PATIENT LED
RESEARCH
FOR LOW- AND MIDDLE-INCOME COUNTRIES

Access to Health Care in India Among Patients with Long COVID

Investigative Research Report from a Patient and Provider Perspective

Authors:

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I. Abstract

Long COVID, also known as Post-Acute Sequelae of SARS-CoV-2 infection (PASC), has emerged as a significant public health challenge following the global COVID-19 pandemic. This white paper provides a comprehensive analysis of Long COVID in India and other Low and Middle-Income Countries (LMICs), examining the unique challenges faced in these regions.

Through extensive research including literature review, expert interviews, and patient testimonials, this paper documents the current understanding of Long COVID, its prevalence, clinical manifestations, and impact on healthcare systems with limited resources. We identify significant gaps in awareness, diagnosis, treatment protocols, and support systems.

Our findings indicate that Long COVID represents a substantial burden in LMICs, exacerbated by pre-existing healthcare inequities, limited diagnostic capacity, and socioeconomic factors that complicate access to care. Based on these insights, we offer actionable recommendations for policymakers, healthcare providers, researchers, and patient advocacy groups to address the immediate and long-term challenges posed by this condition.

This white paper aims to contribute to the global understanding of Long COVID while highlighting the specific needs and considerations relevant to resource-constrained settings, ultimately working toward improved outcomes for affected populations.

II. Executive Summary

Background

Long COVID, a debilitating health condition that can develop after a COVID-19 infection, has affected at least 400 million people worldwide as of 2024. People with Long COVID may experience symptoms such as severe fatigue, cognitive and sleep dysfunction, chronic pain and migraines, which have drastic impacts on quality of life and social participation. In India, where COVID-19 cases were vastly underreported, Long COVID is a growing but overlooked public health crisis. The COVID-19 pandemic has exposed critical barriers in India's health system, including underfunded and overburdened public health facilities, unaffordable private care, and high out-of-pocket expenses that push families into poverty. This report describes the healthcare experiences of people with Long COVID in India and the challenges faced by healthcare professionals who treat Long COVID patients.

Methods

This report was developed through a participatory, patient-centered approach led by the Patient-Led Research Collaborative (PLRC) in partnership with Long COVID India. Recognizing the unique relevance of lived experience, the study was co-designed with patient experts, ensuring the research prioritized the perspectives of those most affected. To describe and contextualize Long COVID healthcare in India, this report combines desk reviews, expert consultations, and in-depth interviews with patients and healthcare professionals treating people with Long COVID.

The team conducted interviews with nine healthcare professionals across India, exploring their clinical experiences with Long COVID and systemic obstacles in diagnosis and treatment. Parallel interviews with Long COVID patients provided firsthand accounts of their healthcare journeys, financial burdens, and unmet needs. Findings were synthesized through iterative thematic analysis. By centering patient voices alongside medical expertise, this report offers a grounded, policy-relevant assessment of experiences with Long COVID healthcare in India, aiming to support equitable healthcare solutions.

Key Findings

Accessing Long COVID Care in India

1. Patients Struggle to Get Proper Diagnosis & Treatment

Healthcare providers often fail to identify and diagnose Long COVID. The absence of standard diagnostic tests leads to frequent misdiagnosis and treatment delays, as reported by specialists treating people with Long COVID. Geographic disparities exacerbate these challenges, with specialist shortages in rural areas forcing patients to undertake burdensome journeys for care. India's delayed national Long COVID guidelines (2022) left physicians relying on care protocols from other countries.

2. Eroded trust in patient-provider relationships in the context of Long COVID care

Healthcare professionals often fail to recognize Long COVID, refuse to acknowledge the condition or use the term "Long COVID". Patients are often dismissed with symptoms attributed to stress or anxiety–particularly women, low income and rural patients. Patients can wait years for acknowledgement of their Long COVID, and healthcare specialists admit many people, including physicians, invalidate and refuse to acknowledge Long COVID.

3. Pathways of care

Long COVID clinics opened briefly, and closed most likely due to lack of sustainable funding. The early patient registries stalled, losing critical data on Long COVID's impact in India and capacity to coordinate research among multiple locations. Some patients were also sceptical of the effectiveness of these clinics, mentioning they encountered the same dismissive attitudes found in general healthcare. While Long COVID clinics were short-lived, patients continue to require long-term healthcare. Without functioning clinics, patients bounce between specialists or give up on care altogether. This systemic under preparedness left primary care doctors overburdened, with no standardized referral system for Long COVID patients.

