

Advancing Narcolepsy Advocacy: Bridging Patient Narratives and Systemic Change

Ahmed Salem BaHammam^{1,2}, Lindsay Jesteadt^{3,4}, Hamza Dhafar^{1,2}, Amir Sharafkhaneh^{5,6}

¹Department of Medicine, College of Medicine, University Sleep Disorders Center, King Saud University, Riyadh, Saudi Arabia; ²The Strategic Technologies Program of the National Plan for Sciences and Technology and Innovation in the Kingdom of Saudi Arabia, Riyadh, Saudi Arabia; ³Sleep Consortium, Jupiter, FL, USA; ⁴Hypersomnia Foundation, Atlanta, GA, USA; ⁵Sleep Disorders and Research Center, Michael E. DeBakey VA Medical Center, Houston, TX, USA; ⁶Section of Pulmonary, Critical Care and Sleep Medicine, Department of Medicine, Baylor College of Medicine, Houston, TX, USA

Correspondence: Ahmed Salem BaHammam, University Sleep Disorders Center, Department of Medicine, College of Medicine, King Saud University, Box 225503, Riyadh, 11324, Saudi Arabia, Email ashammam2@gmail.com

Abstract: We introduce the Stigma-to-Structure Advocacy Framework, a novel, evidence-based model designed to transform narcolepsy advocacy by systematically bridging patient narratives with structural change. Narcolepsy remains a profoundly under-diagnosed and misunderstood neurological disorder, with persistent diagnostic delays and pervasive cultural stigma undermining patient well-being and access to care. Despite recent progress in awareness and support, advocacy efforts remain fragmented and insufficiently integrated with health policy, particularly in low- and middle-income countries. This perspective advances a strategic evolution of narcolepsy advocacy through the Stigma-to-Structure Advocacy Framework, which is anchored in three pillars: narrative-driven awareness, clinical system integration, and policy activation. Drawing on recent evidence, patient testimonies, and global case studies, we identify critical gaps in current advocacy models, such as limited representation of youth and marginalized populations, insufficient adaptation to cultural contexts, and the absence of standardized impact metrics. For example, ongoing diagnostic delays and entrenched cultural stigma continue to impede timely care and social inclusion for many individuals. We outline five priority actions for the next decade: developing outcome metrics, building culturally responsive advocacy hubs, integrating narcolepsy into rare disease registries, expanding peer mentoring networks, and reforming policy frameworks. By centering equity, digital inclusion, and cross-sector collaboration, this framework aims to dismantle entrenched barriers and promote timely diagnosis, effective care, and social inclusion for all individuals with narcolepsy. We conclude by calling for a globally coordinated, patient-powered movement that redefines advocacy as a driver of structural transformation in sleep medicine.

Plain Language Summary: Narcolepsy remains significantly underdiagnosed worldwide, with patients waiting an average of 8-9 years for diagnosis while facing persistent stigma and limited support. Our perspective proposes a strategic evolution in narcolepsy advocacy, moving beyond awareness campaigns toward systemic change that can improve diagnosis times and patient outcomes.

We introduce the “Stigma-to-Structure Advocacy Framework” with three interconnected pillars: narrative-driven awareness, clinical system integration, and policy activation. This approach bridges personal stories with healthcare system improvements and policy reforms.

We identified five priority actions for the next decade:

- Developing standardized metrics to measure advocacy impact
- Building culturally responsive advocacy hubs that prioritize youth leadership
- Integrating narcolepsy into rare disease registries to improve data visibility
- Expanding peer mentoring networks to support treatment adherence
- Reforming policy frameworks to recognize narcolepsy’s disabling impact

These priorities address critical gaps in current advocacy, particularly in low- and middle-income countries where limited specialist access, cultural misconceptions, and digital divides create barriers to care. By centering equity and cross-sector collaboration, this framework aims to transform narcolepsy advocacy into a globally coordinated movement that ensures timely diagnosis, effective treatment, and social inclusion for all affected individuals.

