3rd EUROPEAN PULMONARY FIBROSIS PATIENT SUMMIT

REPORT

26th – 28th April 2024

EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION

Introduction

From April 26th-28th 2024, the third **European Pulmonary Fibrosis Patient Summit** brought together patients and caregivers, healthcare professionals, policy makers and industry representatives. This time the event was hybrid, with a total of **10 Sessions, 6 workshops and 40 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 all sessions and selected workshops in Spanish, Italian, French, Greek & German.

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, Chiesi, CSL Behring, Bristol Myers Squibb, Trevi Therapeutics, Ferrer, Pliant and Vicore.

"If we are going to STOP pulmonary fibrosis, it is essential that all stakeholders – patients, clinicians, researchers, pharmaceutical companies and regulators – work together effectively. This year's European Pulmonary Fibrosis Patient Summit brought together leaders from all, these stakeholder groups and demonstrated how well we are doing. But there is still so much to do in diagnosis, developing new treatments, delivering better care for our patients, and driving the change we want to see in Europe and globally." Steve Jones, EU-IPFF President

For me, the best aspect of the 2024 European Pulmonary Fibrosis Patient Summit was…

“The spirit of collaboration and shared learning. The real sense that this was a summit ***led by patients****, addressing the lived experience of patients and the need for us to continue to do more to improve the quality of life for people living with the disease and to also support future research and to change things for the future. It was both inspiring and re-energizing. We need to invest in greater collaboration to continue in the spirit of the summit - 'together we do better' and become a more powerful voice for PF/ILD.”* (Patient/Caregiver)

“Clear presentations, patients included, time to ask questions.” (Patient/Caregiver)

“The Summit was very inclusive and I felt gave a really good overview of what is happening locally and internationally.” (HCP)

“The diversity of topics.” (Patient)

“The focus on patient engagement, dynamic conversation, action-orientated.” (Patient/Caregiver)

“The sessions were comprehensively helpful and informative.” (Patient/Caregiver)

“The opportunity to learn from the lived experience of the patients and to see the passion of advocates and HCPs to improve lives of people living with pulmonary fibrosis.” (Industry Rep.)

“The focus on patient voice.” (HCP)

“Excellent opportunity to meet the professionals.” (Patient)

“Learning you are not alone.” (Patient)

“Bringing together patients, researchers, clinicians and pharma.” (Caregiver)

“Good human closeness between participants and patients.” (Caregiver)

“The interactive online platform was great, and it was fantastic to see patients there able to ask the questions they want answers to.” (Patient/Caregiver)

“The familiar environment.” (Industry Rep.)

Summit Attendee Feedback Quotes – A Selection

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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


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


Gottfried Huss
Patient Advocate & Lungefibrose e.V. Member, Germany


Pippa Powell
Patient Advocate & ELF Director, United Kingdom


John Solheim
Patient Advocate & EU-PFF Board Member, Norway


Matthew Peter Cullen
Patient Advocate & Leader in Dublin PF Support Group, Ireland


Bradley Price
Patient Advocate & Director of Policy and Public Affairs at Action for Pulmonary Fibrosis, United Kingdom


Achille Abbondanza
Patient Advocate & FIMARP Member, Italy


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


Colin Edwards
Irish Lung Fibrosis Association Board Member, Ireland


Matt Bolz-Johnson
Patient Advocate & Mental Health Lead at Eurordis, Germany


Radostina Getova
Patient Advocate & EU-PFF Board Member, Bulgaria


Jean-Michel Fourrier
EU-PFF Secretary & President of AFPF, France


Wendy Adams
Patient Advocate & Patient Engagement and Research expert at Action for Pulmonary Fibrosis, United Kingdom


Ilaria Galetti
Patient Advocate & FESCA Vice President, Italy


Sue Farrington
President FESCA, United Kingdom


Chantal Vandendungen
Vice President for International Relations at ABFPI, Belgium


Stefano Pavanello
Patient Advocate & EU-PFF Board Member, Italy


Carlos Lines
AFEFPI President and co-founder & Emeritus EU-PFF President


Athol Wells
Patient Advocate, United Kingdom

Healthcare Practitioners & Researchers

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

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

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

Simon Hart
Professor and ILD physician at Hull York Medical School, United Kingdom

Maria Molina Molina
Chief of ILD Unit at Bellvitge University Hospital in Barcelona, Spain

Francesco Bonella
Associate Professor Of Medicine at Ruhrlandklinik University Hospital, Germany

Moises Selman
Emeritus Researcher at Instituto Nacional de Enfermedades Respiratorias, México

Elisabetta Renzoni
Consultant Respiratory Physician at the Royal Brompton Hospital, United Kingdom

Wim Wuyts
Professor and Researcher at ILD Unit, Pneumology Department, UZ Leuven, Belgium

Anne-Marie Russell
Senior Lecturer at University of Exeter, United Kingdom

Lucilla Piccari
Doctor and Respiratory Physician at Hospital del Mar, Barcelona, Spain

Claudia Valenzuela
Chair of the multidisciplinary ILD Unit in the Pulmonology Department at Hospital Universitario La Princesa, Madrid, Spain

Adnan Sayar
Professor of Thoracic Surgery and Lung Transplantation at LIV Hospital in Istambul, Turkey

Pharmaceutical Representatives

Emmanuelle Clerisme-Beaty
Head of Therapeutic Area Inflammation Medicine at Boehringer Ingelheim GmbH & Co. KG,
Germany

Farrell Simon
Chief Commercial Officer at
Trevi Therapeutics,
United States of America

Brian Lee
Senior Director of Patient Advocacy,
Immunology & Neuroscience at
Bristol Myers Squibb,
United States of America

Contributors

Assumpta Ricart
Catalan Health Ministry

Monika Gappa
ERS President

Pilar Rivera-Ortega
Clinical and Research Lead of the ILD Unit, Manchester University NHS Foundation Trust, United Kingdom

Neil Bertelsen
HTA Patient Engagement Specialist

Summit Sessions

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

Summit Agenda

Day 1 – 26th April 2024		
13:00h – 14:00h	The 3rd Pulmonary Fibrosis Patient Summit: Let the Summit Begin!	
14:30h – 15:45h	Navigating Supportive Care for Pulmonary Fibrosis	Person-Centred Care
16:15h – 17:30h	Trials Unveiled: A Workshop on Clinical Trials	Advocacy
	Breathing Easy Workshop: Understanding Your Lungs	Advocacy
	Breath Beyond Borders: Oxygen Access in Europe	Advocacy
17:45h – 18:45h	Industry Symposium by Chiesi: Quality of Life / Holistic approach to ILD	Industry Symposium
	Siel Bleu – Respiratory Session	Person-Centred Care

Summit Agenda

Day 2 – 27th April 2024		
09:15h – 10:45h	Patient Engagement Policy Roundtable	Advocacy
11:00h – 12:30h	Fibrosis Unveiled: Understanding Pulmonary Health and Genetic Factors	Research
14:00h – 15:30h	PF Puzzle: Unravelling the Various Faces of Pulmonary Fibrosis	Advocacy
	Spanish Patients Information Day: Share and Connect	Advocacy
16:00h – 17:30h	PF Connect: A Workshop on Teaming Up Across Different PF Types	Advocacy
	Breath of Life Workshop: Exploring the World of Transplants	Research
17:30h – 18:30h	Industry Symposium by Boehringer Ingelheim: Patient Involvement in HTA – How to bring your unique perspective and evidence into decision-making	Industry Symposium
	Siel Bleu – Respiratory Session	Person-Centred Care

Summit Agenda

Day 3 – 28th April 2024		
09:15h – 10:45h	Latest Research on Pulmonary Fibrosis	Research
11:15h – 12:30h	Roundtable on Clinical Trials: Exploring Opportunities and Insights	Advocacy
13:00h – 14:00h	Pulmonary Fibrosis Summit Finale: Reflect, Connect and Look Ahead	

I. The 3rd Pulmonary Fibrosis Patient Summit: Let the Summit Begin!

The recording of the session can be found here.

Content of the Presentation

Kicking off the third European Pulmonary Fibrosis Summit, Steve Jones welcomed the participants and introduced a minute of silence to remember the approximately 80,000 people who have died from PF in Europe in the last year. He highlighted the fact that participants traveled from Europe, Asia, Australia, North America, and South America, and also welcomed those registered and following the sessions online.

Assumpta Ricart, on behalf of the Catalonian Department of Health, welcomed participants and thanked them for their attendance. She highlighted their approach to the treatment of Pulmonary Fibrosis, as well as the latest data from the region. She reminded everyone how the Summit is a great opportunity for stakeholders to come together and discuss the challenges and opportunities in the diagnosis, treatment, and management of Pulmonary Fibrosis. Monika Gappa, via video recording, introduced the European Respiratory Society and its activities, highlighted the International Respiratory Condition, and encouraged attendees to contact and join their countries' national coalitions. Elisabetta Balestro emphasized the importance of multidisciplinary collaboration and working with patient advocacy groups to advance knowledge and treatment of pulmonary fibrosis. She mentioned their important initiatives, such as publishing a consultation guide in eight languages and conducting a patient survey to understand treatment outcomes. Francesco Bonella defined lung fibrosis and reviewed its history's milestones, including advances in pathology and radiology, diagnosis and treatment with approved medications. He explained how the ILD group is heterogeneous, mentioned its epidemiology and prevalence, discussed the mechanisms of fibrosis, ILD symptoms, and the disease course before reviewing treatment. He concluded by presenting the current gaps, such as the lack of awareness and the design of clinical trials, and the strategies for addressing them.

Key Quotes and Insights

- "We want to get to the stage where pulmonary fibrosis is manageable. And after that we want to your head for a cure. So, I'm optimistic, but there's a long way to go" - *Steve Jones*

Speakers

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

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

Francesco Bonella
Associate Professor Of Medicine
at Ruhrlandklinik University
Hospital, Germany

Monika Gappa
ERS President

Assumpta Ricart
Catalan Health Ministry

The recording of the session can be found here.

II. Navigating Supportive Care for Pulmonary Fibrosis

Content of the Presentation

In this session, moderated by John Solheim, he and Matthew Peter Cullen shared their experiences navigating pulmonary fibrosis. From the importance of a supportive work environment and the crucial role of pulmonary rehabilitation, to the value of support from patient organizations and healthcare professionals, and highlighting the psychological benefits of a supportive community, they provided valuable insights and outlined a pathway for those diagnosed with PF. Pulmonary rehab was highlighted, as well as seated aerobics, yoga, and exercises tailored for pulmonary fibrosis patients, which are accessible nationwide. The crucial role of caregivers was also discussed.

Dr. Anne Marie Russell highlighted the significance of patient-centered care and holistic approaches in treating pulmonary fibrosis. Her presentation underscored the evolution of patient-centered care, emphasizing shared decision-making and recognizing the importance of emotional and social well-being. She stressed the importance of self-management, including monitoring disease metrics and utilizing technological tools, while addressing digital literacy disparities. She also highlighted unmet needs such as psychological impacts and the need for comprehensive information. Dr. Russell discussed the potential of integrated respiratory pathways and community health hubs for early-stage diagnosis and management, and emphasized the importance of annual reviews and comprehensive examinations.

Key Quotes and Insights

- Engaging with patient organizations and pulmonary rehabilitation programs is highly beneficial. These organizations offer training, education, peer support, and advocacy, all of which are crucial for managing PF.
- Maintaining physical activity is important, though expectations should be adjusted based on current capabilities.
- The internet is a valuable but potentially misleading source of information.
- Accepting help from others and offering support in return can create a supportive community, enhancing the patient's quality of life.

Speakers

John Solheim (Speaker & Moderator)
Patient Advocate & EU-PFF Board Member, Norway

Anne-Marie Russell
Senior Lecturer at University of Exeter, United Kingdom

Matthew Peter Cullen
Patient Advocate & Leader in Dublin PF Support Group, Ireland

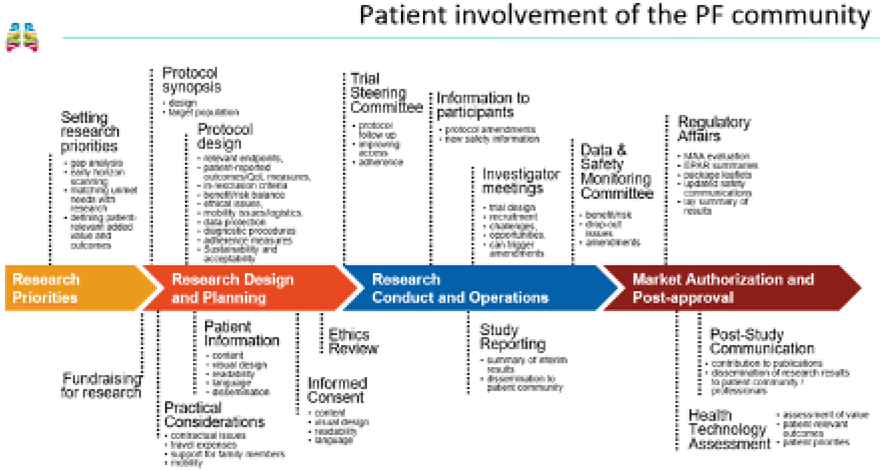
III. Trials Unveiled: A Workshop on Clinical Trials

Session NOT recorded

Content of the Presentation

The workshop began with Wendy Adams welcoming participants and outlining the purpose: to explore the significance of clinical trials and current challenges in the PF (Pulmonary Fibrosis) community. She emphasized the crucial role of patient organizations and advocacy in shaping clinical trials. Jan Geissler presented a roadmap of Patient Engagement, detailing key elements in PF trials and highlighting the involvement of patient organizations and advocacy groups in each stage.