4. Patient support groups and traditional medicine practitioners fill the gaps

Online patient communities provide critical emotional and practical help. Grassroots networks share symptom management tips and recommend trustworthy doctors. Without access to formal healthcare, these patient groups become lifelines. To manage symptoms, patients turn to low cost

alternatives that have limited to no evidence-based support, although traditional medicine practices are culturally rooted and increasingly studied for Long COVID symptom management (e.g., fatigue, inflammation). When routes of care within allopathic medicine fail patients turn to unregulated treatments.

Socioeconomic and Geographic Barriers to Long COVID Care in India

1. Financial hardship limits treatment access

Long COVID patients struggle financially due to loss of income and crippling out-of-pocket costs for tests, specialist visits, and medications—with many forced to abandon care altogether. Tests and specialist visits drain patient's financial savings, with little insurance coverage. Lost income due to chronic illness and disability worsens financial strain, especially for rural and daily wage workers.

2. Social capital facilitates access to Long COVID healthcare

Those with family connections with physicians or higher incomes bypass systemic barriers, securing faster diagnoses and specialist care. Rural and low-income patients disproportionately rely on underqualified providers or untested alternatives.

3. Urban vs. rural access disparities

During Delta COVID-19 waves, rural health systems collapsed. Initial rural skepticism about COVID-19 left lasting mistrust in healthcare systems and left gaps in Long COVID awareness. Many rural patients attribute symptoms to "weakness" or poverty rather than Long COVID, delaying care. Community health hubs became critical lifelines as Long COVID emerged.

4. Gender Bias compounds healthcare access barriers

Women with Long COVID face dismissal of fatigue and menstrual-health related symptoms, with cultural norms discouraging seeking help for health concerns. Rural women's mobility is further restricted by gendered control over finances and transportation. Urban working women report hiding symptoms due to workplace stigma.

Impact of Long COVID on home, in the workplace, and in the community

1. Stigma towards acute COVID-19 and chronic illness

During 2020–2021, fear and misinformation led to severe social ostracization against infected individuals with acute COVID-19 disease. This deep-seated stigma extended to people with Long COVID. Stigma and societal perceptions of chronic illness deter disclosure of having Long COVID due to fears of jeopardizing marriage prospects or social standing. Mental health struggles are pervasive, with patients reporting depression, social neglect, and resentment over their diminished capacity to meet domestic or workplace expectations.

2. Work-related challenges

Long COVID has significantly disrupted India's workforce across formal and informal sectors, with debilitating symptoms like fatigue, cognitive impairment, and chronic pain forcing workers to reduce hours, change jobs, or stop working entirely. The socioeconomic consequences are stark, particularly for laborers and daily wage earners. Even white-collar professionals with Long COVID face workplace discrimination, with employers often dismissing the condition's severity. Clinicians emphasize that Long COVID disproportionately affects India's productive-age population, pushing many into financial precarity or reliance on family support.

Recommendations

We've assembled three areas of high-leverage recommendations based on our interview synthesis and our own expertise at the Patient-Led Research Collaborative.

1. Clinical Care Priority Recommendations

India's vast geographic, cultural, and socioeconomic diversity demands flexible, context-specific models for Long COVID care that align with local populations' needs.

Priority Area	Key Recommendations
Integrated Care Models	• Develop protocols bridging allopathic and Ayush medicine in Long COVID care • Create quality standards for Ayush treatments • Establish Long COVID Centres of Excellence
Provider Training	• Mandate Long COVID and IACC education in medical curricula • Incorporate Long COVID and IACC into continuing education for recertification • Train providers in empathetic communication
Sustainable Care Models	• Create hub-and-spoke care networks • Integrate mobile care for rural access, combining cultural and infrastructure adaptation, and digital literacy • Establish dedicated funding mechanisms for care centres

2. Public Health Policy Recommendations

To effectively address Long COVID, India must formally recognize it within its healthcare system through government-funded awareness campaigns, policies ensuring financial protection for patients, and investments in rural mobile health initiatives.

