



Plain Language Summary: Insights from People with Asthma or COPD and their Healthcare Providers on Disease and Treatment Decisions

Ruth Tal-Singer¹, Miguel Román-Rodríguez^{2,3}, Ilona McMullan⁴, Michelle Warner⁴, Christopher Compton⁴, Jean Orlow⁵, MeiLan K Han⁶

¹Global Allergy and Airways Patient Platform, Vienna, Austria; ²Centro de Salud Dra. Teresa Pique, Mallorca, Spain; ³Instituto de Investigación Sanitaria de las Islas Baleares (IdISBa), Mallorca, Spain; ⁴GSK, London, UK; ⁵COPD patient and COPD Foundation community member; ⁶University of Michigan School of Medicine, Ann Arbor, MI, USA

Where can I find the original article on which this summary is based?

This is a plain language summary of the article 'Perspectives on Treatment Decisions, Preference, Adherence and Long-Term Management in Asthma and COPD: A Qualitative Analysis of Patient, Caregiver and Healthcare Provider Insights'.

The original article that this summary is based on can be accessed for free at: doi.org/10.2147/PPA.S467870.

Summary

What is this summary about?

This research gathered insights on the physical, mental, and emotional impact of asthma or chronic obstructive pulmonary disease (COPD) on people. It also looked at how these lung diseases impacted diagnosis, disease management, and health outcomes.

How to say (download PDF and double click sound icon to play sound)...

- **Asthma:** ass-ma
- **Pulmonary:** puh-l-muh-nuh-ree

What are the key takeaways?

- In our research, we found that patients often delay seeking medical help until symptoms impact their daily lives including, for example, issues with sleep, exercise, work, relationships, and mental health.
- A need for better understanding of how to correctly use medications was observed. In this research, patients wanted to know how long it takes to feel improvements after taking a medication. If they have other medical conditions, patients and caregivers want to know about possible side effects. They often used social media or consulted their healthcare providers (HCPs) to improve their understanding and empower themselves in managing their health.

What were the main conclusions reported by the researchers?

- The research concludes that improved access to reliable, trusted information could improve patients' understanding of their disease. This understanding could also improve patients' communication and partnership with HCPs, helping make informed treatment decisions (shared decision making).



What is the purpose of this plain language summary?

The purpose of this plain language summary is to help you understand the findings from recent research. The results of this research may differ from those of other studies. HCPs should make treatment decisions based on all available evidence, not on the results of a single study.

Who should read this article?

- Patients, their family members and caregivers who are interested in the experiences and behaviors of other patients with similar disease experiences, including their questions, concerns, and hopes about the disease.
- HCPs who want to better understand their patients' disease, opinions on disease, and treatment experience.

Who sponsored this study?

This research was **sponsored** by GSK.

Sponsor: A company or organization that oversees and pays for a clinical research study. The sponsor also collects and analyzes the information that was generated during the study.

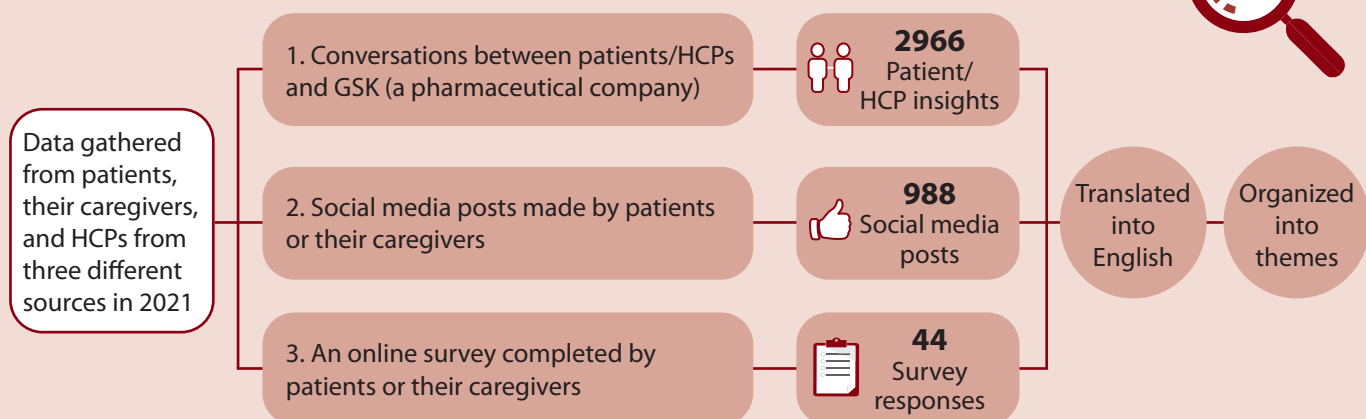
What are asthma and COPD?

