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Importance of Understanding the Patient Experience in Healthcare: An Example of the Integrated Patient Journey in Non-Cystic Fibrosis Bronchiectasis (NCFB)

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Abstract

Aim: To demonstrate how incorporating the patient voice into an Integrated Patient Journey (IPJ) can provide a comprehensive, actionable view of the clinical, emotional, financial, and social aspects of a disease, with non-cystic fibrosis bronchiectasis (NCFB) as a case study.

Materials & Methods: The IPJ was created using literature-based evidence, real-world data, patient-reported outcome measures (PROMs), and qualitative insights from semi-structured patient interviews. Data were mapped into a standardized three-stage framework: Diagnosis, Treatment, and Follow-Up; capturing clinical touchpoints, patient experiences, and access considerations. The model was analyzed to identify key barriers, gaps, and opportunities relevant to product development, trial design, and patient support strategies.

Conclusion: The IPJ revealed an array of unmet needs, including delayed diagnosis, fragmented referral pathways, limited imaging access, high treatment burden, medication adherence challenges, and more. Gathering patient insights within this structured framework enables targeted interventions such as patient advocacy group-driven clinical trial recruitment, inclusion of patient-prioritized endpoints, and inclusive trial designs. By aligning development strategies with lived patient experience, the IPJ advances patient-centered innovation, enhances market access, and shows the overall value of the patient voice.

Introduction

The Patient healthcare journey encompasses all patient interactions with key stakeholders (i.e., Healthcare Providers (HCPs) and payors) along the healthcare delivery continuum, from initial diagnosis to follow up, and is important to assess when (among other aspects) identifying unmet needs; the instructions for product use in medical practice to improve patient care; developing innovative and new products and identifying opportunities and solutions to improve patient care.

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The standard approach has been to purchase a database to evaluate the patient's experience. Either administrative (claims) data augmented by pharmacy data or data from patient electronic medical records, or a combination is purchased, subject to budgetary constraints. Budgets usually impose a restriction on the amount of data that can be collected and analyzed, requiring that patient experience is taken from claims (cheaper source), which often results in a partial view of the patient's healthcare journey. Further, claims data has long been associated with quality problems, with recent attention aimed to fix this problem based on rules -based evaluation (Gadde et al, 2020). The potential loss of follow up patient data, as 45% of health plan participants consider changing plans during open enrollment periods, is also problematic (Hurst, 2021). Data from electronic medical records can also be used to document the patient's journey, but these records often lack the claims record. This is also problematic as a patient may be given a script which is recorded in the patient electronic records, but is never filled by the patient, which leads to an underreporting or misrepresentation of the healthcare touchpoint events. Estimates of abandonment of pharmacy related scripts have increased by 68% since 2006. (Iskowitz, 2010). Data from a survey of healthcare providers demonstrate that 44% of respondents indicated patient no shows were a consequential problem for their practices, (Harrop, 2017), and the lack of a caregiver or support group can translate into abandonment of medical procedures (Mayo Clinic, 2017). Lastly, data-based evaluations do not include the patient disease experience, which can only be ascertained though surveys of the patients themselves or their caregivers/patient advocacy groups. When such data are available, they are often characterized by a high frequency of missing data.

A literature-based evaluation integrated with observations and data from patients can help to better inform the patient experience and the patient disease strategy. Literature based evaluations can help to circumvent the problems associated with using just one source of data. Indeed, even data presented in treatment guidelines can be used to describe the patient journey.

However, literature data is often generated by clinicians using non-structured methods to make judgements that are included in their write-ups, and it is well known that clinical interpretation does not often correlate well with the patients' interpretation of their own disease experience. Differences between clinical and patient judgment may be influenced by biases, clinical experience, and attitudes (Marková, 2005a). For example, a patient may overestimate their pain severity due to fear or distress, while a clinician might underestimate the patient's pain because of preconceived notions or concerns about overprescribing opioids. There is a substantial lack of Patient experience data between points of care, which highlight the emotional aspects that often drive compliance issues. Thus, it is important to incorporate patients' views about their own disease experiences because their feelings, and emotions due to their disease burden, and due to an overburdened and expensive health care system can often dictate patient involvement within their healthcare journey. The integration of data from the patient and the literature to develop the patient journey is referred to as the integrated patient journey (IPJ). As such, the IPJ can, more holistically inform the patient disease strategy. For communications purposes, the presentation of the results can be tailored to meet the needs of diverse audiences. These insights and outcomes when translated into the different formats enable the information to be customized for specific contexts, ensuring that the right level of detail is delivered to the appropriate audience at the right time.