Participants were divided into four groups to discuss the roadmap and identify critical issues. They incorporated perspectives from patient organizations and advocacy groups.



Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap. Geissler, Ryll, Leto, Uhlenhopp. Therapeutic Innovation & Regulatory Science (2017), doi: 10.1177/2168479017706405, and at www.eupati.eu

Facilitators

Wendy Adams
Patient Advocate & Patient Engagement and Research expert at Action for Pulmonary Fibrosis, United Kingdom

Gergely Meszaros
Patient Advocate & EU-PFF Policy Advisor, Hungary

Jan Geissler
CEO of Patvocates & Patient Advocate & EU-PFF Secretariat, Germany

Alba Ubide
Head of NGO Services at Patvocates & EU-PFF Secretariat, Spain

Key insights:

- **Sharing Information:** Importance of sharing trial outcomes, results, and lessons learned with participants, healthcare professionals (HCP), and other stakeholders.
- **Representation and Diversity:** Importance of including representation and diversity in the protocol design.
- **Patient Training and Education:** Importance of training and educating patients to participate in clinical trials, and removing the “guinea pig” perception.
- **Patient Experience:** Importance of understanding the entire experience from the patient’s perspective.
- **Meaningful Measurements:** Importance of choosing the right and most meaningful patient-reported outcomes (PRO) and quality of life measurements and the importance of using patient-centric secondary/exploratory endpoints.
- **Clinical Trial Methods:** Importance of moving towards more hybrid or decentralized clinical trials.

IV. Breathing Easy Workshop: Understanding Your Lungs

The recording of the session can be found here.

Content of the Symposium:

Stefano Pavanello moderated this session in which Prof. Simon Hart discussed the question, "How did I get Pulmonary Fibrosis?" To answer this question, he used the example case of a 75-year-old man with symptoms like shortness of breath and a dry cough, and described the diagnostic process involving chest X-rays, CT scans, and sometimes lung biopsies. After concluding the diagnosis of IPF, he explained normal lung anatomy and the changes observed in patients with PF. Simon Hart discussed the different types of pulmonary fibrosis, emphasizing their common risk factors and suggesting a hypothesis that ties these factors together. He argued for a "lumping" approach in treating pulmonary fibrosis, as many types share similar behaviors and respond to similar therapies, such as the anti-fibrotic drug Nintedanib, which can slow the progression of the disease regardless of its specific type. The presentation finished with an explanation of being short of breath and the separation between what the nerves are sending down and how much mechanical expansion the lung is actually able to do.

Elisabetta Balestro started the round of questions by highlighting that, even though it is not possible to completely predict the progression of the disease, the available drugs positively affect patients and have made a big difference in their lives. The behavior of the disease is now slower than it was ten years ago. Elisabetta Balestro answered several questions from in-person and online participants.

Key Quotes and Insights

- "High-resolution CT scans are crucial for diagnosing pulmonary fibrosis" - *Simon Hart*
- "Multidisciplinary diagnosis is used for pulmonary fibrosis, including radiology tests (as the CT scan), pathology (as a blood test) and clinical (as the clinical history of a patient)" - *Simon Hart*
- Overall, the conversation provided insights into the complexities of managing pulmonary fibrosis symptoms and the importance of a multidisciplinary approach to care.

Speakers

Stefano Pavanello (Moderator)
Patient Advocate & EU-PFF Board Member, Italy

Simon Hart
Professor and ILD physician at Hull York Medical School, United Kingdom

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

V. Breath Beyond Borders: Oxygen Access in Europe

Session NOT recorded

Content of the presentation:

In this session, moderated by Steve Jones, Chantal Vandendungen delivered an insightful presentation on the outcomes of a comprehensive survey spanning 14 European countries, which focused on assessing the accessibility of oxygen for PF patients. This survey, conducted in collaboration with the European Lung Foundation and the European Fibrosis Federation, aimed to gain a deep understanding of oxygen access across different nations and to advocate for meaningful change in this vital aspect of patient care. Different aspects were covered, including differences in access at the hospital and at home; access to concentrator systems, gas cylinders, liquid oxygen, and backup systems; cost reimbursement; and issues with traveling, differentiating between in-country and abroad, and between traveling by air, sea, rail, and road.

Then, Gottfried Huss shared insights on various aspects of oxygen administration from a patient's viewpoint. He emphasized the importance of unrestricted access to oxygen and proposed the concept of an "Oxygen Rights Charter." He highlighted the differences between diagnoses when stationary and moving, stressed the necessity of oxygen for individuals experiencing hypoxia, discussed the different types of oxygen therapy, addressed myths surrounding oxygen therapy, and emphasized the need for patients to advocate for their needs.

Key Quotes and Insights

- Oxygen is a human right.
- Traveling when needing oxygen was highlighted as extremely difficult for patients.
- It is crucial to improve guidelines, giving more emphasis on the specific needs of PF patients, remove medical barriers, stimulate research, and support the acquisition of better equipment.

Speakers

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

Chantal Vandendungen
Vice President for International
Relations at ABFPI, Belgium

Gottfried Huss
Patient Advocate &
Lungefibrose e.V. Member,
Germany

VI. Industry Symposium by Chiesi: Quality of Life / Holistic approach to ILD

Content of the presentation

The session focused not only on explaining the importance of quality of life but also on adopting a holistic approach for patients with interstitial lung diseases, particularly in research and clinical trials. It emphasized the need to understand how to measure and embed parameters related to quality of life effectively in clinical trials to make them meaningful for patients. The discussion aimed to create awareness among health authorities about the significance of considering quality of life beyond traditional measures like pulmonary function and forced vital capacity. The session set the stage for further exploration and discussion on the holistic management of patients with interstitial lung disease during the question and answer session.

Challenges in developing patient-reported outcome measures (PROMs) were addressed, including the complexity of validation, the variety of existing questionnaires, and the need for consensus among stakeholders. Collaboration between patients, caregivers, researchers, and healthcare professionals was emphasized as essential for defining and validating PROMs effectively. The discussion during the session further highlighted the urgency of the situation, emphasizing the need for immediate action and collaboration across stakeholders, including patients, caregivers, healthcare professionals, regulators, and policymakers. It underscored the importance of diversity and representation in decision-making processes and the power of patient voices in shaping the future of healthcare.

The presentation concluded with a call for rigorous validation processes, consensus-building within the research community, and broader representation in research studies to ensure that PROMs accurately reflect the experiences of diverse patient populations worldwide.

Key Quotes and Insights

- Patients should be able to participate in early stages of clinical trials, helping to produce meaningful data for patients.

Speakers

Pilar Rivera-Ortega
Clinical and Research Lead of the ILD Unit, Manchester University NHS Foundation Trust, United Kingdom

Chiesi

The recording of the session can be found here.

VII. Patient Engagement Policy Roundtable

The recording of the session can be found here.

Content of the Roundtable

Colin Edwards moderated this roundtable, which encompassed a wide range of topics related to patient engagement and involvement in healthcare decision-making. Participants emphasized the importance of collaboration and partnership across various sectors, including patient organizations, healthcare providers, pharmaceutical companies, and regulatory bodies.

The discussion emphasized the need for partnerships and connections to enhance patient engagement efforts, suggesting mentoring support and educational programs for decision-makers. Participants highlighted the importance of involving patients from diverse backgrounds in decision-making processes and acknowledged challenges related to regulatory constraints and stakeholder perceptions. They advocated for recognizing patients as equal partners in healthcare decisions, moving away from paternalistic approaches by healthcare systems and pharmaceutical companies. Reforms in regulations were suggested to enable deeper interactions between patients and stakeholders. Standardizing and optimizing dialogue between patients and physicians globally was proposed, though the complexities of creating international guidelines were noted.

Overall, the discussion stressed the importance of collaborative efforts among patients, healthcare providers, pharmaceutical companies, and regulatory bodies to improve patient engagement and healthcare outcomes, advocating for a more inclusive and equitable decision-making approach.

Key Quotes and Insights

- Patient engagement efforts should transcend national boundaries.
- Collaborations involving physicians, patients, and regulators are effective mechanisms for addressing patient needs and facilitating partnerships.

Speakers

Colin Edwards (Moderator)
Irish Lung Fibrosis Association
Board Member, Ireland

Bradley Price
Patient Advocate & Director of Policy and Public Affairs at Action for Pulmonary Fibrosis, United Kingdom

Matt Bolz-Johnson
Patient Advocate & Mental Health Lead at Eurordis, Germany

Jean-Michel Fourrier
EU-PFF Secretary & President of AFPF, France

Emmanuelle Clerisme-Beaty
Head of Therapeutic Area Inflammation Medicine at Boehringer Ingelheim GmbH & Co. KG, Germany

Francesco Bonella
Associate Professor Of Medicine at Ruhrlandklinik University Hospital, Germany

VIII. Fibrosis Unveiled: Understanding Pulmonary Health and Genetic Factors

The recording of the session can be found here.

Content of the Presentation

In this session, speakers delved into the intricacies of genetics in pulmonary fibrosis. They stressed the importance of ongoing monitoring, lifestyle choices, and family support from the patient's perspective, as well as the significance of early knowledge and proactive decision-making. The importance of equitable access to treatment, care, information dissemination, support networks, advocacy, and research funding was also underscored.

The speakers delineated between monogenic and familial forms of pulmonary fibrosis, highlighting the role of genetic testing in identifying pathogenic variants for monogenic forms. They discussed the impact of environmental and cellular factors on the expression of abnormalities related to pulmonary fibrosis. Additionally, the relevance of family aggregation in diagnosing familial forms of pulmonary fibrosis was emphasized, along with the need for ongoing monitoring and consideration of genetic testing in patients with a family history of the disease.

The debate also touched on when to start diagnosing family members based on genetic findings, considering the complexity of genetic influences and the interplay between genetics and environmental factors.

Key Quotes and Insights

- The need for a multidisciplinary approach to diagnosis and management was emphasised.
- The dialogue highlighted the evolving landscape of genetic medicine.
- The dialogue stressed the significance of familial aggregation criteria for diagnosing familial pulmonary fibrosis, stipulating that at least two family members must exhibit ILD symptoms.

Speakers

Wendy Adams
Patient Advocate & Patient Engagement and Research expert at Action for Pulmonary Fibrosis, United Kingdom

Maria Molina Molina
Chief of ILD Unit at Bellvitge University Hospital in Barcelona, Spain

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

Moises Selman
Emeritus Researcher at Instituto Nacional de Enfermedades Respiratorias, México

The recording of the session can be found here.

IX. PF Puzzle: Unravelling the Various Faces of PF

Content of the Presentation

Steve Jones moderated this session in which speakers collectively explored different aspects of interstitial lung diseases (ILDs) and related conditions, highlighting the complexities in diagnosis, treatment, and management.

Wim Wuyts focused on distinguishing between inflammatory and fibrotic hypersensitivity pneumonitis (HP) and emphasized the importance of identifying triggers and multidisciplinary evaluation. Clinical data were highlighted as extremely important for diagnosis, using a practical example of a musician to illustrate the multiple exposures that matter for diagnosis. Ilaria Galetti discussed systemic sclerosis, underscoring its impact on multiple organs and the challenges in early diagnosis and ongoing monitoring. She also highlighted the patient profile for systemic sclerosis and the differences between SSc-ILD and IPF. Lucilla Piccari addressed pulmonary hypertension associated with ILD, explaining why pulmonary hypertension occurs and discussing the frequency and symptoms of PH in patients with ILD. She also emphasized diagnostic challenges and the significance of various tests for suspicion and confirmation. Elisabetta Renzoni delved into ILDs associated with connective tissue diseases (CTDs), covering diagnostic patterns, treatment options, and the necessity of a multidisciplinary approach for comprehensive management.

