The patient journey in pulmonary fibrosis in Greece: diagnostic pathways, delays, and early management

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Introduction

- Patients with pulmonary fibrosis (PF) may experience non-specific symptoms and complex diagnostic pathways involving multiple healthcare contacts, misdiagnosis, and delays before a definitive diagnosis is established [1,2].
- Longer time to diagnosis in progressive fibrotic ILD has been associated with adverse clinical outcomes [3].
- Understanding patient-reported experiences across the diagnostic pathway may help identify gaps in early disease recognition and referral to specialist care [1,2].

Objective

To characterise the diagnostic and early management journey of patients with PF in Greece and explore factors associated with longer diagnostic intervals.

Methods

Study design & Participants

- An online cross-sectional survey was conducted by the Hellenic Pulmonary Fibrosis Association "Lungs of Life" in Greece during May–June 2026.
- Adults with self-reported PF who provided informed consent were eligible.

Data collection

Questionnaires were completed by patients or by caregivers on their behalf. The structured survey captured the following patient-reported domains:

- **Symptom presentation and initial care-seeking:** symptoms prompting medical attention, incidental detection, symptom duration before seeking care, and specialty of the first physician consulted.
- **Diagnostic pathway:** number of physicians or healthcare facilities consulted before diagnosis, specialty establishing the definitive diagnosis, and referral source to a specialist pulmonologist or interstitial lung disease (ILD) clinic.
- **Prior misdiagnosis:** occurrence and type of misdiagnosis before definitive PF diagnosis.
- **Perceived diagnostic barriers:** delayed symptom recognition in primary care, delays in appointments or diagnostic tests, delayed specialist referral, difficulties accessing specialist care, and financial or travel-related barriers.
- **Diagnostic and treatment timelines:** time from symptom onset to diagnosis, first pulmonologist consultation, and treatment initiation, as well as time from diagnosis to treatment initiation.

Statistical analysis

- Results were summarised overall and by diagnosis group (IPF vs other PF), as n (%) or median (Q1–Q3).
- Exploratory analyses examined symptom onset-to-diagnosis intervals, primarily among symptomatic non-incidental respondents, using Wilcoxon rank-sum or Kruskal–Wallis tests, as appropriate.

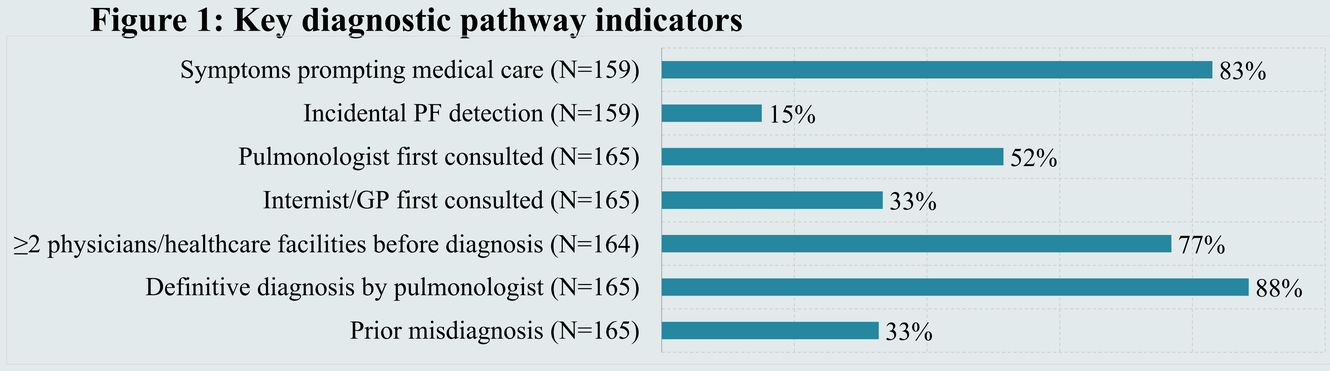
Results

Study population: N=165 · IPF 65% · Median age 74 years · 69% Males

Symptom presentation and diagnostic pathway (Figure 1)

- Among patients reporting symptoms prompting medical care (N=132), the most common were dyspnoea (48.5%), persistent dry cough (47.0%), and fatigue (42.4%). Fatigue was numerically more frequent in IPF than other PF (50.0% vs 28.3%).
- Among patients with available information on prior misdiagnosis type (N=52), respiratory infection was the most frequently reported (46.2%), followed by COPD (13.5%), GERD (11.5%), and asthma (11.5%).
- Definitive diagnosis by a pulmonologist was more frequent in IPF than other PF (96.3% vs 74.1%), whereas diagnosis by a rheumatologist was more frequent in other PF (20.7% vs 0.9%).