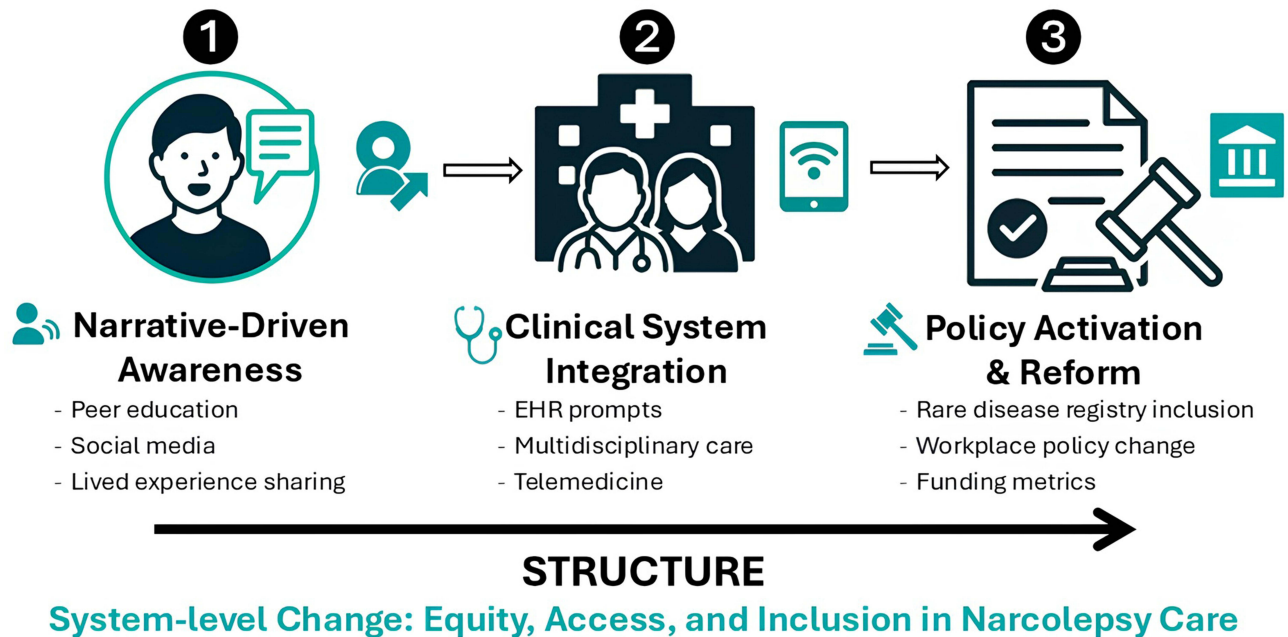
Keywords: support group, stigma, peer support, diagnostic delay, health equity, patient empowerment

Graphical Abstract

STIGMA-TO-STRUCTURE ADVOCACY FRAMEWORK

A 3-Pillar Model

To Advance narcolepsy advocacy through narrative, Clinical, and Policy Integration



The Evolving Mandate of Narcolepsy Advocacy

They think I'm lazy or just odd.

— Paul Tremblay, *The Little Sleep*¹

Narcolepsy is a lifelong, often debilitating neurological disorder that remains substantially underdiagnosed and misunderstood worldwide. Despite increasing awareness, diagnostic delays still average 8 to 9 years.^{2,3} Over 60% are initially misdiagnosed, commonly with mental or neurological disorders, before receiving an accurate diagnosis.⁴ These delays are not just clinical failings but also reflections of societal misconceptions: excessive sleepiness, cataplexy, and fatigue are frequently mistaken for laziness, poor discipline, or psychological weakness.^{4,5}

This dual burden, biological impairment, and sociocultural marginalization erodes the quality of life, mental health, and productivity. Patients frequently report not only external stigma but also internalized shame, social rejection, and a profound sense of isolation, which can exacerbate depression and anxiety.^{5,6} These experiences often undermine self-esteem and a sense of self-agency, leaving individuals feeling incapacitated and fostering negative self-views that further diminish motivation to seek help or advocate for their needs.^{5,7,8} Anticipation of negative judgment by others often leads individuals to conceal symptoms, further delaying diagnosis and support. These internalized experiences must be directly addressed through advocacy strategies that center psychological safety, self-acceptance, and public education, which are cornerstones of improving quality of life and long-term mental health outcomes.



