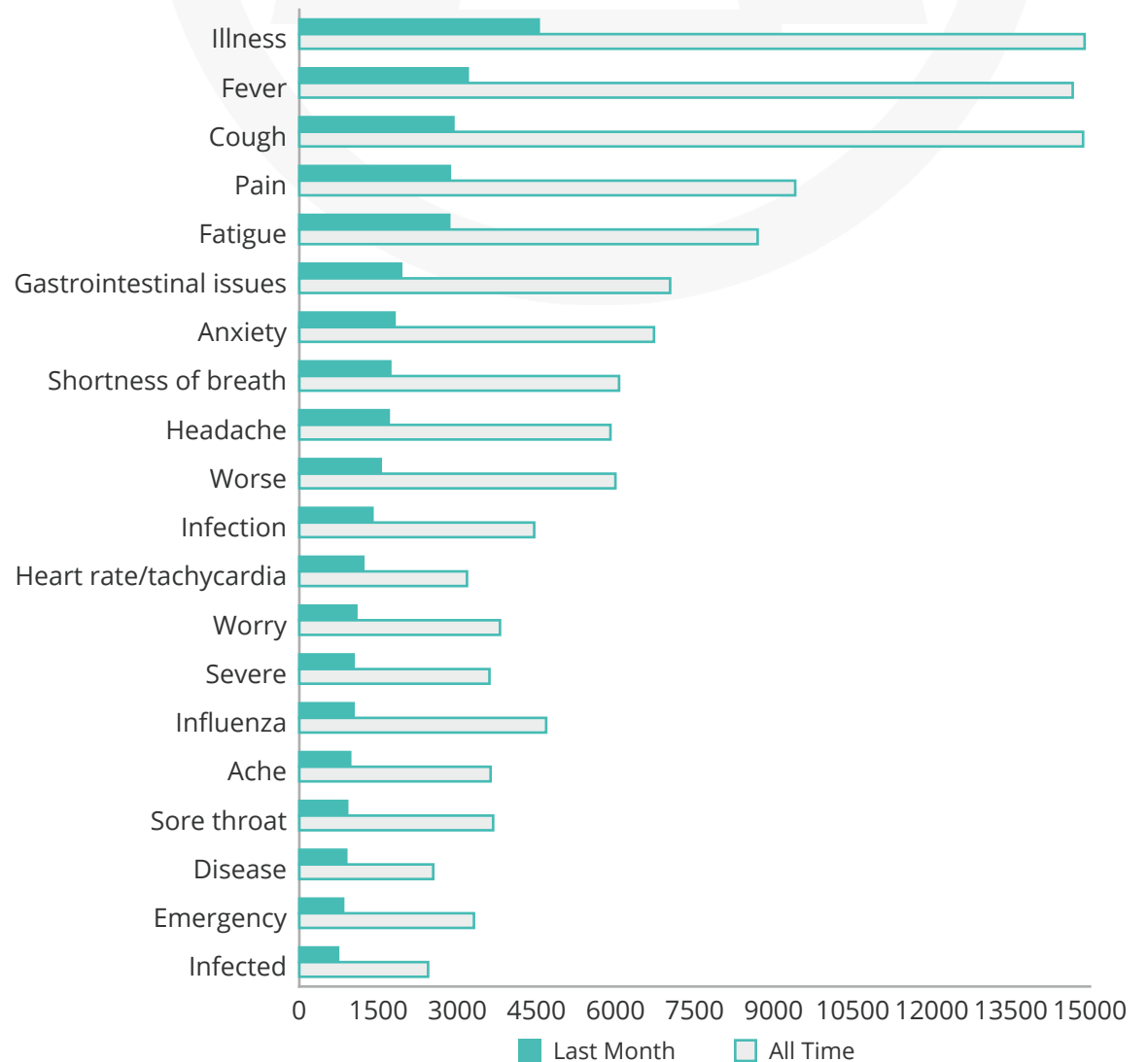
Disease Burden

We found the most discussed symptoms were *fever* (14673 all-time mentions/3195 mentions in the last month²), *cough* (14870/2923), *pain* (9408/2856), *fatigue* (8695/2844), *gastrointestinal issues* (7035/1931), *shortness of breath* (6066/1725), *headache* (5903/1696), *ache* (3629/964), *heart rate/tachycardia* (3181/1213), and *sore throat* (3677/907).