Figure 1: Key diagnostic pathway indicators

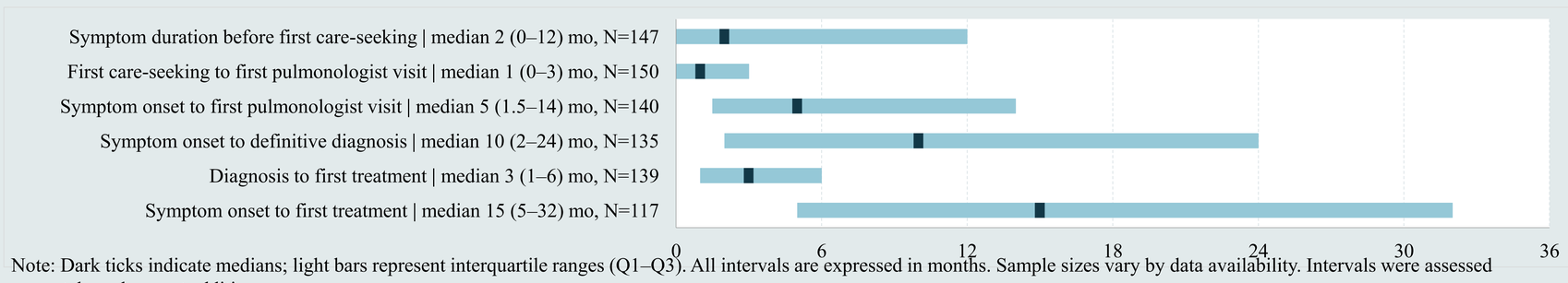


Note: Multiple metrics describe different stages of the patient journey and are not mutually exclusive. Available N varies by indicator.

Diagnostic and treatment intervals

Patient-reported intervals indicated considerable variability across the diagnostic and early treatment pathway, from initial symptom presentation and care-seeking to specialist consultation, definitive diagnosis, and treatment initiation (Figure 2).

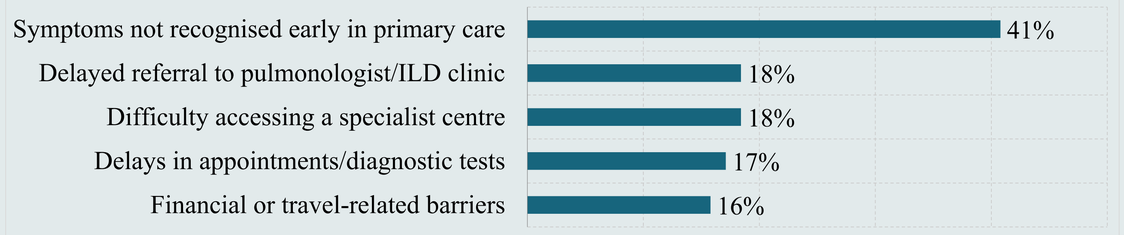
Figure 2: Patient-reported diagnostic and treatment intervals



Note: Dark ticks indicate medians; light bars represent interquartile ranges (Q1–Q3). All intervals are expressed in months. Sample sizes vary by data availability. Intervals were assessed separately and are not additive.

Patient-reported barriers spanned multiple stages of the diagnostic pathway, with difficulties in early symptom recognition reported more frequently than delays in diagnostic testing, specialist referral, or access to specialist care (Figure 3).

Figure 3: Patient-reported diagnostic barriers



Note: Bars indicate the percentage of respondents reporting each barrier (N=152). Barriers were assessed separately and were not mutually exclusive.

Exploratory analyses among symptomatic non-incidental respondents identified longer symptom onset-to-diagnosis intervals in patients reporting prior misdiagnosis, delayed symptom recognition in primary care, or delayed referral to specialist care (Table 1).

Table 1: Factors associated with diagnostic delay

Factor	Comparison	N	Median (months)	Q1–Q3 (months)	p-value
Prior misdiagnosis	No	68	10	2.5–20.5	0.031
	Yes	45	16	7–30	
Symptoms not recognised early in primary care	No	56	9.5	1–25	0.035
	Yes	50	14	7–27	
Delayed referral to pulmonologist/ILD clinic	No	83	10	3–23	0.013
	Yes	23	24	12–33	

Note: Values are median (Q1–Q3), in months. Analyses included symptomatic non-incidental respondents (N=113); sample sizes varied by factor. P-values are from exploratory, unadjusted Wilcoxon rank-sum tests.

Limitations

- The cross-sectional design precludes causal inference.
- Voluntary participation in an online survey may limit representativeness, while self-reported and caregiver-proxy responses may introduce recall and reporting bias.
- Missing data resulted in varying sample sizes. Exploratory comparisons were unadjusted, with no correction for multiple testing.

Conclusions

- Patients with PF in Greece reported substantial variability in their diagnostic pathways, with prolonged intervals from symptom onset to diagnosis and treatment initiation.
- Prior misdiagnosis, delayed symptom recognition, and delayed specialist referral were associated with longer diagnostic intervals, highlighting potential opportunities to improve early disease recognition and referral pathways.

References: [1] N. Chaudhuri et al., Respir. Res., vol. 25, article 364, Oct. 2024; [2] Y. Kaneko et al., Front. Med., vol. 12, article 1526530, Apr. 2025; [3] Z. Deng et al., BMJ Open Respir. Res., vol. 13, no. 1, article e004356, Sep. 2026.

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