Adolescents and young adults are especially vulnerable, with misdiagnosis often interfering with education, identity development, and long-term social participation.³ Although patient-led advocacy organizations have made substantial progress in raising awareness and fostering community, their efforts remain unevenly distributed, fragmented, and often under-theorized in their approach to systemic change.⁹

This fragmentation occurs even as the global health landscape is shifting toward greater equity and inclusion. Recent years have seen a global policy shift toward health equity, with frameworks from the World Health Organization and national health agencies emphasizing the need to address disparities in access, diagnosis, and outcomes for all chronic and rare diseases.^{10–12} These policy directions call for the integration of equity, diversity, and inclusion principles into health systems, aiming to dismantle structural barriers that disproportionately affect marginalized and underdiagnosed populations. Despite these advances, sleep disorders, including narcolepsy and other central hypersomnias, remain largely excluded from rare disease registries, national surveillance programs, and public health agendas.¹³ This omission perpetuates a systemic blind spot, resulting in limited research funding, inadequate clinical pathways, and insufficient policy recognition for affected individuals. This perspective addresses a critical gap in advocacy and health system reform by foregrounding the patient voice and advocating for the inclusion of sleep disorders in rare disease and health equity frameworks.

To meet the complexity of global disparities, narcolepsy advocacy must move beyond awareness campaigns toward a coordinated, equity-focused infrastructure for care, inclusion, and systemic reform. This perspective proposes a conceptual reimagining of narcolepsy advocacy that integrates patient co-leadership, global equity, digital inclusion, and health policy leverage. Drawing on emerging data, patient narratives, and global case examples, we present a new framework for advancing narcolepsy advocacy from storytelling to structural impact.

Despite meaningful advances in narcolepsy advocacy across high-income countries, stark disparities persist in the global distribution of resources, infrastructure, and diagnostic capacity. Low- and middle-income countries (LMICs), home to the majority of the global population, frequently contend with systemic delays in diagnosis, a lack of trained sleep medicine specialists, and culturally embedded interpretations that misattribute symptoms to behavioral or supernatural causes.^{14–16} These inequities are further exacerbated by limited access to health information technology, multi-lingual educational tools, and inclusion in national or global rare disease policy frameworks.

Building equitable advocacy models requires deliberate strategies that go beyond awareness campaigns. Cross-border collaboration, culturally adapted communication, and targeted investment in health systems capacity are essential to bridging these divides.^{13,17} In line with broader efforts to globalize neurological and rare disease care, this perspective emphasizes a reimagined approach to narcolepsy advocacy, one that centers culturally responsive design, digitally inclusive practices, and strategic integration across policy levels to uplift underrepresented regions.

By identifying critical gaps in the current advocacy landscape and outlining future-oriented strategies, we aim to catalyze a new era of narcolepsy advocacy—one that is resilient, intersectional, and capable of dismantling the entrenched barriers that continue to undermine timely diagnosis, effective care, and social inclusion.

Where We Stand: Achievements and Inertia in Current Advocacy

In recent years, narcolepsy advocacy has achieved meaningful progress in shifting the landscape of public discourse, clinical engagement, and peer support. Patient-centered organizations such as Wake Up Narcolepsy, Project Sleep, and the Hypersomnia Foundation have established robust infrastructures for support groups, educational outreach, clinician training, research engagement, and policy advocacy.^{18–20} For example, the Hypersomnia Foundation actively contributes to provider education (eg, CME programming), policy discussions, research engagement, awareness, and peer support.²⁰ Community forums and narrative-sharing platforms have contributed to earlier recognition of symptoms, especially in pediatric and adolescent populations.^{21,22} Diagnostic delay, once averaging over a decade, has shown modest reductions in some regions due to targeted awareness campaigns and clinician education.^{2,23} Social media campaigns, notably World Narcolepsy Day, have expanded visibility and community solidarity on a global scale.^{20,24}

Social media is an invaluable tool for spreading awareness and connecting the narcolepsy community, but advocates must ensure that the information shared is accurate, credible, and sensitive to privacy and stigma concerns.¹⁸ Balancing personal experiences with evidence-based facts and encouraging professional advice can maximize the positive impact of digital advocacy.

