

Early View

Original article

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Patients' perspectives on Bronchiectasis: findings from a social media listening (SML) study

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Take home message:

Patients' journey in bronchiectasis (BE) from symptoms and diagnosis to everyday life with the disease described for the first time through Social Media Listening (SML), a novel approach to gather unbiased insights into patients' experiences and emotions.

ABSTRACT

Although it is of great importance for healthcare professionals to ensure that patients' needs and concerns are valued and that they feel confident in the quality of the care they receive, there have been few studies specifically addressing the opinions, experiences and needs of patients with Bronchiectasis (BE), and more importantly the emotional impact of the disease, diagnosis and treatment.

Using enterprise grade social listening tools, a comprehensive search around BE was performed in 5 languages, on different social media platforms between January 2018 and December 2019 to obtain the perspectives of patients and caregivers from 9 countries on symptoms, treatments and burden of the disease.

Over 27,000 mentions of BE were identified on social media channels, 38.8% of which were posted by patients and caregivers. Approximately 1,600 posts were found on BE symptoms, out of which persistent cough, shortness of breath and mucus production (22%, 20% and 18%, respectively) were the most commonly discussed. The research revealed that existing diagnostic tests often delay diagnosis or provide inaccurate results, leading to multiple rounds of consults and substantial delays in treatment initiation and management of the disease. Misdiagnosis was common across different age groups, especially among patients without severe symptoms and this was associated with an emotional burden of anger, confusion, frustration and anxiety.

Analysis of social media presents a new approach to derive insights on patients' experiences and emotions with BE and has the potential to complement more traditional approaches to drive more patient-focused drug development.

Introduction

Bronchiectasis (BE) is a chronic respiratory disease defined by abnormal and irreversible dilatation of the bronchi. The disease can be caused by many different aetiologies and it is clinically characterised by a variety of symptoms, including cough, sputum production and airway infection, and can often present with recurrent exacerbations [1]. BE has been a neglected area of research in respiratory medicine for decades despite its high morbidity and associated mortality across all ages [2]. Nowadays BE is seen as a distinct, although heterogeneous condition in its own right [3] and is receiving much more attention.

Although it is of great importance for all health care professionals to make sure that the patient's values, needs and concerns are valued at all stages of treatment and that patients feel confident in the quality of the care they receive, there have been only a very few studies specifically addressing the opinions, experiences and needs of patients with BE.

A novel approach to listen to the voice of patients is represented by social media listening (SML): conversations on social media can offer unprecedented insights on how patients live with their disease and how they think about their condition. Nowadays patients do not only use internet as a source of information but also to exchange information with other users leveraging on platforms like Facebook, forums or blogs. The online data volume has been getting bigger exponentially in recent years, making social media one of the largest, most diverse and most valuable sources of information available [4]. SML offers access to genuine opinions, emotions and comments: as the internet offers anonymity, patients are more willing to share their experiences, fears, concerns and challenges with others with the same condition [4].

This is the first study using SML to understand patients' experience of living with BE. We hereby give an insight into the patients' emotional journey from symptoms and diagnosis to everyday life with the disease from a unique and unbiased perspective: that of the patients.

Material and methods

Study design and data source

A comprehensive search around BE was performed on different open social media platforms (e.g. Twitter, Instagram, YouTube, as well as blogs, news, forums and public Facebook pages or groups) in English, Spanish, French, Italian and German languages to obtain patients' and caregivers' perspective on symptoms, treatments and burdens of the disease. Social media posts between January 2018 and December 2019 from the United Kingdom (UK), Spain, France,

Italy, Germany, the United States (US), Canada, Australia and New Zealand were retrieved using enterprise grade social listening tools. BE-related posts and conversations were extracted using the following predefined search terms: “Bronchiectasis” or “Non-cystic fibrosis bronchiectasis” or “Non-CF Bronchiectasis” or “NCFBE”. These key words were combined with other search terms related to symptoms, disease severity and diagnosis (supplementary table S1).