Other terms concerning burdens included *illness* (14899/4542), *influenza* (4683/1029), and *disease* (2540/890). When it came to the spread of the virus *infection* (4456/1387) and *infected* (2443/735) were mentioned. Emotions such as *anxiety* (6729/1806) and *worry* (3807/1081) also were common topics. People also discussed the severity of the disease or their symptoms with terms such as *worse* (5997/1545) and *severe* (3607/1030).

Discussions of disease burdens were more frequent overall than of disease management.

DISEASE BURDEN: LAST MONTH VS. ALL TIME



This figure shows the number of mentions of concepts related to disease burden for 30 days worth of conversations and all of the conversations.



Disease Management

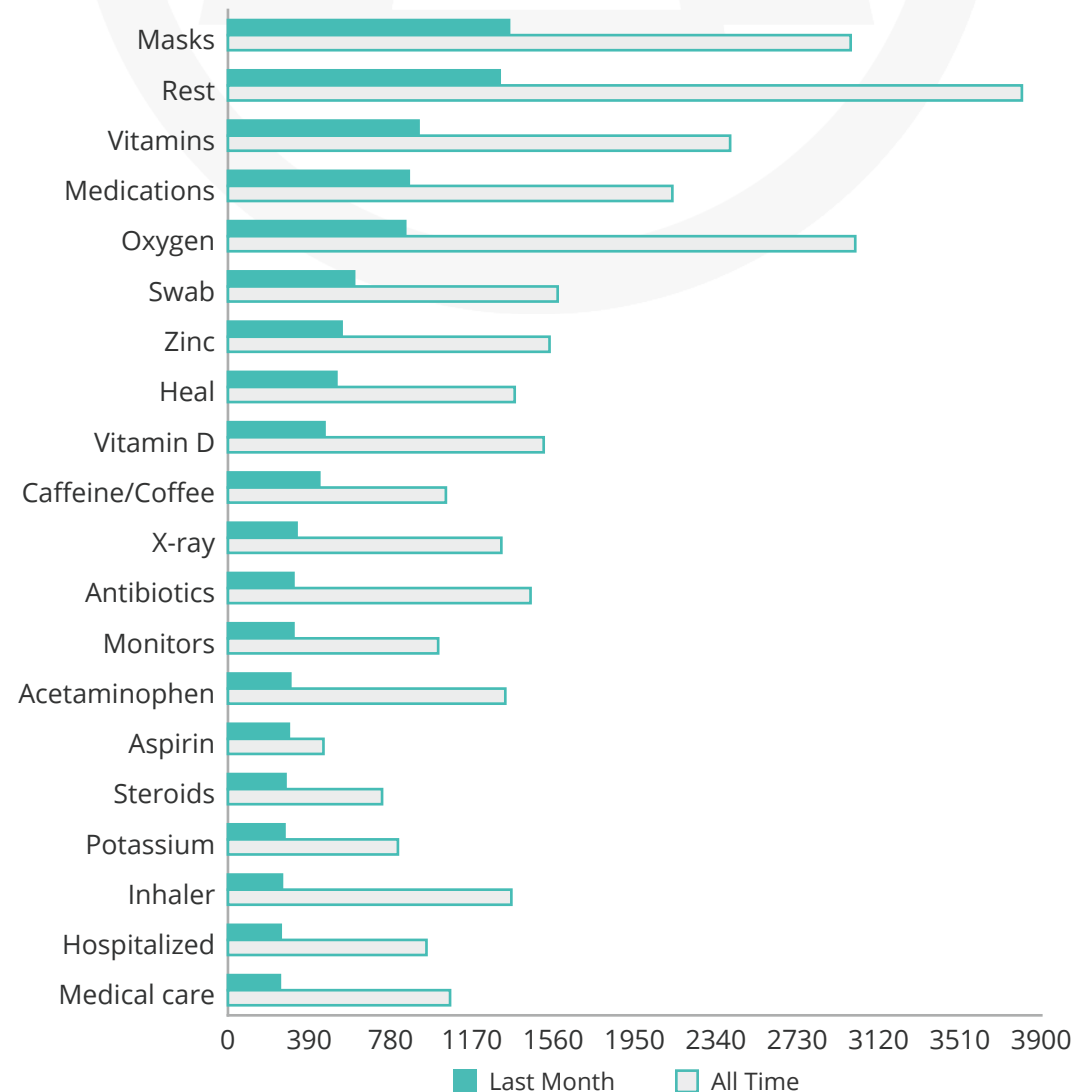
Masks (2986 all-time mentions/1348 mentions in the last month) were mentioned frequently, particularly in the most recent month, although they are primarily about managing the spread of the illness, rather than managing the symptoms. *Rest* (3807/1303) and *oxygen* (3008/850) were the management techniques most frequently discussed. *Medications* (2131/867) were discussed in general with specific mentions of *caffeine/coffee* (1045/438), *antibiotics* (1451/314), *acetaminophen* (1330/299), *aspirin* (458/292), and *steroids* (739/276). *Inhaler* (1359/259) was also mentioned.