The successes of rare disease advocacy offer a powerful template for narcolepsy. Across multiple countries, patient-led organizations have catalyzed measurable advances: securing inclusion in national registries, shaping clinical guideline development, and influencing research funding decisions.^{13,25–27} These outcomes underscore how sustained and coordinated advocacy can transform systems, not just for one diagnosis, but across the rare disease spectrum.^{28,29} As narcolepsy remains underrecognized in many policy frameworks, this moment presents an opportunity to embed narcolepsy within rare disease reform efforts, ensuring it is visible not just in awareness spaces, but in funding strategies, surveillance tools, and policy agendas.

There is growing evidence that advocacy-driven interventions, including peer support, targeted education, and awareness campaigns, are associated with improved patient outcomes in rare and chronic diseases.^{30–32} For narcolepsy and similar conditions, advocacy has been linked to earlier diagnosis, reduced stigma, and better psychosocial adjustment.^{7,21,33,34} Studies in other rare disorders and neurological conditions further demonstrate that advocacy efforts can increase research engagement, enhance access to care, and drive policy changes that benefit patients and families.^{29,35–37}

Despite notable progress in raising awareness and empowering individuals, advocacy efforts for narcolepsy and similar conditions often remain insufficiently aligned with broader health policy frameworks. This disconnect has contributed to persistent disparities in access to diagnosis and care, particularly across socioeconomic and geographic lines. While studies such as Franceschini et al and Ong et al highlight the value of peer support and reveal the significant quality-of-life burden faced by individuals with narcolepsy, they also point, albeit indirectly, to systemic challenges that remain unaddressed.^{7,33} More broadly, health policy analyses underscore that without strategic integration into national and global policy agendas, advocacy risks becoming fragmented and uneven in its impact. For instance, the US Centers for Medicare & Medicaid Services (CMS) has emphasized the need for health equity to be embedded across all levels of care delivery to prevent disparities from deepening.¹⁰ Similarly, the National Health Council stresses that without intentional alignment between advocacy, infrastructure, and regulation, vulnerable communities will continue to face barriers to care.³⁸ Moreover, recent policy analyses advocate that equity should be treated not as an add-on, but as a core system-wide priority, a position that highlights the limitations of advocacy that is not structurally integrated.¹¹ These insights point to a pressing need to evolve advocacy efforts into more policy-conscious, equity-driven strategies that can generate sustainable, system-wide improvements in narcolepsy care.

Furthermore, the voices of underrepresented groups, such as patients from non-Western cultures, youth, and those with comorbid mental health conditions, are frequently marginalized or under-researched.^{4,5} Recent qualitative and patient-centered studies in narcolepsy advocacy have emphasized the importance of storytelling and patient experience, while highlighting a relative lack of published frameworks for evaluating long-term impact or systemic change.^{39,40} These limitations underscore the need for a more strategic, intersectional, and globally equitable framework to guide the next decade of narcolepsy advocacy.

Gaps in the Advocacy Ecosystem: What is Missing and Who is Left Behind

Despite growing global momentum in narcolepsy advocacy, several blind spots continue to impede equity and systemic progress. Pediatric and adolescent populations remain insufficiently represented in advocacy leadership and research. Although onset often occurs before age 18, youth frequently face longer diagnostic delays and are less able to articulate symptoms or access accommodations in school environments.^{21,22,41} Early peer support, mental health integration, and school-based education initiatives are often underdeveloped.