Social media contents selected for the study include posts by probable patients (who either had received a confirmed diagnosis, were awaiting for a diagnosis or had been misdiagnosed) and by probable caregivers.

Selection of posts

Keywords and phrases related to BE or non- cystic fibrosis BE in reference to lung conditions along with their misspellings, abbreviations and synonyms were used to query a two-year historical database of social media conversations.

The keywords set was refined in an iterative process, starting from broader keywords and refining them further to reduce noise and irrelevant mentions. Moreover, data set was cleaned to ensure that they included only posts and responses of probable patients or probable caregivers (detailed in the supplementary material).

Ethical considerations

All data analysed in this study was obtained from publicly accessible sources without accessing password-protected information and in compliance with applicable data protection laws. All data presented within this study has been aggregated and anonymised and does not include any personally identifiable information (PII).

Categorisation and indexing of posts

First-person mentions of the disease or treatment were automatically classified as patient conversations, whereas third person references to the disease experiences of a child, parent or family member, or their care were identified as caregiver conversations. This classification was further validated and checked by human analysts to ensure accuracy.

Passive conversations like retweets and shares of popular content were not included in the analysis of first and second person mentions.

Patient journey stages (symptoms, diagnosis, treatment) were identified using predefined taxonomies of keywords and expressions, and further analysed for concerns expressed by patients and caregivers. Conversations in each stage were examined by analysts and classified into pain points and needs expressed by patients, as well as decision points and drivers of discussion (detailed in the supplementary material).

Results

Of the total 61,694 posts retrieved, 34,000 were excluded as they were considered irrelevant mentions. The most common source of the remaining 27,694 BE posts was Twitter (51%), followed by other channels e.g. Instagram, YouTube, as well as blogs and forums.

The UK and the US were regions with the majority of mentions (86% cumulatively) around the disease followed by Australia, and Spain which contributed to 4% of overall disease mentions in each region (Figure 1).

10,770 out of 27,694 were identified as posts from patients or caregivers and selected for the study, the remaining were news on research updates, fundraisers and general disease awareness related posts from other stakeholders including advocacy groups and industry experts. Of the selected conversations, 90% were from patients and 10% were from caregivers.

Twitter emerged as the key channel with 78% of conversations among BE patient and caregiver community. Supplementary table S2 provides an overview of popular channels of conversation among patients and caregivers discussing BE, while supplementary table S3 elaborates the share of patient and caregiver conversations from various regions.

Symptoms

Based on 1,600 total mentions of BE symptoms, persistent cough, shortness of breath and mucus production (22%, 20% and 18% of mentions, respectively) were found to be the most commonly discussed symptoms among patients online. Shortness of breath was found to be one of the critical symptoms to aid diagnosis, while persistent cough and mucus in lungs led to inconclusive diagnosis.

The discussions around symptoms do not only concern patients who have been living with the disease for quite some time, but also those who are new to the condition or have previously been misdiagnosed. Although mentions of clubbing, presence of blood in sputum and weight

loss were low (5%, 3% and 2% of mentions, respectively), these symptoms were reportedly crucial in raising suspicion of BE.

Diagnosis

Across all studied geographies, 128 patient and caregiver conversations raised concerns about the accuracy of existing diagnostic tests (e.g. X-rays, pulmonary function tests, bronchoscopy), which could potentially result in inaccurate or inconclusive results leading to multiple rounds of consults and consequently causing delays in the treatment initiation and management of the disease. In addition, 328 patient conversations reported experience regarding misdiagnosis that led to worsening of their symptoms.

Some aspects however seemed to be country specific. In France, patients discussed about the absence of specialist diagnostic centres, in Canada, the insurance coverage for the diagnostic tests is considered a major problem, in Australia patients seems not to have access to non-invasive tests for detecting BE and in the UK, patients complained about the difficulty of getting a specialist appointment in the National Health Service (NHS). Moreover, in Germany, patients perceived a lack of knowledge among HCPs regarding the detection of BE and in the US the pulmonologist's and the radiologist's opinion seem to differ when it comes to determining the diagnosis.