Priority Area	Key Recommendations
National Recognition	• Develop comprehensive national guidelines • Create Long COVID surveillance systems • Standardize diagnostic criteria
Financial Protection	• Expand insurance coverage for Long COVID • Create disability support systems • Implement sliding fee scales

Long COVID and IACC Awareness Campaigns	• Launch anti-stigma education programs • Target workplace discrimination • Focus on prevention messaging
Equity Initiatives	• Expand rural and mobile health services • Develop gender-responsive care protocols

3. Research Priorities

To address India's unique Long COVID challenges—from diverse symptom profiles to resource constraints—it is critical to safeguard sustained investment in patient-centered research, develop India-specific studies and accessible diagnostics, while fomenting creating and participation in international research networks, as well as collaboration between public funding, philanthropy, and healthcare providers.

Priority Area	Key Recommendations
Patient-Centered Research	• Fund community-led research initiatives • Integrate patient advisory groups • Support grassroots health organizations
India-Specific Studies	• Conduct longitudinal population studies • Research traditional medicine effectiveness • Study reinfection impacts
Diagnostic Research	• Develop biomarker discovery programs • Create cost-effective diagnostic tools • Establish patient registries
LMIC Networks	• Build resource-appropriate research capacity • Share successful models between countries • Support local researcher training

III. Background

The emergence of COVID-19 in late 2019 and its subsequent global spread has led to unprecedented challenges for healthcare systems worldwide. While initial efforts focused on addressing acute infections and reducing mortality, it has become increasingly clear that COVID-19 can lead to persistent symptoms in a significant proportion of patients, a condition now widely referred to as Long COVID.

This section provides essential context on Long COVID, exploring its definition, prevalence, and specific challenges in the Indian healthcare landscape.

What is Long COVID?

Long COVID is an infection-associated chronic condition that develops after a SARS-CoV-2 infection and is present for at least three months as a continuous, relapsing and remitting, or progressive disease state. Internationally, there are several definitions of Long COVID, though the Ministry of Health and Family Welfare of India clinically defines Long COVID as signs and symptoms lasting over 12 weeks after a COVID-19 infection that do not have an alternative diagnosis. Long COVID can last years or may be lifelong, and can have a profound impact on quality of life. Anyone is at risk of developing Long COVID, including people who have been vaccinated for SARS-CoV-2. Multiple COVID-19 infections increase this risk. It is estimated that at least 400 million people worldwide had Long COVID in 2023. People with Long COVID may experience one to multiple symptoms affecting several organ systems. Common symptoms include fatigue, cognitive dysfunction, post- exertional symptom exacerbation (PESE) (also known as post-exertional malaise or PEM), headaches, insomnia, and joint and muscle aches. Although the mechanisms that cause Long COVID are still being understood, research advances have found evidence of multiple and potentially overlapping pathophysiologies, which may include immune dysregulation and autoimmunity, persistence of SARS-CoV-2 in reservoir sites, reactivation of latent viral infections, neurological abnormalities and neuroinflammation, tissue and organ damage, vascular dysfunction and endothelial disease, fibrin amyloid microclots, and microbiome dysregulation. Despite advances in the understanding of Long COVID, there are no approved treatments or cures, and no standardized care pathways. Clinical management of Long COVID has been focused on providing symptom management and controlling comorbidities. Healthcare for people with Long COVID widely varies worldwide across different health systems

and patient demographics, but most patients are suffering with nil to minimal social support and care.

Long COVID in India

According to the World Health Organization (WHO), India ranks third in the cumulative number of notified COVID-19 cases globally – after the United States and China – and ranks first among low and middle-income countries (LMICs). The toll of COVID-19 in India is most likely much higher than what is reported for notified cases due to lack of or poor surveillance systems in most Indian states, with COVID-19 deaths estimated to be 8-10 times higher than officially recorded. COVID-19 morbidity in India is also likely to be underestimated, with Long COVID prevalence expected to be severely underestimated. Due to India's size and diversity, and varying surveillance capacity, prevalence of Long COVID varies by region. In a population-based survey of 11 districts in Delhi, 79.7% participants who had COVID-19 reported at least one symptom of Long COVID. In a web survey with health care workers in India, 66% reported experiencing Long COVID, with 28% saying they faced daily health issues after COVID-19. At one year follow-up using clinical registry data from 31 hospitals in India, 11.9% of people who had been hospitalized for COVID-19 between September 2020 and October 2022 reported having Long COVID (Khumar, Balla, et al 2023). After the first Omicron wave in Eastern India, 8.2% of people who had tested positive for SARS-CoV-2 reported having Long COVID (Arjun, Singh 2022).