School health doctors, nurses, and counselors should receive targeted education to recognize the atypical presentations of excessive daytime sleepiness in students. Moving beyond the common assumption that such sleepiness is always due to poor sleep hygiene or behavioral issues is essential. Greater awareness at the school level can support timely identification and referral, particularly in pediatric and adolescent narcolepsy cases.^{21,41,42} Recent studies demonstrate that mental health and sleep education programs for school staff significantly improve early recognition, reduce stigma, and foster appropriate help-seeking behaviors.^{5,42}

Advocacy frameworks also remain poorly adapted to LMICs, where systemic barriers such as healthcare workforce shortages, limited access to sleep diagnostics, and cultural stigma complicate timely diagnosis and care. Also, cultural

insights and locally held beliefs, such as attributing symptoms to supernatural causes like the “evil eye” or black magic, can contribute to delays in diagnosis and access to care.⁴ These findings suggest that similar sociocultural dynamics may be at play in other underrepresented or medically underserved regions, where narcolepsy is poorly recognized or mischaracterized.

Cultural misconceptions and stigma remain pervasive barriers to narcolepsy care in many regions. Recent studies highlight that attributing narcolepsy symptoms to supernatural or moral failings, such as divine punishment, witchcraft, or spiritual weakness, can be found not only in the Middle East but also in Africa, South Asia, and parts of Latin America.^{43–45} These beliefs often delay medical help-seeking, encourage social exclusion, and reinforce internalized shame among patients. Evidence from mental health and neurological research shows that individuals exposed to such cultural stigma are less likely to access care, disclose symptoms, or adhere to treatment, underscoring the urgent need for advocacy initiatives that directly engage with local explanatory models and community leaders.^{4,15,43,46}

As digital platforms expand advocacy reach, inequities in internet access, linguistic inclusion, and neurodiverse design limit engagement for many communities.^{7,39} Collaboration with employers and educators, key players in daytime function, remains sparse. A review of national rare disease plans across 11 countries further reveals a striking lack of standardization in how patient support, care coordination, and diagnosis are addressed across healthcare systems.¹³ Most plans fail to include sleep disorders or conditions like narcolepsy, and advocacy metrics often focus on treatment access rather than diagnostic speed or patient quality of life, dimensions especially relevant to narcolepsy’s burden. Additionally, advocacy remains hampered by a lack of standardized impact metrics, limiting scale, policy translation, and funding.⁴⁰

From Stories to Systems: A Strategic Framework for Impact

To bridge the gap between patient experiences and systemic reform, we propose a “Stigma-to-Structure Advocacy Framework”, a strategic model grounded in patient-centered action, clinical integration, and policy transformation (Figure 1). While storytelling remains a powerful awareness tool, its greatest impact is realized when embedded within systems that translate visibility into infrastructure and access.^{33,47}

The Stigma-to-Structure Advocacy Framework emerged from our analysis of current literature on narcolepsy advocacy, rare disease frameworks, and patient-centered care models. We identified key themes in successful advocacy approaches, including region-specific challenges from LMICs. Through iterative refinement and consensus-building among the authors, we developed a framework that synthesizes evidence-based approaches and patient-centered priorities. This perspective aligns with contemporary health advocacy development practices, as seen in recent work on rare diseases²⁹ and health literacy advocacy.³⁶ The resulting framework is designed to be adaptable across diverse healthcare contexts while addressing the specific needs of the narcolepsy community.

Pillar 1: Narrative-Driven Awareness

Patient testimonies catalyze public empathy and destigmatization but also serve as qualitative evidence to inform advocacy priorities.⁴⁸ Platforms such as Project Sleep’s *Rising Voices of Narcolepsy* exemplify how lived experiences can shift social narratives, engage policymakers, and inspire others to share their stories, helping to normalize the disorder and reduce stigma.¹⁸ Sharing personal stories in public forums and advocacy campaigns has proven to be a powerful way to humanize narcolepsy, foster empathy, and correct misconceptions among both the general public and healthcare professionals.^{7,49,50}