The results of the study indicate that patients are likely to get a confirmed diagnosis at a later stage of the disease due to inappropriate or delayed diagnosis.

Based on a sample of conversations (N=50) where age was revealed by the commenter, it was noted that a high number of patients (~46%), discussed being diagnosed while they were young adults, while conversations around diagnosis of children with BE was less discussed online.

Moreover, based on 957 mentions, 46% were posts from patients who presented to their health-care professional (HCP) with symptoms such as chronic cough, hemoptysis, shortness of breath and wheezing and were misdiagnosed with asthma and/or chronic obstructive pulmonary disease (COPD). Moreover, 20% of patient conversations suggested that they remained undiagnosed and were requested to undergo further assessments and 34% of these discussions indicated that patients were diagnosed as having BE as a consequence of other condition(s).

Treatment

BE treatment journey

Observations from social media data suggested that treatments are likely to be chosen by HCPs based on guideline recommendations. In addition, the physician's experience in treating patients with BE plays an important role as well. Patients who are suspected having BE are generally prescribed treatments to manage symptoms (e.g. cough, blood in sputum) and those living with comorbidities such as asthma or COPD are advised to solely continue with the treatments they receive for their obstructive respiratory condition. On the other hand, patients, whose diagnosis is not confirmed, frequently seek advice on online forums and consult with multiple specialists in hope of finding a cure for the physical and psychosocial obstacles they are facing with on a daily basis.

The Ven diagram on Figure 2 represents the treatment regimens that patients are often prescribed during exacerbation. The size of the circle correlates with the number of mentions of the different treatments. According to the mentions, all patients are given Steroid/Inhaler therapy to control breathing symptoms like cough and wheezing. Antibiotic and/or Mucolytic therapies are prescribed in order to combat associated infections and to reduce mucous production, respectively. There were no mentions of any treatments that are specific to BE. Patients are categorised in each of these groups based on their conversations and experiences shared online.

Treatment-related side effects

Only a very few patients (~2.5%) shared their experience online related to side effects associated with treatment.

The side effects reported were: risk of infection (N=64) and diabetes (N=16) related to steroid therapy; acid reflux (N=6) and tremor (N=10) related to inhaler therapy; allergic reaction (N=26) and neuropathy (N=3) associated with antibiotics and dryness of mouth (N=3) and sore throat (N=16) linked to other therapies (e.g. mucolytics).

Antibiotic treatment and airway clearance devices

Conversations around antibiotic treatment were limited constituting ~12% of all patient and caregiver conversations (detailed in the supplementary material). Although antibiotic therapy helps in managing severe BE symptoms, patients show apprehension towards the long-term use of them. The research revealed that patients feel exhausted of being on antibiotics for prolonged periods (N=235), they fear that long-term use poses a threat of resistance and low tolerability that could potentially lead to further difficulties in managing their condition (N=54). They also find it extremely burdensome having to provide sputum samples on a regular basis in order to guide the decision making in relation to selecting the most suitable antibiotic option (N=65).

150 conversations were identified as discussions during the early treatment phase and use of antibiotic therapy during reinfection or post-surgery phase. 23% of these conversations discussed side effects concerning prolonged use of treatment, whilst 18% of the discussions captured among patients with recurrent infections and/or in post-surgical phase were speculating that the potential reason for the deterioration of their condition may be due to having refused antibiotic treatment earlier on. Other topics of discussions with lower number of mentions included switching medication for better tolerability (19% of conversations) and allergy to antibiotics reducing treatment options (14% of these conversations).

