

LAUNCH REPORT: IgG4-RD

July 28, 2024



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, Krystie™, enables TREND to identify conversations that tend to be prevalent in social media. After isolating conversations within domains of interest such as disease burden, management, mental health, TREND leverages a variety of analytical techniques to characterize the language and emotions associated with patient experiences and perspectives.

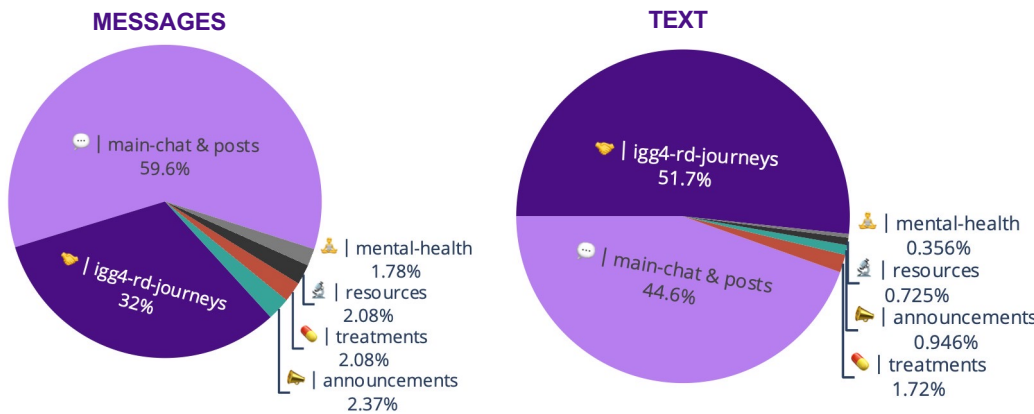
This report showcases the most recent themes discussed in a newly launched social media community, IgG4-RD Connect, dedicated to supporting those living with IgG4-RD. The goal is to amplify the voices of those living with this condition to shed light on their experiences to drive action and improved 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

GROUP: IgG4-RD Connect (Discord platform)

MEMBERS: 18	CAUCASIAN: 14	UNITED STATES: 15	CONTRIBUTORS: 12	TIME RANGE: Jan 2024 – Jun 2024
FEMALE: 15	ASIAN: 2	CANADA: 1	MESSAGES: 337	
MALE: 3	MULTI-RACIAL: 2	AUSTRALIA: 1 NEW ZEALAND: 1	AVG ENGAGEMENT: 1.30 reactions/message	

CHANNEL BREAKDOWN



Messages are posted in one of six channels. The pie charts show the distribution of messages by channel, as well as the distribution of the actual text content of the group by channel.

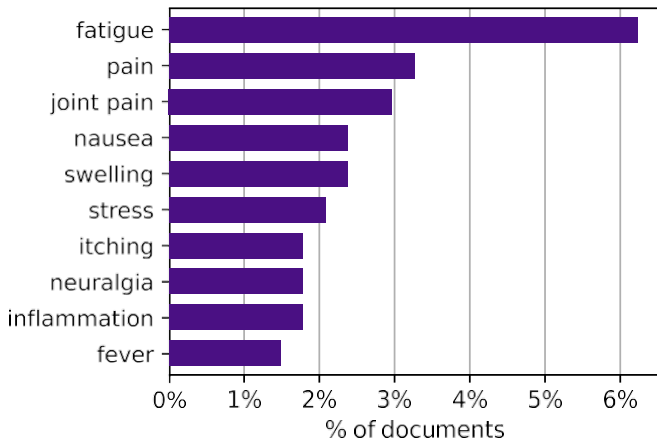
Most conversations occur in two channels: main-chat & posts and journeys.

While the journey channel has fewer messages, journeys are long form messages by distinct authors that delve into their 10 individual journeys as patients.

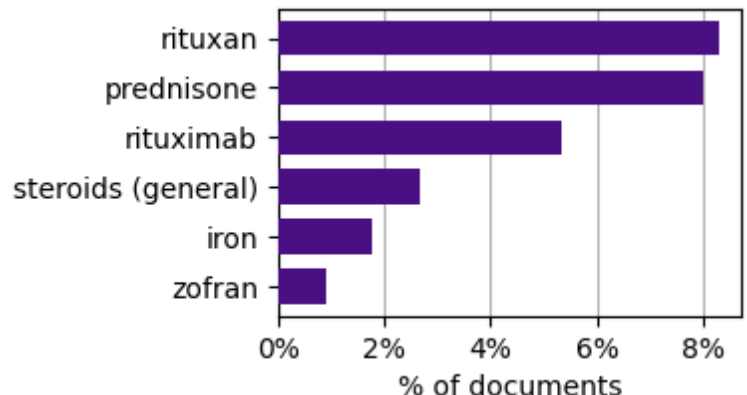
CLINICAL CONVERSATION

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).

SYMPTOMS



MEDICATIONS



¹ IgG4-Related Disease (IgG4-RD). IgG4-related disease (igg4-rd). (n.d.). <https://rheumatology.org/patients/igg4-related-disease-igg4-rd>