To expand this impact, engaging well-known public figures and leveraging popular events, such as televised performances or sporting events, can help normalize narcolepsy and counteract misinformation. Strategic involvement of celebrities or inclusion of educational messages during major broadcasts can rapidly correct misconceptions, reduce stigma, and encourage early recognition and support.^{18,33,51}

Pillar 2: Clinical System Integration

A growing body of evidence demonstrates that narcolepsy is frequently accompanied by a range of comorbid conditions, including metabolic disorders (such as obesity and dyslipidemia), mood and anxiety disorders, and an increased risk of cardiovascular events.^{7,52–56} These comorbidities not only exacerbate the clinical burden of narcolepsy but also contribute

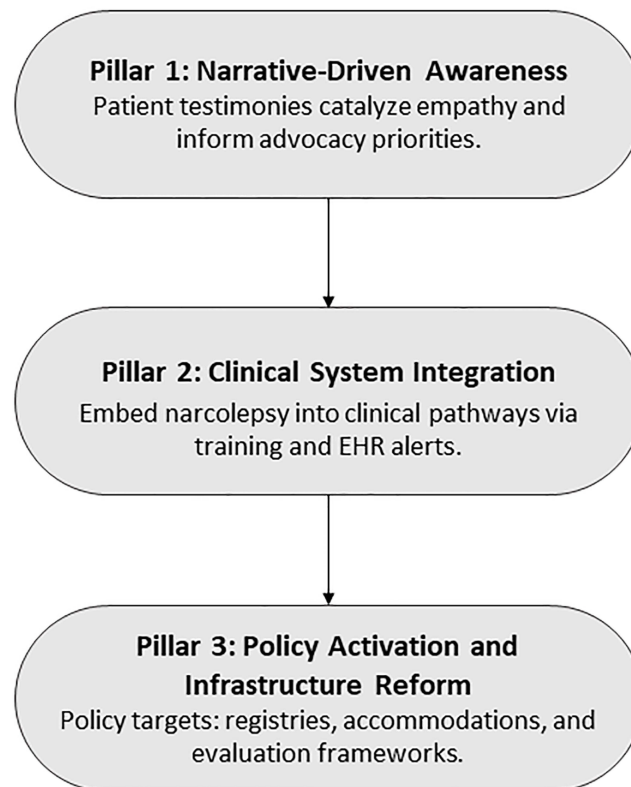


Figure 1 The Stigma-to-Structure Advocacy Framework for Narcolepsy. This model illustrates the sequential pillars needed to translate patient narratives into sustainable clinical and policy reforms: (1) Narrative-Driven Awareness, (2) Clinical System Integration, and (3) Policy Activation and Infrastructure Reform. Arrows indicate the progression from individual patient stories (stigma) toward system-level change (structure).

Abbreviation: EHR, electronic health records.

to diminished quality of life and increased healthcare utilization.^{7,53} Moreover, psychiatric comorbidities, particularly depression and anxiety, are prevalent and often underdiagnosed, further complicating disease management.⁵⁶

Given this complex clinical profile, advocacy efforts must explicitly promote multidisciplinary teamwork in both diagnostic and therapeutic pathways. Integrating sleep specialists, endocrinologists, cardiologists, mental health professionals, and primary care providers is essential to ensure the timely identification and management of comorbidities.^{57,58} The adoption of multidisciplinary care models, including telemedicine approaches, has demonstrated feasibility and effectiveness in improving access to comprehensive care for patients with narcolepsy, especially in regions with limited specialist availability.⁵⁹

Furthermore, long-term follow-up and systematic screening for comorbidities should be embedded in clinical management protocols to mitigate adverse health outcomes and optimize patient well-being.⁶⁰ Advocacy initiatives should, therefore, prioritize developing and disseminating guidelines that support multidisciplinary assessment and ongoing monitoring, ensuring that comorbidities are not overlooked in pursuing holistic narcolepsy care.