Swab (1581/605) is used as part of the testing for COVID-19, and as such they were mentioned frequently in conversation. *X-ray* (1311/329) is also diagnostic, often giving information about the disease's presence in people's lungs.

"I couldn't have done it without others going through it too. I searched the Internet for weeks trying to read people's experiences before finding the support group. These were people not only going through the symptoms just like me, but also the medical failings and frustrations."

— Community Member

DISEASE MANAGEMENT: LAST MONTH VS. ALL TIME



This figure shows the number of mentions of concepts related to disease management for 30 days worth of conversations and all of the conversations.

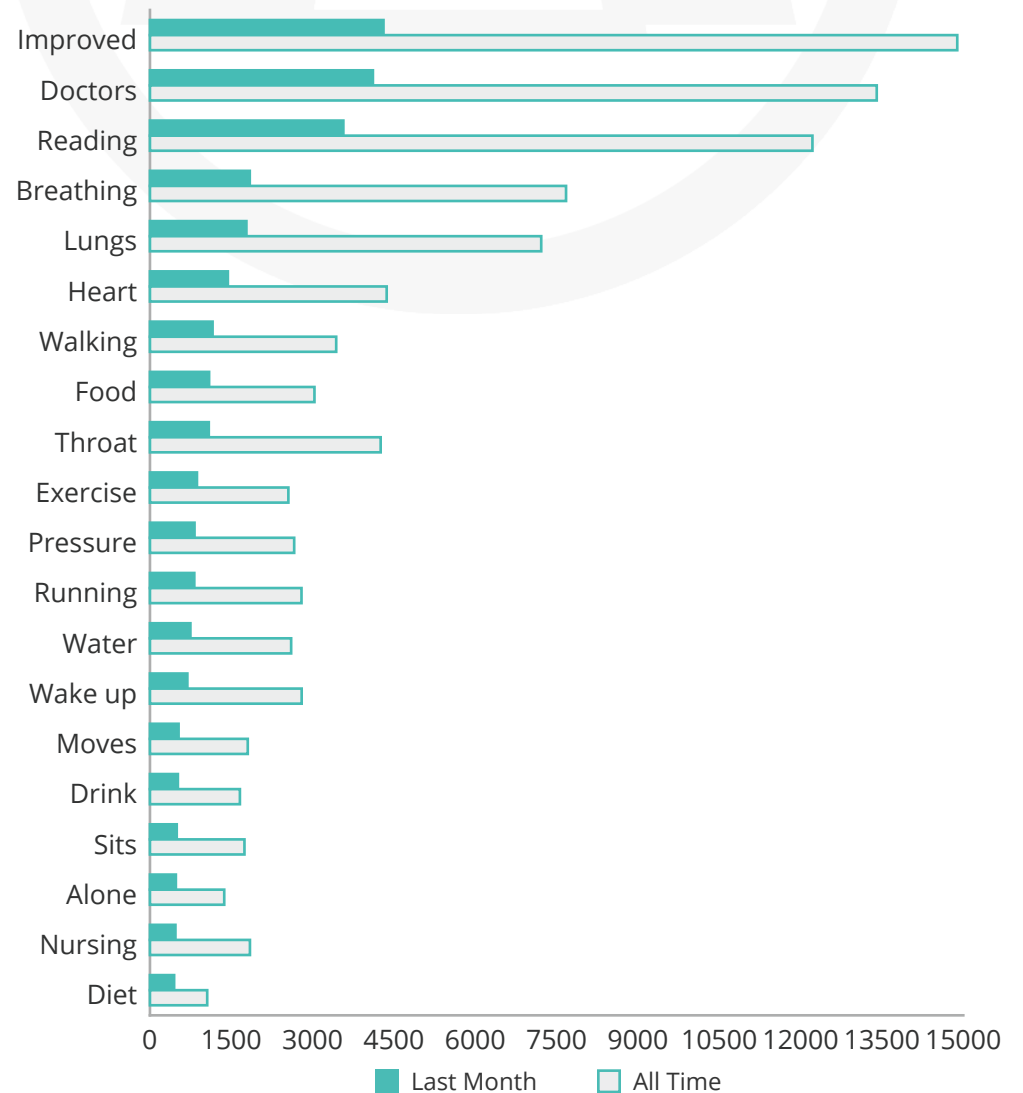


Significant Terms

It can be difficult to see if a word or phrase is about a burden or a management technique, but the following terms were discussed at a high rate. *Breathing* (7674 all-time mentions/1841 mentions in the last month), for example, is highly discussed, partly because many people have difficulty breathing, but also because some people use deep breathing to help increase lung capacity and get their oxygen rates up. Parts of the body are also discussed, such as *lungs*, (7216/1779), *heart* (4366/1437), and *throat* (4255/1085), as these are all sometimes painful or otherwise involved in the symptoms of the disease.

