

2nd VIRTUAL EUROPEAN PULMONARY FIBROSIS PATIENT SUMMIT

REPORT



3rd – 5th November 2022



Introduction

From November 3rd-5th 2022, the second virtual **European Pulmonary Fibrosis Patient Summit** brought together patients and caregivers, healthcare professionals, policy makers and industry representatives, with **12 Sessions and 37 speakers** covering a wide range of topics including clinical, treatment, patient involvement and research.

The event and its programme were **designed by patients for patients**, offering plenty of variety, new and relevant insights from research and care – and, above all, put the patients' perspective at the centre. Conceived as a **European Summit**, the event also offered **live translations** for each session in Spanish, Italian, French, Greek, Bulgarian, Dutch, Polish, German, Romanian & Portuguese.

We would like to sincerely thank our sponsors again this year for making it possible for us to host the European PF Patient Summit and allow the Pulmonary Fibrosis community to come together with a common goal: to shape the future of research & care in Pulmonary Fibrosis together and in the best interest of patients. Thank you for your continuous support, Boehringer Ingelheim, CSL Behring, Three Lakes Foundation and Chiesi.



“In research towards a cure, access to clinical trials, early and timely involvement of Pulmonary Fibrosis patients in these as well as improving their quality of life, and, not least, empowering and better supporting caregivers – there is an awful lot of work to be done in many areas of PF. With this year's European Pulmonary Fibrosis Patient Summit, we again sought to give impetus and momentum to these processes, by providing a platform that allows for synergy effects and fosters exchange of information, learning and collaboration. Let's drive change together – with the patient at the centre.” Steve Jones, EU-IPFF President



For me, the best aspect of the 2022 European Pulmonary Fibrosis Patient Summit was...

"...that it showed all the important elements of the disease, and the participants were all fantastic." (Patient/Caregiver)

"...learning how to cope."
(Patient/Caregiver)

"...the information on oxygen use." (Patient/Caregiver)

"...the positive message of hopefulness that progress being made worldwide to find future treatments for IPF."
(Patient/Caregiver)

"...having experts, patients and caregivers all involved. Newly diagnosed patients and partners/family want to have straight forward information. Ron's short discussion about oxygen therapy brought this home to me. Ron explained what it was, why it was important and the challenges involved."
(Other)

"...new information."
(Patient Advocate)

"...interactivity."
(Patient/Caregiver)

"...hearing the latest developments in treatment of this disease." (Patient/Caregiver)

"...everything, and that it was patient-centred."
(Researcher)

"...that it was easy to understand, evidence-based, clinically oriented and patient-friendly." (HCP)

"...the closing session which ended the entire conference on a positive note, well done."
(Patient/Caregiver)

"...that it perfectly connected patients, research and doctors." (Patient Advocate)

"...interaction with patients across Europe."
(Researcher)

"...the diversity of medical and academic research."
(Patient/Caregiver)



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Summit Speakers

*Patients, Caregivers/& Patient Advocates · Healthcare Practitioners
& Researchers · Pharmaceutical Representatives · Others*



Patients/Caregivers & Patient Advocates



Steve Jones

EU-PFF President &
Chair of Trustees for Action
for Pulmonary Fibrosis,
United Kingdom



Liam Galvin

CEO of the EU-PFF
Secretariat & Director of Irish
Lung Fibrosis Association,
Ireland



Maxine Flewett

Caregiver,
United Kingdom



Ron Flewett

PF Patient & Trustee of
the Pulmonary Fibrosis Trust,
United Kingdom



John Solheim

EU-PFF Board Member,
Norway



Clive and Sue Green

Patient Advocates &
Tameside Pulmonary
Fibrosis Support Group, UK



Jean-Michel Fourrier

EU-PFF Secretary &
President of AFFF,
France



Chantal Vandendungen

Vice President for International
Relations at ABFPI,
Belgium



Bernd Quadder

Vice Chairman of Deutsche
Sarkoidose-Vereinigung,
Germany



Louise Wright

CEO of Action for Pulmonary
Fibrosis,
United Kingdom



Aïcha Kawak

Secretary General AFFF,
France



Clare Beckett

Patient Advocate & Research
Officer at Action for Pulmonary
Fibrosis,
United Kingdom



Sharon Lee

Executive Director
Canadian Pulmonary
Fibrosis Foundation
Canada



Sue Farrington

President FESCA,
United Kingdom



Healthcare Practitioners & Researchers



Elisabetta Balestro

Chair of EU-PFF Scientific Advisory Board,
University Hospital of Padova,
Italy



Nazia Chaudhuri

Interim Clinical Senior Lecturer in Medicine
at Ulster University, Londonderry,
United Kingdom



Vincent Cottin

Professor of Respiratory Medicine at Louis
Pradel University Hospital and Claude
Bernard University, France



Marlies Wijsenbeek

Pulmonary Physician at the Centre of
Interstitial Lung Diseases, Erasmus MC,
University Medical Centre, Rotterdam
The Netherlands



Gizal Nakshbandi

PhD Student at the Erasmus Medical Centre
in Rotterdam,
The Netherlands



Francesco Bonella

Associate Professor Of Medicine at
Ruhrlandklinik University Hospital,
Germany



Carlos Robalo Cordeiro

ERS President & Head of the Pulmonology
Department at Coimbra University Hospital,
Portugal



Paolo Spagnolo

Associate Professor of Respiratory Medicine
& Director of the School of Specialization in
Respiratory Medicine at the University of
Padua, Italy



Wendy Adams

Research Manager at Action for Pulmonary
Fibrosis,
United Kingdom



Naftali Kaminski

Professor of Internal Medicine and Chief of
Pulmonary, Critical Care and Sleep
Medicine, at Yale School of Medicine,
United States of America



Anne-Marie Russell

Senior Lecturer at University of Exeter,
United Kingdom



Philip Molyneaux

Asthma and Lung UK Chair of Respiratory
Research at the Royal Brompton Hospital,
United Kingdom



Irina Strambu

Lecturer at the University of Medicine and
Pharmacy Carol Davila, Bucharest,
Romania



Elisabetta Renzoni

Consultant Respiratory Physician at
the Royal Brompton Hospital,
United Kingdom



Katerina Antoniou

Professor of Respiratory Medicine at
the Medical University of Crete,
Greece



Pharmaceutical Representatives



Lizette Moros

Senior Global Medical Advisor at
Boehringer Ingelheim GmbH & Co. KG,
Germany



Rohit Batta

Chief Medical Officer at
Vicore Pharma Holding AB,
United Kingdom



Robina Weermeijer

Global Patient Relations Manager
Inflammation at Boehringer Ingelheim GmbH
& Co. KG,
The Netherlands



Ioannis Sapountzis

Therapeutic Area Head Inflammation
at Boehringer Ingelheim GmbH & Co. KG,
Germany

Others



Charlotte Turner

Senior Account Director at
Ogilvy Health PR Ltd UK,
United Kingdom



Eamonn Costello

Co Founder & CEO
at patientMpower,
Ireland



Bertrand Verwee

Verwee Consulting,
Switzerland



Josh Lehmann

Business Director at
Ogilvy Health UK,
United Kingdom



Summit Sessions

Speakers · Content · Key Quotes and Insights · Key Figures and Metrics



Summit Agenda

Day 1 – 3rd November 2022		
11:00h - 11:30h	PF Patient Summit Opening Session	
12:30h - 13:30h	Pulmonary Fibrosis and Covid-19	Research
14:30h - 16:00h	Latest Research on Pulmonary Fibrosis: Trials and Treatments	Person-Centred Care
16:30h - 17:30h	Industry Symposium by Boehringer Ingelheim: Raising awareness for PF through collaboration	Advocacy

Day 2 – 4th November 2022		
10:00h – 11:00h	PF-ILD - A Big Tent Disease	Industry Symposium
11:30h - 12:30h	Caregivers - The unrecognised patients	Person-Centred Care
12:30h - 13:30h	Challenges in Familial Pulmonary Fibrosis diagnosis	Advocacy
16:00h - 17:00h	Industry Symposium by Chiesi: Acute exacerbations and comorbidities of IPF	Research

Day 3 – 5th November 2022		
11:00h - 12:00h	Oxygen use in Pulmonary Fibrosis	Person-Centred Care
12:30h - 13:30h	Patient Involvement – Roles, Research and Industry	Research
16:00h - 17:00h	Digital Health and electronic devices and Pulmonary Fibrosis patients	Advocacy
16:00h - 17:00h	PF Patient Summit Closing Session	



I. PF Patient Summit Opening Session

The recording of the session can be found [here](#).