Key Quotes and Insights

- "Multidisciplinary evaluation is essential for accurate diagnosis and treatment planning, with lung transplantation considered in severe cases" - *Wim Wuyts*
- "The typical patient of systemic sclerosis is a middle-age woman with a history of Raynaud phenomenon, presenting harding of the skin and internal organ dysfunction" - *Ilaria Galetti*
- "Most common form of pulmonary hypertension is caused by problems in the left side of the heart" - *Lucilla Piccari*
- "Several factors (risk factors, disease behaviour, severity of the ILD, patient factors as age and comorbidities and specific concerns) needs to be addressed for deciding who needs treatment for their CTD-ILD" - *Elisabetta Renzoni*

Speakers

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

Elisabetta Renzoni
Consultant Respiratory Physician
at the Royal Brompton Hospital,
United Kingdom

Wim Wuyts
Professor and Researcher at ILD
Unit, Pneumology Department, UZ
Leuven, Belgium

Ilaria Galetti
Patient Advocate & FESCA
Vice President, Italy

Lucilla Piccari
Doctor and Respiratory Physician
at Hospital del Mar, Barcelona,
Spain

Session NOT recorded

X. Spanish Patients Information Day: Share and Connect

Content of the Panel Discussion

This session started with Carlos Lines sharing valuable information about the AFEFPI (Spanish Association of Idiopathic Pulmonary Fibrosis, Familial Pulmonary Fibrosis, and Other Progressive Pulmonary Fibrosis), focused on uniting efforts to achieve access to the best treatments, and ultimately, a cure. They engage in activities related to information and guidance, advocacy for patients' interests, Patient Classrooms, online informational sessions, psychological support service, development of informative materials, among others.

Moisés Selman spoke about treatment, focusing on the current problems in finding suitable treatment, reviewing clinical trials, and sharing interesting potential treatment avenues (such as Stem Cells or Omega-3).

Claudia Valenzuela shared great information about treatment options (which slow down the disease progression but do not fully stop it) and the huge importance of multidisciplinary teams, which gather the efforts of professionals such as pulmonologists, radiologists, or rheumatologists.

This session ended with María Molina, who explained how we got where we are in terms of national and international clinical level. Maria thoughtfully explained patients' access to clinics in different points of Spain and, along with Claudia, answered a few questions from patients.

Key Quotes and Insights

- Multidisciplinary care is crucial to Pulmonary Fibrosis.
- Upon a diagnosis of PF, we now have two treatment options available — a significant milestone when compared to previous decades
- Except for Extremadura, which only has one center, Spanish regions are all well equipped in terms of assistance for PF patients.

Speakers

Carlos Lines
AFEFPI President and co-founder & Emeritus EU-PFF President

Claudia Valenzuela
Chair of the multidisciplinary ILD Unit in the Pulmonology Department at Hospital Universitario La Princesa, Madrid, Spain

Maria Molina Molina
Chief of ILD Unit at Bellvitge University Hospital in Barcelona, Spain

Moises Selman
Emeritus Researcher at Instituto Nacional de Enfermedades Respiratorias, México

XI. PF Connect: A Workshop on Teaming Up Across Different PF Types

Session NOT recorded

Content of the Presentation

The workshop started right at the moment attendees entered the room and were asked to select which group they wanted to participate in from the different disease areas available: IPF, SSC-ILD and PH-ILD. Once participants were grouped, Pippa Powell made an introduction of the European Lung Foundation, followed by a presentation of FESCA organisation by Sue Farrington and Ilaria Galetti as an example of collaboration in the Scleroderma community between different types of the disease. Then participants were asked to review the IPF Pathway that was available in the room in printed A2 papers on the tables. They had to run through the steps and associated challenges previously identified.

Based on the pathway, participants were asked to identify common aspects of their disease area as well as missing steps or challenges. Once that was completed, they were asked to select the top 3 most pressing challenges and brainstormed on and discussed about the activities that patient organisations could do to act upon the challenges.

After the collective exercise, the workshop highlighted the importance of having collaboration between different patient organisations and working together, learning from each other and collaborating to improve the patient experience and pathway. Even there are common steps of the disease area under pulmonary fibrosis, there are also very relevant and important steps that need to be considered separately. Yet the main challenges of organ transplantation or oxygen therapy remain common to all three disease areas.

Action to be carried away from the workshop is to pave and establish those relationships between patient organisations that may face similar challenges and issues, and brainstorm together on common actions.

Key Quotes and Insights

- The need of collaboration between different stakeholders and patient organisations specifically.

Speakers

Pippa Powell
Patient Advocate & ELF Director, United Kingdom

Alba Ubide
Head of NGO Services at Patvocates & EU-PFF Secretariat, Spain

Ilaria Galetti
Patient Advocate & FESCA Vice President, Italy

Sue Farrington
President FESCA, United Kingdom

Facilitators

Gergely Meszaros
Patient Advocate & EU-PFF Policy Advisor, Hungary

Mercè Cases
Senior Research Project Manager at Patvocates, Spain

XII. Breath of Life Workshop: Exploring the World of Transplants

The recording of the session can be found here.

Content of the Presentation

This session, moderated by Steve Jones, focused on organ donation and transplantation in Europe. The presentation began with a historical overview, tracing the development of tuberculosis treatment in Turkey after World War II, progressing from government initiatives to the establishment of specialized hospitals. The focus then shifted to recent advancements, particularly in lung transplantation procedures, detailing the process of lung transplantation, highlighting key statistics such as the number of transplants performed or the types of procedures undertake.

From a personal narrative, the journey from diagnosis to transplantation was also discussed, sharing experiences with pulmonary fibrosis, including symptoms, diagnostic tests, and the eventual decision to undergo lung transplantation.The narrative highlighted the emotional and physical challenges faced by transplant recipients, as well as the transformative impact of the procedure on their quality of life.

Additionally, the presentation addressed challenges related to organ donation shortages and initiatives aimed at raising awareness about the importance of organ donation. The challenges post-transplant, particularly with anti-rejection drugs and chronic rejection, were discussed, underscoring the need for ongoing research and improvement in treatment options. Additionally, the presentation touched upon efforts to address chronic rejection and the complexities involved in treatment.

Key Quotes and Insights

- The speakers emphasized the significance of quality of life after a lung transplant, highlighting that even with challenges, being alive is the most important outcome.
- Each individual's journey with transplant is different and equally valuable.

Speakers

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

Achille Abbondanza
Patient Advocate &
FIMARP Member, Italy

Radostina Getova
Patient Advocate & EU-PFF
Board Member, Bulgaria

Adnan Sayar
Professor of Thoracic Surgery
and Lung Transplantation at LIV
Hospital in Istanbul, Turkey

XIII. Industry Symposium by Boehringer Ingelheim: Patient involvement in HTA: How to bring your unique perspective and evidence into decision-making

Content of the presentation

Neil Bertelsen focused on patient experience data and the importance of patient involvement in decision-making processes, particularly in health technology assessment (HTA). Neil highlighted his experience advocating for patient involvement and the progress made in the past decade. He emphasized the significance of including patient preferences and needs in decision-making processes.

Neil provided an overview of HTA, explaining its role in assessing the impact of new technologies on health outcomes and healthcare systems. He discussed the process of HTA and its role in informing healthcare decisions, emphasizing the importance of evidence-based decision-making. Furthermore, Neil addressed the misconception that HTA solely determines healthcare availability, highlighting the role of policymakers in decision-making. He emphasized the need for collaboration between patients, policymakers, and healthcare professionals in HTA processes.

Overall, the talk emphasized the importance of patient involvement in HTA processes and the role of evidence-based decision-making in improving healthcare outcomes. It underscored the need for collaboration between patients, policymakers, and healthcare professionals to ensure that HTA accurately informs healthcare decisions.

Key Quotes and Insights

- Patient perspectives needs to be included to ensure that HTA accurately reflects the needs and preferences of diverse patient populations.
- Patient insights are very valuable in assessing the benefits of new technologies

Speakers

Neil Bertelsen
HTA Patient Engagement Specialist

Boehringer Ingelheim

The recording of the session can be found here.

XIV. Latest Research on Pulmonary Fibrosis

The recording of the session can be found here.

Content of the Presentation

In this session, moderated by Steve Jones, Vincent Cottin discussed recruiting and upcoming trials, as well as hot topics; and Marlies Wijsenbeek spoke about non-pharmacological and latest technological advancements, including quality of life home monitoring and biomarkers diagnostics. The changes in pulmonary fibrosis clinical trials were first covered, starting with multidisciplinary team discussions – although this discussion focuses on very few classes of drugs (IPF vs. Non-IPF Fibrotic ILD). Approved drugs were mentioned, as well as unmet medical needs. Examples of trials were also mentioned, including key points, as the different end points.

Marlies Wijsenbeek discussed diagnosis, monitoring, and support advances for pulmonary fibrosis. She mentioned misdiagnosis and delays in diagnosis – which are extremely common in pulmonary fibrosis. The diagnosis process is also complicated and long, needing lots of procedures and professionals involved. Furthermore, the current diagnosis process also comes with risks. Overall, Marlies emphasized how better diagnosis techniques are needed. Artificial Intelligence in diagnosis was also discussed (although not perfect, they can help). Monitoring devices were reviewed, including digital devices (and their barriers, from a patient perspective). Palliative care and personal care guides were also mentioned, as well as different treatments' side effects.

Key Quotes and Insights

- "Several promising compounds are entering or soon entering Phase 3 clinical trials" – *Vincent Cottin*
- "37% of pulmonary fibrosis patients reported at least one misdiagnosis" - *Marlies Wijsenbeek*

Speakers

Steve Jones (Moderator)
EU-PFF President,
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

XV. Roundtable on Clinical Trials: Exploring Opportunities and Insights

The recording of the session can be found here.

Content of the Presentation

This session, moderated by Liam Galvin, stakeholders (patient representatives, industry members, a clinician and a researcher) joined forces to discuss Clinical Trials.

Speakers emphasized the importance of patient participation in drug development. They stressed the value of early patient involvement, even in the discovery and Phase 1 trials, and highlighted efforts to educate patients about clinical trials, gather input at every stage, and simplify trial design based on patient feedback.

Speakers advocated for better representation to address disparities in care, considering factors beyond trial protocols, such as disease burden and logistical challenges. They called for more inclusive trial designs and recruitment strategies to improve clinical trial processes. The need for increased communication among stakeholders, including regulators, to better address patient needs was also emphasized. Additionally, speakers advocated for collaboration among companies for combination trials to accommodate various patient needs and enhance the overall drug development process.

Key Quotes and Insights

- "What we've heard over the last several years is the patient community would love to be involved more with the pharmaceutical industry early and earlier. And I completely agree. We need to involve the patients as early as possible".- *Brian Lee*
- "When we're bringing voice to the development of clinical trials, we need to ensure that that represents everybody's needs". - *Wendy Adams.*

Speakers

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

John Solheim
Patient Advocate & EU-PFF Board Member, Norway

Brian Lee
Senior Director of Patient Advocacy, Immunology & Neuroscience at Bristol Myers Squibb,
United States of America

Farrell Simon
Chief Commercial Officer at
Trevi Therapeutics,
United States of America

Elisabetta Renzoni
Consultant Respiratory Physician at the Royal Brompton Hospital,
United Kingdom

Wendy Adams
Patient Advocate & Patient Engagement and Research expert at Action for Pulmonary Fibrosis,
United Kingdom

XVI. Pulmonary Fibrosis Summit Finale: Reflect, Connect and Look Ahead

The recording of the session can be found here.

Content of the Presentation

In this final session of the Summit, moderated by Steve Jones, Prof. Athol Wells discussed the topic *What's going to be achieved by 2035?*. Prof. Wells explained how the diagnosis and treatment of idiopathic pulmonary fibrosis (IPF) have significantly improved over the years, reducing the reliance on invasive surgical biopsies. Advances such as increased awareness among clinicians, the use of cryobiopsies, and the acceptance of probable IPF diagnoses have contributed to this trend. These developments have led to a decrease in the recommendation for surgical biopsies to about 30% of cases, driven by heightened awareness, improved diagnostic tools, and the potential of AI technologies to enhance diagnosis by detecting subtle patterns in CT scans.

AI and biomarkers are playing increasingly important roles in diagnosing IPF and predicting patient outcomes. While AI has the potential to improve diagnostic accuracy, its full integration into clinical practice will take several years. Biomarkers, including genomic classifiers, can enhance diagnosis and predict outcomes, but their effectiveness is contingent on the pre-test probability of IPF and must be applied cautiously. The goal is to make IPF diagnosis more accurate, less invasive, and more informed by these advanced technologies and biomarkers. Future advancements in IPF treatment are expected to focus on personalized medicine, recognizing that IPF has subtypes with varying treatment outcomes. Combining precision medicine with personalized therapies, similar to cancer treatment strategies, is crucial.

Liam Galvin concluded the session - and the Summit - with words of gratitude to everyone who took part in the summit.

Key Quotes and Insights

- Advocacy groups play a vital role in raising awareness and pushing for better treatments, especially with the increasing prevalence of lung diseases due to factors like vaping.

Speakers

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

Athol Wells
Patient Advocate,
United Kingdom

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

Session NOT recorded

Siel Bleu – Respiratory Sessions

During the Summit, Siel Bleu held 2 respiratory sessions, one on Friday afternoon and another one on Saturday afternoon. The sessions were mainly addressed to patient attendees but anyone interested was welcomed to join the sessions.

Content of the Presentation

The Benefits of Adapted Physical Activity for Patients with Pulmonary Fibrosis
Pulmonary fibrosis is a chronic and progressive disease that affects the lungs by causing the development of scars (fibrosis) in the lung tissues. These scars lead to a decrease in respiratory capacity and a reduction in blood oxygenation, which can significantly impact patients' quality of life. However, adapted physical activity (APA) can play a crucial role in managing this disease. Here are some of the main benefits of APA for patients with pulmonary fibrosis.