Similarly, *water* (2604/746), *food* (3034/1091), *drink* (3034/1091), and *exercise* (2553/867) may be discussing ways of treating the disease. Hydration was mentioned as a treatment. On the other hand, a few people mentioned having excessive thirst, possibly related to kidney issues.

SIGNIFICANT TERMS: LAST MONTH VS. ALL TIME



This figure shows the number of mentions of concepts that are significant but not clearly related to burden or management for 30 days worth of conversations and all of the conversations.



Conversation Shifts Over Time

In our analysis of the data, we looked at the last month of conversations and compared that to the conversations since the group began. The group started on March 14th, and we gathered the data on June 23rd, so “mentions in the last month” refers to May 23rd through June 23rd. Because this disease is so new and the knowledge surrounding it is constantly evolving, it would be beneficial to analyze how topics of conversation have changed over time in relation

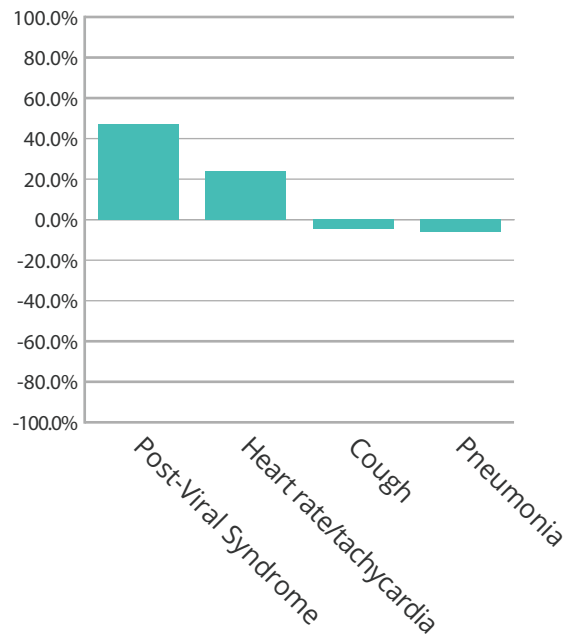
to new information becoming available.

For disease burden, we saw an increase in the discussions about *post-viral syndrome* (46.9%) and *heart rate /tachycardia* (23.9%). Post-viral syndrome increases make sense as more people have now had the disease long enough to be experiencing those effects. We saw slight decreases in the conversations about *cough* (-4.6%) and *pneumonia* (-6.0%).

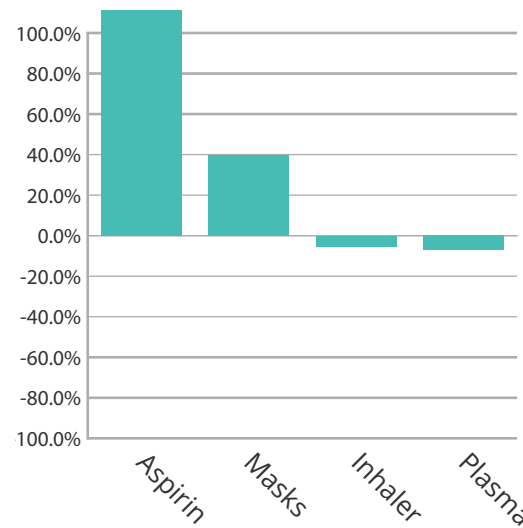
In disease management, we saw a large increase in the conversation about *aspirin* (111.5%) and *masks* (39.8%). Conversations about *inhaler* (-5.3%) and *plasma* (-7.2%) decreased in the last month.