Advocacy must move beyond public messaging to embed narcolepsy into clinical pathways through provider training, diagnostic guidelines, and potentially Electronic Health Records (EHR)-based alerts.^{25,41} EHR-based alerts, ie, automated prompts integrated into clinical software, have been proposed as a way to help providers identify early symptom patterns and reduce time to referral in some diseases.⁶¹ A recent scoping review demonstrates that EHR-integrated digital technologies, including alert systems, can improve clinical outcomes and support health equity in hospital settings.⁶²

Complementing these digital tools within health systems, telemedicine offers a promising pathway to bridge access gaps in underserved areas. Establishing a national tele-sleep consultation program would enable primary care providers in remote or resource-limited regions to consult with sleep medicine specialists. This approach can facilitate timely, accurate diagnosis and tailored management plans for patients with narcolepsy, addressing disparities in specialist access.^{25,44,63}

**Table 1** Stigma-to-Structure Advocacy Framework for Narcolepsy

Pillar	Primary Stakeholders	Key Strategies & Tools	Expected Outcomes
Narrative-Driven Awareness	Patients, storytellers, NGOs, media, advocacy organizations	Peer education, social media campaigns, and lived experience forums	Destigmatization, increased symptom recognition, and public buy-in
Clinical System Integration	Sleep specialists, primary care providers, researchers, and health IT teams, advocacy organizations	Medical education, referral protocols, EHR alerts, and diagnostic pathways	Earlier diagnosis, improved quality of care, and interdisciplinary collaboration
Policy Activation & Infrastructure Reform	Advocacy groups, policymakers, funders, employers, and educators	Rare disease registries, workplace accommodation mandates, and funding metrics	Long-term equity, sustained funding, and institutional accountability

Notes: The table summarizes the Stigma-to-Structure Advocacy Framework, highlighting key pillars, stakeholders, strategies, and anticipated outcomes to advance narcolepsy advocacy from individual storytelling to systemic reform.

Abbreviations: NGOs: Non-Governmental Organizations; EHR: Electronic Health Records.

For example, an EHR alert could automatically prompt a primary care provider to consider narcolepsy when a young patient presents repeatedly with unexplained daytime sleepiness or episodes of sudden muscle weakness, encouraging timely referral to a sleep specialist. While this strategy has shown promise in other fields, it remains to be evaluated specifically for narcolepsy.^{25,41} Multi-stakeholder collaboration between patients, sleep clinics, and rare disease consortia is essential.

Pillar 3: Policy Activation and Infrastructure Reform

Dharssi et al¹³ argue that national rare disease plans rarely address narcolepsy or align with patient needs. While some national strategies acknowledge rare diseases broadly, conditions like narcolepsy remain underprioritized, lacking dedicated registries or reimbursement pathways across most of the 11 countries analyzed by Dharssi et al.¹³ Sustainable advocacy requires formal policy targets: integration into rare disease registries, employer accommodation mandates, and outcome-based evaluation frameworks. To this end, strengthening the advocacy role of national sleep societies is critical. These organizations can serve as key catalysts for stakeholder education, interdisciplinary collaboration, and the development of health policies that directly address narcolepsy care.^{13,44}

Formal partnerships with employers and schools can institutionalize accommodations, as seen in Japan's rare disease subsidies and Taiwan's workplace support policies.¹³ The key components, stakeholders, strategies, and anticipated outcomes of the Stigma-to-Structure Advocacy Framework are summarized in Table 1.

Toward Global Inclusion: Advocacy in a Digitally Divided World

I didn't want to upset my loved ones, but I couldn't carry this alone.