- Improvement of lung capacity
- Reduction of dyspnea
- Improvement of quality of life
- Muscle strengthening
- Personalized adaptation

Key Quotes and Insights

- Physical Adapted Activity has changed my life. Before I started doing exercises, I could not do any effort. It was hard mentally! Now I feel that I have much more energy.
- "I started the online program FP&Me of Siel Bleu a few years ago. After a few weeks, I felt much better : I was able to climb the stairs with less difficulties. The collective class is very nice to get motivated, because each week you see the same person, you exchange news and advice about the disease: it's not just a moment of physical activity, it's also a moment of discussion and sharing!" - *Jean Michel Fourrier*

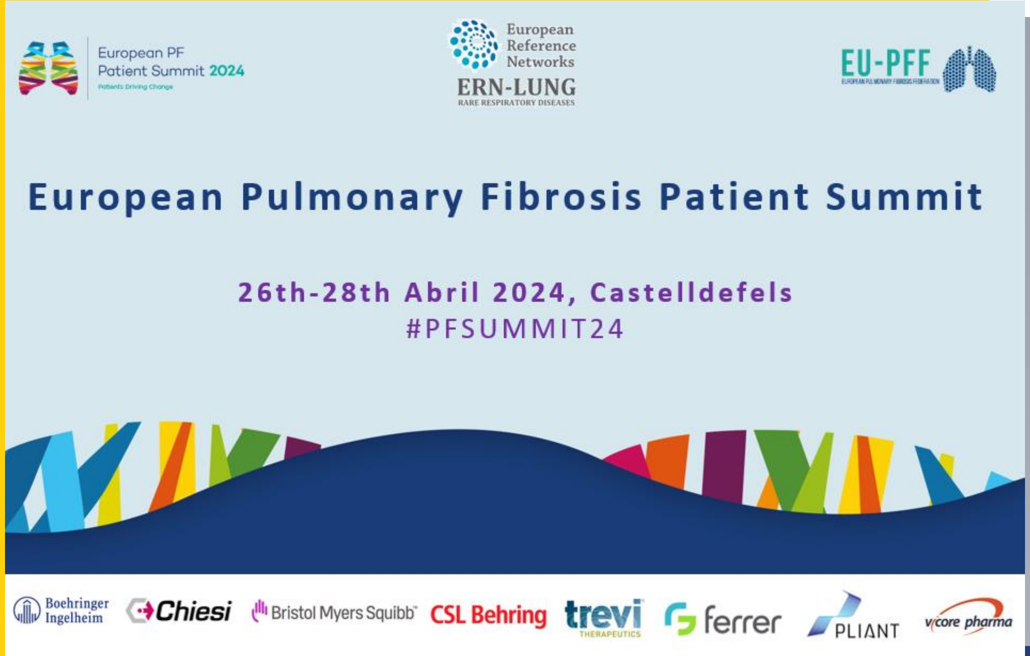
PF Patient Summit Sessions: Key Figures and Metrics

PF Patient Summit Sessions: Key Figures and Metrics

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

Over the three-day Summit, 8 plenary sessions, 6 workshops, 2 industry symposiums and 2 respiratory sessions were held.

- A total of 170 attendees onsite
- More than 250 attendees registered virtually



European Pulmonary Fibrosis Patient Summit

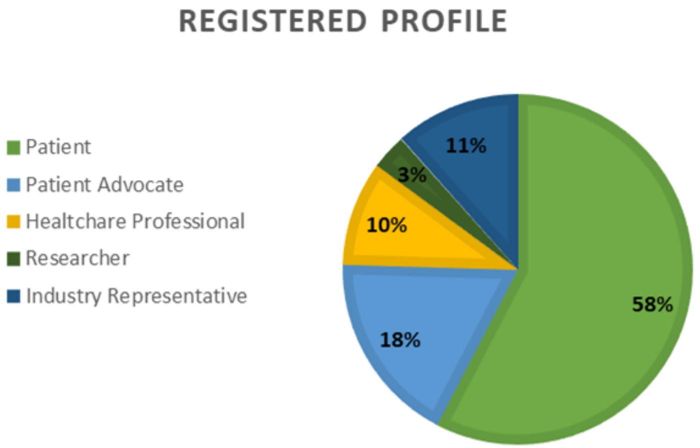
26th-28th Abril 2024, Castelldefels
#PFSUMMIT24

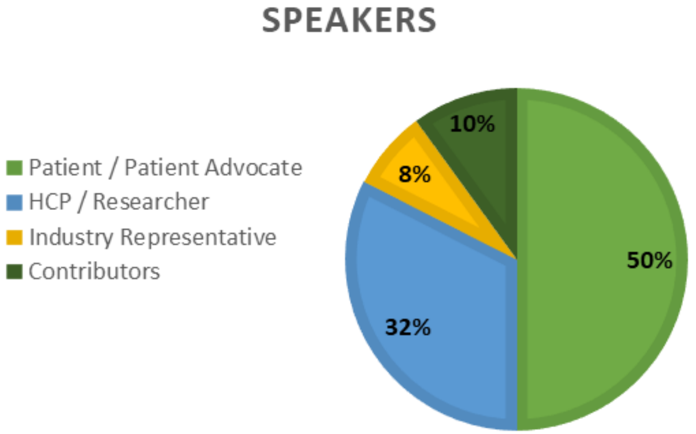
Attendee Participation – General Numbers

432 people had registered for the three-day event, 392 as attendees and 40 as speakers.

- According to general numbers, almost 60% of total registered people were patients, and the 18% were patient advocates, figures confirming again the summit as a patient event.

- With the aim of giving voice and visibility to the central figure of the summit, the patient, half of the speakers were also patients/patient advocates.

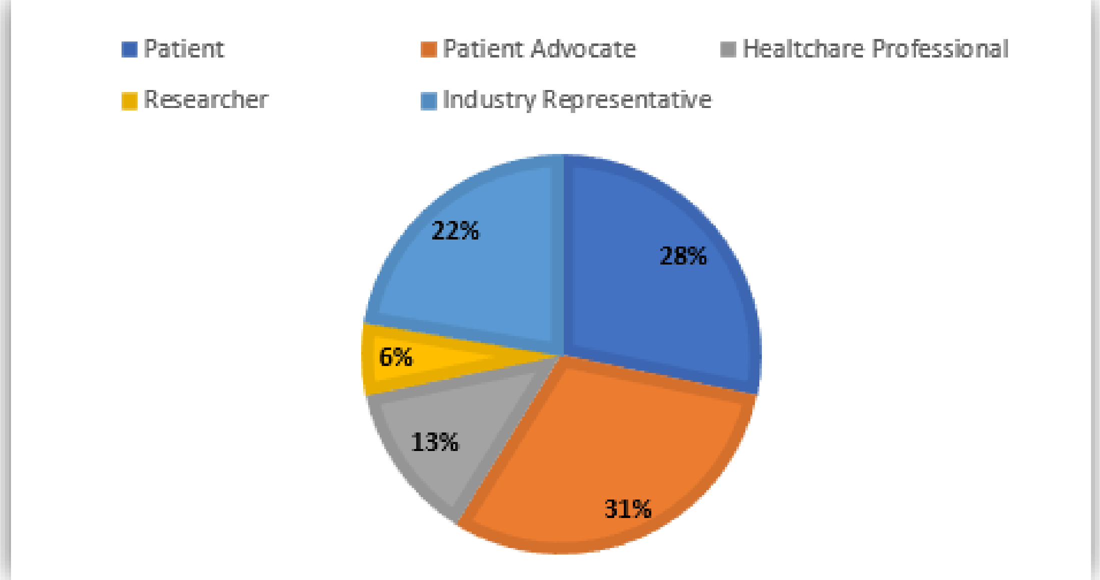




Attendance Participation

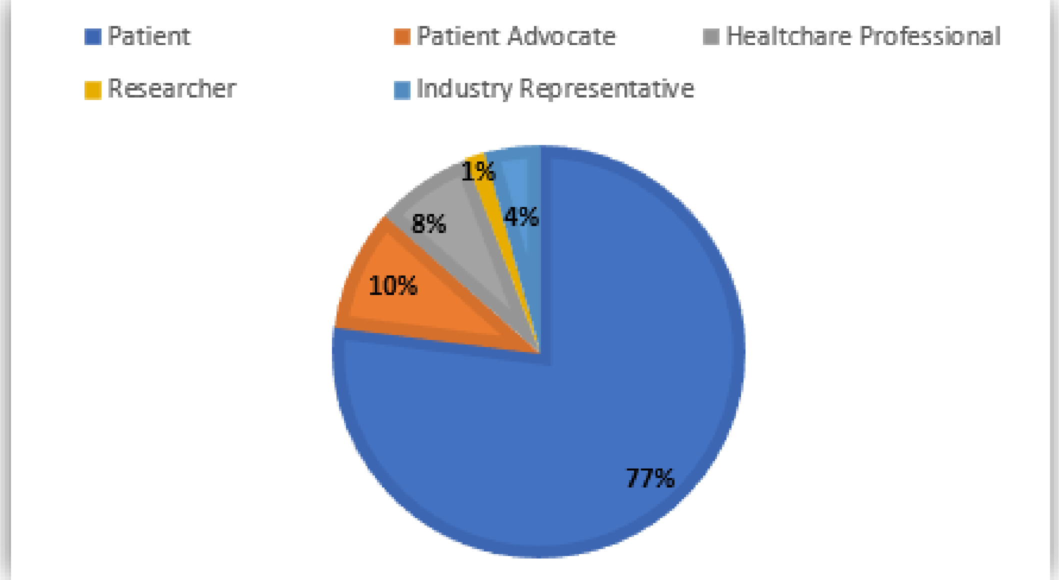
Onsite attendee profile

Total attendees:
170



Virtual attendee profile

Total attendees:
262



Posters & Abstracts

PF Patient Summit 2024

Posters and Abstracts

Person-Centered Care

- Educate and Empower: Novel edu-therapeutic model of supportive care for patients and care partners living with pulmonary fibrosis (*Jennifer Wescoe et al.*)
- Patient perspectives on home monitoring and virtual care for pulmonary fibrosis (*Rebecca Borton et al.*)
- Pulmonary Fibrosis Trust: a UK charity and a support group (PF Trust)

Policy and Patient Advocacy

- Like a fish out of the water (*Achille Abbondanza*)
- Sharing Breath initiative (AMMP)
- Establishing a public and patient involvement Research Advisory Group (*ILFA et al.*)

Research

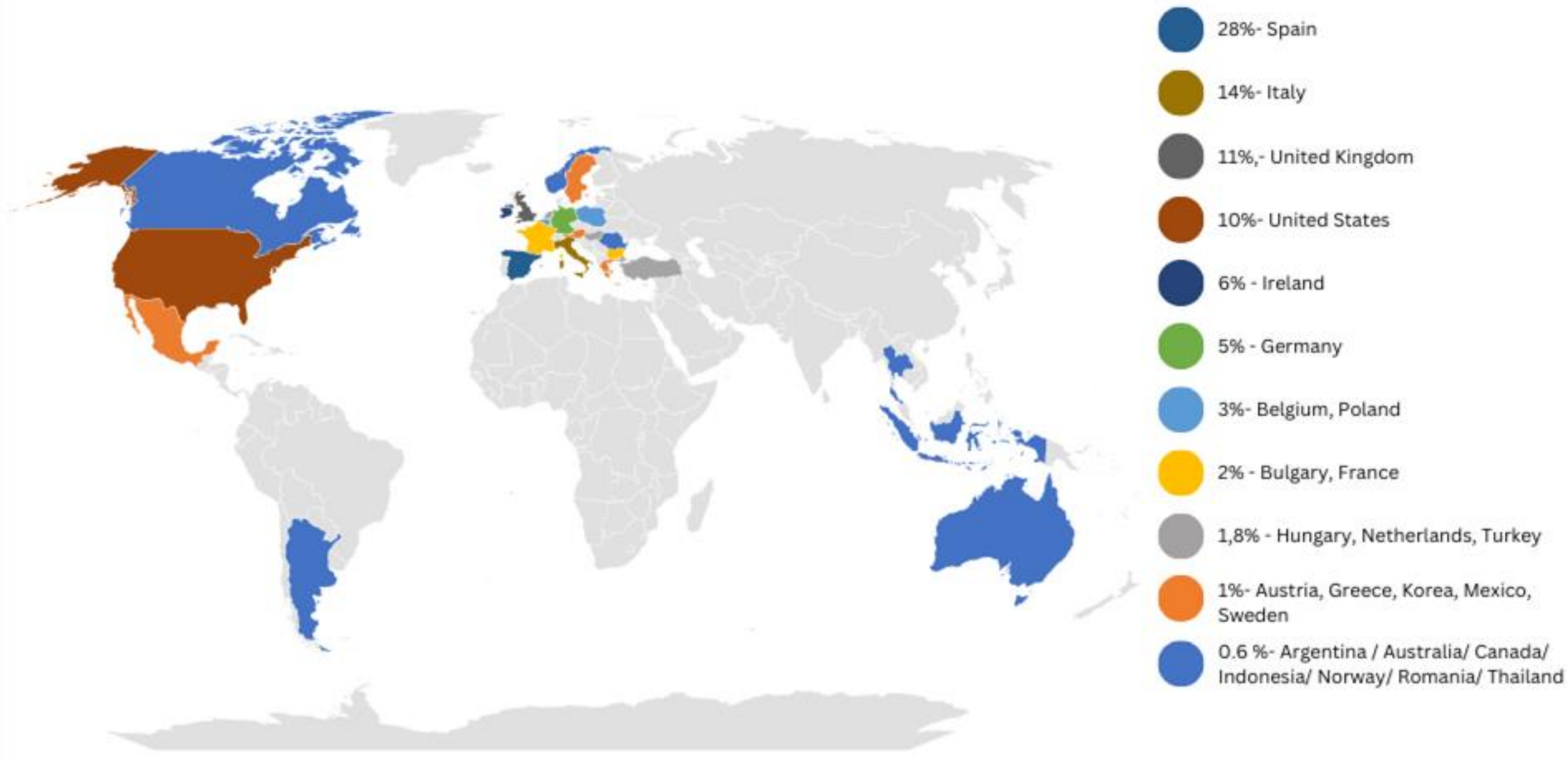
- Registry for scientific and clinical research on Idiopathic Pulmonary Fibrosis (FIMARP)
- Impact of Pulmonary Fibrosis on the lives of patients and carers in Ireland in 2022 (ILFA)
- Embedding patient and public involvement in a mixed methods study to explore the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (*Carita Bramhill et al.*)
- Nabulphine extended-release tablets reduced cough in people with IPF (Trevi)
- Interim analysis of AIR trial (Vicore)
- ASPIRE – A patient friendly trial evaluating whether C21 improves lung function in IPF (Vicore)
- COMPANION – A digital therapy to address the anxiety (Vicore)