Two topics, *lungs* (1.8%) and *breathing* (0.9%) barely shifted in the amount they were discussed. *Diet* (32.7%) and *food* (19.7%) saw the biggest increases.

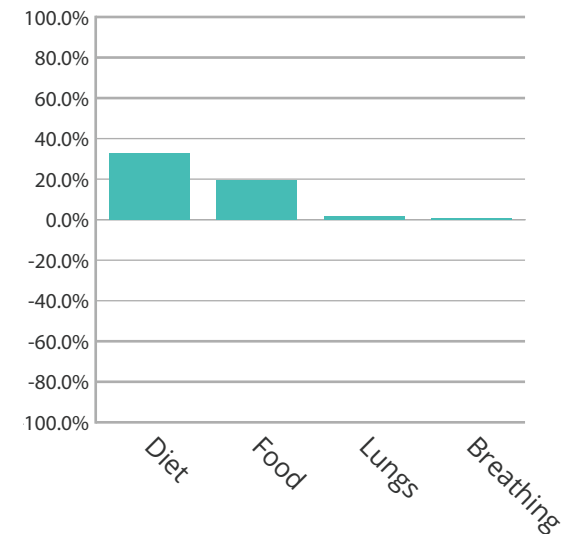
DISEASE BURDEN



DISEASE MANAGEMENT



SIGNIFICANT TERMS



The above figures chart the percent change in mentions of concepts in the three areas of interest, burden, management, and significant terms.



Discovering Unmet Needs

Because this disease is so new, healthcare professionals are learning about the disease alongside their patients. People want to know when they will cease being contagious and when they will be fully recovered. People want to know when they can see family and friends, and also when they can safely return to work and go about the business of living. Some of these people have been tested and know that they have antibodies to the disease but are still unsure if this means they can associate with others.

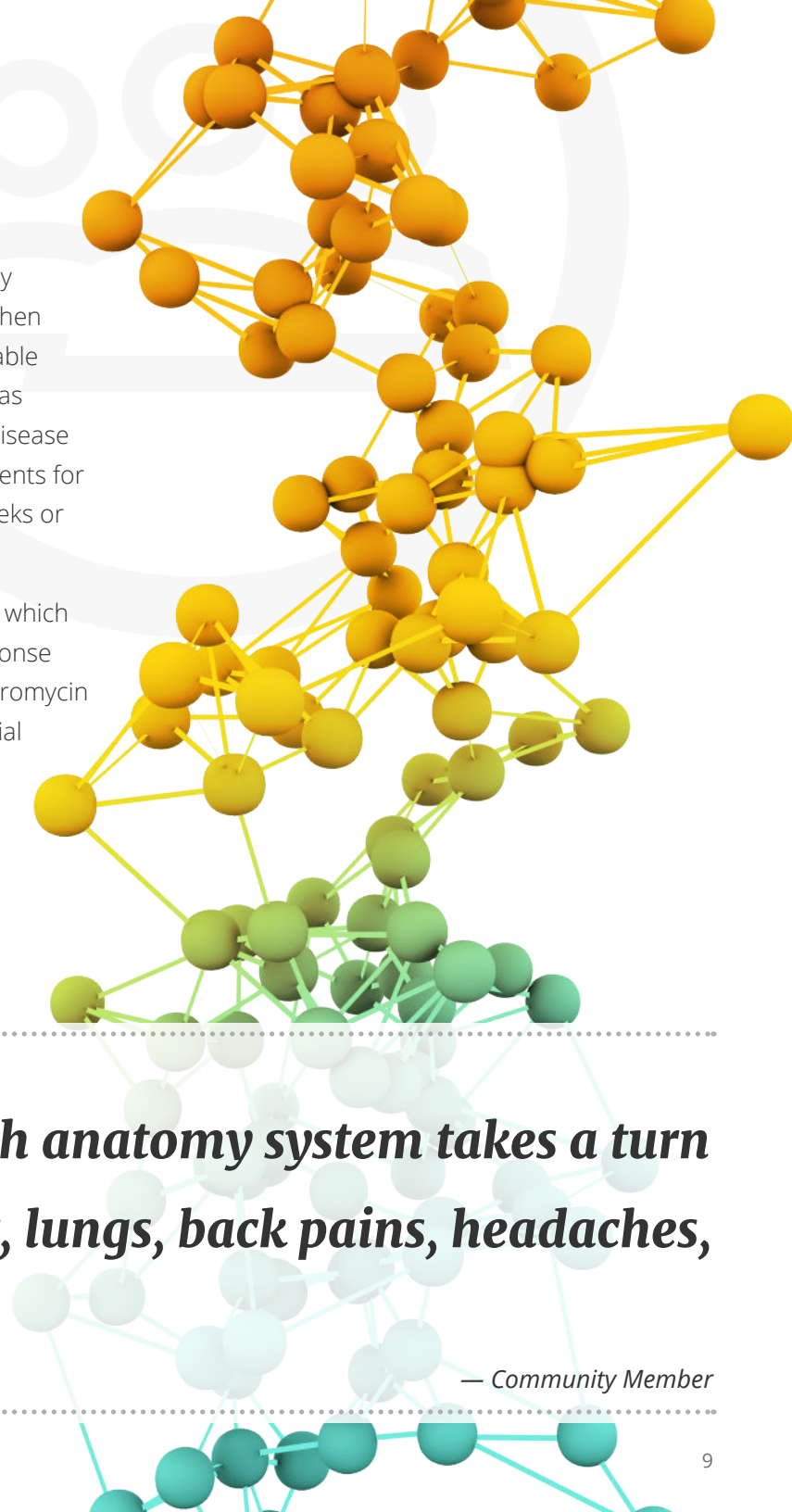
For some people, the symptoms of the disease resolve in 1-3 weeks and they feel fine. For many others, some symptoms persist for months, or come back for a few days, go away, and come back in waves. For those with persistent symptoms, they don't know

