

Most internet resources for IPF are inaccurate, incomplete and outdated

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Credit: ATS

After evaluating content on idiopathic pulmonary fibrosis on almost 200 websites, researchers with medical backgrounds found that the information on IPF from these sites was often incomplete, inaccurate and outdated. The study, "Accuracy and Reliability of Internet Resources for Information on Idiopathic Pulmonary Fibrosis" highlights the need for the medical community to continually reassess the accuracy of online information. The research was printed online ahead of print in the American Thoracic Society's *American Journal of Respiratory and Critical Care Medicine*.

Characterized by a progressive decline in lung function, specifically shortness of breath, IPF is chronic and ultimately fatal. Patients who rely on the Internet for treatment recommendations may be putting themselves at considerable risk. "Nearly half of IPF-related websites suggested a role for at least one medication with no proven benefit, and more than a third of websites recommended medications that are harmful in IPF," said coauthor Christopher Ryerson, MD, Assistant Professor at the Centre for Heart Lung Innovation at St. Paul's Hospital and the University of British

Columbia.

Using DISCERN, a validated instrument for assessing the quality of written medical <u>information</u>, the researchers evaluated IPF-related content on sites that included foundation/ advocacy organizations, news/media reports, blogs, and scientific resources as well as industry/for profit companies. Each site received a score based on the quality of the content, the quality of the information regarding treatment options, the overall publication, and the reliability of the publication.

The researchers found that foundation/advocacy websites were more likely to recommend nonindicated therapies for treatment. News/media reports were less likely to provide an overview of IPF, instead focusing on a single item such as newly-approved treatment. The top two websites for both content and quality scores were Wikipedia and Medscape.

"The Internet will remain a common source of health information for patients," said Jolene Fisher, MD, Respirologist at University Health Network, University of Toronto and study co-author. "The medical community, including IPF specialists, needs to take a more active role in ensuring patients have access to accurate and up-to-date online medical information. Patients with IPF should be aware that the information they are accessing may be inaccurate and that harmful recommendations may be made, even on websites from reputable organizations."

Provided by American Thoracic Society



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