Content of the Presentation

Kicking off the second virtual European Pulmonary Fibrosis Summit, for which about 400 people had registered, Steve Jones welcomed the participants, introduced the aims and objectives of the summit as well as of the Federation itself and highlighted the educational webinars leading up to the summit which are now available as recordings and short summaries in 8 languages. After a minute of silence to remember the approximately 100,000 people who have died from PF in Europe in the last year as well as the people of Ukraine suffering as a result of Russia's war of aggression, he showed the video version of the new EU-PFF Consultation Guide "[A guide to living with Pulmonary Fibrosis](#)", published in 2022.

Carlos Robalo Cordeiro, President of the European Respiratory Society, then underlined why collaboration between national respiratory societies, patient organisations, industry, foundations and others to create national plans to promote lung health and combat lung diseases is crucial, and, amongst other things, talked about early detection and the prevention of lung diseases, e.g. in schools, and the importance of health service provision for migrants with lung diseases.

Elisabetta Balestro, Chair of the EU-PFF Scientific Advisory Board (SAB), introduced the SAB and projects its members have been involved in, such as the webinars leading up to the summit, the EU-PFF awareness campaign or the Federation's consultation guides, before briefly discussing unmet needs, for example in genetics and biomarkers.

Key Quotes and Insights

- "We can work even harder to empower patients with Pulmonary Fibrosis. And it is my goal to promote the self-management for these patients, including through digital support." *Carlos Robalo Cordeiro*
- "We will not solve the problems in PF, unless we work with our partners in other respiratory diseases." *Steve Jones*
- "I'm delighted to continue to work with all the amazing people of the EU-PFF." *Elisabetta Balestro*



Steve Jones (Moderator)
EU-PFF President,
United Kingdom



Elisabetta Balestro
University Hospital of Padova,
Italy



Carlos Robalo Cordeiro
ERS President,
Portugal



II. Pulmonary Fibrosis and Covid-19

The recording of the session can be found [here](#).

Content of the Presentation

Still a highly relevant topic, especially for those affected by pulmonary fibrosis, the ongoing Covid-19 pandemic was also part of the 2022 Summit: Francesco Bonella discussed the latest insights in Covid-19 in patients with pulmonary fibrosis, epidemiology of the disease, management and treatment approaches as well as prevention of a severe disease course and related complications, stressing that Covid-19 prophylaxis strategies should be adopted in patients with ILD under immunosuppression and in patients with pulmonary fibrosis.

What is more, Clive Green, a PF patient, and his wife Sue talked about the impact Covid-19 has had and continues to have on their lives, the precautions they take to avoid infection, the role of monoclonal antibodies, and what the British government could do to help immunocompromised patients.

Key Quotes and Insights

- Francesco Bonella concluded that existing vaccines are safe and only few cases of complications have been reported; that patients with inefficient vaccine response or who experienced side effects are eligible for pre-exposure prophylaxis every six months to prevent them from getting COVID-19, and he underlined that studies are needed on efficacy and safety of Covid-19 vaccines and treatments in patients with pulmonary fibrosis.
- "We know now that there is a higher frequency of infection with Covid-19 in patients with ILD, although they are more likely to wear masks, and also despite vaccines and follow-up visits and so on." *Francesco Bonella*
- "We haven't been to a pub in 2,5 years." *Clive Green*
- "I don't want to lose my husband." *Sue Green*

Speakers



Steve Jones (Moderator)
EU-PFF President,
United Kingdom



Francesco Bonella
Ruhrlandlinik University Hospital,
Germany



Clive and Sue Green
Patient Advocates, Tameside
Pulmonary Fibrosis Support Group
United Kingdom

Howard Almond
Action Pulmonary Fibrosis UK



III. Latest Research on Pulmonary Fibrosis: Trials and Treatments

The recording of the session can be found [here](#).

Content of the Presentation

In this session moderated by Louise Wright, Jean-Michel Fourrier gave an overview of why – from a PF patient’s perspective research in pulmonary fibrosis is crucial, discussing the progressive nature of the disease, the impact of its symptoms on patients and the importance of better understanding PF and its various sub-diseases. He further discussed, that it is not only important to find a treatment to stop or even reverse the disease, but also to improve symptom management and early diagnosis as well as the importance of involving patients in research at every stage of the process.

The second speaker, Vincent Cottin, amongst other aspects discussed ongoing studies aimed at improving diagnosis, prognosis and treatment response with the help of algorithms, the relevance of collaboration between different research and health institutions as well as the importance of clinical probability of disease, and potential barriers to a timely and accurate diagnosis of fibrotic ILDs.

Philip Molyneaux concluded the session with an overview of the current clinical trial landscape as well as Phase II/III trials in Pulmonary Fibrosis, and addressed issues of conducting trials in the antifibrotic era and why therapies might be the new standard of care and what this means for PF patients.

Key Quotes and Insights

- "I'm glad I'm participating in a clinical trial because it means I have a consultation with my pulmonologist every month." *Jean-Michel Fourrier*
- "Research must accelerate. We are not asking for comfort. We are asking for decent conditions of life." *Jean-Michel Fourrier*
- "We need to challenge the inclusion criteria for clinical trials." *Jean-Michel Fourrier*
- "Now that we know that fibrosis can at least be slowed down, we can hope for the involvement of many more stakeholders." *Vincent Cottin*
- "If we were doing this talk 10 years ago we wouldn't have much to talk about other than negative results." *Philip Molyneaux*

Speakers



**Louise Wright
(Moderator)**

CEO Action for Pulmonary Fibrosis,
United Kingdom



Philip Molyneaux

Royal Brompton Hospital,
United Kingdom



Vincent Cottin

Louis Pradel University Hospital
and Claude Bernard University,
France



Jean-Michel Fourrier

EU-PFF Secretary,
President of AFPP,
France



IV. Industry Symposium by Boehringer Ingelheim: Raising awareness for PF through collaboration



The recording of the session can be found [here](#).

Content of the Symposium:

This industry symposium hosted by Boehringer Ingelheim and moderated by Lizette Moros Burgos examined why it is crucial to raise awareness of pulmonary fibrosis, and how early diagnosis and detection could make a positive difference in the lives of many people.

Charlotte Turner and Josh Lehmann from advertising, marketing, and public relations agency Ogilvy shared basic information about social media and discussed what success in terms of raising awareness looks like. Sharon Lee, Executive Director of the Canadian Pulmonary Fibrosis Foundation, then talked about concrete examples of how she has been raising awareness for this condition with the foundations she leads and what campaigns have been successful from her experience.

The concluding panel discussion with Robina Weermeijer from Boehringer Ingelheim focused on how pharma and patient organisations can work together to raise awareness.

Key Quotes and Insights

- “We give facts and information and people are grateful for that. But they’re just facts, they don’t touch our hearts. So we mobilised our members and said to them: ‘September is your month. What would you like to do in your community? How would you like to raise awareness? Here are the tools we created for you.’ And the personal stories we got from our members really empowered our community.” *Sharon Lee*
- “It’s good advice to keep things brief on social media.” *Josh Lehmann*

Speakers



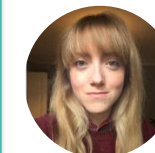
Lizette Moros (Moderator)
Boehringer Ingelheim, Germany



Sharon Lee
Executive Director Canadian Pulmonary Fibrosis Foundation, Canada



Robina Weermeijer
Boehringer Ingelheim, The Netherlands



Charlotte Turner
Ogilvy Health UK, United Kingdom



Josh Lehmann
Ogilvy Health UK, United Kingdom



V. PF-ILD - A Big Tent Disease

Content of the presentation:

This session, moderated by EU-PFF CEO Liam Galvin, revolved around the group of diseases that can include pulmonary fibrosis and how they differentiate, but ultimately share commonalities, both clinically and from a patient perspective. Nazia Chaudhuri started her session by giving a classification of Interstitial Lung Diseases (ILDs), how this group of diseases is diagnosed, and how progression – which is disease-specific – can be defined and why early detection is crucial.

Bernd Quadder, President of Deutsche Sarkoidose-Vereinigung e.V., then gave an overview of Sarcoidosis, how it can affect the lung and upper airways and discussed the need for new clinical parameters for initiating and managing antifibrotic treatment in non-IPF PF-ILDs, as well as the importance of multidisciplinary and holistic care, including the multi-professional ILD panel model and specialised ILD nurses.

Lastly, Sue Farrington introduced the work of her organisation FESCA (Federation of European Scleroderma Associations), its central goals, e.g. access to treatments, adoption of best Clinical Practice Guidelines and a network among HCPs, and the link between Scleroderma and ILD, as well as a policy paper, outlining a lack of national registries in some countries and a lack of diagnostic guidelines and unequal access to treatment across Europe.