In India, Long COVID has also been associated with loss of quality of life and loss of income. A survey with undergraduate students with Long COVID in Kochi, southwest India, has shown that 61.5% have poor quality of life. A study of patients from the Long COVID clinic from the Kalinga Institute of Medical Sciences in Bhubaneswar, northeast India, demonstrated that Long COVID was associated with a 16.6% loss of family income, with 20% of people with Long COVID having lost their entire source of income.

IV. Research Process & Team

Project Team

- **Gina Assaf, MSc** - Project Lead
- **Hannah Wei** - Project Lead
- **Padma Priya** - Interview Lead, India Partner
- **Sourya Dash** - Patient-Researcher, India Partner
- **Teresa Akintonwa** - Interviewer, Project Manager
- **Kathleen Banks** - Analyst
- **Letícia Soares, PhD** - Senior Researcher & Writer

Reviewers

- Megan Fitzgerald, PhD
- Tessa Green, PhD
- Emma-Louise “Emmilie” Aveling, PhD
- Julia Moore Vogel, PhD
- Lisa McCorkell, MPP

Research Process

Overview

PLRC conducts participatory, patient-centered research, often partnering with stakeholders in multiple sectors to provide essential patient expertise that advance research, clinical care, and data-driven advocacy for policies that can increase the quality of life of people with Long COVID.

The process for writing this report included desk research and interviews with Long COVID patients, healthcare workers, and public health professionals who interact with patients or research Long COVID. The investigation started in the fall of 2022, with the majority of the interviews conducted between April 2023 and September 2023, and the follow up literature review

and report writing in 2024. In this section, we outline the process, describe the methods used, and provide details about who was interviewed.

Desk Research

The planning for this investigation began in the fall of 2022 by consulting reports and existing research on Long COVID in LMIC countries. The team brainstormed directions for this report taking into account its impact and accessibility to patients.

Conversations with Authors of Prior Work

We conducted unstructured interviews over Zoom with four experts who did similar studies in other countries like Kenya, or who had information on Long COVID and healthcare in India. From these sessions, we pulled together recurring themes such as healthcare access and cultural amnesia. We decided to focus on India as a country due to access to our network there.

Partnership Recruitment

In line with PLRC's work approach and valuing of lived experience, this project was co-led by patient experts in India, who are most knowledgeable about the issues faced by patients and most affected by the outcomes of this work. For this participatory collaborative work, we brought on Long COVID India, a support and advocacy group led by journalist Padma Priya, as well as Sourya Dash, a patient-researcher.

Refine Scope of Investigation

After considering our desk research, listening sessions, and Long COVID India and PLRC's unique areas of expertise, we decided to focus the project on healthcare access for Long COVID. The team sourced patients to interview from the networks of team members Padma and Sourya. We interviewed patients from a variety of backgrounds focusing on diversity of location, urban vs. rural, age, and gender.

Health Professionals Interviewed

We interviewed ten healthcare professionals in India from various medical backgrounds and health care sectors. In these interviews, we sought to understand experts' experiences in diagnosing, treating, and managing Long COVID patients, as well as the barriers, challenges, and successes they encountered. We asked about their perceptions of Long COVID, the support they received from government or medical institutions, and the resources they felt were needed to improve care. The semi-structured format allowed experts to freely discuss areas they were most knowledgeable about and found most relevant to Long COVID.