if they are still contagious, given that they have symptoms. They also don't know when they will stop having symptoms and be able to resume all aspects of their lives such as exercising. Many find the length of the disease frustrating and desperately want treatments for the symptoms they contend with for weeks or months.

People also discuss other unmet needs, which shifted over time as the healthcare response changed. Hydroxychloroquine and Azithromycin or Remdesivir were discussed as potential treatments in need of further research.

“The symptoms happen in waves. It’s like each anatomy system takes a turn hurting you. For example, your kidneys, heart, lungs, back pains, headaches, etc.”

— Community Member



Data Exploration and Health Initiatives

As the disease continues to spread, we are learning more about it every day. The symptoms lists have been changing as more people have the disease or as it mutates. Listening to patients can help us clarify the early symptoms and the main symptoms of the disease. Many people in the group take the time to list their personal story of the disease—when they got sick, when they got tested, what symptoms they experienced and when. These self-guided natural histories give rich and detailed information about the progression of the disease and could help everyone understand the different ways people experience this illness.

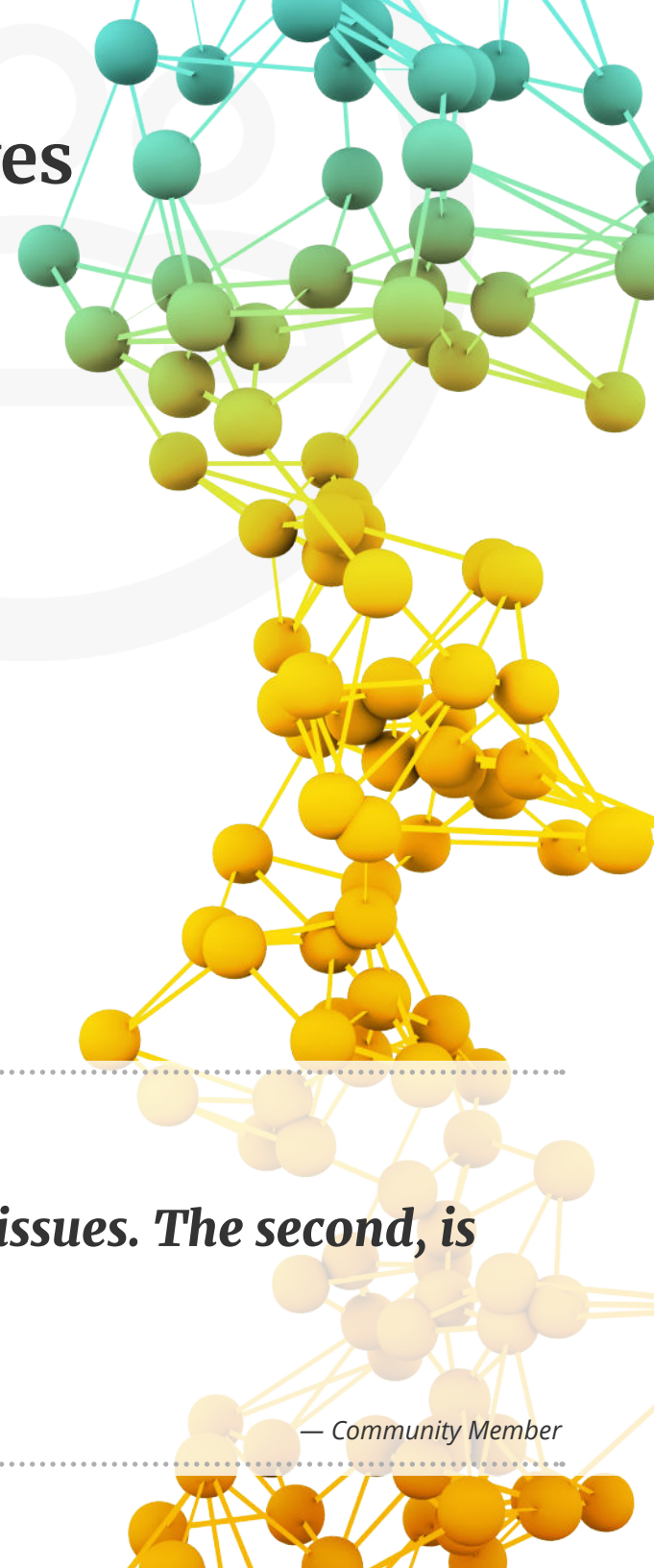
Some people list various self-management techniques, including vitamins, foot baths and other ways to relieve symptoms. As we wait

for a vaccine and a medical treatment plan, looking at the various ways patients handle the illness may give health care providers some suggestions. We could explore some of these ideas and their efficacy in a health initiative.

Much is unknown about this disease, and social listening gives us insights into the patient experience of the disease. This report scratches the surface of what can be learned from this rich data set on Reddit.

“I have two main worries. The first, is long term health issues. The second, is lack of immunity. Will I be in a vicious cycle of illness?”

— Community Member



Appendix

Endnotes

1 https://www.who.int/health-topics/coronavirus#tab=tab_3