Key Quotes and Insights

- “Pulmonary Fibrosis is not a diagnosis, it is a disease behaviour.” *Nazia Chaudhuri*
- “The most important thing is, that as a clinician, I cannot make a diagnosis on my own. I really need the help of my colleagues to have a multidisciplinary approach.” *Nazia Chaudhuri*
- “When we ask you questions about for example stiffness in your joints we are trying to make sure we’re not missing a diagnosis where there is a known cause.” *Nazia Chaudhuri*
- “Only by working collaboratively we are going to achieve the changes that are needed across the healthcare system.” *Sue Farrington*
- “What is obvious to all of us is that patient organisations, whatever their specific disease area, and clinicians are all singing from the same choir book. We have identified targets where there is unmet needs, regardless of the disease area.” *Liam Galvin*

Speakers



Liam Galvin (Moderator)
CEO of the EU-PFF Secretariat & Irish Lung Fibrosis Association, Ireland



Nazia Chaudhuri
Ulster University, Londonderry, United Kingdom



Bernd Quadder
Deutsche Sarkoidose-Vereinigung, Germany



Sue Farrington
President FESCA, United Kingdom



VI. Caregivers - The unrecognised patients

Content of the presentation

Moderated by Anne-Marie Russell, this round table discussion gave the floor to caregivers: the impact of pulmonary fibrosis on caregivers and loved ones, their role, and their own unmet needs were the focus of this session. It examined the evidence around caregiver burden and addressed the question of what recognition and support is due to those who care for a patient. After a brief presentation by Anne-Marie Russell on studies that have been done on the importance of caregivers in PF and on the burden it places on caregivers, Aïcha Kawak, Maxine Flewett and Chantal Vandendungen gave fragmented and personal accounts of their respective experiences as caregivers and also partners sharing the disease with their husbands, and described how PF has affected their lives and changed their roles in their relationships.

Key Quotes and Insights

- “In the beginning I thought PF was just an intruder, but I realized it crept more and more in our lives and became very important.” *Aïcha Kawak*
- “His personality has changed in a way that he is hypersensitive when it comes to things that are difficult to face. He is my journey partner in life. So I help him to keep some distance from the disease.” *Aïcha Kawak*
- “The more you learn, the more you understand, the more you can support your other half. But you’re suddenly facing the changes that occur due to the disease, and nobody tells you about them.” *Maxine Flewett*
- “We probably spot the changes first, even before the patients themselves can see them.” *Maxine Flewett*
- “We decided to take it one day at a time. I never decided to become a carer - I sort of slipped into the role. We joined forces against the disease. And we were very lucky to have a lot of support from friends and family.” *Chantal Vandendungen*
- “I was called a co-patient once. And I think that is exactly what carers are. So I think we deserve better recognition and support.” *Chantal Vandendungen*
- “It isn’t always easy being a clinician either. We feel the trauma of giving a diagnosis. And I wonder sometimes if this impacts on the ability of the clinician to have these open and frank discussions, and to convey realistic hope appropriately.” *Anne-Marie Russell*

Speakers



Anne-Marie Russell (Moderator)
University of Exeter,
United Kingdom



Maxine Flewett
Caregiver,
United Kingdom



Aïcha Kawak
AFPF,
France



Chantal Vandendungen
ABFPI,
Belgium



VII. Challenges in Familial Pulmonary Fibrosis diagnosis

Content of the Presentation

This session moderated by Wendy Adams, Research Manager at Action for Pulmonary Fibrosis, focused on the decisions clinicians, patients and their families face in terms of genetic testing and the potential benefits, the limitations and challenges associated with making these decisions. Elisabetta Renzoni gave a presentation on known genes involved in Pulmonary Fibrosis, when patients with fibrotic ILD – and possibly their relatives – should be tested, for which genes should be tested, the lack of guidelines as well as the pitfalls and gaps of genetic testing.

Patient advocate Clare Beckett, who has lost several close family members to PF, then shared her personal story, giving her perspective on genetic testing, and outlined where there is still potential for change in the healthcare system.

Key Quotes and Insights

- “Families are often given mixed messaging about genetic testing and when and how often it should happen. Your perspective on genetic testing changes once your life choices have an impact on others.” *Clare Beckett*
- “I am confident for my daughter that she will be able to live a life without limitations due to PF.” *Clare Beckett*
- “I firmly believe that any approach to genetic testing should be family-centric.” *Clare Beckett*
- “What is lacking at the moment is information about clinical genetic services, the referral process and the eligibility for testing.” *Clare Beckett*

Speakers



**Wendy Adams
(Moderator)**

Action for Pulmonary Fibrosis,
United Kingdom



Elisabetta Renzoni

Royal Brompton Hospital,
United Kingdom



Clare Beckett

Action for Pulmonary Fibrosis,
United Kingdom



VIII. Industry Symposium by Chiesi: Acute exacerbations and comorbidities of IPF



The recording of the session can be found [here](#).

Content of the Symposium

In this second industry symposium, hosted by Chiesi, Paolo Spagnolo, Professor of Respiratory Medicine at the Respiratory Disease Unit Department of Cardiac, Thoracic, Vascular Sciences and Public Health University of Padova, Italy, gave a detailed presentation on acute exacerbations and comorbidities in Idiopathic Pulmonary Fibrosis.

Key Quotes and Insights

- The majority of IPF patients suffer from at least one pulmonary or extrapulmonary comorbidity
- Optimal management of IPF requires a comprehensive approach, which includes the identification and treatment of comorbid conditions to optimise patient outcomes
- Acute exacerbations are important events in the natural history of IPF and indicate a poor prognosis
- The management of AE-IPF represents an area of major unmet medical need
- “We have no clear biomarkers that can predict who will develop an acute exacerbation.” *Paolo Spagnolo*
- “We now have clear evidence that immunosuppressants are dangerous for patients with IPF.” *Paolo Spagnolo*
- “We now know more about what should not be done.” *Paolo Spagnolo*

Speakers



Paolo Spagnolo

School of Specialization in Respiratory Medicine at the University of Padua, Italy



IX. Oxygen use in Pulmonary Fibrosis

The recording of the session can be found [here](#).

Content of the Presentation

Moderated by Irina Strambu, this session took an in-depth look at the guidelines for oxygen use, why it is important to follow these and the challenges that come with oxygen use in daily life, both from a clinical and a patient perspective.

Katerina Antoniou opened the session with a detailed presentation on oxygen therapy, touching on important aspects such as different oxygen delivery devices, different studies highlighting the importance of oxygen use for patients with ILD, when oxygen should be administered and how it benefits patients' quality of life, especially during physical activities.

Ron Flewett then gave a personal account of his experience using and getting used to using oxygen in everyday life as a PF patient as well as the logistics and challenges that come with it, and he also shared some practical advice on for example travel or mundane, yet hazardous situations for oxygen users.

Lastly, Chantal Vandendungen, the third speaker of this session, shared the findings of a survey by the European Lung Foundation and the EU-PFF on patients' access to oxygen therapy across Europe the full and final results and analysis of which will be shared in 2023.

Key Quotes and Insights

- “At first I felt embarrassed to use oxygen, but after a while I realised it is helping me, and even though I was getting stared at, it improved my quality of life.” *Ron Flewett*
- “Be aware of your surroundings, for example when someone sits down next to you and lights a cigarette.” *Ron Flewett*
- “We need some more research and support from industry that is dedicated to developing new portable oxygen devices and to make them more affordable and user-friendly.” *Irina Strambu*
- “We had this huge oxygen tank, and I was in charge of regulating the output because there is no remote control for this, so my husband when sitting down could not change the output. These tanks should come with a remote control.” *Chantal Vandendungen*

Speakers



Irina Strambu (Moderator)
University of Medicine and Pharmacy
Carol Davila, Bucharest,
Romania



Chantal Vandendungen
ABFPI,
Belgium



Katerina Antoniou
Medical University of Crete,
Greece



Ron Flewett
Pulmonary Fibrosis Trust,
United Kingdom



X. Patient Involvement – Roles, Research and Industry

Content of the Panel Discussion

In this session moderated by Bertrand Verwee, key opinion leaders in Advocacy, Research and Industry, namely Steve Jones, Marlies Wijsenbeek, Ioannis Sapountzis and Rohit Batta, evaluated where patient involvement is now, where it is heading – and where it should be headed – and how all stakeholders can develop and provide a collaborative approach to establish and further consolidate patient involvement in all research steps.