While regulatory efforts have led to significant advancements in understanding the patient experience, critical gaps remain. Specifically, traditional data collection methods, such as surveys and focus groups, often fail to capture the complexity and dynamic nature of patient experience over time. Furthermore, these methods can be costly and time-consuming, limiting their large-scale applicability. Consequently, a need has emerged for a more comprehensive and integrated approach to understanding the patient experience: the Integrated Patient Journey (IPJ).

The IPJ approach is distinguished by its focus on integrating data from multiple sources, including literature-based assessments, real-world data, and, crucially, the direct patient perspective. This holistic approach aims to map not only the patient's clinical journey but also their emotional and social journey, offering a 360-degree view of the lived experience. By integrating these diverse perspectives, the IPJ enables a deeper, more contextualized understanding of the patient experience, which can then be used to inform the development and commercialization of more effective and patient-centric interventions.

Aim

The aim of this paper is to highlight the importance of incorporating the patients' disease experience into the IPJ using NCFB to illustrate the process. This approach can support the development of a product, including informing clinical trials, and access and medical use of a new pharmaceutical product(s) so that all considerations of the holistic patient lived experience are anticipated and proactively supported across the product life cycle.

Specifically, this analysis will examine how incorporating the patient voice can enhance clinical trial design, improve treatment adherence, and inform the development of patient-centric support programs. By focusing on the lived experiences of individuals with NCFB, this study aims to provide practical recommendations for developing and commercializing treatments that better address patient needs and improve overall outcomes.

The etiology of NCFB begins in either childhood or as the result of repeated lung infections and caused by several factors such as inflammatory disorders, autoimmune disorders, and most commonly idiopathic etiology. The cycle of lung damage and flare-ups results in the widening and thickening of the airways in the lung making the clearance of mucus from the airways difficult. A higher risk of infection is a consequence of the accumulation of mucus. Typical symptoms include persistent cough over 8 weeks that produces phlegm or sputum, shortness of breath, wheezing, chest pain, fevers and/or chills, fatigue, and clubbing of the fingers. (National Heart, Lung, and Blood Institute, 2023).

Methods

To gain insight into the patient journey and disease manifestation, we examined a NCFB treatment paradigm (Figure 1), a conceptual model (Figure 2), and other publicly available data sources related to these. Data sources included patient interviews & surveys, published PROM analyses, clinical guidelines, and more. PROMs quantified quality-of-life impacts, while literature provided broader disease and treatment context.

The literature reviewed focused on English-language sources from 2015-2024, on the adult NCFB population in the United States and Europe, with emphasis on moderate to severe disease defined by clinical metrics - Bronchiectasis Severity Index (BSI), lung function measures (FEV1), exacerbations, microbiology. Sources included peer-reviewed articles, patient advocacy publications, surveys, and interviews conducted by the sponsor (n=5). Representative examples are cited in the Results section to illustrate how these materials informed the IPJ and clinical trial design considerations.

The literature-based approach together with patient insights was used to develop an IPJ to map out the diagnosis, treatment, and follow-up touch points of the patient in their journey. The framework used is shown below, in Figure 3 with the subsequent analysis steps, used to identify gaps and opportunities, illustrated in Figure 4. Potential opportunities included:

- Acceleration of clinical trial recruitment through patient advocacy groups (PAGs) partner relationships and study campaigns.
- Differentiation of new therapies through label enhancing patient reported outcomes (PRO) endpoints focused on patient priorities.
- Patient-centric, inclusive trials that minimize patient burden and reflect patient priorities.
- Market and/or policy shaping to allow access and increase awareness.