- Dr. Sarath Menon, Senior Consultant Neurologist & Specialist in Autonomic Neurology & Neuromuscular diseases, Aster Medcity Kochi, Kerala
- Dr. Rajeev Jayadevan, Senior Consultant Gastroenterologist and former President of Indian Medical Association Cochin
- Dr. Rakhal Gaitonde, senior epidemiologist
- Anonymized, a researcher in global health, health policy and bioethics
- Jasmine Kalha, Researcher, community mental health, M.A (Social Work), M.Phil. (Sociology)
- Dr. Joyeeta Basu, primary care physician specializing in family medicine, Consultant Physician, Doctors Hub, Gurgaon
- Dr. Lancelot Pinto, pulmonologist and epidemiologist at Hinduja Hospital in Mumbai
- Dr Ashwin Rajenesh, Senior Consultant Physician and Chief, Emergency Department, NS Hospital in Kerala state
- Priyanka Hosangadi, holistic healing medicine practitioner based in Mumbai, India

Patient Interviews

The patient interviews aimed to understand each participant's entire Long COVID journey, from their initial COVID-19 infection to their condition at the time of the interview. We discussed their quality of life with Long COVID, community reactions, and their comprehension of the illness, as well as what they felt would help them move forward. These semi-structured interviews were conducted primarily by Padma Priya and Souriya Dash on the Long COVID India team, with support from PLRC team members. Most interviews were conducted on Zoom while some interviews were conducted via WhatsApp, mostly in participants' native language, Hindi. The Hindi interviews were conducted and translated by the Long COVID India team members. When possible, a few patients were re-contacted to update their health status.

Aliases are used in place of real names in this report to protect patient privacy.

- **P1:** Female, 39, Gujarat/Ahmedabad urban area, Works in a museum
- **P2:** Male, 25-30, Delhi Urban area
- **P3:** Female, 55-60, Hyderabad urban area
- **P4:** Male, 25-30, Poi Semi-urban
- **P5:** Male 40-45, Mangalore, Urban
- **P6:** Female, 47, Maharashtra, Rural
- **P7:** Male, 45, Mumbai, Slum
- **P8:** Female, 46, Gulbarga, Karnataka Rural
- **P9, P10:** Couple: Male & Female 57/58, Adilabad, Telangana, Rural

Synthesis

The team conducted several rounds of thematic analysis of the data collected from all the interviews and the desk research. Because the team consists of all Long COVID patients, we contributed our knowledge and lived experiences to interpret some of the findings.

Further Literature Review and Interview Followup

We conducted continuous literature reviews throughout the research process. The purpose of this endeavor was to ensure that we incorporated newly available data pertinent to the context of Long COVID in India. As new evidence emerged, we were able to further contextualize our findings from the interviews. We followed up with several interviewees to better understand their entire experience between the time of our interviews and the report writing.

Investigative Report Writing

To strike a balance between rigour, accessibility and impact, the team decided to publish an investigative report reflecting on the state of Long COVID in India with a strong focus on healthcare access from Long COVID patients' and healthcare professionals' perspectives.

V. Findings

Our investigation reveals significant barriers to Long COVID care in India, highlighting systemic challenges that affect both patients and healthcare providers. Through interviews with healthcare professionals and patients across diverse geographic and socioeconomic backgrounds, we identified three major areas of concern that collectively illustrate the complex landscape of Long COVID healthcare access in India.

Accessing Long COVID Care and Treatment in India

Patients Struggle to Get Proper Diagnosis & Treatment

Healthcare providers often fail to identify and diagnose Long COVID due to the absence of standard diagnostic tests, leading to frequent misdiagnosis and treatment delays. As one specialist noted: “Many doctors don’t even acknowledge Long COVID exists, so patients are left without proper care pathways.”

Geographic disparities exacerbate these challenges, with specialist shortages in rural areas forcing patients to undertake burdensome journeys for care. India’s delayed national Long COVID guidelines (released in 2021, updated in 2022) left physicians relying on care protocols from other countries during the critical early period of the pandemic.

Eroded Trust in Patient-Provider Relationships

Healthcare professionals often fail to recognize Long COVID or refuse to acknowledge the condition. Patients are frequently dismissed with symptoms attributed to stress or anxiety—particularly women, low-income, and rural patients. As one patient shared: “The doctor told me it was all in my head and that I should just rest more.”

Patients can wait years for acknowledgment of their Long COVID, and healthcare specialists admit that many people, including physicians, invalidate and refuse to acknowledge Long COVID as a legitimate medical condition.

Pathways of Care

Long COVID clinics opened briefly but closed, most likely due to lack of sustainable funding. Early patient registries stalled, losing critical data on Long COVID’s impact in India and the capacity to coordinate research among multiple locations.

Some patients were also skeptical of the effectiveness of these clinics, mentioning they encountered the same dismissive attitudes found in general healthcare. While Long COVID clinics were short-lived, patients continue to require long-term healthcare.