Key Quotes and Insights

- “The benefits of involving patients in everything that we do so greatly outweigh the risks, that we shouldn’t even be thinking about it.” *Ioannis Sapountzis*
- “In the way industry is designing trials they should be thinking of patients from the outset and design it a way that makes it attractive for patients to join, so it doesn’t involve too many visits to the hospital for example, because PF patients find it difficult to travel.” *Steve Jones*
- “Patient involvement is about collaborating with industry to optimise the research pathway for patients.” *Bertrand Verwee*
- “Patient involvement might mean a lower drop-out rate, which might also mean that we get to new treatments quicker.” *Ioannis Sapountzis*
- “I think the rules on patient involvement and collaborating with industry should be made together with patients, and then you come up with sensible rules. The rules have to reflect what patients want.” *Marlies Wijsenbeek*
- “Anyone can be affected by Pulmonary Fibrosis, so we need everyone to be involved. We have to lower the threshold.” *Marlies Wijsenbeek*
- “I think, we learn a lot from the tech world, where it’s all about simplicity.” *Rohit Batta*

Speakers



Bertrand Verwee
(Moderator)

Verwee Consulting,
Switzerland



Steve Jones

EU-PFF President,
United Kingdom



Marlies Wijsenbeek

Centre of Interstitial Lung
Diseases, Erasmus MC, University
Medical Centre in Rotterdam,
The Netherlands



Ioannis Sapountzis

Boehringer Ingelheim,
Germany



Rohit Batta

Vicore Pharma,
United Kingdom



XI. Digital Health and electronic devices and Pulmonary Fibrosis patients

The recording of the session can be found [here](#).

Content of the Presentation

Digital health, new tools and technology – what those terms mean, how PF patients are already benefiting from new technological developments at home, and how the future will change healthcare were the topics of the penultimate session of the summit, moderated by John Solheim.

In her presentation, Gizal Nakshbandi focused on home monitoring, the development process of new technologies, the effect the Covid-19 pandemic has had on these processes, and discussed issues that might arise in the future, such as reimbursement, ethical implications or data protection and ownership.

Eamonn Costello gave a brief history and overview of the technological journey – from the invention of the spirometer in 1846 to Smartphones and health apps available today. Reimbursement policies, barriers that might still exist in digital health, and how learning from other areas of medicine can lead to better outcomes and ultimately benefit PF patients were also points he addressed in his presentation.

Key Quotes and Insights

- “There is potential, for example looking at the lung crackles. Could there be digital stethoscopes that could capture and analyse those?” *Eamonn Costello*
- “Home spirometry can be very useful in the early stages of the drug development process because it can guide safety.” *Gizal Nakshbandi*
- “My big hope is that digital health will be part of the standard of care.” *Eamonn Costello*
- “In the programmes that we use we also capture patient-reported outcomes and symptom scores and you can track that over time.” *Gizal Nakshbandi*

Speakers



John Solheim (Moderator)

EU-PFF Board Member,
Norway



Eamonn Costello

patientMpower,
Ireland



Gizal Nakshbandi

Erasmus Medical Centre Rotterdam
The Netherlands



XII. PF Patient Summit Closing Session

Content of the Presentation

In the final session of the 2022 European Pulmonary Fibrosis Summit, Naftali Kaminski in his presentation “Lessons on the road to cure Pulmonary Fibrosis” talked about milestones, key findings and lessons learned over the past 20 years, before EU-PFF President Steve Jones gave his closing remarks. The increase of interest and research as well as clinical trials in PF during this time, increased knowledge about the genetics and mechanisms of the disease and the development of new treatments were important points of Naftali Kaminski’s talk before he concluded his presentation with an optimistic outlook for the future.

Closing the Summit, Steve Jones highlighted the various tasks and challenges that still remain and lie ahead – creating awareness, supporting not only patients, but also caregivers – and underlined the importance of collaboration, before he thanked the speakers, attendees, the members of the EU-PFF, and the Secretariat behind the Summit.

Key Quotes and Insights

- “20 years ago, people said to me: ‘This is too rare, you will never be able to run a randomized clinical trial. You will never be able to actually get funding, because it is not a big enough market.’ But here’s the thing: 20 years later IPF science is exploding.” *Naftali Kaminski*
- “I think the next 2 years will give us some good news. And I think the paradigm will shift completely in the next 5 to 8 years.” *Naftali Kaminski*
- “I think, that in the future we will be able to stop the progression of pulmonary fibrosis, and once we can do that, I think we can think about reversing it.” *Naftali Kaminski*
- “Participation in clinical trials is key. Sometimes patients don’t get how important they are.” Naftali Kaminski
- “The next generation of drugs will also improve patients’ quality of life.” *Naftali Kaminski*
- “We are only just realising the incredible importance of caregivers. This disease not only affects patients, it affects the whole family. There is an awful lot of work we need to do in this regard.” *Steve Jones*

Speakers



Steve Jones (Moderator)

EU-PFF President,
United Kingdom



Naftali Kaminski

Yale School of Medicine,
United States of America



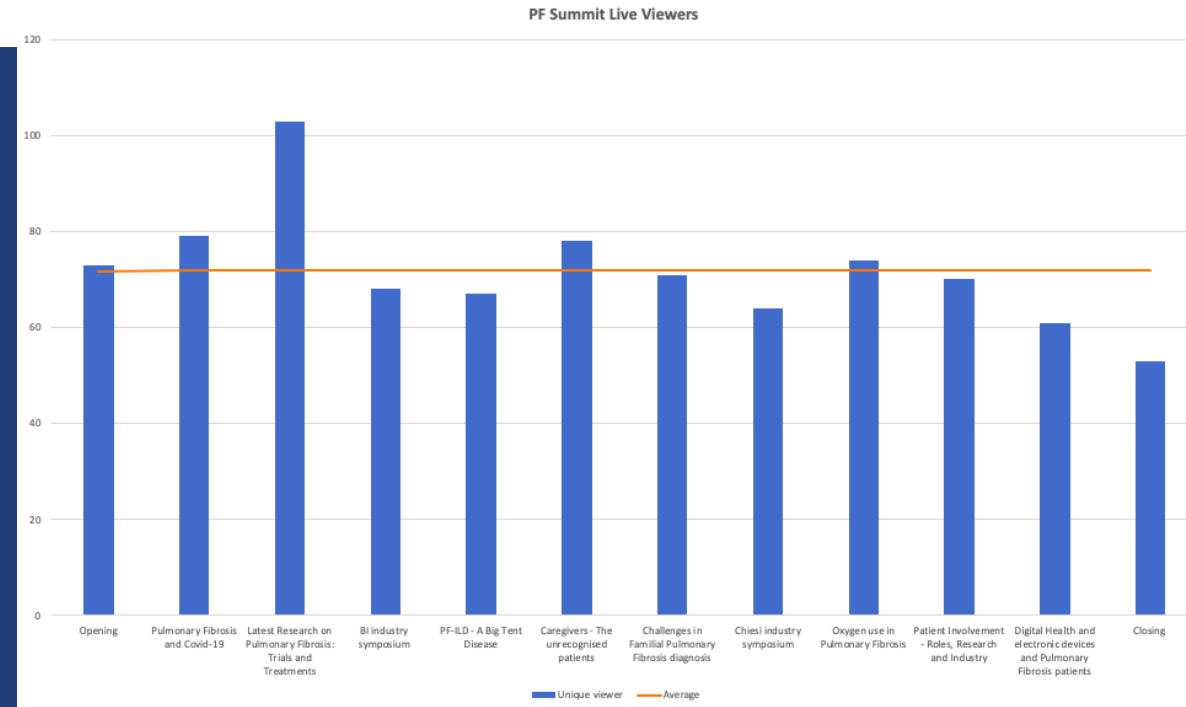
PF Patient Summit Sessions: Key Figures and Metrics



