

IPF Charter – Reason and Stakeholders

There was an IPF Patient Charter launched 2014. Who funded this activity and what was the motivation behind?

The **IPF Patient Charter (2014)** is a good example of a **multi-stakeholder advocacy initiative** that sits at the intersection of patient groups, clinicians, and industry support—so the funding and motivation are intertwined.

1. What was the initiative?

The **IPF Patient Charter** was launched in **2014** to:

- Define a **global standard of care expectations** for Idiopathic Pulmonary Fibrosis
- Highlight **delays in diagnosis and treatment access**
- Call for **policy action** across healthcare systems

It was endorsed by clinicians and patient organisations worldwide.

2. Who funded it?


The charter was:

Led by patient and clinical organisations

- **European Idiopathic Pulmonary Fibrosis and Related Disorders Federation**
- Supported by international respiratory experts and advocacy groups

Financially supported by industry (key point)

- The initiative received funding from:
 - **Boehringer Ingelheim** (developer of Ofev)
 - **InterMune** (developer of pirfenidone / Esbriet)

 This type of funding is typically described as “**unrestricted educational grants**” in disclosures.

3. What was the motivation?

a) Genuine unmet medical need

At the time (pre-/early 2014):

- IPF was:
 - Underdiagnosed
 - Poorly understood
 - Associated with **very high mortality (~3–5 year median survival)**
- Access to treatment was:
 - Highly unequal across Europe
 - Still emerging (pirfenidone rollout ongoing, Ofev not yet approved in EU)

 There was a **real clinical and patient-driven need** to standardise care expectations.

b) Reduce diagnostic delay

A major focus:

- Patients often waited **1–2+ years for diagnosis**
- Misdiagnosis (e.g., COPD, asthma) was common

 Earlier diagnosis → earlier eligibility for antifibrotic therapy

c) Push for reimbursement and access

This is where the timing matters:

- Charter launched: **2014**
- Ofev EU approval: **2015**
- Esbriet still rolling out unevenly

The charter explicitly called for:

- Equal access to approved therapies
- Faster reimbursement decisions
- Specialist centre availability

 In practice, this aligns strongly with **market access expansion**

d) Industry-aligned incentives (important nuance)

While the charter was not a “marketing document,” the incentives were aligned:

For industry:

- Expand **diagnosed patient pool**
- Reduce **HTA resistance** via awareness of disease severity
- Support **faster uptake of antifibrotics**

For patients/clinicians:

- Earlier diagnosis
- Better access to life-prolonging therapies

➡ This is a classic **convergence of interests**, not necessarily a conflict—but it’s not neutral either.

4. Bottom line (critical perspective)

- **Funded by:** pharma (Boehringer Ingelheim, InterMune)
- **Fronted by:** patient organisations and clinical experts
- **Motivation:**
 - Legitimate: improve IPF care and awareness
 - Strategic: accelerate access and uptake of newly available therapies

👉 The timing (just before Ofev approval and during pirfenidone rollout) strongly suggests it also functioned as a **market-shaping tool**, even if framed as advocacy.
