

Understanding pulmonary fibrosis

Phenomenological research into the lived experience of patients with primary pulmonary fibrosis and/or scleroderma

Investigators: Dr. Tamás Bereczky, Dr. Daniela Rojas-Castro, Dominique Hamerlijnck

This study researches the lived experience of pulmonary fibrosis patients who live with primary pulmonary fibrosis and/or with scleroderma. This study is conducted by The European Patients' Academy for Therapeutic Innovation [EUPATI](#) under an unrestricted research contract with Boehringer-Ingelheim (sponsor). While providing funding for this study, the sponsor does not exert any influence on the conduct, methods, or outcomes of the research.

By participating in this study, you contribute to a better understanding of how people living with pulmonary fibrosis think and feel about their condition, and how their condition influences their quality of life and how they live in general. There is no financial reward available for participants in this study.

Participation in this study consists of an interview. If you agree to participate, we will schedule the interview when it is convenient for you. The interview will last approximately 60 minutes. It will be conducted online by one of the researchers who has extensive experience in qualitative research. The interview guide has been reviewed by patient organisations. Online interviews will be conducted via the online conferencing tool Zoom. The interview can be interrupted at any time should you feel unwell or in any way uncomfortable. The information shared with the interviewer will be part of the analysis, even if you decide to stop the interview.

With your permission, the interview will be recorded in Zoom and transcribed with the support of Zoom's automated transcription tool, reviewed and corrected by one of the investigators.

The interview and the transcript will contain no information that may identify you. All interviews will be anonymised, while information from the interviews will be combined and analysed in a way that does not allow the identification of any of the participants. The transcript of the interview will be stored on a secure server of EUPATI for five years, and then it will be deleted. Interview recordings will be deleted upon completion and review of the transcript.

The findings generated through this study will be disseminated via academic publications, via presentations (to the sponsor and other audiences), via newspapers, magazines, blogs, and other outlets with a public character. You, together with other participants, will be invited to a presentation of the results if you decide that you want to participate in such a presentation.

The principal investigator on this project is Dr. Tamás Bereczky. He can be contacted using this email address: tamasbereczky@me.com.

The administrative and logistical arrangements of this study are taken care of by Dr. Jana Popova at EUPATI. She can be contacted using this email address: jana.popova@eupati.eu.

Below you are provided with the informed consent form. Please read it carefully and do not hesitate to discuss it with colleagues, family and friends, or to contact the investigator, if you have any questions or require any clarification.

You are kindly invited to send the investigator the signed informed consent form by email prior to the interview.