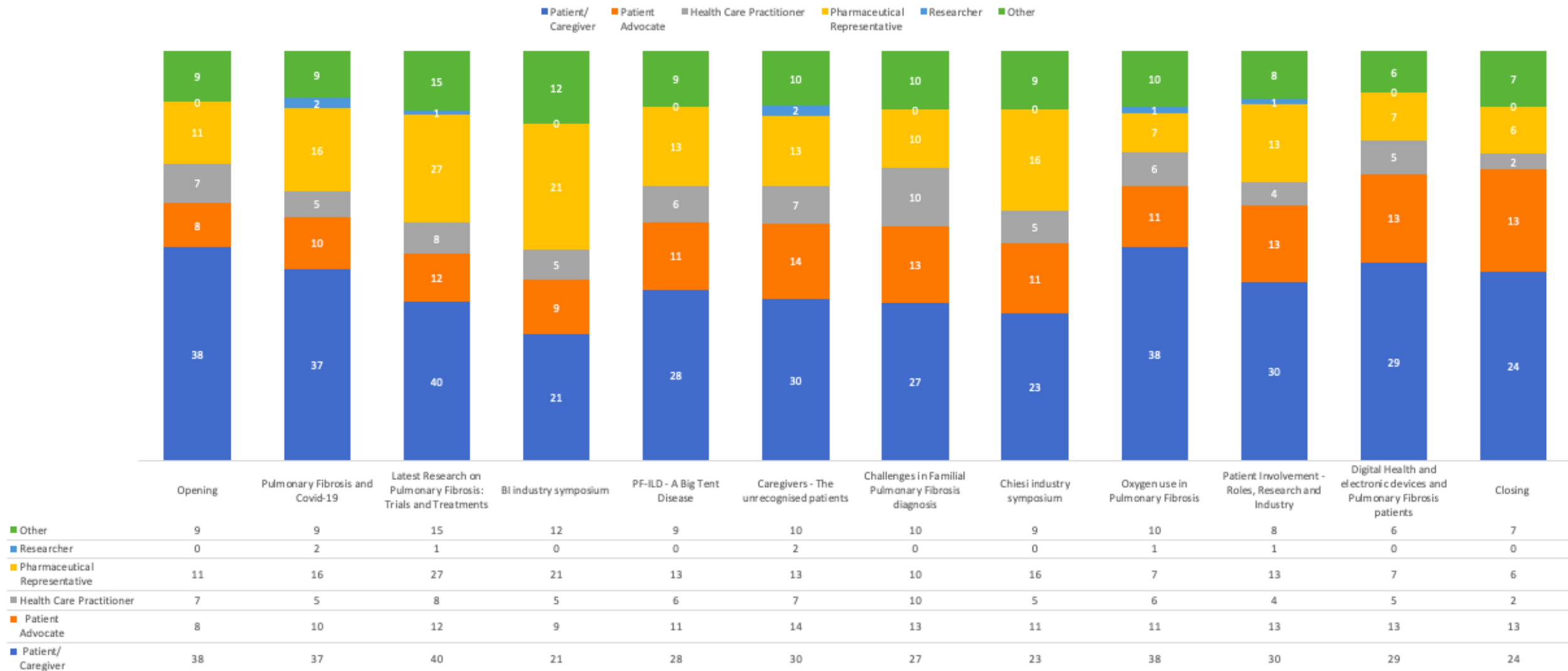
PF Patient Summit Sessions: Key Figures and Metrics

All sessions of the PF Summit were streamed live via the Summit Platform in Swapcard. During the sessions, the attendees were able to send questions and comments in the live discussion panel.

Over the three-day Summit, 10 official sessions and 2 industry symposiums were held. The average number of viewers connected to the live **72**. The session with the highest number of live views was **Latest Research on Pulmonary Fibrosis: Trials and Treatments (103)**.



STAKEHOLDER DISTRIBUTION OF THE PF SUMMIT LIVE VIEWERS

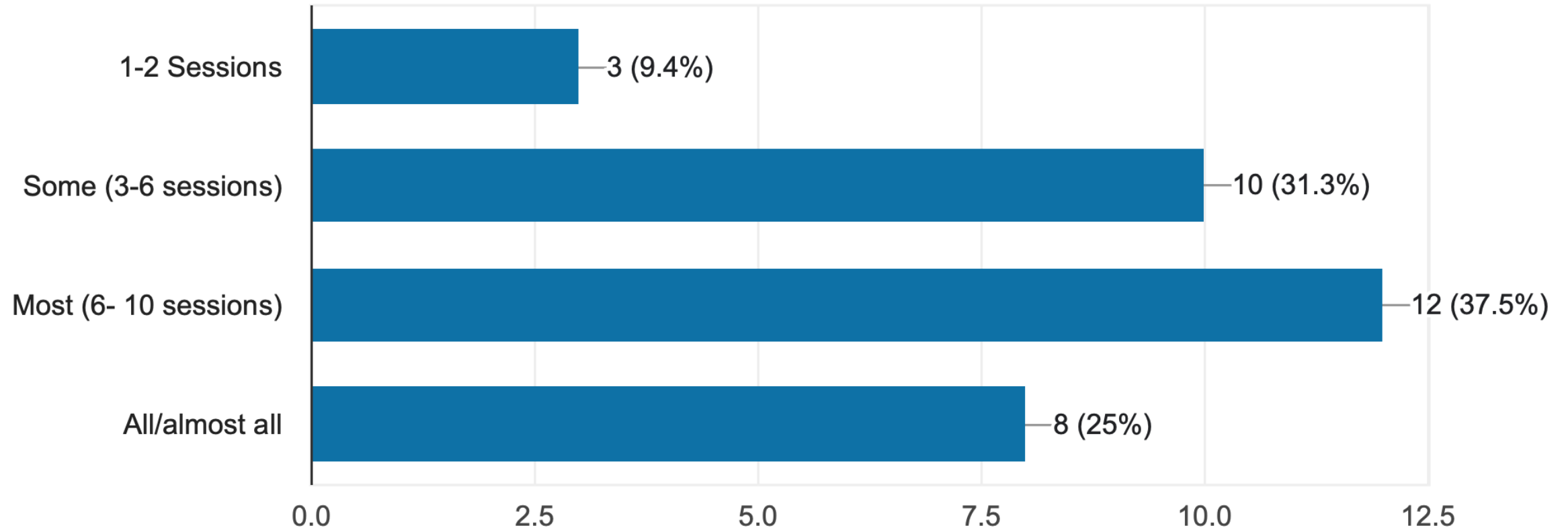


These graphs show the number of live viewers for each official session of the European PF Patient Summit 2022. Furthermore, you can see the distribution of the viewers based on the type of stakeholder.



How many sessions did you attend?

32 responses



Posters & Abstracts

PF Patient Summit 2021 & 2022



Posters and Abstracts (2022)

Patient-Centered Care

- Patient-centred Supportive Palliative Care Ecosystem for IPF Patients (*Panos Bamidis, Sofia Reppou, Vasileios Kiosses, Niki Pandria, George Ntakakis, Iraklis Tsoupouroglou, Christina Plomariti, Annita Varela, L. Fernandez-Luque*); access the abstract [here](#)

Research

- Computed Tomography imaging adapted to small animals (micro-CT) to derive ventilation biomarkers able to access lung fibrosis progression and response to anti-fibrotic treatment in mouse (*Chiesi / Francesca Pennati, Erica Ferrini, Nicola Sverzellati, Franco Fabio Stellari, Andrea Aliverti*); access the poster [here](#)
- Progressive Pulmonary Fibrosis: Top Ten Research Priorities (*L. Fabbri, K. Cowan, L. Wright, S. Jones, W. Adams, S. Hart, A. M. Russell, M. Gibbons, N. Chaudhuri, J. Lynch-Wilson, G. Jenkins* on behalf of the Progressive Pulmonary Fibrosis Priority Setting Partnership steering group); access the poster [here](#)



Posters and Abstracts (2021)

Person-Centered Care

- Improving The Quality Of Life With Dietotherapy (*Klaudia Vincze*)
- Interim Analysis Of Patient Satisfaction With The Digital Ecosystem Used In The STARLINER Study Of Disease Behaviour In Interstitial Lung Disease (*Marlies S. Wijsenbeek et al.*)
- Interim Analysis Of Patients With Interstitial Lung Disease Enrolled In The STARLINER Study (*Marlies S. Wijsenbeek et al.*)
- Patient reported experiences and delays during the diagnostic pathway for pulmonary fibrosis: results from a multinational survey (*I.G. van der Sar et al.*)
- Home Spirometry as an Endpoint in Interstitial Lung Disease Clinical Trials – Lessons Learned (*Toby M. Maher et al.*)

Policy and Patient Advocacy

- Study design of an international patient-led registry in fibrotic interstitial lung diseases using eHealth technology: I-FILE (*drs. G. Nakshbandi, drs. C.C. Moor, dr. M.S. Wijsenbeek*)
- The “IPF & Me” program (*Guillame Lefebvre and Fleur-Amelie Fayard*)
- The Trials and Tribulations of Forming a Support Group (*John Conway, Dr Dimitra Nikoletou*)
- Voice of the Patient Social Media Analysis: Idiopathic Pulmonary Fibrosis disease awareness and Patient Journey (*Carmela Pratelli et al.*)
- Do you know the Netherlands’ Pulmonary Fibrosis Patient Association? (*Raymond Blessing*)