Without functioning clinics, patients bounce between specialists or give up on care altogether. This systemic unpreparedness left primary care doctors overburdened, with no standardized referral system for Long COVID patients.

Patient Support Groups and Traditional Medicine Fill the Gaps

Online patient communities provide critical emotional and practical help. Grassroots networks share symptom management tips and recommend trustworthy doctors. Without access to formal healthcare, these patient groups become lifelines.

To manage symptoms, patients turn to low-cost alternatives that have limited to no evidence-

based support, although traditional medicine practices are culturally rooted and increasingly studied for Long COVID symptom management. When routes of care within allopathic medicine fail, patients turn to unregulated treatments.

Socioeconomic and Geographic Barriers to Care

Financial Hardship Limits Treatment Access

Long COVID patients struggle financially due to loss of income and crippling out-of-pocket costs for tests, specialist visits, and medications—with many forced to abandon care altogether. Tests and specialist visits drain patients' financial savings, with little insurance coverage.

Lost income due to chronic illness and disability worsens financial strain, especially for rural and daily wage workers. As one patient explained: "I had to choose between buying medicines and feeding my family."

Social Capital Facilitates Access to Healthcare

Those with family connections to physicians or higher incomes bypass systemic barriers, securing faster diagnoses and specialist care. Rural and low-income patients disproportionately rely on underqualified providers or untested alternatives.

Urban vs. Rural Access Disparities

During Delta COVID-19 waves, rural health systems collapsed. Initial rural skepticism about COVID-19 left lasting mistrust in healthcare systems and gaps in Long COVID awareness.

Many rural patients attribute symptoms to "weakness" or poverty rather than Long COVID, delaying care. Community health hubs became critical lifelines as Long COVID emerged.

Gender Bias Compounds Healthcare Access Barriers

Women with Long COVID face dismissal of fatigue and menstrual-health related symptoms, with cultural norms discouraging seeking help for health concerns. Rural women's mobility is further restricted by gendered control over finances and transportation.

Urban working women report hiding symptoms due to workplace stigma. As one female patient noted: "I couldn't tell my employer about my condition because I was afraid of losing my job."

Impact of Long COVID

Stigma Towards Acute COVID-19 and Chronic Illness

During 2020–2021, fear and misinformation led to severe social ostracization of individuals with acute COVID-19 disease. This deep-seated stigma extended to people with Long COVID.

Stigma and societal perceptions of chronic illness deter disclosure of having Long COVID due to fears of jeopardizing marriage prospects or social standing. Mental health struggles are pervasive, with patients reporting depression, social neglect, and resentment over their diminished capacity to meet domestic or workplace expectations.

Work-Related Challenges

Long COVID has significantly disrupted India's workforce across formal and informal sectors, with debilitating symptoms like fatigue, cognitive impairment, and chronic pain forcing workers to reduce hours, change jobs, or stop working entirely.

The socioeconomic consequences are stark, particularly for laborers and daily wage earners. Even white-collar professionals with Long COVID face workplace discrimination, with employers often dismissing the condition's severity.

Clinicians emphasize that Long COVID disproportionately affects India's productive-age population, pushing many into financial precarity or reliance on family support. As one healthcare provider observed: "We're seeing people in their prime working years unable to maintain their livelihoods due to this condition."

Family and Social Relationships

Long COVID affects not just patients but entire family systems. Caregiving responsibilities often fall disproportionately on family members, particularly women, creating additional strain on household resources and relationships.

Social isolation is common as patients struggle to maintain relationships while managing unpredictable symptoms. The invisible nature of many Long COVID symptoms makes it difficult for others to understand the severity of the condition, leading to social withdrawal and loneliness.

VI. Recommendations

We've assembled high-leverage recommendations based on our interview synthesis and own expertise at the Patient-Led Research Collaborative. These recommendations are designed to work together in coordination between Indian government agencies, healthcare institutions, research organizations, and patient communities. In alignment with disability justice, we advocate for implementation efforts that center patient voices, ensuring those directly affected by Long COVID have meaningful influence over policies and programs designed to address their needs.

Clinical Care Priority Recommendations

India's vast geographic, cultural, and socioeconomic diversity demands flexible, context-specific models for Long COVID care that align with local populations' needs.