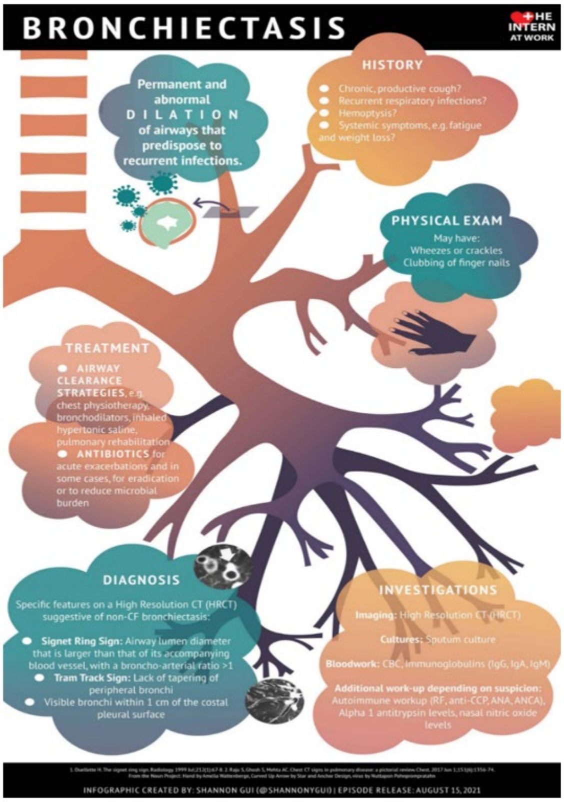


Figure 1: Patient disease treatment paradigm (Medicine Pods, 2021).

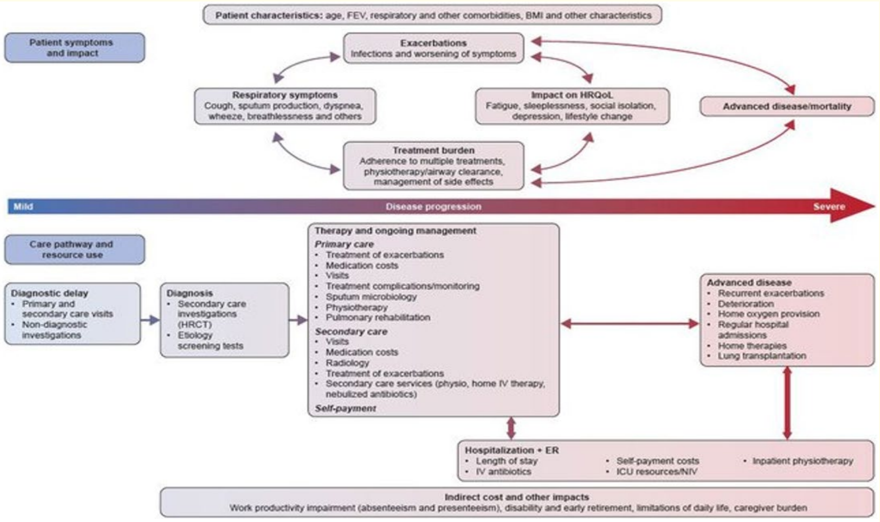


Figure 2: Conceptual Model for NCFB (Goeminne et al., 2019).

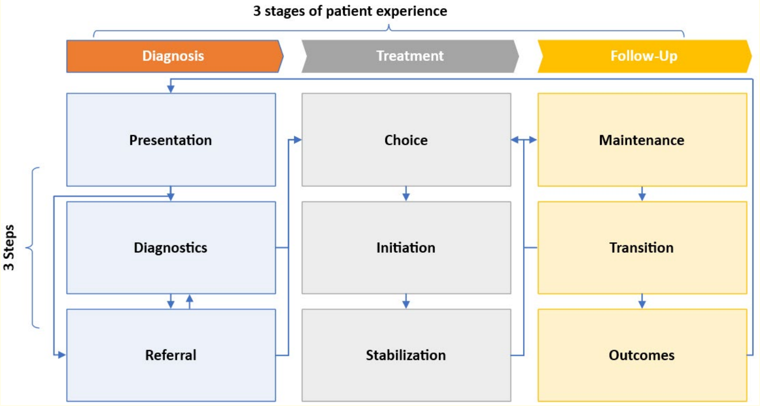
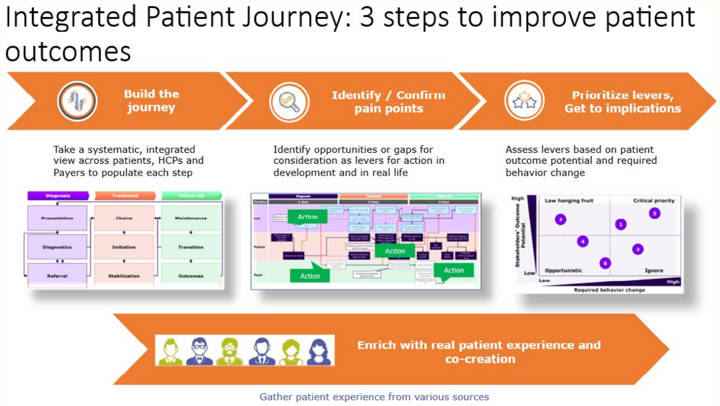


Figure 3: Three stages of patient experience.