Research

- Investigating The Effects Of Stimulating The Angiotensin II Type 2 Receptor On Lung Function In Patients With IPF (*Rohit Batta, Joanna Porter, Göran Tornling, Johan Raud*)
- Bleomycin and Collagens: A Focus on The Rat Model of Lung Fibrosis (*Chiesi*)
- Time-course analysis of multiple readouts in the bleomycin-induced pulmonary fibrosis mouse model (*Chiesi*)
- Artificial intelligence-based histological scoring of lung fibrosis in rodent models of lung fibrosis (*Chiesi*)



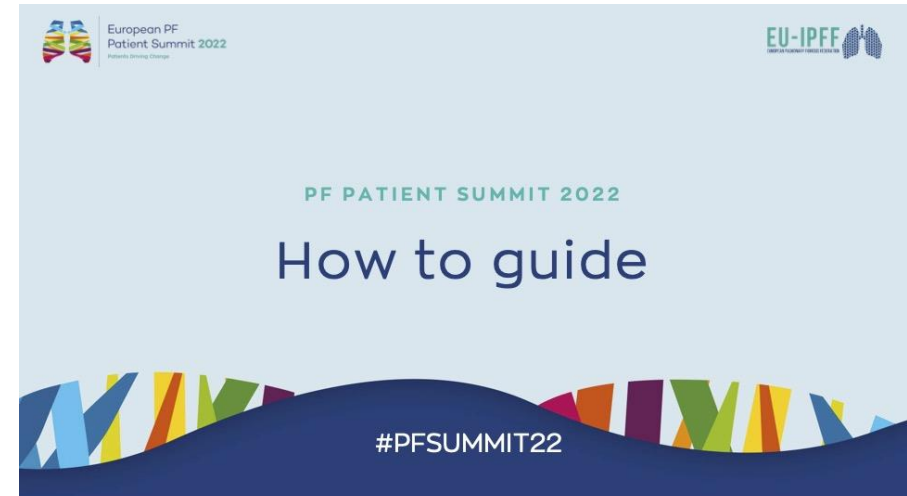
PF Patient Summit 2022: How To Guide



PF PATIENT SUMMIT 2022: How To Guide

To make the second virtual European Pulmonary Fibrosis Patient Summit as pleasant an experience as possible for all participants, the EU-PFF has compiled a **guide** containing the most important information on the summit platform Swapcard and how to navigate it with ease.

The 22-page guide can be downloaded [here](#).



How to access a live-streamed session?

There are two ways to access a live streaming session.

From your **Event Home**, click on the **"LIVE! Watch Now!"** button which should be displayed.

You will be redirected to the current session, or the following one if no live stream is taking place at that time.

From the **Agenda** or **My Event** tab, click on the current session you want to follow. You'll be taken to the page where the live session is taking place.

#PFSUMMIT22

Summary

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#PFSUMMIT22



Review and metrics of the PF Summit Attendance



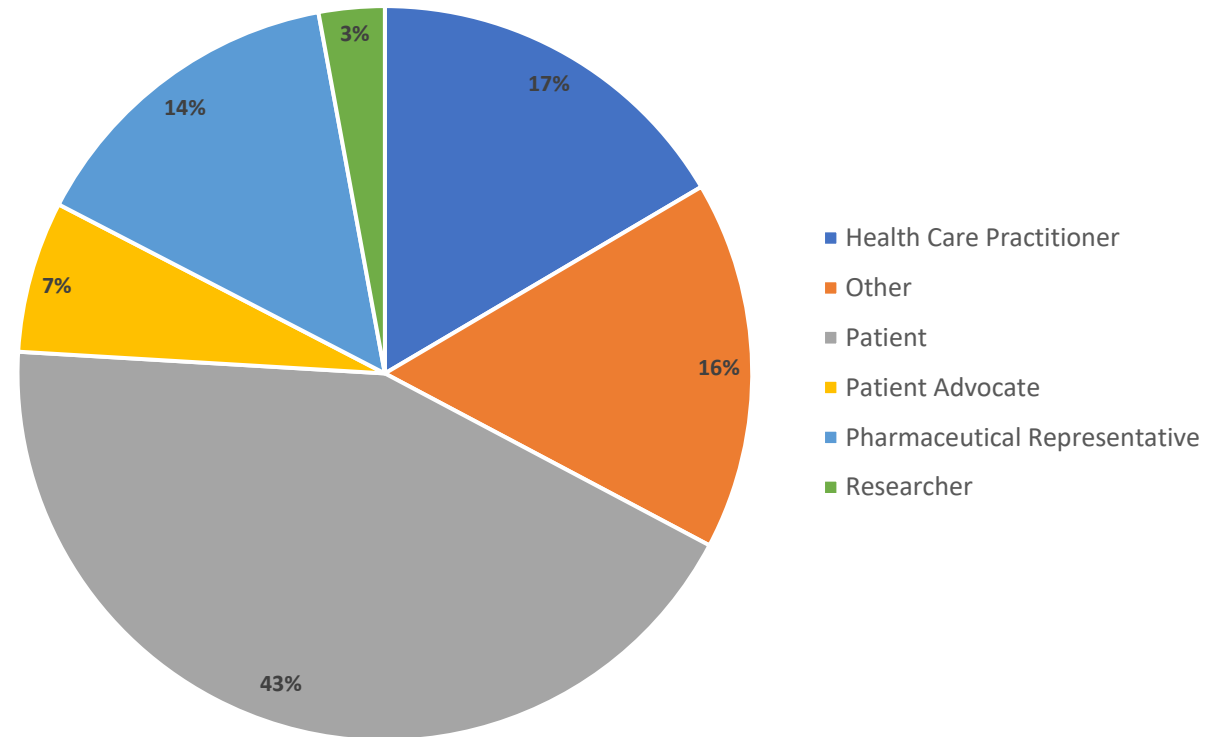
Attendee Participation - Overview

395 people had registered for the three-day event, 358 as attendees and 37 as speakers.

According to feedback from participants, about 50 percent of the attendees were either patients or patient advocates, again confirming the summit as a patient event.

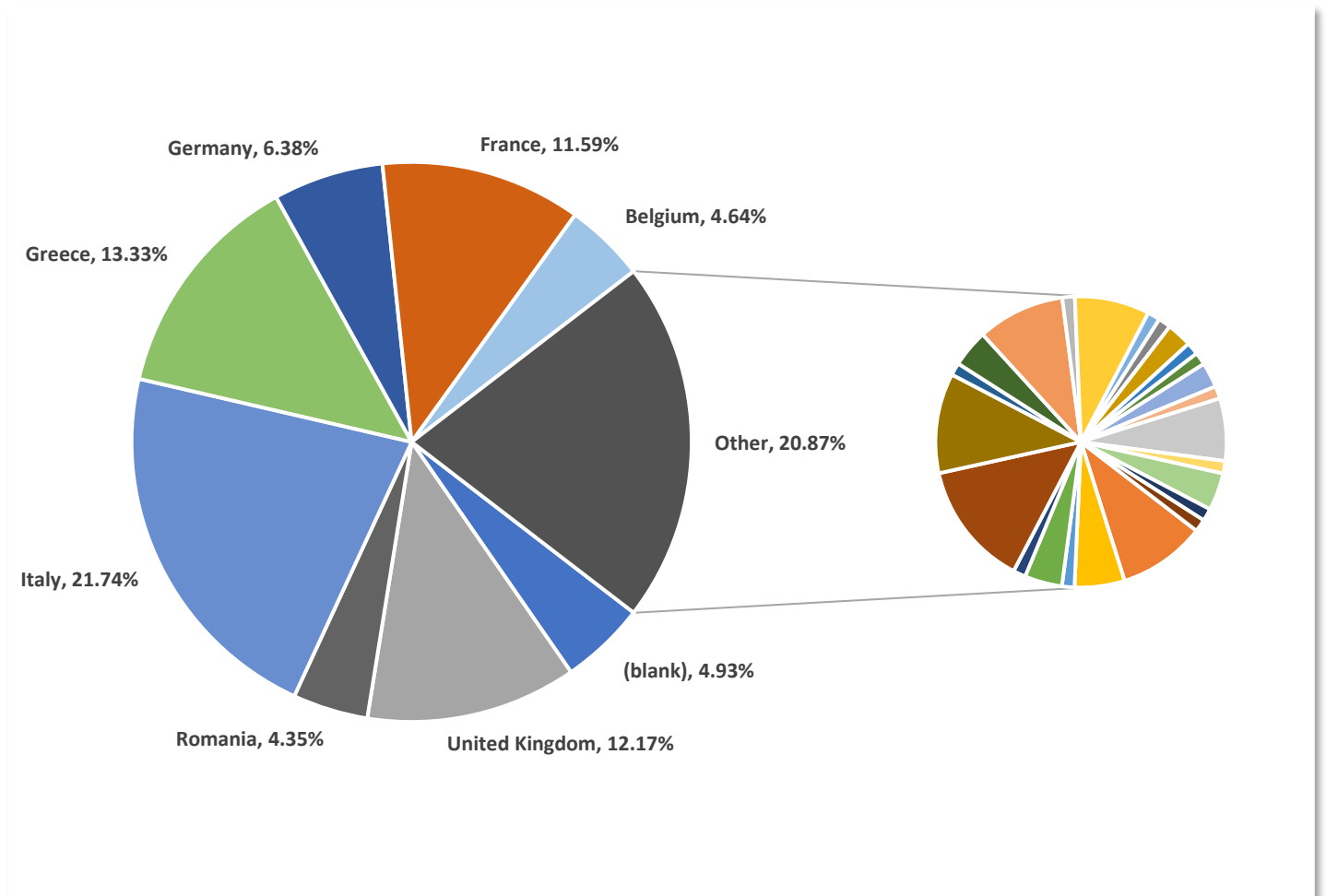
It is important to note that a significant number of participants, probably for flexibility reasons and because the summit was held on two working days, participated via a link that did not require registration and was distributed via social media and the EU-PFF newsletter on the conference days.