The study also revealed that patients often seek advice from each other on their experience of managing excessive mucus with airway clearance vests and apparatus. Those who are new to these often look for tutorials and practical advices on how to clean and maintain them. A few discussions were captured on airway clearance device availability in the market and their key features. Although low (<50 mentions), some patient conversations expressed concern about the prescription, availability and cost of these devices as well as oral thrush due to the use of inhalers. Inhalers and airway clearance devices are considered unaffordable for those with limited or no insurance cover. Moreover, delays due to insurance approval have as well a significant negative impact on patients. It was reported that a battery-operated portable device may contribute to better compliance as it has the great advantage of giving the patients the freedom to move around during the session. The management of infections such as oral thrush caused by the usage of spacers along with inhalers was also discussed.

Living with BE

Overall, there were 3500 mentions related to the experience of living with BE. Based on the nature of the conversations two main topics were identified, one related to emotions and one related to awareness and knowledge.

Emotions

Conversations were analysed for emotional impact of the condition on commenters. Over 2,500 disease mentions from patients were identified for this analysis.

The experience of living with BE has been recognised as a source of various emotions (Figure 3).

The results of our research show that the process leading to the diagnosis of BE is often very complicated mainly due to the commonality of symptoms with other diseases; patients struggle with daily symptoms and respiratory infections for years before being diagnosed. Patients are tired of waiting months or even years for a correct diagnosis during which time they are subject to several specialists' consultations often without a conclusive result (N=213). They feel confused about the process related to diagnosis (N=420) and frustrated about not receiving the right treatment (N=342). Once diagnosed, fear of recurrent respiratory infections, side effects of treatments and uncertainty regarding future life with the condition were the most prominent emotions discussed by patients (N=309). Embarrassment and frustration were commonly associated with the difficulties to accomplish simple activities and daily tasks (N=544).

Awareness and knowledge

Patients' experience of living with the condition is also shaped by the need to seek and generate awareness and knowledge around their condition and to share their own experiences with other people. Patients turn to peers for support through online forums and offline support groups. They primarily seek advices from peers as they learn about the condition followed by support from caregivers and physicians.

942 conversations revealed that people are focused on trying to maintain a normal life while managing BE and hence continuously seek information on how to manage and improve their quality of life. They strongly believe in modifying their lifestyle along with exercise and healthy diet, because this may play an important role in their daily quality of life.

Discussion

The widespread involvement of patients, families and caregivers is fundamental to the delivery of appropriate, meaningful and safe healthcare and is essential at every stage of the care cycle including drug development and regulatory decision making [5]. Collecting data from patients provides important insights into the most significant symptoms of their disease and their impact on daily life. Traditionally, approaches such as conducting face-to-face interviews, surveys or focus group discussions have been used to gather information on the patient's experiences and perspectives on their condition [6], however, technology advancements have revolutionised the communication channels which now offer opportunities for improving medical care often in a faster pace. Patients are more and more active online and use social media to share experiences, to debate health care practice issues, to discuss treatment options, to search for health care professionals as well as to participate and express themselves openly [7, 8]. In addition, the advocacy groups are increasingly empowered to contribute to this novel approach, and social media offer means for directly engaging patients to obtain input and perspectives.

Open-source social media search may provide a valuable tool in assessing patient perspectives on a disease and therefore offers an innovative approach to collect patient experience data. Patients have a unique ability to contribute to the understanding of the broader context of their disease, which is becoming increasingly important to all who care for them and to all facing the many challenges of the drug development process. The patient led model of research represents a step forward in healthcare as it recognises the value in patient involvement at every stage of clinical research [9, 10].

The strengths of SML methodology can be identified in the authentic and unbiased insight emerging from patients' conversations. The thoughts and opinions expressed openly by patients online distinguish this approach from traditional, structured and solicited patient research, and it is considered that the results of such SML studies should reflect spontaneous patient perspectives on their disease their unmet needs and the emotional burden using their natural language [11, 12]. In the case of SML on BE conversations it is important to highlight that the outcomes of the analysis are in line with patient registry data. The EMBARC (European Multicentre Bronchiectasis Audit and Research Collaboration) registry confirms that congestion, cough, sputum production and shortness of breath are the most burdensome

symptoms affecting up to 90% BE patients [13]. These symptoms, together with exacerbations and tiredness represent aspects of BE found either difficult or very difficult to manage by patients [14].