Review and metrics of the PF Summit Attendance

Participants by country - Onsite

- Participants joined from all parts of the world, including Argentina, Australia, Canada, Indonesia, Mexico, Korea and Thailand.

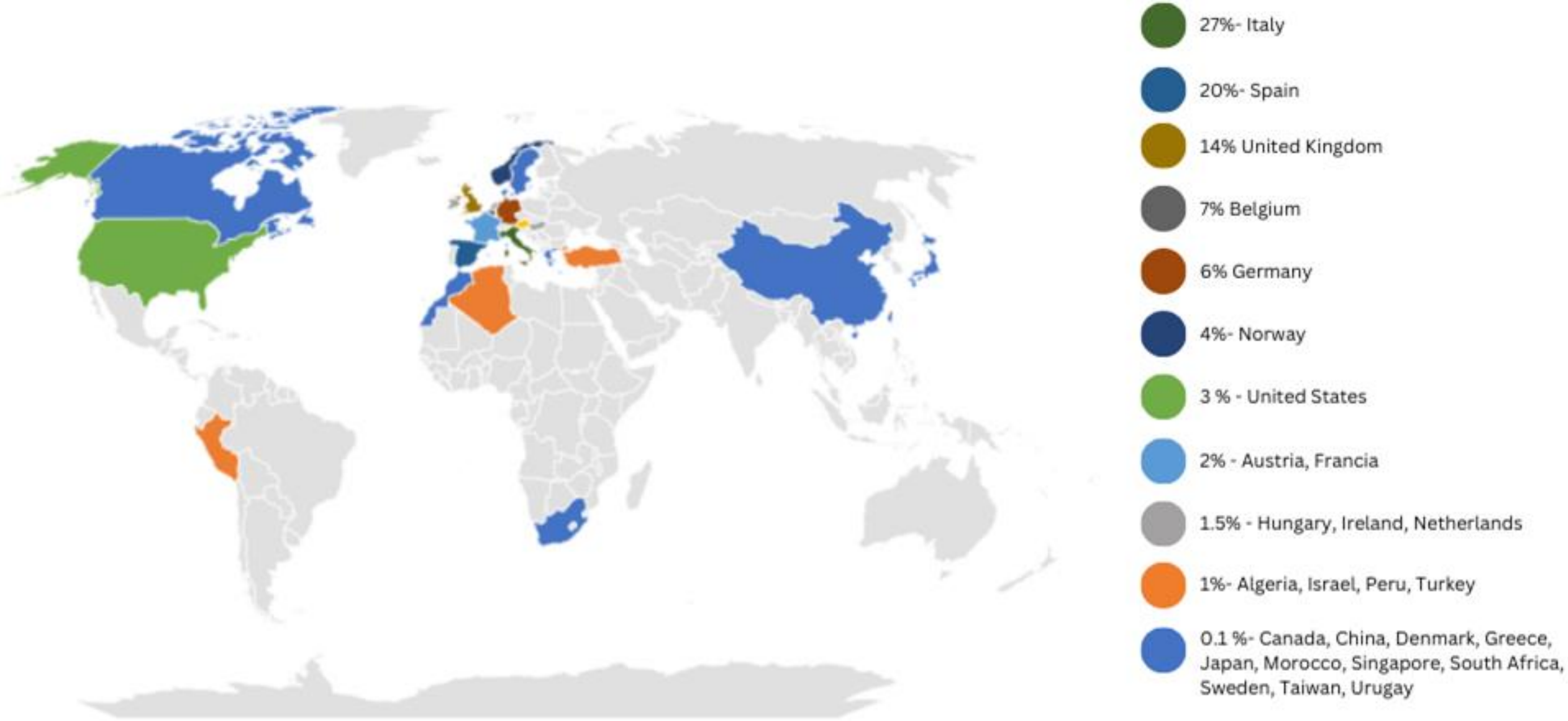
- The country with the **highest number** of onsite participants were **Spain** (27.65%) and **Italy** (13.52%), followed by **United Kingdom** (11.17%) and **United States** (10.58%).



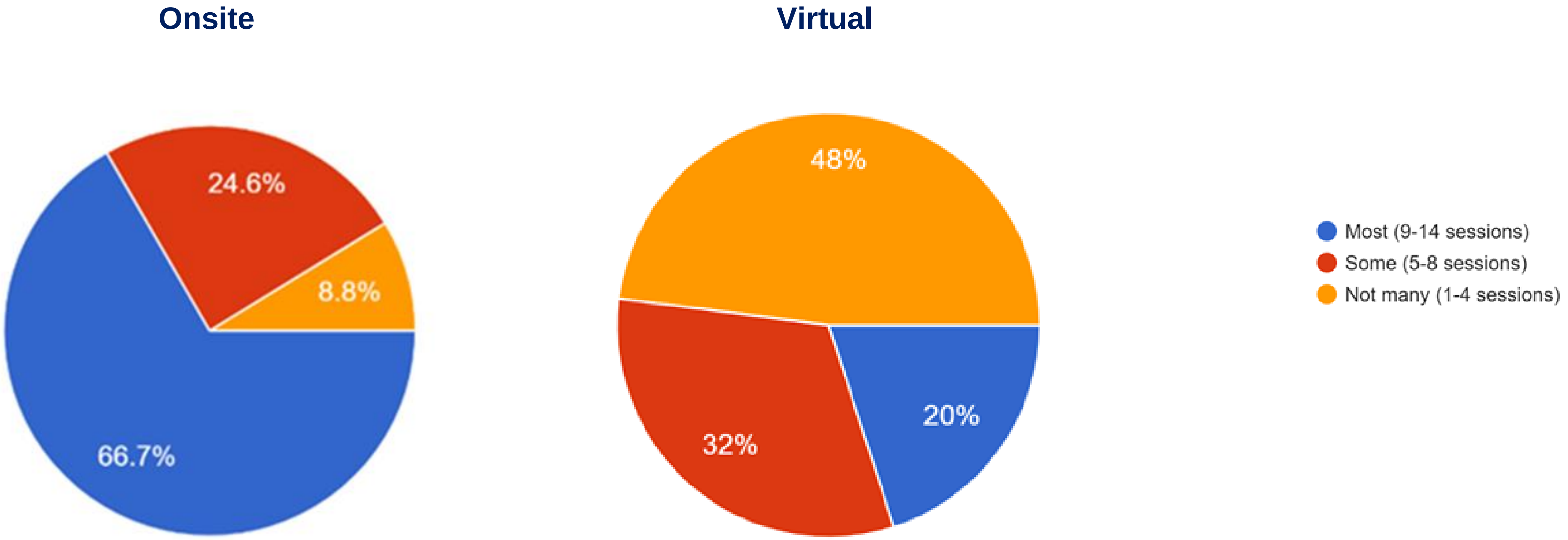
Participants by country - Virtual

- Participants joined from all parts of the world, including Israel, Japan, Peru, South Africa, China, Singapore and Taiwan.

- The country with the **highest number** of registered participants was **Italy** (23%), **Spain** (17%) and the **United Kingdom** (12%).



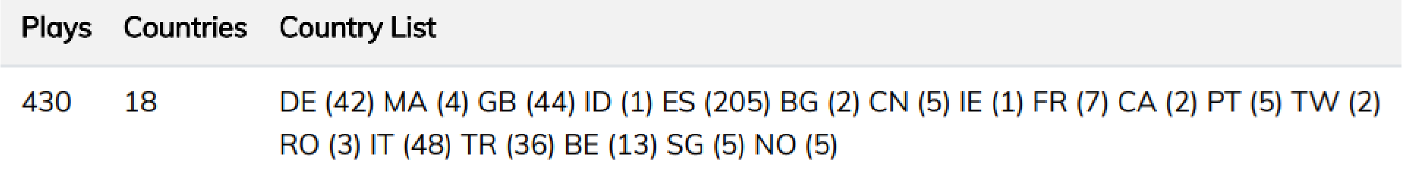
How many sessions did you attend?



Virtual Attendance - Metrics

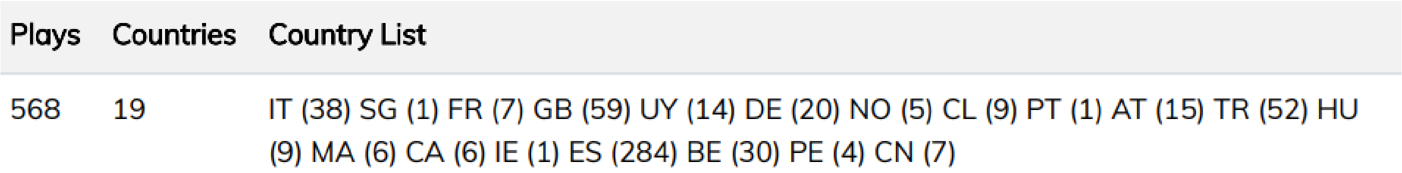
Per Day - TOTALS

Day 1 - 26.04



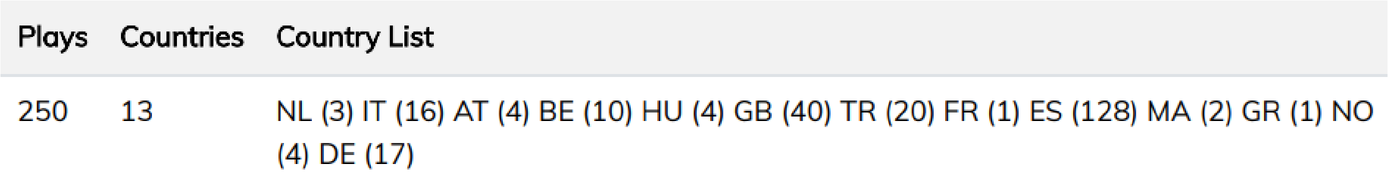
Plays	Countries	Country List
430	18	DE (42) MA (4) GB (44) ID (1) ES (205) BG (2) CN (5) IE (1) FR (7) CA (2) PT (5) TW (2) RO (3) IT (48) TR (36) BE (13) SG (5) NO (5)

Day 2 - 27.04



Plays	Countries	Country List
568	19	IT (38) SG (1) FR (7) GB (59) UY (14) DE (20) NO (5) CL (9) PT (1) AT (15) TR (52) HU (9) MA (6) CA (6) IE (1) ES (284) BE (30) PE (4) CN (7)

Day 3 - 28.04



Plays	Countries	Country List
250	13	NL (3) IT (16) AT (4) BE (10) HU (4) GB (40) TR (20) FR (1) ES (128) MA (2) GR (1) NO (4) DE (17)