For example, over the 3 days of the summit, more than 150 unique attendees joined via the newsletter links.



Participants by country

- Participants joined from all parts of the world, including Cambodia, Australia, Basil, Indonesia, Mexico, Spain and the United States.
- The country with the **highest number** of registered participants was **Italy** (21.74%), followed by **Greece** (13.33%) and the **United Kingdom** (12.17%).
- **Please note that these are users who registered on the Swapcard platform.** Those participants who registered via social media or joined the live sessions via links distributed on Social Media and via the Eu-PFF newsletter are **not included** here.



Review and metrics of the PF Summit Social Media footprint



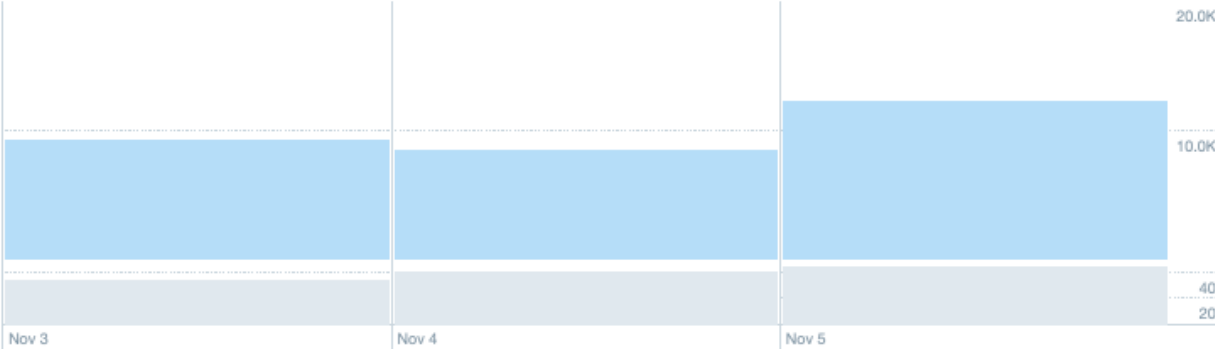
Twitter Stats for @EU_IPFF from Nov. 3-5 2022

Top Tweet (2,043 impressions):



EU-IPFF @EU_IPFF · Nov 5
 "I think, that in the future we will be able to stop the progression of **#PulmonaryFibrosis**, and once we can do that, I think we can think about reversing it." - Naftali Kaminski (@KaminskiMed) at the 2nd European **#PFPatientSummit**. **#PF**

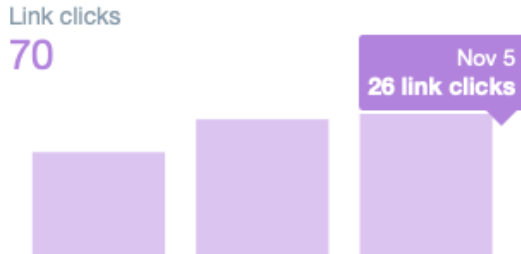
Your Tweets earned **29.8K impressions** over this **3 day period**



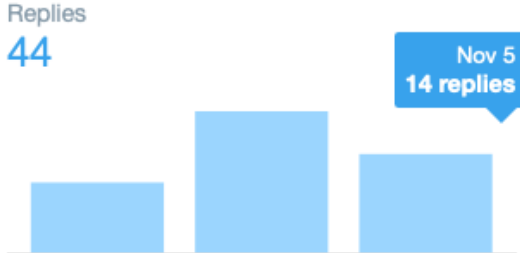
Engagements:



On average, you earned **189 likes** per day



On average, you earned **23 link clicks** per day



On average, you earned **15 replies** per day



On average, you earned **46 Retweets without comments** per day

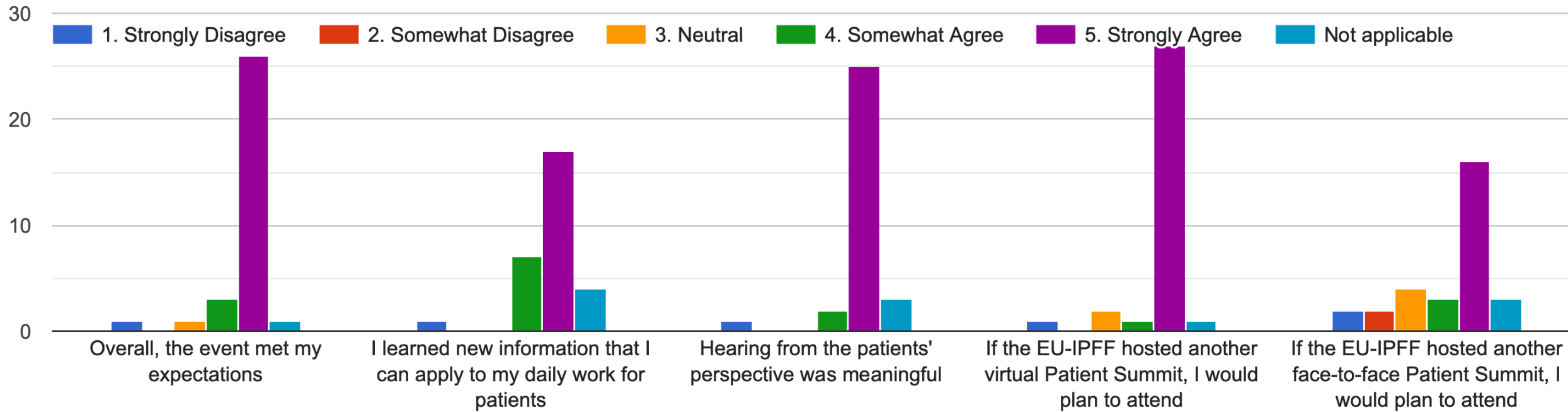


PF Patient Summit 2022: Attendee Feedback

32 responses



Overall Attendee Feedback

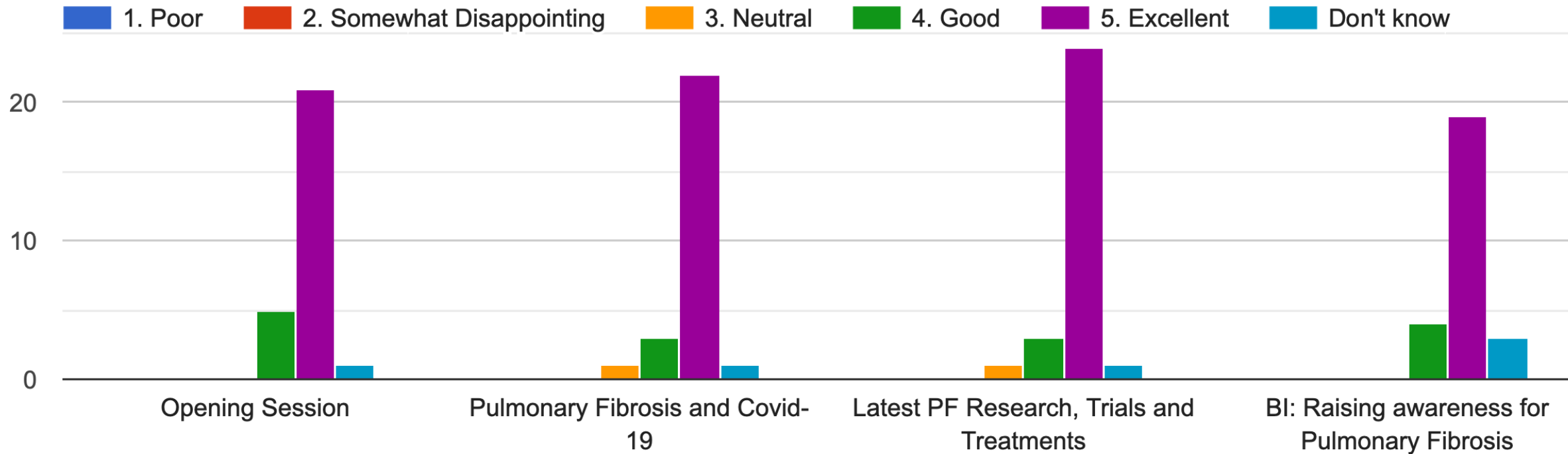


- 84% of the surveyed attendees confirmed that the Summit strongly met their expectations.
- 58% of the surveyed attendees confirmed that they learned new information which they can apply to their daily work.
- 81,2% of the surveyed attendees confirmed the meaningfulness of hearing from patients' perspective.