Due to the interactive nature and given the popularity of social media across different geographies, SML can also provide the ability to research and analyse the perspectives of large groups of patients across different countries and languages, which would be unfeasible with traditional research [15, 16].

The main limitations of SML are related to the quality and reliability of the conversations which may affect accuracy. We cannot confirm with certainty whether all patients have clinically verified diagnoses or are self-diagnosed [16]. Another limitation is that not all patients are equally likely to write about their medical experiences online. As a result, we may only have the opportunity to view and analyse the experiences of a certain segment of the population [16]. Some social media channels investigated in this study are particularly popular and often only used in certain countries (e.g.US). This could represent a limitation of the present study and therefore caution must be applied, as the findings might not be translated to other countries [17, 18].

Additionally, negative conversations may be vocalised more often than positive perceptions/experiences. [11] However, in our study, we examined more than 27,000 mentions of BE identified on several social media channels, which should allow for discussions and conversations from a variety of different communities, individuals and age groups allowing the mitigation of these limitations.

In summary, patients with BE actively share experiences on forums and seek information online through social media. SML presents a new method to derive insights on patients' experiences with BE and has the potential to complement traditional approaches to drive more patient-focused drug development. The results of our research indicate that from the patients' perspective, relief from cough, shortness of breath and mucus production would possibly be the most valuable aspects of disease management in BE. In addition, increased awareness among physicians about the tests and procedures in BE would be fundamental to timely diagnose the condition and provide appropriate care and support to the patients.

A key element of novelty provided by this SML study is the possibility of mapping the emotional journey of BE patients from the start of symptoms onward: this type of analysis provides an understanding of how the predominant emotions are evolving along with the disease stages, and at what stage the emotional challenges are the highest. Emotional journey analysis gives us an opportunity to gain a richer picture of the patient, understand the potential factors that could lead to an improved quality of life and the potential drivers and barriers to proper disease management adoption.

The findings from qualitative SML studies should be interpreted with caution considering that the quality and reliability of the conversations cannot be verified and therefore the accuracy of the information shared is not guaranteed. Nevertheless, the importance of such studies and in particular the recognition of patients' perspective as a source of information that allows HCPs to serve their patients' multiple and complex needs, cannot be emphasised enough.

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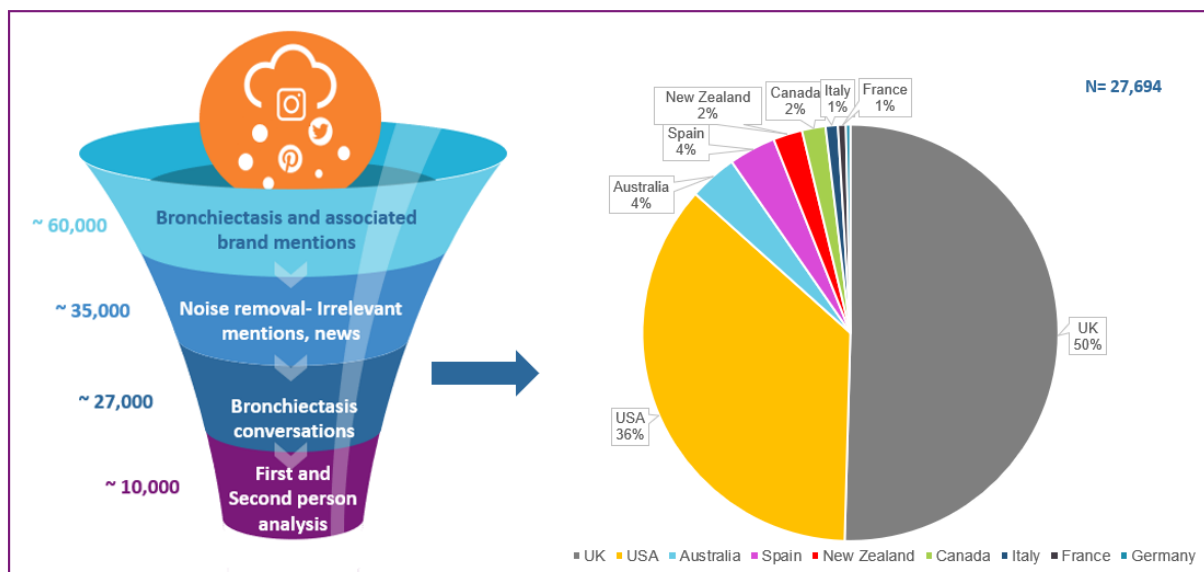


