



PureTech Announces Publication of New Research Highlighting Untold Experiences of People Living with Idiopathic Pulmonary Fibrosis (IPF)

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PureTech Announces Publication of New Research Highlighting Untold Experiences of People Living with Idiopathic Pulmonary Fibrosis (IPF)

Research conducted in collaboration with IPF experts and the Pulmonary Fibrosis Foundation reveals critical gaps in diagnosis, treatment, and quality of life for people living with IPF

Findings highlight the profound physical, emotional, and psychosocial burden of IPF and underscore urgent need for enhanced education, streamlined diagnosis, patient-focused treatment plans, and more effective therapies

[PureTech Health plc](#) (Nasdaq: PRTC, LSE: PRTC) ("PureTech" or the "Company"), a clinical-stage biotherapeutics company dedicated to changing the lives of patients with devastating diseases, today announced the publication of new research in [BMC Pulmonary Medicine](#) that provides a comprehensive view into the lived experiences of people with idiopathic pulmonary fibrosis (IPF). Conducted in collaboration with Tejaswini Kulkarni, MD, MPH, from the University of Alabama at Birmingham, Lisa Lancaster, MD, from Vanderbilt University Medical Center, and Jessica Shore, RN, PhD, from the Pulmonary Fibrosis Foundation (PFF), the study identifies critical barriers to treatment, opportunities for improved community engagement, and the need for patient-centered approaches in the development of new therapeutics. Initial findings from this research were presented at the 2023 Pulmonary Fibrosis Foundation Summit, the American Thoracic Society 2024 International Conference, and the CHEST 2024 Annual Meeting.

"It's remarkable that despite the availability of approved therapies, antifibrotic uptake remains persistently low. This lack of engagement reflects not just clinical barriers but fundamental gaps in understanding the experiences of people living with IPF, and we wanted to highlight their voices in this study," said Camilla Graham, MD, MPH, Senior Vice President of Medical Affairs at PureTech and lead author of the study. "By integrating the perspectives of people with IPF into every stage of diagnosis, disease management, education, and clinical development, we have a real opportunity to shift the paradigm for IPF care to one that is more empathetic, effective, and aligned with the realities of living with this serious disease. This study is just the beginning; academic centers, professional societies, advocacy organizations, and pharmaceutical companies need to continue to collaborate on patient-informed innovation that bridges the current gaps in diagnosis, treatment, and quality of life."

"As a clinician and researcher deeply involved in the care of individuals with IPF, I often witness the challenges patients face in understanding their diagnosis and treatment options," said Dr. Kulkarni. "This work uniquely captures the real-world experiences of people living with IPF, bringing to light critical gaps in education, awareness, and early intervention that we see play out in everyday clinical practice. By integrating these perspectives into our clinical strategies and research priorities, we have the opportunity to drive more empathetic, effective care that aligns with what truly matters to those living with IPF."

"At the Pulmonary Fibrosis Foundation, our mission is to accelerate the development of new treatments and improve the quality of life for people affected by pulmonary fibrosis. This study provided an opportunity to truly listen to patients, capturing their experiences with diagnosis, antifibrotic therapy, and oxygen use-areas where we know there are gaps in understanding and support," said Dr. Shore. "These findings highlight the critical need for high-quality educational resources, to strengthen advocacy efforts, and to enhance collaboration with healthcare providers to ensure that patient voices remain at the center of care decisions."

Key research highlights include:

1. The need for enhanced disease awareness and education

- Diagnosis timelines varied widely, with some participants experiencing years of delays and extensive evaluations for other conditions before receiving an IPF diagnosis. These findings underscore the need for an increase in awareness campaigns and more efficient diagnostic protocols to ensure earlier identification and intervention.
- While the majority of participants expressed satisfaction with their healthcare provider interactions, most also turned to the internet and support groups for information. This underscores the need for widely accessible, high-quality resources about IPF and its management.
- IPF affected many aspects of participants' lives, including their ability to keep up with family, work, travel, and household tasks, while also straining relationships with family and friends. This highlights the need to enhance management strategies that address not only the physical but also the emotional and psychological needs of people living with IPF and their caregivers.

2. The perceived impact of antifibrotics and the need for clearer treatment expectations

- Of the participants who had never been treated with an antifibrotic, the most common reason for delay was that they were waiting until their symptoms worsened, highlighting a critical gap in understanding the potential benefits of early intervention.
- While the majority of participants on antifibrotics reported that their medication helped slow disease progression, many still found it difficult to perceive tangible benefits due to the lack of visible improvements. Additionally, side effects associated with antifibrotic treatments often impacted quality of life, leading some participants to reduce dosing or discontinue therapy - further complicating perceptions of effectiveness. Despite these challenges, most people taking antifibrotics shared that the treatment gave them hope. These findings emphasize the need for clearer communication about the expected benefits and limitations of antifibrotic therapy, as well as strategies to manage side effects and maintain therapeutic benefit.
- The study explored both the adverse effects participants ascribed to their antifibrotic treatment and the broader impact of managing those side effects on daily life. More than half adjusted their dosing to help manage adverse effects. These findings suggest opportunities for more patient-centered education on symptom management and highlight the need for better-tolerated medications to treat IPF.
- Clear, empathetic communication between healthcare providers and patients is essential to set realistic expectations, manage consequences of IPF and side effects of antifibrotic treatment, and empower patient engagement with all aspects of their care.