Virtual Attendance - Metrics

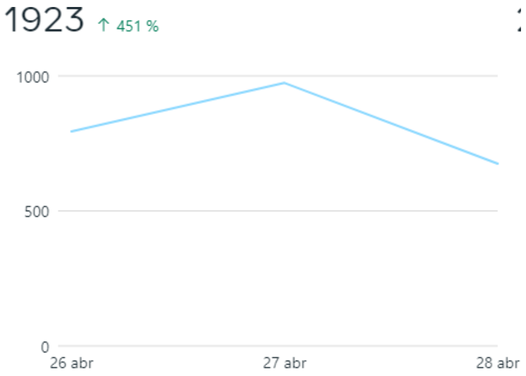
Per Day - TOTALS

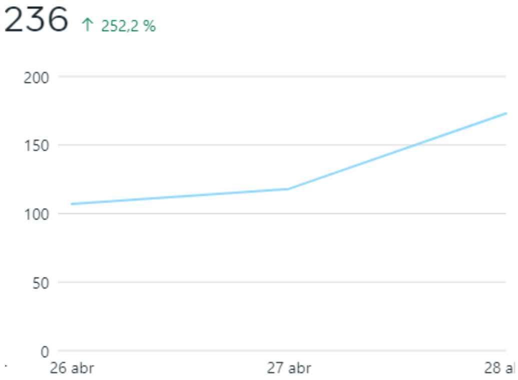
		Unique viewers
Day 1 - 26.04	The 3rd Pulmonary Fibrosis Patient Summit: Let the Summit Begin!	36
	Navigating Supportive Care for Pulmonary Fibrosis	30
	Breathing easy workshop: understanding your lungs	34
	Industry Symposium #1 - Quality of life / holistic approach to ILD	21
Day 2 - 27.04	Patient Engagement Policy Roundtable	22
	Understanding Pulmonary Health and Genetic Factors	30
	PF Puzzle: The Various Faces of Pulmonary Fibrosis	29
	Breath of life workshop: exploring the world of transplants	16
	Industry Symposium #2 - Patient involvement in HTA: how to bring your unique perspective and evidence into decision-making	11
Day 3 - 28.04	Latest Research on Pulmonary Fibrosis	21
	Roundtable on Clinical Trials: Exploring Opportunities and Insights	17
	Pulmonary Fibrosis Summit Finale: Reflect, Connect, and Look Ahead	10

Review and metrics of the PF Summit Social Media footprint

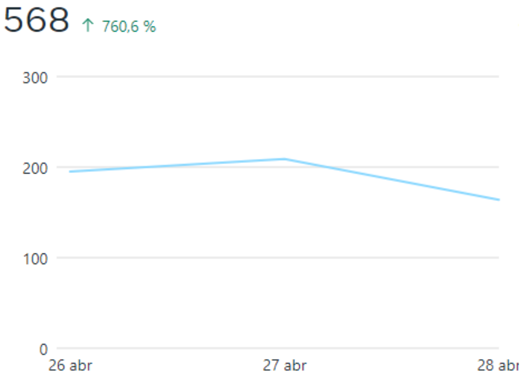
Facebook & Instagram Stats from Apr. 26-28 2024

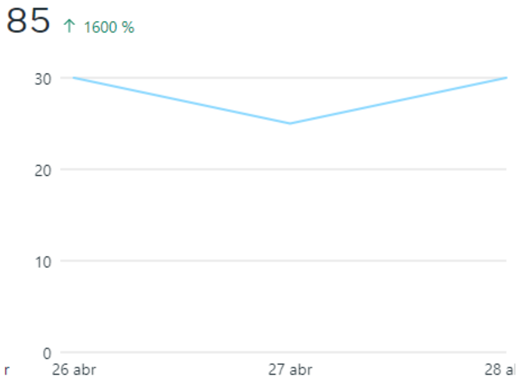
Reach





Profile visits





Posts with most impressions

Three parallel workshops on...

viernes, 26 de abril 8:43

↗ 1024 ♥ 27
💬 0 ➦ 6

We start the second day of the third...

sábado, 27 de abril 0:23

↗ 776 ♥ 18
💬 0 ➦ 16

We would like to sincerely thank Ferr...

domingo, 28 de abril 12:00

↗ 1234 ♥ 7
💬 0 ➦ 7

Good morning everyone! The 3rd...

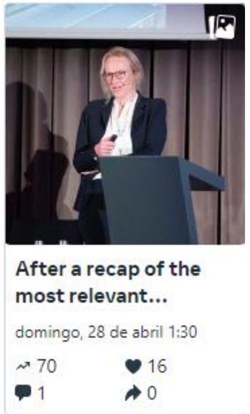
viernes, 26 de abril 3:34

↗ 103 ♥ 20
💬 1 ➦ 2

We start the second day of the third...

sábado, 27 de abril 0:57

↗ 163 ♥ 20
💬 1 ➦ 1



After a recap of the most relevant...

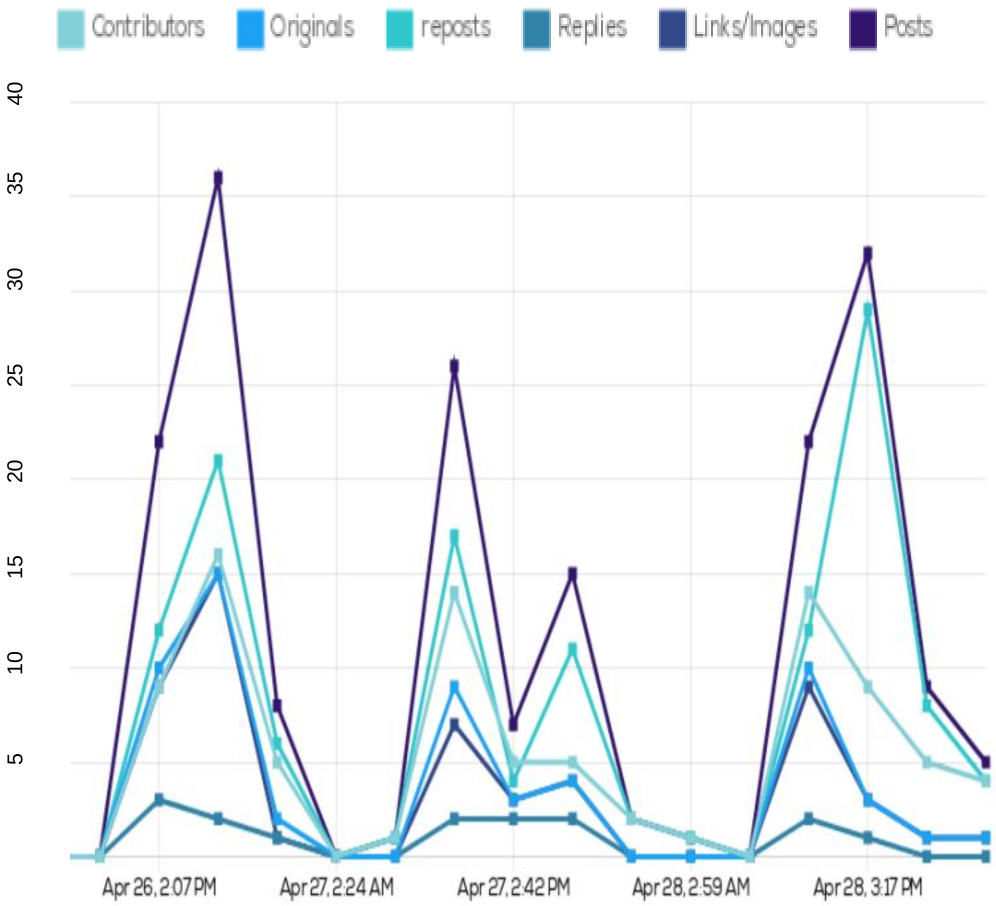
domingo, 28 de abril 1:30

↗ 70 ♥ 16
💬 1 ➦ 0

EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION

X Stats from Apr. 26-28 2024

Activity



Most liked Posts

EU_IPFF | 4 days ago | 23 Likes

Tomorrow the 3rd European #PulmonaryFibrosis Patient Summit opens its doors - in Castelldefels & virtually on Swapcard. Over 3 days patients, researchers, clinicians & others will discuss, share knowledge & create synergies - and set the agenda for the coming years. #PFSUMMIT24 https://t.co/Ygi70dq4FT

EU_IPFF | 2 days ago | 21 Likes

Three parallel workshops on different topics – on #Oxygen access in Europe, on the role of patients in the design of #clinicaltrials trials, and on fundamental aspects of the organ of the lungs. Which workshop did you choose? #PFSUMMIT24 #PulmonaryFibrosis https://t.co/JCxYudETSF

Top Hashtags

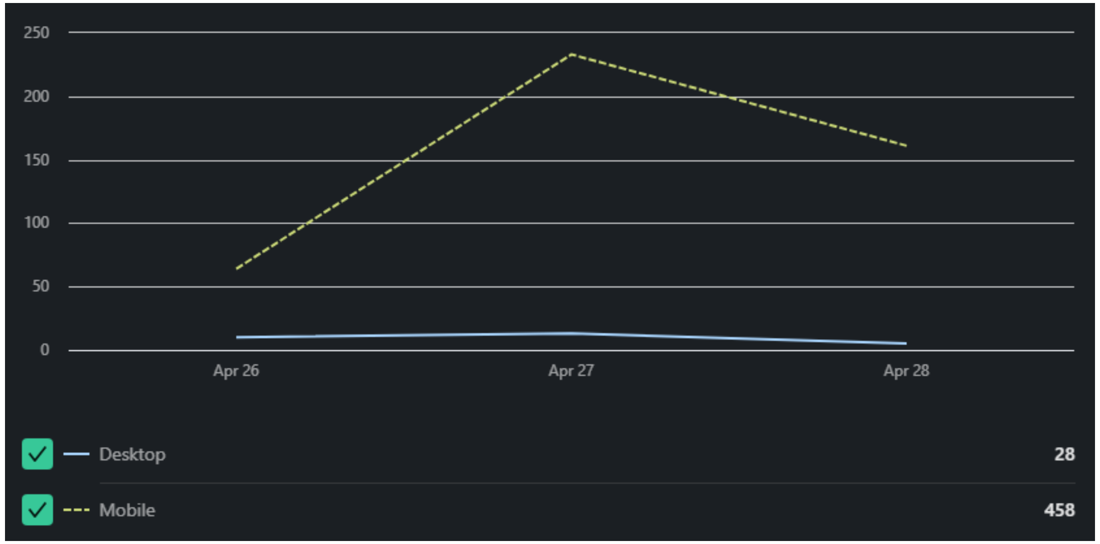
#OXYGEN	6	#PFSUMMIT24	198
#ILD	5	#PULMONARYFIBROSIS	65
#MDT	4	#PF	23
#LUNGS	4	#CLINICALTRIALS	9
#MENTALHEALTH	3	#CUREPF	9

LinkedIn Stats from Apr. 26-28 2024

Profile visits

486 Page views ▲683.9%

123 Unique visitors ▲434.8%

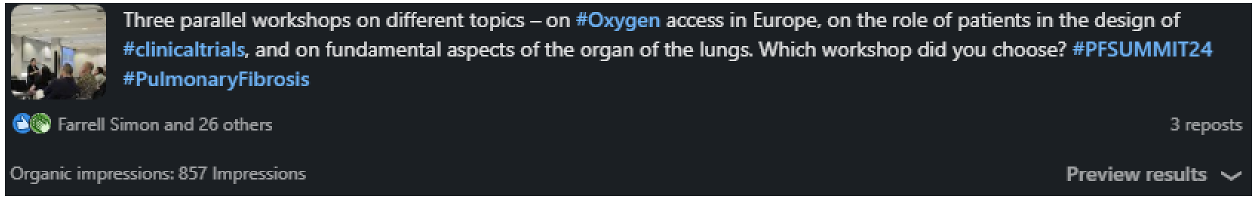


☑ — Desktop 28

☑ --- Mobile 458

Posts with most impressions

26 April

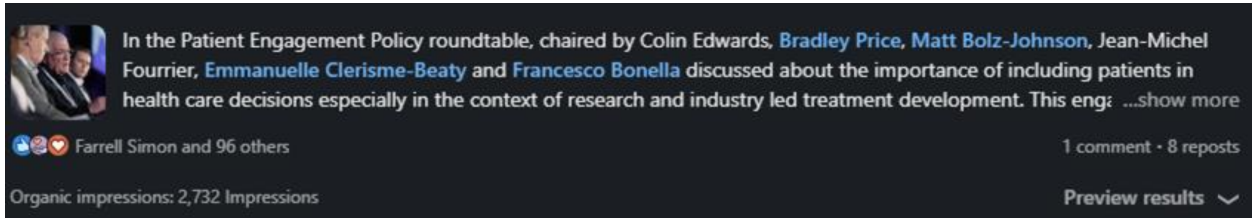


Three parallel workshops on different topics – on #Oxygen access in Europe, on the role of patients in the design of #clinicaltrials, and on fundamental aspects of the organ of the lungs. Which workshop did you choose? #PFSUMMIT24 #PulmonaryFibrosis