Figure 1. Volume of BE mentions across geographies

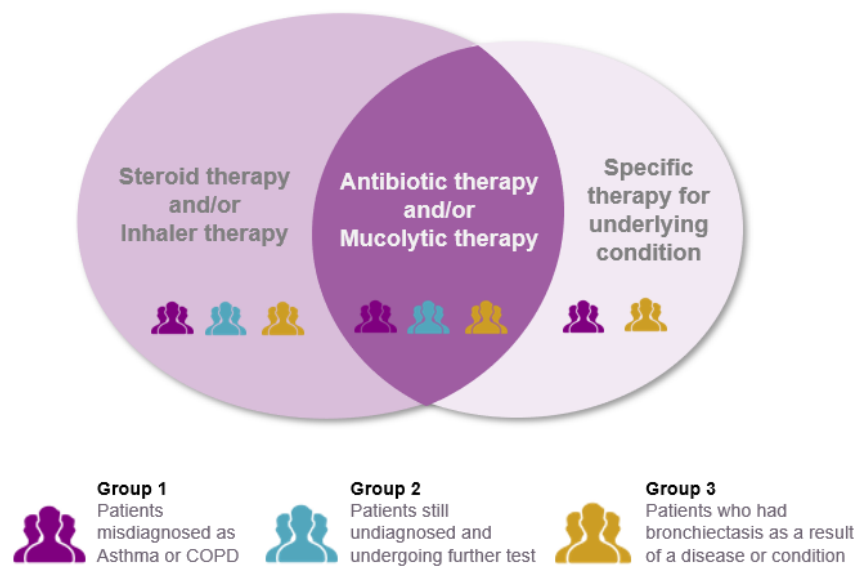


Figure 2. Treatment regimen for BE patients

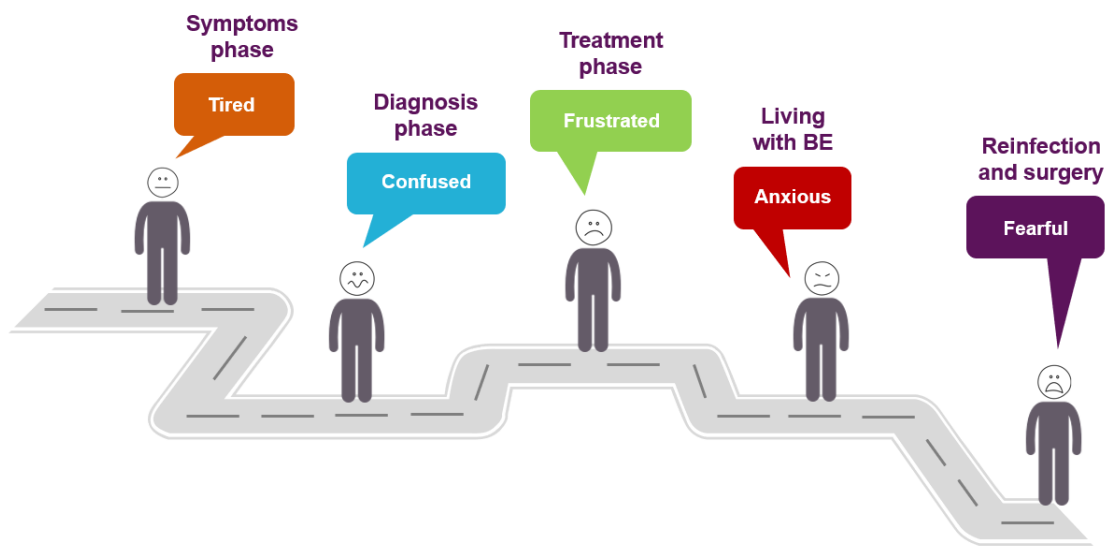


Figure 3. The emotional journey of BE

CONTENT

METHODS: Data Cleaning

TABLE S1: Search Terms

METHODS: Categorisation and indexing of posts

TABLE S2: RESULTS: Key social channels in the study design

TABLE S3: RESULTS: Patient and Caregiver conversations across regions

RESULTS: Antibiotics

Methods: Data Cleaning

Social media posts were collected after a comprehensive search across social media platforms. This data was downloaded in a Microsoft excel and was cleaned to remove spam and duplicates (based on social media link and/or content).

The process of spam removal was essential to eliminate posts which were not relevant to the scope of this study (i.e. social media posts around buying and selling of drugs by online retailers and content leading to market research or market forecasts available for pharma companies). Industry news and updates were also excluded.

Several misspellings and hashtags were also used in the data aggregation process to account for social media texts which are written casually and include disease hashtags for better online reach. It might be possible that some online content was missed during the search due to incorrect spelling of the online posts.

Posts clearly mentioning CF-associated bronchiectasis were excluded from the study. Nevertheless, due to the qualitative nature of this type of analysis uncertainty about the reliability of the declared diagnosis still represents a potential limitation.

Table S1:

Search terms:

The keywords noted in the table below were translated into local languages to provide better coverage in European regions.

Disease Related	Symptom Related	Diagnosis Related/Other
Bronchiectasis	Cough	Chest-X Ray
Non-cystic fibrosis bronchiectasis	Wheezing	Computerized tomography (CT) scan