- Asthma and COPD are long-term lung conditions that cause breathing-related problems. They impact the lives of millions of people worldwide, reducing their quality of life over many years. This is due to the physical, mental, and social effects of the disease, and increased visits to HCPs and hospitals.
- Currently, there is no cure for asthma or COPD. However, there are many treatment options with a significantly positive impact on patients. These treatments enable patients to enjoy a long and active life.
- The families, friends, and caregivers of patients can also be impacted. Many caregivers feel the burden of their role and may feel confused about the best ways to help.
- Early diagnosis can help patients receive treatment sooner. This can help slow disease progression (worsening), avoid flare-ups, and help patients to stay active and independent.

Why was this research done?

- Many patients do not receive optimal treatment. They also experience symptoms that impact their lives. This research aimed to gain a deeper understanding of the patient journey, and their experience of disease and treatment management.
- This research aimed to gather insights from patients and HCPs. They provided insights on diagnosis, different treatment options, and the impact of the disease and treatments on quality of life.
- Many factors could help patients decide about their preferred inhaled medication. These factors include how easy it is to use and how often it needs to be taken.

How did we do this research?



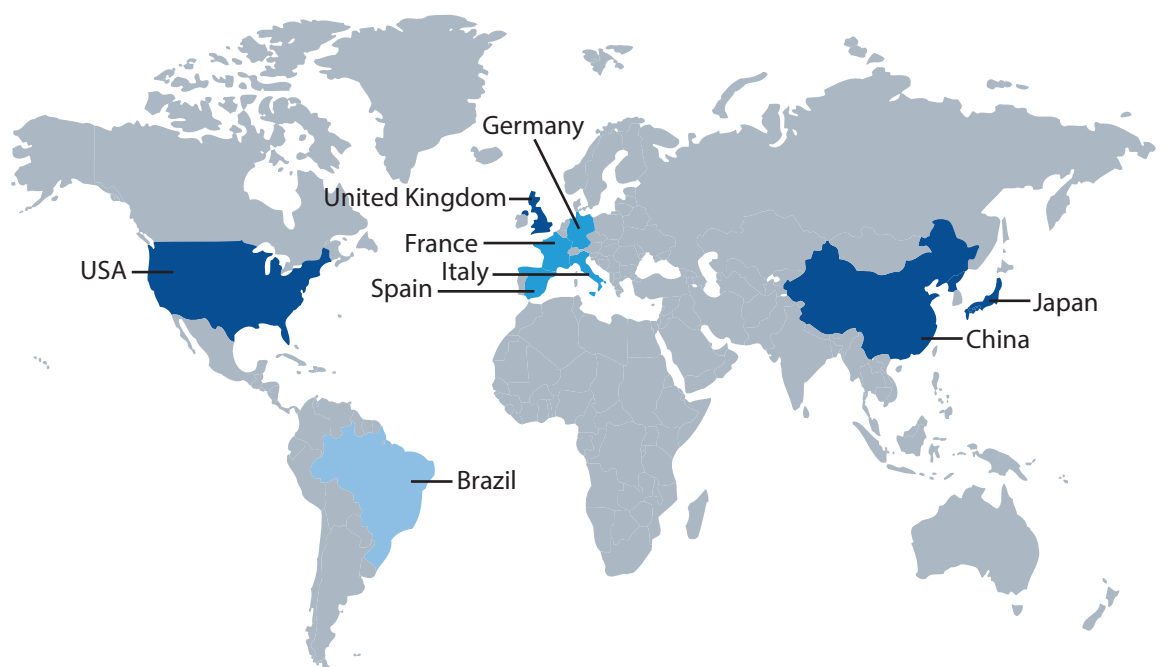
- 38% (1150) from patients
- 62% (1816) from HCPs



- 988 posts across more than 400 social media sites
- 97% by patients
- 3% by their caregivers



- 75% (33) were patients with mild to moderate asthma
- 25% (11) were caregivers
- No patients with COPD completed the survey



- **Dark blue:** countries where both conversation data and survey data were collected
- **Mid blue:** countries where conversation data were collected
- **Light blue:** country where only survey data were collected

What was the patient's experience of getting a diagnosis?