Integrated Care Models

Protocols must be developed that bridge allopathic and Ayush medicine in Long COVID care while creating quality standards for Ayush treatments. Long COVID Centers of Excellence should be established at institutions like AIIMS to coordinate research, registries, and specialist referrals while partnering with the private sector to expand reach. As Dr. Lancelot Pinto noted: "it would be very useful to have one umbrella place to send people with all sorts of complaints, to see if they fit into any particular syndrome, or they fit into any constellation of symptoms that you know people are researching to […] enroll them in studies or registries."

Provider Training

Long COVID and IACC education must be mandated in medical curricula and incorporated into continuing education for recertification through the National Medical Commission and State Medical Councils. As Dr. Joyeeta emphasized: "The Indian Medical Association, ICMR, and the Ministry of Health need to hold seminars, update guidelines every three months, and engage with medical professionals."

The need for such training approaches is globally recognized, as a consensus study involving 179 healthcare professionals in 28 countries found that few recommendations and no formal training exists for medical professionals to assist with clinical evaluation and management of patients with Long COVID, emphasizing the urgent need for comprehensive training programs (Ewing et al., 2025).

Sustainable Care Models

Hub-and-spoke care networks should connect district hospitals with rural primary health centers,

enabling specialist consultation through teleconsultation. This model has proven successful in India (Devarakonda, 2016a), where smaller hospitals and clinics in outlying towns treat patients with straightforward needs and refer complex cases back to the hub or use telemedicine to consult with hub specialists, demonstrating that medical care can be provided to even the most rural areas at a much more nominal cost.

Mobile care must be integrated for rural access, with CHOs and ASHA workers trained to recognize Long COVID symptoms and traditional healers engaged as care partners. Dedicated funding mechanisms must be established for Long COVID care centers.

Priority Area	Key Recommendations	Key National Stakeholders
Integrated Care Models	• Develop protocols bridging allopathic and Ayush medicine in Long COVID care • Create quality standards for Ayush treatments • Establish Long COVID Centres of Excellence	AIIMS AYUSH practitioners ICMR Ministry of Health
Provider Training	• Mandate Long COVID and IACC education in medical curricula • Incorporate Long COVID and IACC into continuing education for recertification • Train providers in empathetic communication	National Medical Commission State Medical Councils AYUSH practitioners
Sustainable Care Models	• Create hub-and-spoke care networks • Integrate mobile care for rural access, combining cultural and infrastructure adaptation, and digital literacy • Establish dedicated funding mechanisms for care centres	AIIMS Ministry of Health Primary Care Providers ASHA workers

Public Health Policy Recommendations

Long COVID must be formally acknowledged within India's healthcare system to drive clinical awareness, education, and direct public health policy. We advocate for government funded awareness campaigns, implementing policies that expand financial protection for patients, and investing in mobile health initiatives in rural regions.

Priority Area	Key Recommendations	Key National Stakeholders
National Recognition	• Develop comprehensive national guidelines • Create Long COVID surveillance systems • Standardize diagnostic criteria	Ministry of Health ICMR
Financial Protection	• Expand insurance coverage for Long COVID • Create disability support systems • Implement sliding fee scales	Government (general policy & support) Insurance Companies Ministry of Health
Long COVID and IACC Awareness Campaigns	• Launch anti-stigma education programs • Target workplace discrimination • Focus on prevention messaging	Ministry of Health (for public health education policy)
Equity Initiatives	• Expand rural and mobile health services • Develop gender-responsive care protocols	ASHA workers Ministry of Health (for policy oversight)

“It is time for Long COVID to be recognized as a real entity and for doctors to discuss it just like they discuss diabetes, heart attacks, or tuberculosis. We can’t ignore it—it needs to be included.”, Dr. Rajeev Jayadevan highlighted. Developing national protocols for Long COVID diagnosis and care integrated with clinical education strategies can strengthen surveillance efforts and support resource allocation. According to Dr. Joyeeta: “The Indian Medical Association, ICMR, and the Ministry of Health need to hold seminars, update guidelines every three months, and engage medical professionals. Nobody is talking to us.”

Dr. Jayadevan further argues the importance of Long COVID surveillance: “[…] with testing going down, we simply have no way of counting the number of infections that person has. You can’t really count the number of scars on the skin […]. And with each reinfection the risk of long covid increases. That’s been confirmed.”

