LAUNCH REPORT: IgG4-RD



July 28, 2024

l igg4-rd-journeys 32%

IgG4-related disease (IgG4-RD) is an immune-mediated condition, meaning that it involves the occurrence of disease in organs as the result of an abnormally regulated immune system. Some patients with IgG4-RD have disease in only one organ. Others, however, have diseases that affect multiple organs at the same time. It is not unusual for disease to affect anywhere between two to six organs. The following organs are often involved in IgG4-RD; (1) meninges, (2) orbits, (3) lacrimal glands, (4) major salivary glands, (5) thyroid gland, (6) lungs, (7) aorta, (9) kidneys (10) pancreas, (11) bile ducts.1

TREND Community is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights. Our analytics engine, KrystieTM, enables TREND to identify conversations that tend to be prevalent in social media. After isolating conversations within domains of interest such disease burden, management, mental health, TREND leverages a variety of analytical techniques to characterize the language and emotions associated with patient experiences and perspectives.

This report showcases the most recent themes discussed in a newly launched social media community, IgG4-RD Connect, dedicated to supporting those living with IgG4-RD. The goal is to amplify the voices of those living with this condition to shed light on their experiences to drive action and improved outcomes. To join the community, please click on the QR code above. We are very grateful to our partner, Amgen, for its support. We also have been partnering with the team at Global Healthy Living Foundation (GHLF) and we appreciate their time and efforts as well.

DATA SOURCE and COMMUNITY COMPOSITION

mental-health

1.78%

resources

treatments

announcements

2.08%

2.08%

2.37%

GROUP: IgG4-RD Connect (Discord platform)				
MEMBERS: 18 FEMALE: 15 MALE: 3	CAUCASIAN: 14 ASIAN: 2 MULTI-RACIAL: 2	UNITED STATES: 15 CANADA: 1 AUSTRALIA: 1 NEW ZEALAND: 1	CONTRIBUTORS: 12 MESSAGES: 337 AVG ENGAGEMENT: 1.30 reactions/message	TIME RANGE: Jan 2024 – Jun 2024
CHANNEL BREAKDOWN MESSAGES TEXT				Messages are posted in one of six channels. The pie charts show the distribution
• main-chai		► igg4-rd-journ	of messages by channel, as well as the distribution of the actual text content of the group by channel.	
59.6%		51.7%		Most conversations occur

in two channels: main-chat & posts and journeys. While the journey channel has

| mental-health

announcements

0.946%

treatments

0 356%

resources

0.725%

1.72%

3

fewer messages, journeys are long form messages by distinct authors that delve into their 10 individual journeys as patients.

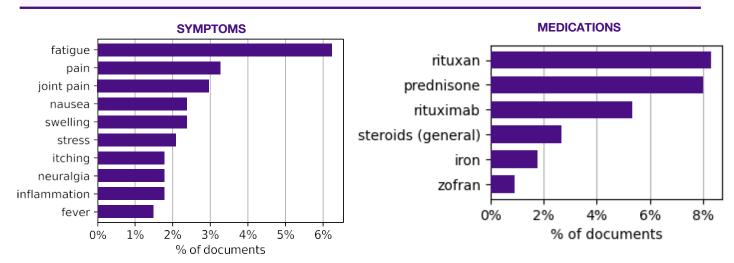
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CLINICAL CONVERSATION

🗢 | main-chat & posts

44.6%

Krystie[™]recognizes and extracts clinical terminology from a data source. The top Symptoms and Medications from the community, by proportion of messages which mention the concept, are presented here. The most frequent in each category were fatigue (6.2% of Symptoms messages) and Rituxan (8.3% of Medications messages).



LAUNCH REPORT: IgG4-RD (Continued)

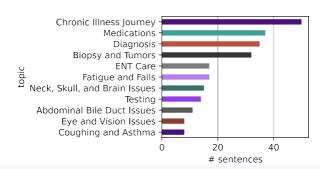
TOPIC ANALYSIS

Topic analysis involves clustering language that has similar meaning. Documents were split into paragraphs, which were then clustered.

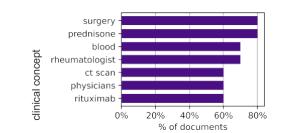
The most frequent topics are presented to the right and the top ones are as follows: *IgG4-RD diagnosis and management, chronic illness journey, community support, and Rituxan infusions.*

SUMMARY OF PERSONAL JOURNEYS

To understand common themes in patient journeys, the sentences in the journeys were clustered into topics. The most common 11 themes are shown below and the top 4 include *chronic illness journey, medications, diagnosis, and biopsy and tumors*.



To gain an initial understanding of clinical experiences, the clinical concepts which appear in more than half of the journeys are shown below. These include *surgery, prednisone, blood, rheumatologist, CT scan, physicians, and rituximab.*



IgG4-RD Diagnosis and Management Chronic Illness Journey Community Support Rituxan Infusions Personal Health Tracking Prednisone Interactions with Healthcare System Movies Medical Events Leading to Surgery 0 20 40 60 # paragraphs

WORD FREQUENCY

A word cloud was generated to illustrate the most frequent words used by community members.

The most frequent words include *infusion*, *thank*, *journey*, *start*, *and feel*.



CONCLUSION



More than 330 conversations were investigated with the goal of gleaning an initial understanding of a budding online community dedicated to the IgG4-RD experience. Fatigue, pain, and inflammation emerged as some of the predominant symptoms while both the generic (rituximab) and brand name (Rituxan) along with prednisone were the most frequently mentioned medications. Steroids in general were mentioned less often but still frequently. In the exploration of patient journeys, specific experiences associated with the diagnostic process and management approaches emerged. The most common experiences included biopsies of inflamed glands/organs and/or tumors/masses, ENT evaluations, and radiological and serological testing. In addition, patients reported abdominal bile duct issues, vision problems, cough, and asthma. The ability to characterize the unique diagnostic odyssey and manifestation of a condition is essential to understand rare and emerging diseases. As the conversations continue, we aim to identify patterns that lead to earlier diagnosis and improved treatment outcomes.