Farrell Simon and 26 others · 3 reposts

Organic impressions: 857 Impressions

27 April

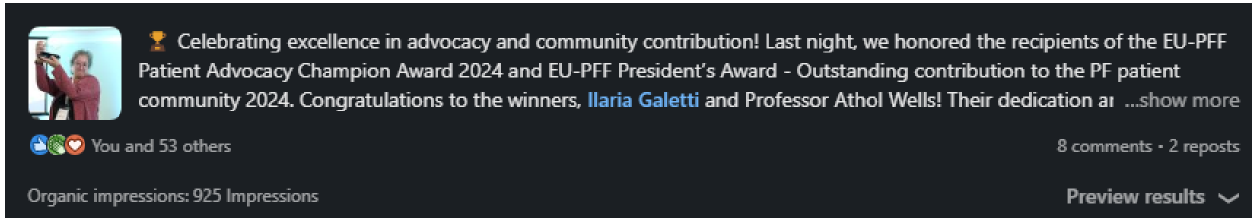


In the Patient Engagement Policy roundtable, chaired by Colin Edwards, Bradley Price, Matt Bolz-Johnson, Jean-Michel Fourrier, Emmanuelle Clerisme-Beaty and Francesco Bonella discussed about the importance of including patients in health care decisions especially in the context of research and industry led treatment development. This enga ...show more

Farrell Simon and 96 others · 1 comment · 8 reposts

Organic impressions: 2,732 Impressions

28 April



🏆 Celebrating excellence in advocacy and community contribution! Last night, we honored the recipients of the EU-PFF Patient Advocacy Champion Award 2024 and EU-PFF President's Award - Outstanding contribution to the PF patient community 2024. Congratulations to the winners, Ilaria Galetti and Professor Athol Wells! Their dedication ar ...show more

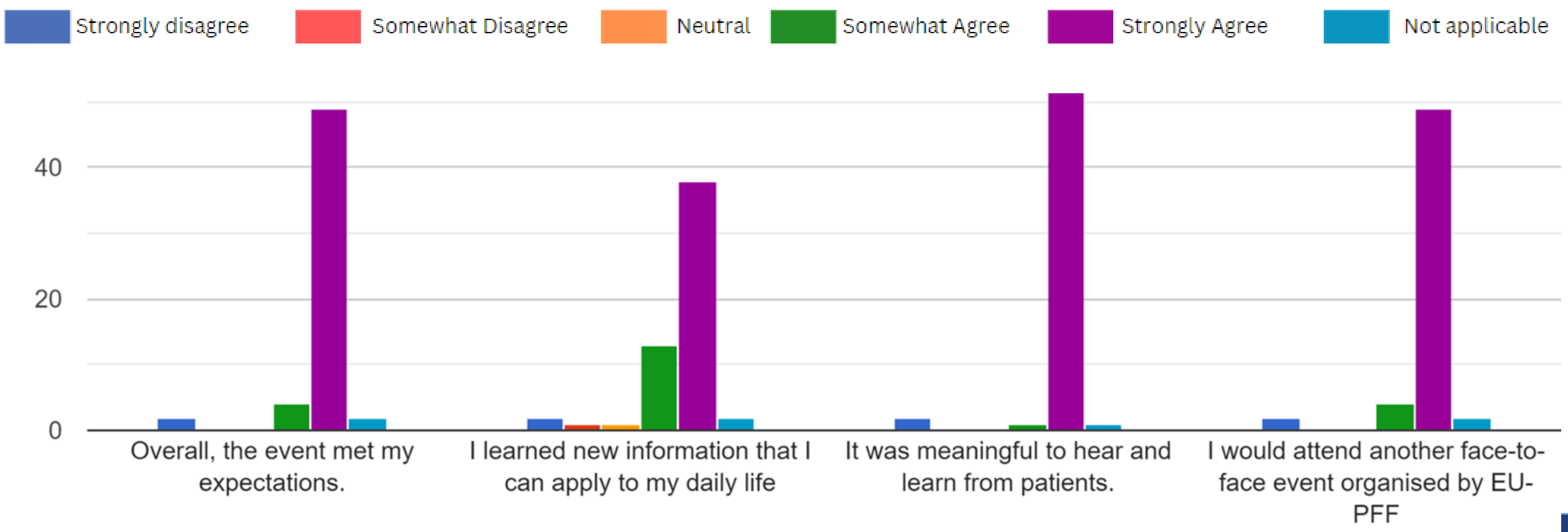
You and 53 others · 8 comments · 2 reposts

Organic impressions: 925 Impressions

PF Patient Summit 2022: Attendee Feedback

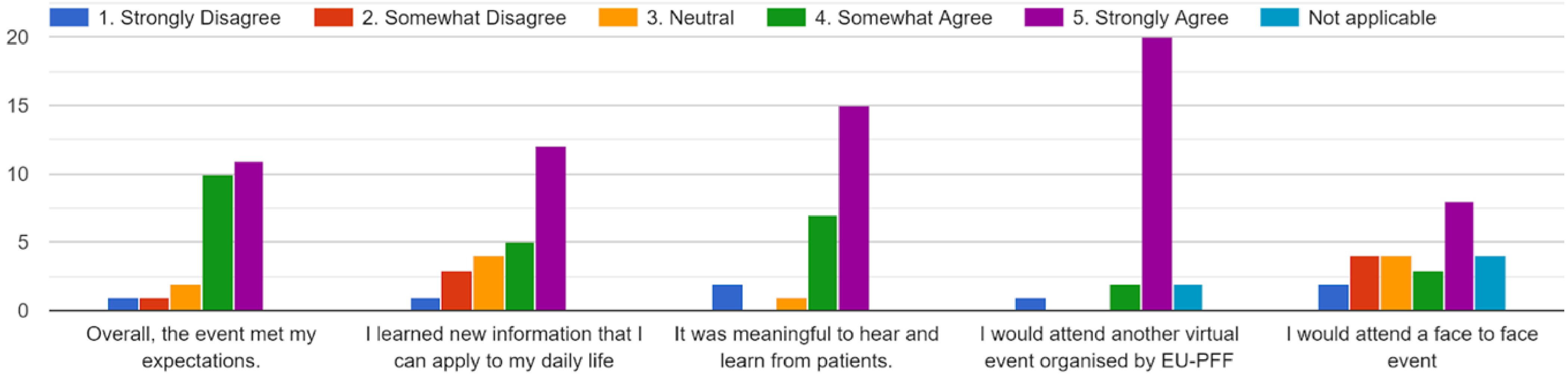
32 responses

Overall Attendee Feedback - Onsite



- 86% of the surveyed attendees confirmed that the Summit strongly met their expectations.
- 66.7% of the surveyed attendees confirmed that they learned new information which they can apply to their daily work.
- 93% of the surveyed attendees confirmed the meaningfulness of hearing from patients’ perspective**.**
- 86% of the surveyed attendees confirmed that they would attend another face-to-face event

Overall Attendee Feedback - Virtual

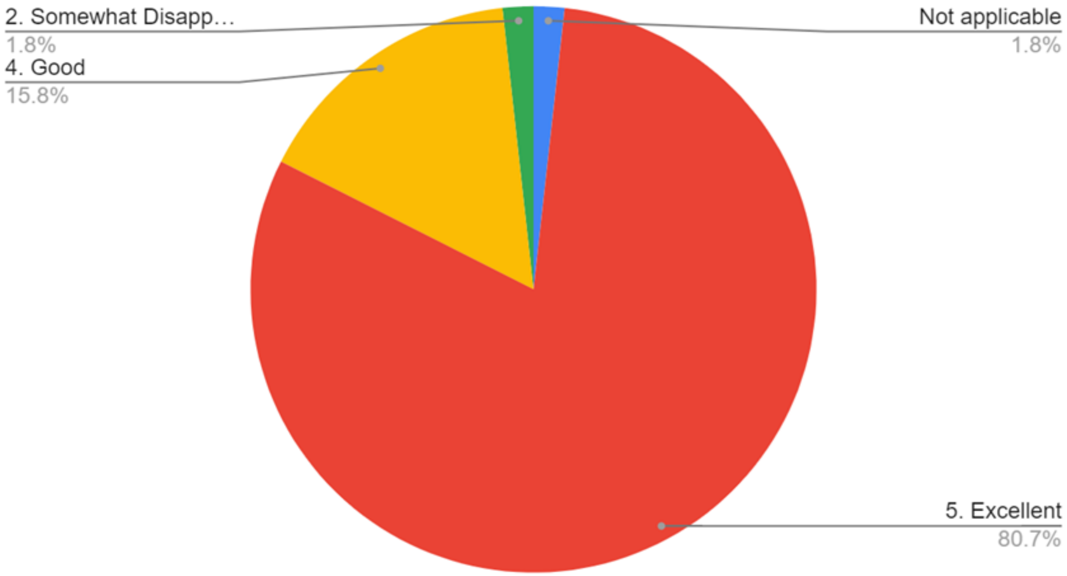


- 44% of the surveyed attendees confirmed that the Summit strongly met their expectations while 40% confirmed it met their expectations.
- 48% of the surveyed attendees confirmed that they learned new information which they can apply to their daily work.
- 60% of the surveyed attendees confirmed the meaningfulness of hearing from patients' perspective.
- 80% of the surveyed attendees confirmed that they would attend another virtual event while 32% are willing to join an onsite event

