

# The potential role and impact of patients, advocates, and caregivers on medical publications and acceptance of treatments in rare diseases

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### Abstract

In an era of massive data proliferation, trusted information is very difficult to find. This situation is exacerbated in rare diseases where despite there being > 7000 types, they comprise < 0.2% of the medical literature. Furthermore, patients, advocates, and caregivers (PACs) are almost nonexistent as authors even though they are experts in their own diseases and often more knowledgeable than medical professionals. In recent years, there is an increased interest in having PACs as co-equal authors on medical manuscripts. Articles authored or coauthored by PACs can have far-reaching impact, including identifying problems with access to medication or post-treatment support and influencing change of regulatory decisions that can affect all patients with that particular rare disease. The value of having PACs as authors cannot be overstated. Including PACs as authors on publications provides the articles with an authenticity that is inherently absent in clinical manuscripts authored by physicians, which is currently the norm. Inclusion of PACs in the development of a trial protocol and as authors on the ensuing publication can help the sponsor recruit and retain patients and potentially speed up the discovery and approval of novel therapies. Inclusion of PACs as authors on manuscripts reporting the results of that trial can help other patients feel more confident and reassured about trying new medications or treatments. In short, inclusion of PACs is beneficial to all stakeholders, including other patients, researchers, clinicians, sponsoring organizations, and industry, and can positively influence decisions by regulatory agencies.

### Biography

Mukund Nori holds the position of Director, Medical Affairs and Principal Medical Writer at rareLife solutions with over 16 years of experience in medical communications and over 12 years in pharmaceutical drug discovery. He has a PhD in Biology from University of South Carolina, an MBA from University of New Haven, and is an International Society of Medical Publication Professionals (ISMPP) Certified Medical Publications Professional (CMPP) and serves as the Chair of the Ethics and Standards Committee. He is a published author and a recipient of the President's Volunteer Service Award in 2012.

### Publications

1. Publication ethics from the ground up, February 2018 International Journal of Clinical Practice 72(2), DOI:10.1111/ijcp.13063
2. Inhibition of epidermal growth factor receptor biosynthesis caused by the, April 1990, Molecular and Cellular Biology 10(3):1254-8, DOI:10.1128/MCB.10.3.1254

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