



The Criticality of Publications in Rare Disease

Many of the usual information dissemination avenues have evolved in light of the current pandemic



COVID-19 has brought with it a new reality that directly impacts the methods we use to communicate and disseminate information to patients, advocates, caregivers (PAC), and physicians alike. No longer do we jump on planes and head to conferences around the world. We have observed major medical conferences cancelled, postponed, and converted to virtual events. We have watched advocacy groups move from their very important face-to-face events to virtual educational sessions. We have noticed pharmaceutical sales representatives can no longer visit physicians to share information about their treatments. Our world has changed, and our approaches need to adjust. However, the critical need of communicating information to all of our stakeholders remains.

Role of traditional publications

Peer-reviewed medical publications remain a mainstay of trusted communication of disease and treatment information. They influence everything from prescribing options to treatment guidelines and payer decisions. They are even more essential in rare diseases as PACs seek to educate themselves and often their physicians. The burning need for them to research and find critical information has never been more pressing. Moreover, some of the most important roles of peer-reviewed publications are to inspire conversation, inform scientific discourse, and promote critical thinking. Those discussions can lead to new creative approaches and even stimulate further research.

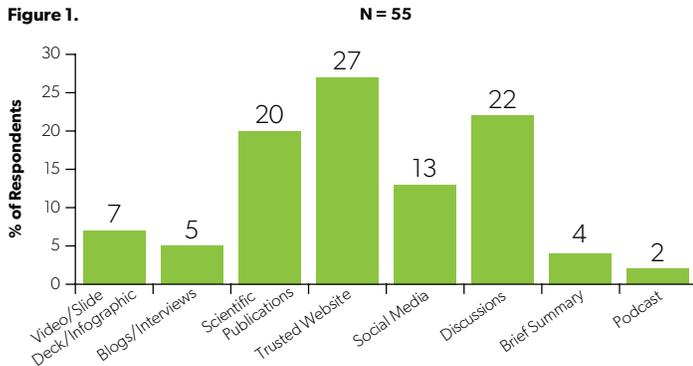
Emerging urgency for publications

There is an emerging urgency to use publications as a substitute for face-to-face meetings to personally exchanging ideas and knowledge. We have seen an evolution of an evidence-based medicine approach to encourage engagement across diverse groups. It is not just about getting published or about the publications themselves, but how, who, and to whom we disseminate medical and scientific information. The need for information is shifting and evolving with the patient being the impetus for publishing urgently. On the bright side, when we are in isolation with limited outside communication, we have an increased opportunity to read and more time to absorb the information in a publication. When we are not in that high-pressure work environment that often comes with traditional workdays, we often try to compress so much into a fixed number of hours.



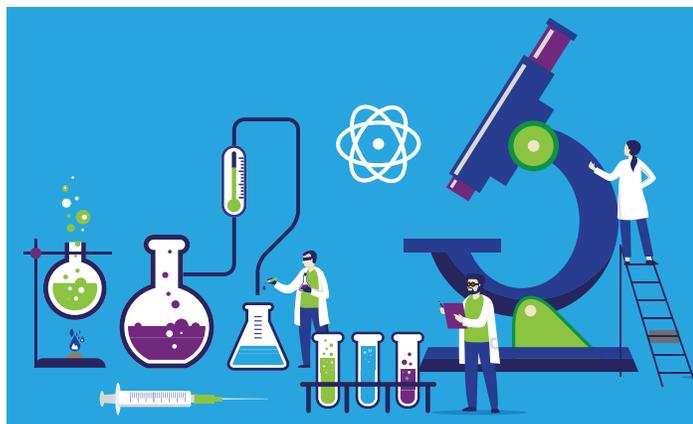
Adding fuel to the fire: The need for publications in rare

There is already a well-documented paucity of information on rare diseases in medical literature.¹ The impact of that dearth of reliable information is compounded in today's environment by the inability to share what is there or discuss new information using traditional methodologies. In order to best communicate, we need to know what rare community members want. It is comforting to know that in a survey of rare disease patients and caregivers, publications (no surprise) were among the top 3 most-preferred sources of information (**Figure 1**):



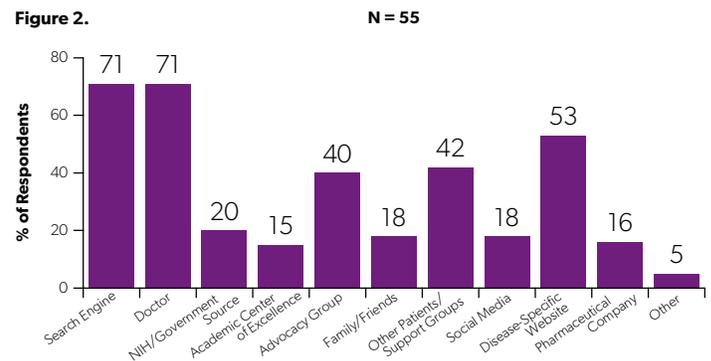
What are the ways we can extend the reach of the publications in order to inspire discussion and ensure rare disease community members are getting attention?

- Start with what they want (listen)
- Share it where they go (trust)
- Initiate discussions in creative ways (engage)



Combining the top 3 sources of information may be pointing us in the direction of a solution and a way to make up for what we miss from live conferences. The process becomes: get the work published, share it in a trusted place, and initiate engagement.

Knowing where our rare community members go for their information helps too (**Figure 2**). We listened. In addition to our publication expertise in rare, we build cloud-based rare disease communities. We share information there too.



What can we do?

Don't delay. Get going on your publication programs. We know the benefits of starting early, but we rarely do it. Phase II is an ideal time. PACs will be looking for emerging treatments where urgency in finding those options is paramount. The approach must not only be through evidence-based medicine, but encompass a collaborative, diverse engagement. This will culminate in trusted, vetted medical and scientific information to remain resolute on patient centricity, and provide information through trusted avenues to strive for collaborative engagement.

To expand your rareIQ, contact Dan Donovan at ddonovan@rarelifesolutions.com or Peter Snyder at psnyder@rarelifesolutions.com.

Reference:

1. Walewski JL, Donovan D, Nori M. How many zebras are there, and where are they hiding in medical literature? A literature review of publications on rare diseases. *Expert Opin Orphan Drugs*. 2019;7(11):513-519.