Symptoms

- Patients sought medical help when symptoms started to impact their daily lives. This included their sleep, mental health, finances, and relationships.
- Patients tended to delay seeing their HCP for up to a year after their symptoms started. This was sometimes because they were worried about their medical condition.
- According to survey responses, symptoms that had the biggest impact on patients' lives were shortness of breath, wheezing, trouble sleeping and tiredness, coughing, chest pain, trouble exercising, and a lack of energy.



"My Dr gave me a different drug [...] and it has helped my breathing tremendously"

Current patient



"Couldn't go on a long hike with friends, I felt like I was missing out"

Patient, USA

"Chest tightness, breathlessness, poor sleep. Visited the hospital after that"

Caregiver, China

Treatment and impact on their life

- Patients are thankful and relieved, but feel burdened by remembering what medication to take and when to take it.
- Patients measure how well a treatment works by if it effectively alleviates their symptoms enough for them to do what they enjoy, such as exercising or socializing (Patient survey & social media).



"Relieved as I then knew what the problem was"

Patient, UK

Receiving a diagnosis

- Patients were relieved once they got a diagnosis and were receiving treatment.
- Some patients also felt anxious about what their diagnosis meant for their future.



Thinking to the future

- Patients were trusting and hopeful. Even post-diagnosis, symptoms continued to impact patients' lives, with around three-quarters of patients reporting shortness of breath (Patient survey). However, patients remained optimistic and realistic.

What did patients say about their treatment options?



Some patients mentioned that they did not trust steroids



Some patients also mentioned that they did not like powdered therapies. They disliked the taste and said the powders can irritate the mouth and throat



Many patients said that they would like more information from the companies that make their medicines. They want to understand their treatment options



Both patients and HCPs mentioned the need for education about how to use inhalers correctly

"I was using [multiple inhaled medicines]; [a single inhaled medicine] is much more convenient and seems to help"

Patient insight on preferences for treatment convenience

"Over the long term [a single inhaled medicine] makes cost of managing disease [...] lower"

HCP insight on how affordability is a reason for changing treatment. Other reasons included side effects and lack of treatment effect

What did patients say about their HCPs?



Some patients were concerned about HCPs changing their medication without an explanation for the change



Most patients said that they trusted their HCPs, built a strong relationship with them, and that their HCPs provided them with support, advice, and reassurance



Many patients described their HCPs as professional, saying that they explained things in detail, and made them feel like they could ask questions during appointments



Most patients reported seeing their HCPs every six months or more frequently. Appointments with HCPs lasted 10 to 30 minutes in Brazil, the UK, and USA, and 3 hours or more in China and Japan

"My GP keeps changing my meds so I don't know if he knows what I have – one minute I'm on [new medicine] and then [...] I go back to my old medication"

What questions did patients have?

- Patients had questions about how long it takes to feel improvements after taking their medication, the potential effects of their medication on other medical conditions, and allergies.
- Patients asked about the safety of steroids and whether their treatments could stop working over time.
- Patients also mentioned some uncertainties about their inhalers.

"Aren't steroids dangerous?"