Integrated Patient Journey: 3 steps to improve patient outcomes

Take a systematic, integrated view across patients, HCPs and Payers to populate each step

Identify opportunities or gaps for consideration as levers for action in development and in real life

Assess levers based on patient outcome potential and required behavior change

Figure 4: Integrated Patient Journey.

Results

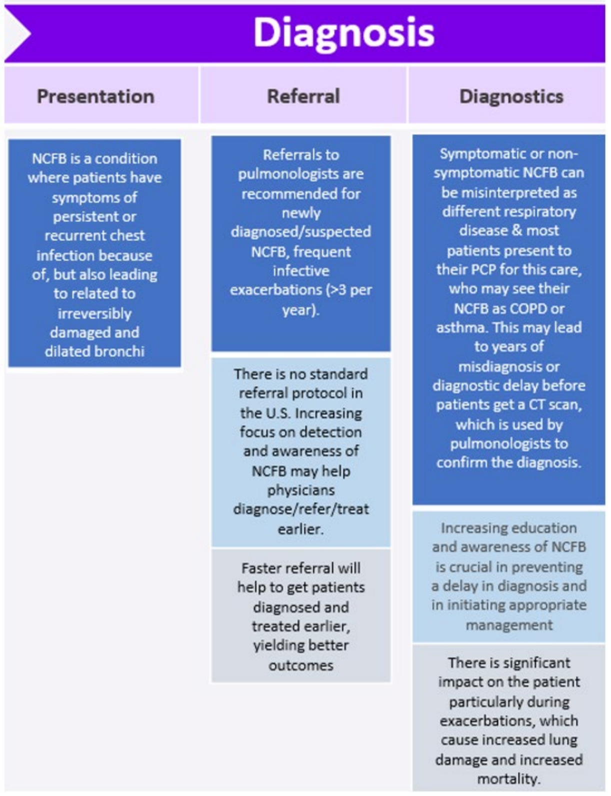
As described above, the ***Integrated Patient Journey (IPJ)*** framework was organized into three major categories: ***Diagnosis***, ***Treatment***, and ***Follow-Up***. Each category was further divided into subcategories to provide a comprehensive understanding of the patient experience in NCFB care. Below is a high-level and broad description of each category and its subcategories:

Diagnosis (see Figure 5a)

This category focuses on the initial steps in identifying NCFB and the methods used to confirm a diagnosis. The subcategories are:

- ***Presentation***: Highlights the common symptoms associated with NCFB, such as chronic cough, sputum production, and recurrent respiratory infections. This section sets the stage for further diagnostic workup. Patient interviews revealed that the initial symptoms of NCFB are often vague and non-specific, leading to delays in diagnosis. Many patients reported experiencing multiple respiratory infections before receiving a correct diagnosis, which contributed to feelings of frustration and anxiety. (Smith et al., 2017).

- ***Primary and Secondary Referral***: Details the pathways through which patients are referred for diagnosis. Primary referrals are from general practitioners, while secondary referrals often involve specialists such as pulmonologists. Patients often experienced a complex and fragmented referral process, with multiple visits to different healthcare providers before being referred to a specialist. This resulted in significant delays in receiving appropriate care and increased emotional burden on patients and their families.
- ***Diagnostics***: Discusses the diagnostic tools and processes, primarily emphasizing the use of high-resolution computed tomography (HRCT) scans to confirm the presence and extent of NCFB. Patients and literature highlighted the importance of timely and accurate diagnostic testing, particularly high-resolution computed tomography (HRCT) scans. However, access to these tests varied, and some patients reported experiencing long wait times, adding to their anxiety and uncertainty. (Spinou, 2024).



Diagnosis

Presentation

NCFB is a condition where patients have symptoms of persistent or recurrent chest infection because of, but also leading to related to irreversibly damaged and dilated bronchi

Referral

Referrals to pulmonologists are recommended for newly diagnosed/suspected NCFB, frequent infective exacerbations (>3 per year).

There is no standard referral protocol in the U.S. Increasing focus on detection and awareness of NCFB may help physicians diagnose/refer/treat earlier.