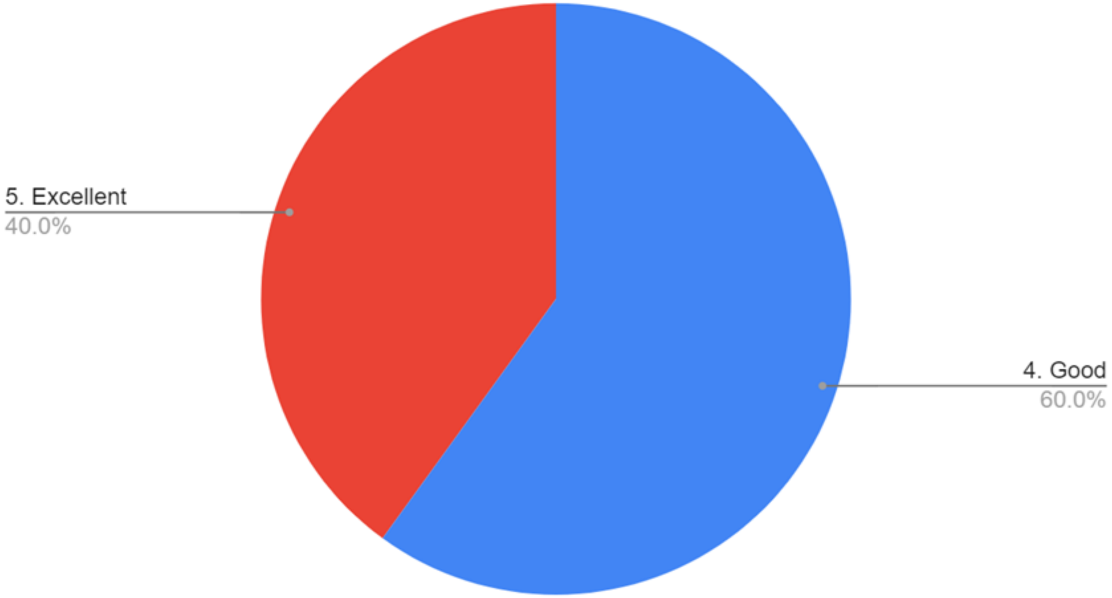
Overall Programme

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

Onsite

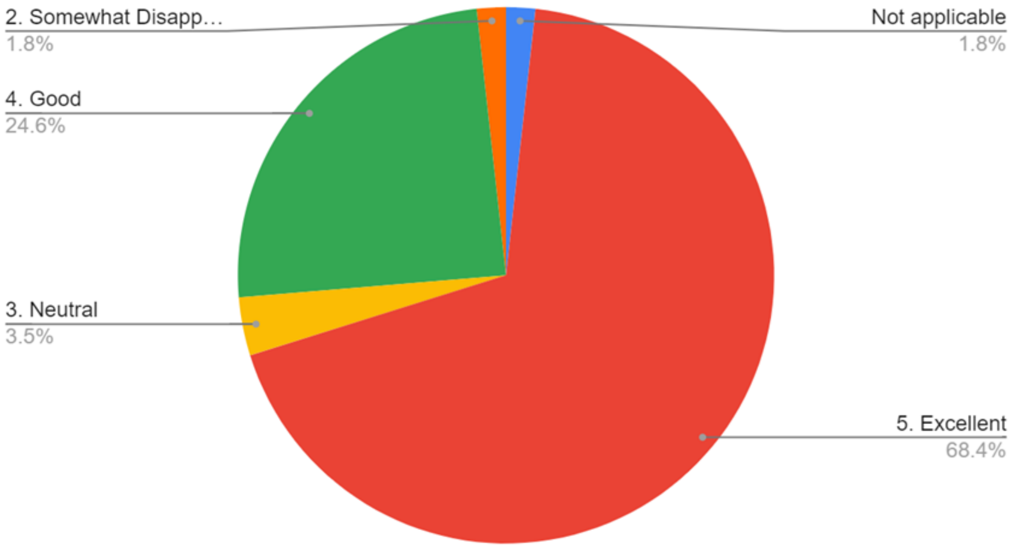


Virtual



Sessions Content Rating – Onsite

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



Plenary sessions - Top 3

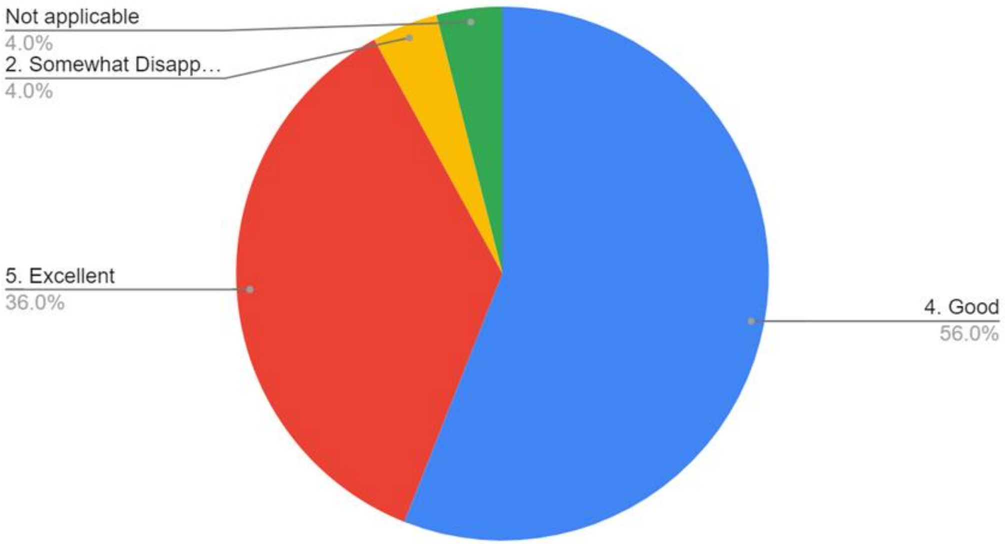
- Fibrosis Unveiled: Understanding Pulmonary Health and Genetic Factors (**70.2%** rated it as *excellent*)
- Latest Research on Pulmonary Fibrosis (**66.7%** rated it as *excellent*)
- Roundtable on Clinical Trial: Exploring opportunities and insights (**63.2%** rated it as *excellent*)

Highest rated workshops

- Trials Unveiled: A workshop on clinical trials (**43.9%** rated it as *excellent*)
- Breath of Life Workshop: Exploring the world of transplants (**42.1%** rated it as *excellent*)
- PF Connect: A workshop on teaming up across different PF type (**35.1%** rated it as *excellent*)

Sessions Content Rating – Virtual

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



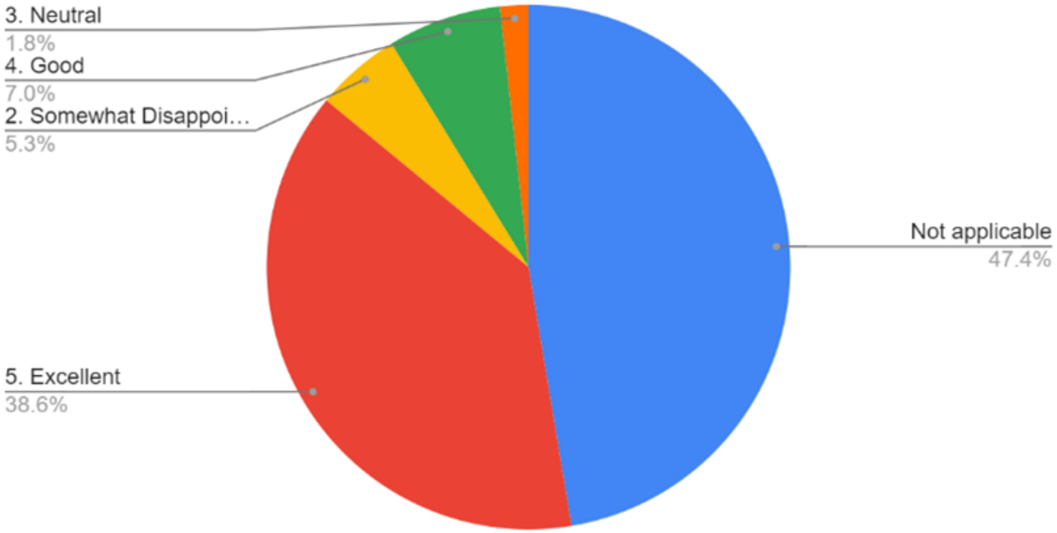
Highest rated sessions

- Breathing Easy Workshop: Understanding your lungs (**40%** rated it as *excellent*)
- Fibrosis Unveiled: Understanding Pulmonary Health and Genetic Factors (**36%** rated it as *excellent*)
- Navigating Supportive Care for Pulmonary Fibrosis (**32%** rated it as *excellent*)

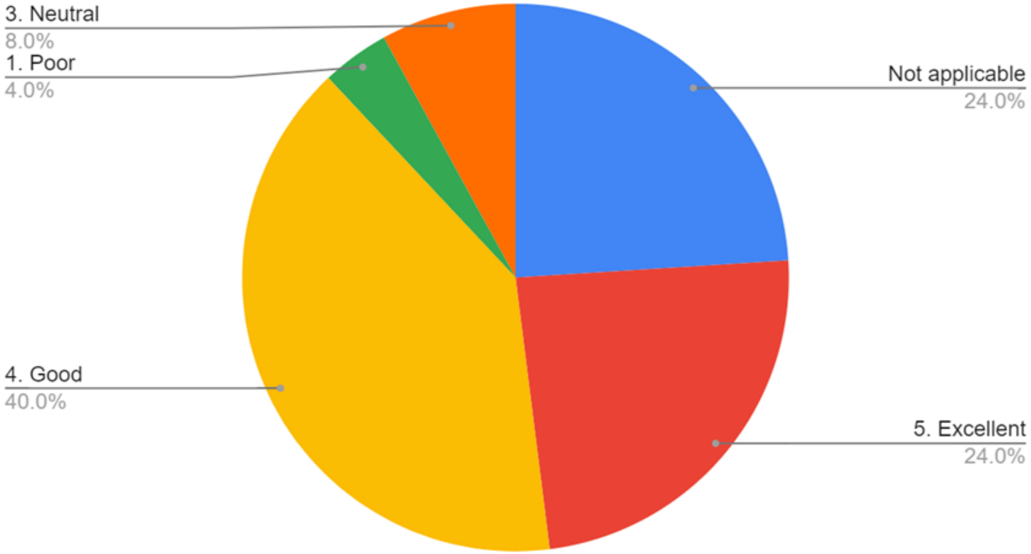
The quality of the language interpretation (if used)

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

Onsite



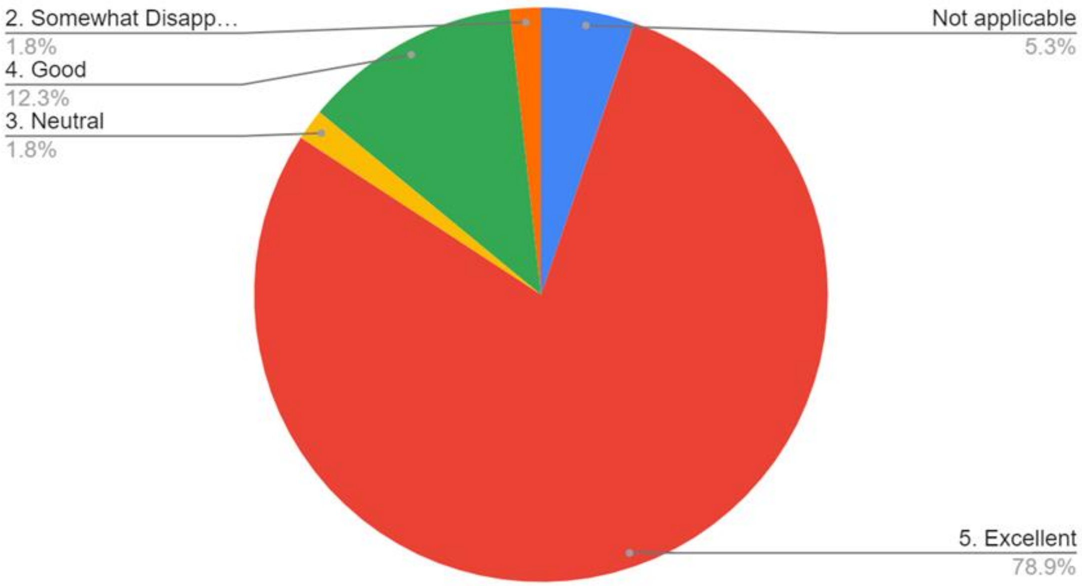
Virtual



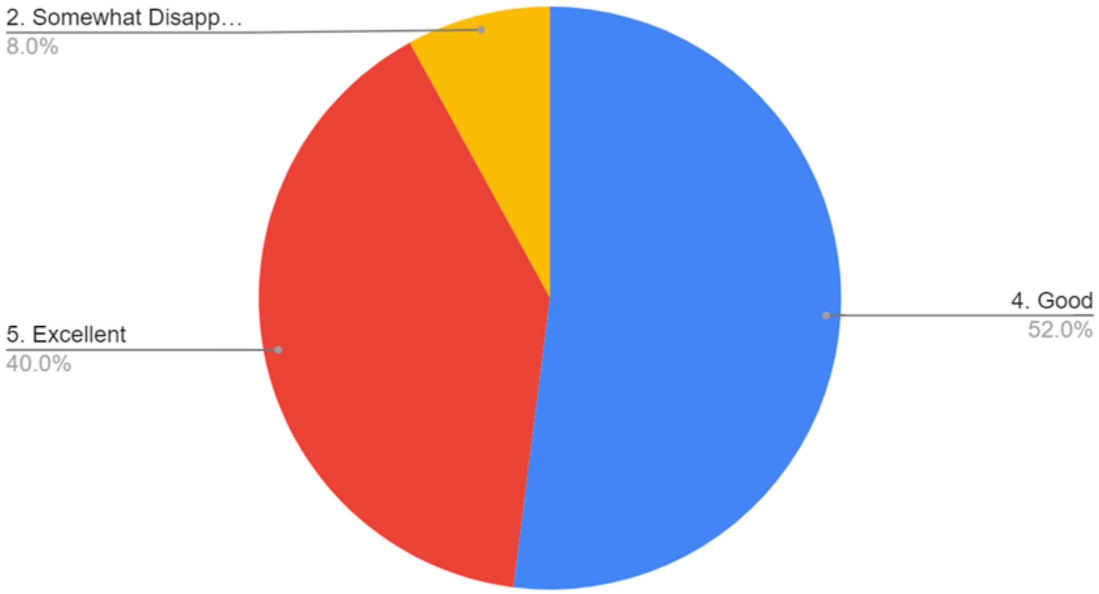
Overall impression of the Summit

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

Onsite



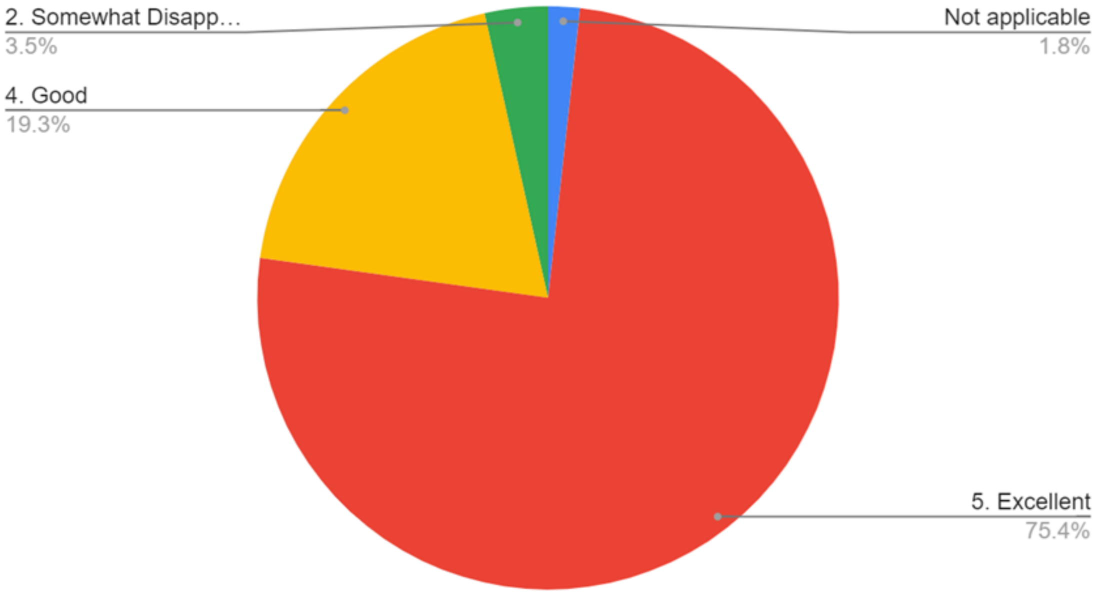
Virtual



Meeting Organisation

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

Onsite



From the feedback received from a total of 56 people who attended the summit onsite, **75%** rated the organization of the event as **excellent**.

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