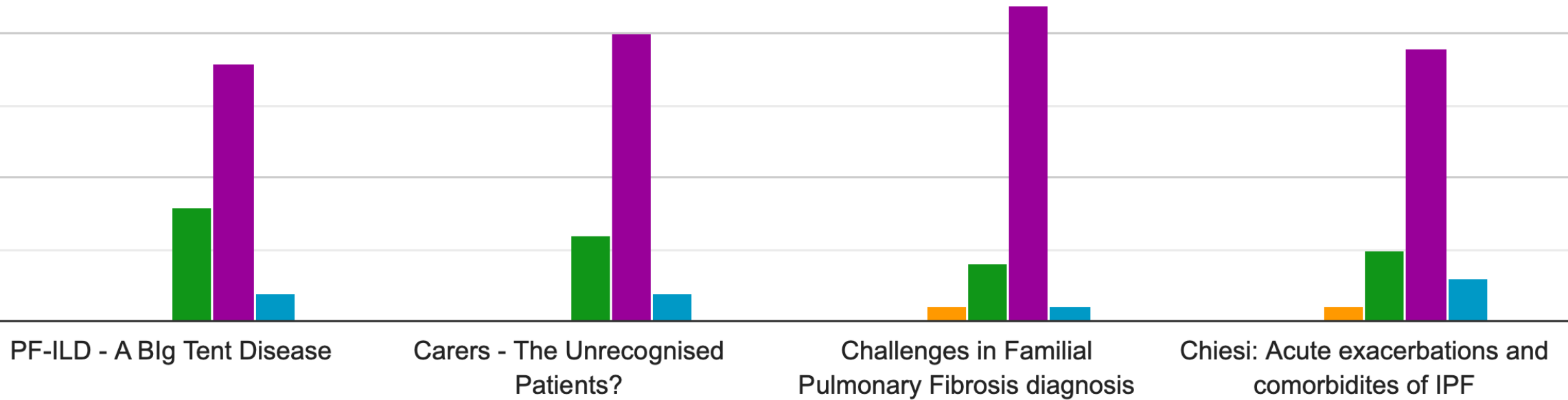
Attendee Feedback – Live Sessions

(on a scale of 1-5, with 5 being excellent)



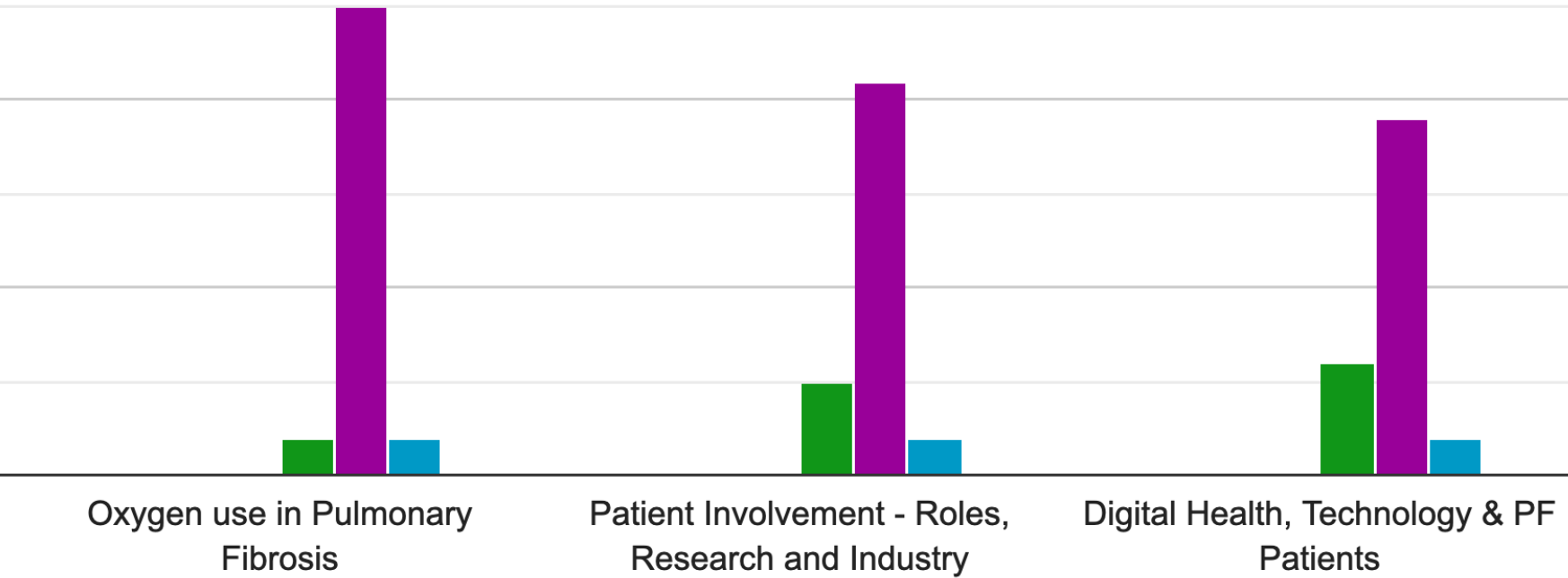
Attendee Feedback – Live Sessions

(on a scale of 1-5, with 5 being excellent)



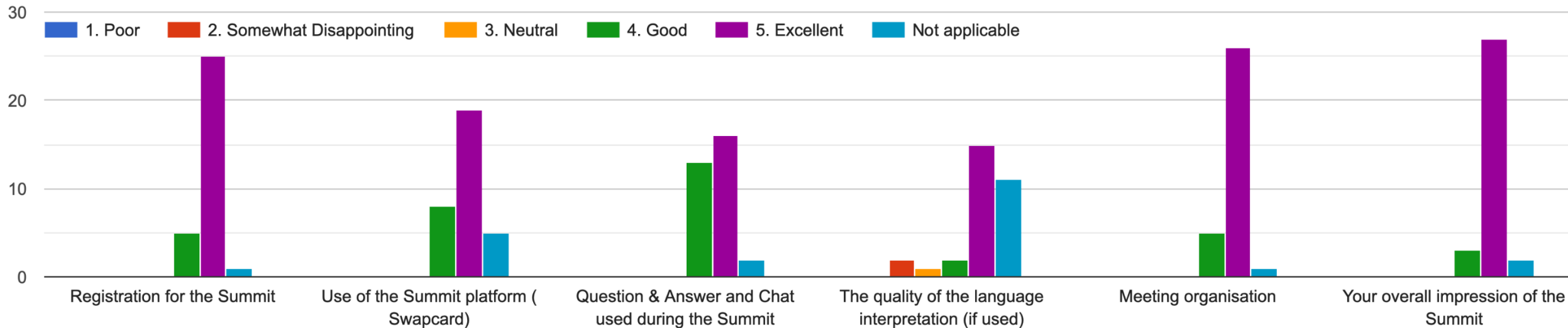
Attendee Feedback – Live Sessions

(on a scale of 1-5, with 5 being excellent)



Overall Attendee Feedback: Logistics

Please rate your satisfaction with the following on a scale of 1 to 5, with 5 being "excellent"



- **83.33%** of the surveyed attendees found the registration process for the Summit *excellent* compared to 16.66% that thought it was *good*.
- **70.37%** of the surveyed attendees thought the Summit platform was *excellent* compared to 29.62% that thought it was *good*.
- **55.17%** of the surveyed attendees found the Q&A *excellent* and 44.82% found it *good*.
- Of those using the live translation **75%** found the quality of the interpretation *excellent* while 10% of them thought it was *good*.
- **90%** of the survey participants rated the summit as *excellent*.



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