Faster referral will help to get patients diagnosed and treated earlier, yielding better outcomes

Diagnostics

Symptomatic or non-symptomatic NCFB can be misinterpreted as different respiratory disease & most patients present to their PCP for this care, who may see their NCFB as COPD or asthma. This may lead to years of misdiagnosis or diagnostic delay before patients get a CT scan, which is used by pulmonologists to confirm the diagnosis.

Increasing education and awareness of NCFB is crucial in preventing a delay in diagnosis and in initiating appropriate management

There is significant impact on the patient particularly during exacerbations, which cause increased lung damage and increased mortality.

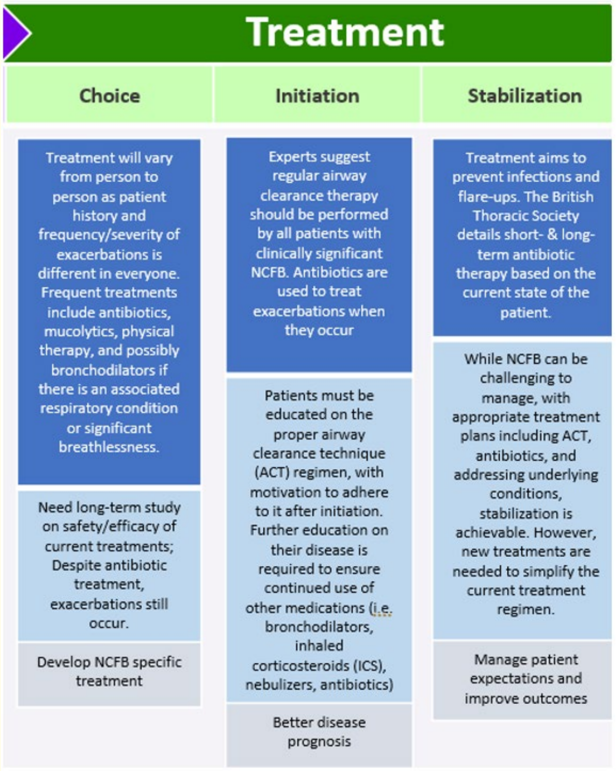
Figure 5a: Diagnosis section of the IPJ for NCFB.

Treatment (see Figure 5b)

This category outlines the therapeutic strategies for managing NCFB, emphasizing both pharmacological and non-pharmacological approaches. The subcategories are:

- ***Choice***: Explores the available treatment options, including antibiotics, airway clearance techniques, and the unmet need for more effective therapies. Patients expressed a desire for more personalized treatment options that consider their individual needs and preferences. Many patients also highlighted the importance of shared decision-making with their healthcare providers.

- ***Initiation***: Focuses on the initiation of treatment protocols as guided by the European Respiratory Society's guidelines, including detailed algorithms for disease management. The initiation of treatment was often challenging for patients, requiring significant lifestyle adjustments and adherence to complex medication regimens. Support from healthcare providers and caregivers was crucial during this phase. (Hill, 2019).
- ***Stabilization***: Covers strategies to mitigate infections, manage exacerbations, financial implications and address comorbid conditions, ensuring the patient's condition does not worsen. Patients would benefit from ongoing support and education to help them manage their condition and prevent exacerbations. Access to pulmonary rehabilitation programs and support groups was also highlighted as a key need. (Athanazio, 2021).



Treatment

Choice

Treatment will vary from person to person as patient history and frequency/severity of exacerbations is different in everyone. Frequent treatments include antibiotics, mucolytics, physical therapy, and possibly bronchodilators if there is an associated respiratory condition or significant breathlessness.

Need long-term study on safety/efficacy of current treatments; Despite antibiotic treatment, exacerbations still occur.

Develop NCFB specific treatment

Initiation

Experts suggest regular airway clearance therapy should be performed by all patients with clinically significant NCFB. Antibiotics are used to treat exacerbations when they occur

Patients must be educated on the proper airway clearance technique (ACT) regimen, with motivation to adhere to it after initiation. Further education on their disease is required to ensure continued use of other medications (i.e. bronchodilators, inhaled corticosteroids (ICS), nebulizers, antibiotics)

Better disease prognosis

Stabilization

Treatment aims to prevent infections and flare-ups. The British Thoracic Society details short- & long-term antibiotic therapy based on the current state of the patient.