Research Priorities

To close the gap in Long COVID surveillance, diagnostics, care and treatment, India must prioritize sustained investment in research that can inform public health policy and policies in social support systems. We advocate to expand the pipeline of research opportunities to study Long COVID in India, not just from publicly funded research, but also philanthropic initiatives, academic.

Patient-Centered Research

As Dr. Anant Bhan highlights, understanding the range of symptoms and complaints unique to Indian patients is critical. Community-led research and patient involvement ensures that studies capture the diverse manifestations of Long COVID in India.

India-Specific Studies

India-specific research is essential to address the unique challenges posed by Long COVID in the region. India's climate, culture and healthcare system differ from challenges observed in Western populations.

Dr. Anant Bhan spoke to its importance: "We need to understand better what is the range of symptoms and complaints which patients are coming with…because again, there might be some aspects which are unique to say an Indian patient population. It's not the case that everything will necessarily be the same as what patients in the West might have."

Longitudinal studies and investigations into Ayush medicine can provide evidence-based solutions tailored to India's healthcare landscape, while reinfection studies can inform public health strategies to mitigate long-term impacts on the region to region basis. Dr. Rajeev Jayadevan emphasized the need for location-specific surveillance: "what I would like to know is how the Indian sub-continent and the regions around the area are responding to relentless infections."

Diagnostic Research

Accurate and accessible diagnostics are critical for effective Long COVID management. As Dr. Bhan notes, “Even a small subset here is large enough for robust studies.” Leveraging India’s vast patient population through registries can yield insights that benefit both national and global efforts in Long COVID research. Due to the lack of Long-COVID clinics, research into cost-effective biomarker testing can improve care accessibility in rural and low-income communities.

LMIC Resource Networks for Research

An international network of patients, healthcare providers, clinical researchers, and policy makers from LMIC countries can exchange research capacities and facilitate grants for Long COVID. When we asked Dr. Anant Bhan, how research into Long COVID could be better funded, he advocated sector groups like the ICMR and philanthropy organization, and emphasized the importance of supporting practicing medical professionals to publish papers and case studies: “That is good if it happens from the government sector and especially bodies like ICMR. It can also be other groups of philanthropy organizations looking at this as something which is a good medical question to understand, it could sometimes be medical researchers by themselves, as they said, doing some academic studies to try to find out among patients with covid that they saw, whether there are complaints which could be part of what is currently described among the various manifestations under Long COVID”

Priority Area	Key Recommendations	Key National Stakeholders
Patient-Centered Research	• Fund community-led research initiatives • Integrate patient advisory groups • Support grassroots health organizations	ICMR Patient-Led Research Collaborative (PLRC) Jan Swasthya Abhiyan
India-Specific Studies	• Conduct longitudinal population studies • Research traditional medicine effectiveness • Study reinfection impacts	ICMR Philanthropic organizations Traditional medical practitioners (AYUSH system for research)
Diagnostic Research	• Develop biomarker discovery programs	ICMR

	• Create cost-effective diagnostic tools • Establish patient registries	
LMIC Networks	• Build resource-appropriate research capacity • Share successful models between countries • Support local researcher training	Patients Healthcare providers Researchers Policymakers (as components of the network, from India and other LMICs)

VII. How to Cite This Report

This report can be cited using the following formats:

APA Style

Wei, H., Priya, P., Soares, L., Dash, S., Akintonwa, T., Banks, K., & Assaf, G. (2025). *Access to Health Care in India Among Patients with Long COVID: A Patient and Provider Perspective*. Patient-Led Research Collaborative.

MLA Style

Wei, Hannah, et al. “Access to Health Care in India Among Patients with Long COVID: A Patient and Provider Perspective.” *Patient-Led Research Collaborative*, 2025.

Chicago Style

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IX. Appendix

Additional Resources

For additional resources and supplementary materials related to this report, please visit the following links:

Glossary of Terms

For definitions of key terms and concepts used throughout this report, please visit: https://india.patientledresearch.com/glossary/

Executive Summary

For a comprehensive overview of the key findings and recommendations from this report, please visit: https://india.patientledresearch.com/executive-summary/

These online resources provide additional context and detailed explanations that complement the findings presented in this investigative report.