3. The need for coordinated care to manage multiple comorbidities

- Nearly 90% of study participants reported managing additional health challenges alongside IPF, underscoring the importance of coordinated care among IPF-treating providers and the broader care team.
- The prevalence of comorbidities suggests that improving communication and strategic care planning across specialties could improve outcomes and overall quality of life for people living with IPF. Integrated care pathways that address both IPF and its comorbidities could significantly reduce the burden on people living with IPF and their caregivers.

4. The need for holistic support in managing the benefits and burdens of supplemental oxygen

- While participants widely recognized the symptom relief provided by supplemental oxygen therapy, many described the associated logistical challenges, daily disruptions, financial burdens, and emotional toll. These insights underscore the need for treatment planning that accounts for both the benefits and challenges of oxygen therapy, while exploring innovations in delivery and holistic support to enhance quality of life.

The research, which included 106 people living with IPF across the United States, utilized both qualitative interviews and online surveys to capture their experiences. Sponsored by PureTech, the study underscores the Company's commitment to amplifying patient voices in the development of breakthrough treatments. By understanding the lived experiences and unmet needs of people with IPF, PureTech aims to drive meaningful advances in care, education, and therapeutic development that are deeply reflective of patient realities. The paper, titled "[Perspectives of People Living with Idiopathic Pulmonary Fibrosis: A Qualitative and Quantitative Study](#)," is now available on the journal's website.

Acknowledgments and Appreciation

PureTech would like to extend its sincere gratitude to all the participants who generously shared their time and experiences to make this research possible. PureTech is also grateful to the Pulmonary Fibrosis Foundation and Breathe Support Network, whose support was instrumental in developing a comprehensive study that reached a diverse group of participants to provide these critical insights. PureTech is proud to amplify the voices of those living with IPF and remains committed to fostering patient-driven innovation and care that is reflective of real-world needs.

About Idiopathic Pulmonary Fibrosis (IPF)

Idiopathic Pulmonary Fibrosis (IPF) is a rare, progressive and fatal lung disease characterized by irreversible scarring of lung tissue. Median survival following diagnosis is estimated to be two to five years.^[1] IPF affects more than 230,000 people across the United States and EU5 (France, Germany, Italy, Spain, and the United Kingdom)^[2].

Although two therapies are approved to treat IPF, their use remains limited, and nearly three out of four people with IPF in the United States have

never received either treatment.^[3] There remains a significant need for therapies that can more effectively slow or stabilize disease progression, improve long-term outcomes, and maintain quality of life for people living with IPF.

About PureTech Health

PureTech is a clinical-stage biotherapeutics company dedicated to giving life to new classes of medicine to change the lives of patients with devastating diseases. The Company has created a broad and deep portfolio through its experienced research and development team and its extensive network of scientists, clinicians, and industry leaders that is being advanced both internally and through its Founded Entities. PureTech's R&D engine has resulted in the development of 29 therapeutics and therapeutic candidates, including three that have been approved by the U.S. Food and Drug Administration. A number of these programs are being advanced by PureTech or its Founded Entities in various indications and stages of clinical development, including registration-enabling studies. All of the underlying programs and platforms that resulted in this portfolio of therapeutic candidates were initially identified or discovered and then advanced by the PureTech team through key validation points.

For more information, visit www.puretechhealth.com or connect with us on X (formerly Twitter) @puretechh.

Cautionary Note Regarding Forward-Looking Statements

This press release contains statements that are or may be forward-looking statements within the meaning of the Private Securities Litigation Reform Act of 1995. All statements contained in this press release that do not relate to matters of historical fact should be considered forward-looking statements, including without limitation those related to our idiopathic pulmonary fibrosis program and development plans, our future prospects, developments and strategies. The forward-looking statements are based on current expectations and are subject to known and unknown risks, uncertainties and other important factors that could cause actual results, performance and achievements to differ materially from current expectations, including, but not limited to, those risks, uncertainties and other important factors described under the caption "Risk Factors" in our Annual Report on Form 20-F for the year ended December 31, 2024, filed with the SEC and in our other regulatory filings. These forward-looking statements are based on assumptions regarding the present and future business strategies of the Company and the environment in which it will operate in the future. Each forward-looking statement speaks only as at the date of this press release. Except as required by law and regulatory requirements, we disclaim any obligation to update or revise these forward-looking statements, whether as a result of new information, future events or otherwise.

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[1] Fisher, M., Nathan, S. D., Hill, C., Marshall, J., Dejonckheere, F., Thuesson, P., & Maher, T. M. (2017). Predicting Life Expectancy for Pirfenidone in Idiopathic Pulmonary Fibrosis. *Journal of Managed Care & Specialty Pharmacy*, 23(3-b Suppl), S17-S24. <https://doi.org/10.18553/jmcp.2017.23.3-b.s17>

[2] GlobalData Epidemiology and Market Size Search, EU5=United Kingdom, France, Germany, Italy and Spain

[3] Dempsey TM, Payne S, Sangaralingham L, Yao X, Shah ND, Limper AH. Adoption of the Antifibrotic Medications Pirfenidone and Nintedanib for Patients with Idiopathic Pulmonary Fibrosis. *Ann Am Thorac Soc*. 2021 Jul;18(7):1121-1128

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