While NCFB can be challenging to manage, with appropriate treatment plans including ACT, antibiotics, and addressing underlying conditions, stabilization is achievable. However, new treatments are needed to simplify the current treatment regimen.

Manage patient expectations and improve outcomes

Figure 5b: Treatment section of the IPJ for NCFB.

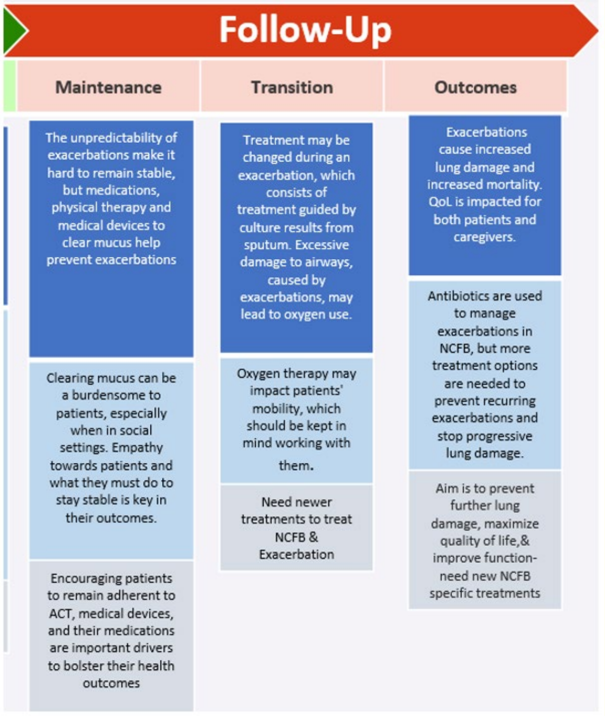
Follow-Up (see Figure 5c)

This category delves into the long-term management of NCFB, ensuring continuity of care and improved patient outcomes. The subcategories are:

- ***Maintenance***: Expands on stabilization, focusing on the ongoing care needed to prevent exacerbations. It also highlights the economic burden that NCFB places on patients and healthcare systems. Patients reported that maintaining long-term control of NCFB required significant effort and self-management. This highlights the need for quick access to healthcare providers, medications, and support services. (European Lung Foundation, 2022).

- ***Transition***: Examines the timing and process of transitioning between different therapies, such as shifting from pharmacological to physiotherapeutic interventions or vice versa. Transitions between different phases of care, such as from hospital to home or from one treatment regimen to another, seem too often to be difficult for patients. Clear communication and coordinated care were essential for successful transitions.
- ***Outcomes***: Emphasizes the goal of treatment: to prevent further lung damage and ensure care is tailored to the individual patient rather than a one-size-fits-all approach to the disease. Patients defined successful outcomes in terms of improved quality of life, reduced exacerbations, and increased ability to participate in daily activities. These patient-defined outcomes should be considered when evaluating the effectiveness of treatments and interventions. (Lee, 2021).

Figures 5a-5c: The colors blue, light blue, and grey denote the step within the IPJ, the corresponding opportunity for intervention, and the impact on the NCFB community, respectively.



Follow-Up

Maintenance	Transition	Outcomes
The unpredictability of exacerbations make it hard to remain stable, but medications, physical therapy and medical devices to clear mucus help prevent exacerbations	Treatment may be changed during an exacerbation, which consists of treatment guided by culture results from sputum. Excessive damage to airways, caused by exacerbations, may lead to oxygen use.	Exacerbations cause increased lung damage and increased mortality. QoL is impacted for both patients and caregivers.
Clearing mucus can be a burdensome to patients, especially when in social settings. Empathy towards patients and what they must do to stay stable is key in their outcomes.	Oxygen therapy may impact patients' mobility, which should be kept in mind working with them.	Antibiotics are used to manage exacerbations in NCFB, but more treatment options are needed to prevent recurring exacerbations and stop progressive lung damage.
Encouraging patients to remain adherent to ACT, medical devices, and their medications are important drivers to bolster their health outcomes	Need newer treatments to treat NCFB & Exacerbation	Aim is to prevent further lung damage, maximize quality of life,& improve function- need new NCFB specific treatments

Figure 5c: Follow-up section of the IPJ for NCFB.

Discussion

While basic science will always be the engine of medical discovery, the earlier we understand treatment decision-making, patient experiences, access dynamics, and the support mechanisms that drive disease literacy, trial participation, and personal management, the better positioned we are to deliver differentiated products that address real needs based on patient experience. The purpose of the IPJ is to gain rapid, deep insights to guide development and improve patient outcomes.