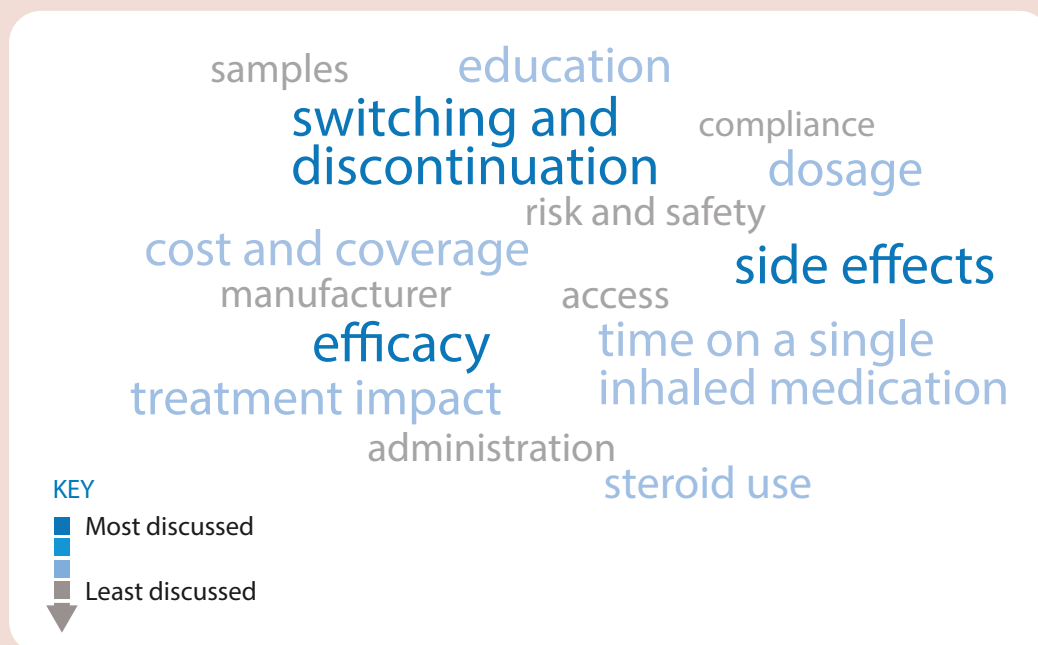
"Is it safe for me to use [steroids] with my heart meds and insulin?"

"I think my meds have stopped working because I've been on [medicine] for over a year now and I think I'm getting worse again. Does it stop working?"

"I'm not sure what the counter window means"

Where did patients look for answers?

- The number of patients using social media to seek support about symptoms, and what actions to take, is rising.
- The most common topics among social media posts were changing treatments and stopping treatment.
- Side effects from treatment mentioned on social media included cough, thrush, high blood pressure, weight gain, anxiety, and depression.



What were the main findings?

- The main treatment factors that patients care about is the impact of treatment on their disease and symptom improvement.
- Many patients seek advice and information from social media.
- HCPs play an important role in patients' treatment choices, and should encourage patients to seek earlier treatment and contribute to shared decision making.

Why do patients prefer some treatments to others?

- The different methods of taking treatments, together with factors such as frequency of dosing, can affect patient preferences.

What is shared decision making, and why does it matter?

- Shared decision making considers the views of both the patient and their HCP in treatment decisions.
- Patients co-deciding on their treatment tend to be more content with their treatment. They may experience improved outcomes, such as a reduced burden of asthma or COPD on their daily activities, and more consistent control of the disease.
- Patients involved in the decision making process are more likely to communicate with their HCPs when treatment does not work or needs adjusting.

What is the overall conclusion from this research?

- Even though it can be hard to live with the effects of asthma or COPD, sometimes patients delay getting help because they don't know enough about the signs and symptoms, which can be treated.
- Helpful information and talking to HCPs could help patients to better understand their condition and lead to shared decision making.

How does this research support the patient community?

"It is recommended that HCPs increase their awareness about asthma and COPD, and actively engage with patients to promote earlier diagnosis and treatment after symptom onset which may not always be evident."

– M Román-Rodríguez, HCP

Patient perspectives

"Early diagnosis is very important to improving the lives of patients living with asthma and COPD. Increased awareness among HCPs and patients can encourage improved communication before and after diagnosis. A knowledgeable and engaged patient is more likely to invest in a treatment plan with the goal of living the healthiest life possible."

– J Orlow, Patient

"We must work together to raise awareness among global policy makers of the burden of lung diseases like COPD and asthma to inform public education, guidelines, and policies that ensure prevention, early diagnosis, and access to care."