Non-CF Bronchiectasis	Fatigue	Blood tests
Non cystic fibrosis bronchiectasis	Clubbing	Lung function tests (LFT)
NCFBE	Respiratory infection	Pulmonary function tests (PFT)
	Breathlessness	Bronchoscopy
	Shortness of breath	Pulmonologist
	Mucus	Antibiotic
	Sputum	Mucolytic
	Chest pain	Airway clearance
	Coughing up blood	Device
	Weight loss	Inhaler

NCFBE: Non-Cystic Fibrosis Bronchiectasis

Methods: Categorisation and indexing of posts

Each post was reviewed to evaluate the mention of different parameters. Among those selected for the study, not every post included all parameters such as symptoms, treatment, severity, diagnosis, etc. However, each post has a mention of one or more parameters.

Demographic information about the users (sex, age and time since diagnosis) was collected only when mentioned in the text. No background information was collected from the studied data.

Table S2:

Results: Key social channels in the study design

Channel	Share of voice among patient and caregiver conversations
	<i>Total included posts: N=10,770</i>
Twitter	78%
Forums and Reddit	8%
Blogs/ YouTube	4%
Others	10%

Table S3:

Results: Patient and Caregiver conversations across regions

Country	Volume of patient and caregiver mentions
	<i>Total included posts: N=10,770</i>
United Kingdom	5,384
United States of America	4,807
Australia	258
Italy	130
France	55
Canada	48
Spain	42
Germany	31
New Zealand	15

Results: Antibiotics

Among various antibiotics discussed online, conversations around Azithromycin (N= 348) were the most prominent as patients and caregivers discussed efficacy and their experiences as well as ongoing research about the drug. Other key antibiotic therapies discussed online included doxycycline,

amoxicillin and ciprofloxacin. The majority of the conversations (N= 734) did not specify the type of antibiotic the commenters had been prescribed or treated with and the comments remained generic.