Hu Y, Sun J, Dai Z, et al. Prevalence and severity of corona virus disease 2019 (COVID-19): A systematic review and meta-analysis. J Clin Virol 2020;127:104371.

2 May 23, 2020 - June 23, 2020

Social Channels Analyzed	People	Posts	Comments	Gender	Age	Top 5 Countries
Reddit Group: <i>r/Covid-19positive</i>	67,000	7850	113,922	Female: N/A Male: N/A Other: N/A	N/A	N/A



About TREND Community

Founders

TREND Community™ was founded by the parents of a child with Prader-Willi Syndrome who understand the needs of the rare and chronic disease community.

Our mission is to improve the quality of life for everyone living with rare, chronic, and emerging diseases.

Security

TREND secures all social data with state-of-the-art, private cloud servers. Our security practices comply with current HIPAA, FDA, and GDPR guidelines.

Disclaimer

The researchers who prepared this report are not doctors, are not providing medical advice, and are only reporting what was said in the online conversations.

IRB Exemption Status

Western Institutional Review Board determined that this study is exempt under 45 CFR § 46.104(d)(4), because the aim of the research is to collect de-identified information from social

media posts to better understand disease burden, disease management strategies, quality of life, and the unmet needs of patient communities living with rare and chronic diseases. The research is not FDA-regulated nor classified, does not involve prisoners, and is consistent with the ethical principles of the Belmont Report.

Quotes

All quotes were provided by consenting community participants through one-on-one interviews or online focus groups conducted on the TREND Community™ platform. Names are not included to protect participant privacy.

Data Ownership

Ownership of public posts or conversations from other social media platforms shared with TREND for analysis are subject to the social media platform's privacy policy, terms of service and other applicable policies. Participants who share data and experiences on the TREND Community™ platform give their consent for TREND to analyze it. TREND Community owns the results of our analysis and all other data and output that we produce including our Community Voice Reports.

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