– R Tal-Singer, Patient Advocate

Additional information

The original article is available for free at: doi.org/10.2147/PPA.S467870

Full citation

Román-Rodríguez M, *et al.* Perspectives on Treatment Decisions, Preferences, and Adherence and Long-Term Management in Asthma and COPD: A Qualitative Analysis of Patient, Caregiver, and Healthcare Provider Insights. *Patient Preference and Adherence*. 2024;18, 1–12.

Ethical declaration

This research was non-clinical and non-interventional and was for patient insight purposes only. Institutional Review Board (IRB) and Research Ethics Committee (REC) approvals were not required nor sought because the research did not meet the requirements for needing ethical approval, per section 1.3 of the EphMRA guidelines. The ethical principles 120 established by the Declaration of Helsinki were respected. Patients, caregivers and HCPs included in this research were not classified as vulnerable, nor would participation induce undue psychological stress or anxiety. Data from patient/HCP and GSK interactions were collated in accordance with GSK internal processes. All data were anonymized and consent to use them was obtained during the interactions. Consent to use the social listening data was considered implicit due to the published terms and conditions of each social media platform, and the website privacy agreement with users (where relevant). Social listening data were limited to publicly available sources and anonymized to ensure that no personally identifiable information was included. These data were retained for 90 days only. Informed consent was obtained from all participants of the online survey; those who did not consent were excluded. Any findings for which consent was not provided were not included in the final analysis.

Acknowledgments

The authors would like to acknowledge Raj Sharma for his contributions to the research and manuscript development. Medical writing support for the development of this manuscript, under the direction of the authors, was provided by Rosie Robson, MSc, of Ashfield MedComms, an Inizio company, and funded by GSK.

Funding

This research, including study design, data collection, analysis and interpretation, and medical writing and submission support for the manuscript, was funded by GSK.

Disclosure statement

RTS is former President and CEO of the COPD Foundation, and she is currently a volunteer Chief Scientific Officer with the Global Allergy and Airways Patient Platform. She reports consulting fees from AstraZeneca, Boehringer Ingelheim, ENA Respiratory, GSK, Global Allergy and Airways Patient Platform, Immunomet, ItayAndBeyond, Renovion, Roche, Samay Health, Teva, and Vocalis Health. She is a retiree and shareholder of GSK and holds share options in ENA Respiratory.

MRR received grants for research from GSK and AstraZeneca, and fees for lectures and advice from GSK, Boehringer Ingelheim, AstraZeneca, Menarini, FAES, Gebro, Chiesi, and Pfizer.

IM, MW, and CC are employed by, and hold financial equities in GSK.

MKH received personal fees from GSK, AstraZeneca, Boehringer Ingelheim, Cipla, Chiesi, Novartis, Pulmonx, Teva, Verona, Merck, Mylan, Sanofi, Roche, DevPro, Aerogen, Polarian, Regeneron, Amgen, Genentech, UpToDate, Altesa Biopharma, Apreo Health, RS Biotherapeutics, Owkin, Medscape, NACE, MDBriefcase, Integrity and Medwiz. She has received either in-kind research support or funds paid to the institution from the NIH, Novartis, Sunovion, Nuvaair, Sanofi, AstraZeneca, Boehringer Ingelheim, Gala Therapeutics, Biodesix, the COPD Foundation, and the American Lung Association. She has participated in Data Safety Monitoring Boards for Novartis and Medtronic with funds paid to the institution. She has received stock options from Meissa Vaccines and Altesa Biopharma.

The authors report no other conflicts of interest in this work.

Patient reviewers on this PLSP have received honorarium from *Patient Preference and Adherence* for their review work but have no other relevant financial relationships to disclose.

Peer reviewers on this manuscript have no relevant financial or other relationships to disclose.

Patient Preference and Adherence

Publish your work in this journal

Patient Preference and Adherence is an international, peer-reviewed, open access journal that focusing on the growing importance of patient preference and adherence throughout the therapeutic continuum. Patient satisfaction, acceptability, quality of life, compliance, persistence and their role in developing new therapeutic modalities and compounds to optimize clinical outcomes for existing disease states are major areas of interest for the journal. This journal has been accepted for indexing on PubMed Central. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/patient-preference-and-adherence-journal>

Dovepress
Taylor & Francis Group