Specifically, our findings highlight the need for a more patient-centric approach to drug development and commercialization. By understanding the patient's journey in detail, pharmaceutical companies can identify unmet needs, develop more targeted treatments, and design more effective support programs. This can lead to improved patient outcomes, increased treatment adherence, and greater patient satisfaction.

Applying this methodology helps to:

- Put the ***patient at the center*** of the ecosystem.
- Take a deeper look, ***in parallel, at the different experiences*** of patients, HCPs and payers.
- Unify current insight mining approaches into ***one consistent framework*** across functions.
- Evaluate the need for diversity and inclusion (D&I) initiatives to mitigate issues related to care barriers, diagnosis literacy (or lack of), and treatment support.
- Provide a ***systematic***, patient-centric perspective focusing on the 3 lenses shown below (Figure 6).

Clinical

What are the key touch points in the journey between the patient. HCPs and caregivers?

How are the treatment decisions made?

Experience

What are the good and bad moments? How does the environment impact condition and behaviors? When behaviors and experience inhibit or enhance patient progress?

Access

How do access policies, coverage, affordability and funding flows impact physician and patient choice?

Figure 6: Lenses of Patient Centricity.

Another benefit of this structured approach is that it ensures a comprehensive understanding of the patient journey in the therapeutic area of interest. By categorizing insights into clear sections such as diagnosis, treatment, and follow-up, the framework provides a detailed yet organized view of the patient experience. This approach highlights critical gaps in care, identifies opportunities for improvement, and underscores the urgent need for enhanced treatment and management strategies for NCFB patients. By addressing these gaps and unmet needs, the framework reinforces the importance of a patient-centered perspective that focuses on tailoring care to individual needs rather than a one-size-fits-all approach.

Conclusion

An assessment of the patient's journey that incorporates the lens of the patients, healthcare professionals, caregivers, advocacy groups, payors and providers gives a visual 360-degree landscape of the patient's experience. The patient's journey can serve to identify and fill the gaps in education, geographical considerations, evidence and care pathways. For example, IPJs can be used to ensure that clinical guidelines are developed to meet patients' specific and diverse needs and experiences, from symptom onset, diagnosis to follow-up. A corollary of the impact of the IPJ is to elevate the company brand amongst patients and key patient advocacy groups (PAGs).

It is well known that there is considerable discordance between patient and clinician in determining optimal treatment strategies. This is partly due to the nature of the disease and the experience of the patient dealing with the disease. Thus, and as others have recognized, IPJ can be harnessed to support structured discussions between patient representatives, clinicians, hospital managers and/or health and social care authorities, specifically to ensure that clinical and care pathways are designed and implemented to meet the underlying needs of the respective patient populations. Further, the IPJ can provide information to researchers on unmet needs, patient experience, and how best to prioritize opportunities to ensure optimal market access for new products.

The IPJ is a powerful tool that allows the stakeholder to better understand and connect with the patient's disease progression, management strategies and healthcare utilization. This tool can inform the patient disease strategy, specifically, showing what patients' needs are most essential to them, how their healthcare experience can be bolstered, and gives insights on new innovative product development that exemplifies the patient voice.

Limitations of this study are: 1) Not much consideration has been given to the idea of developing the list of opportunities to prioritize (detailed in Figure 4 above) to further support manufacturers and other stakeholders in developing patient disease strategies. 2) The IPJ depicted in this example assumes that the patient is insured. The IPJ for those patients who are uninsured has not been discussed. These patients may or may not be diagnosed and they may or may not be able to receive treatment from specialists. Future work should discuss the implication of developing an opportunity set and understanding the patient journey of those who are uninsured. Moreover, another avenue for future work involves the integration of the use of Artificial Intelligence applied to social media listening methods into the IPJ.

In sum, the IPJ offers a valuable framework for understanding the complexities of the patient experience. By incorporating patient insights into all stages of drug development and commercialization, pharmaceutical companies can develop more effective and patient-centric treatments that ultimately improve patient lives. Future research should focus on refining the IPJ methodology, expanding its application to other disease areas, and evaluating its impact on patient outcomes and healthcare costs. Implementing IPJ principles has the potential to transform healthcare delivery and empower patients to play a more active role in managing their own health.

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