— Julie Flygare, *Wide Awake and Dreaming: A Memoir*⁵⁰

LMICs face multiple intersecting barriers: limited access to sleep medicine specialists, uneven referral networks, and culturally embedded explanatory models. In many parts of Africa and Asia, core symptoms such as cataplexy or hallucinations may be interpreted through cultural or supernatural lenses, patterns also observed in other neurological conditions in LMICs, such as autism.^{4,43–45,64–66}

Adding to this, recent clinical insights from LMICs contexts reveal that excessive sleepiness in young individuals is often dismissed as laziness or weakness of character, rather than being medically investigated, a misattribution that delays recognition and care.⁶⁷ Even when patients seek help, diagnostic tools like polysomnography and multiple sleep latency tests are not widely available, and few clinicians are trained to interpret their findings.^{44,68} Moreover, medical narratives around narcolepsy often fail to resonate with local idioms of distress, leading families and even healthcare providers to downplay or misclassify symptoms like hallucinations, dissociation, or fatigue as stress-related or behavioral in origin.⁶⁹ Social stigma compounds the diagnostic gap. Individuals are often reluctant to report episodes of sudden

muscle weakness or sleep attacks for fear of being misunderstood, socially marginalized, or seen as unreliable in work or school settings.⁶⁹ These cultural and systemic hurdles underscore the need for locally grounded, cross-sectoral advocacy approaches that can demystify narcolepsy, integrate it into broader neurological and mental health programs, and equip frontline providers in LMICs to recognize its nuanced presentation.

These interpretations are not simply misinformed; they reflect culturally rooted explanatory frameworks that must be engaged through locally contextualized advocacy. However, even when narcolepsy is correctly recognized, health system constraints often prevent timely treatment in LMICs, where specialist availability is critically low, and the mental health workforce is among the most understaffed globally.⁴⁶ Promoting the formal recognition of sleep medicine as a distinct medical specialty is essential to expand training opportunities, increase the number of qualified providers, and elevate awareness of narcolepsy and related disorders across healthcare systems.^{14,44} Without an integrated public health infrastructure or insurance frameworks that recognize narcolepsy, advocacy is too often reduced to narrative-sharing without clinical follow-through.

In parallel, the digital divide exacerbates invisibility. Limited access to mobile devices, broadband, or localized health information limits participation in global awareness, peer engagement, and digital health literacy programs.^{7,70} Multilingual mHealth tools and asynchronous digital communities, especially those adapted for mobile-first environments, may offer low-barrier entry points to education and peer engagement, but they remain underutilized. Evidence from global health research further underscores that convenience, affordability, and local adaptation are critical for the uptake of digital health innovations in resource-limited settings.⁷¹ For digital health solutions to foster equity, they must reflect the lived realities of under-resourced populations through affordability, cultural alignment, and support for digital skills and access.^{44,72}

Emerging advocacy models must shift from top-down design, where strategies are created and implemented by external experts or organizations with little local input, to community-based participatory leadership. Supporting regional champions, developing culturally resonant materials, and strengthening local research capacity will help globalize narcolepsy visibility. Finally, global sleep societies, WHO rare disease programs, and public-private funders must expand narcolepsy's inclusion in diagnostic coding, workforce planning, and policy platforms to reduce these deep-rooted gaps.

Support groups and community networks play a vital role in narcolepsy advocacy by fostering social connection, emotional resilience, and practical coping skills. Peer-led and hybrid (in-person/online) support models have been shown to reduce isolation, improve mental health, and empower individuals to manage their condition more effectively.^{21,29,33} In rare disease communities, support groups are also critical for sharing resources, navigating healthcare systems, and amplifying patient voices in research and policy.^{73,74} Importantly, culturally and linguistically tailored support initiatives are needed to ensure equitable access and engagement across diverse populations.^{15,64}

Empowering patients to advocate for themselves is a cornerstone of effective narcolepsy advocacy. Education and advocacy training can help patients gain confidence in discussing narcolepsy, communicating their needs, and understanding their rights regarding accommodations in education and the workplace.^{75,76} Shared decision-making and strong partnerships with healthcare providers further enable patients to participate actively in their care and advocate for appropriate support.

Emerging research underscores the critical role of health literacy, communication skills, and awareness of legal rights in empowering individuals to advocate for accommodations and actively participate in care decisions.^{36,77} Programs that promote patient empowerment, such as advocacy training, resource toolkits, and mentorship networks, have been shown to improve treatment adherence, care satisfaction, and overall quality of life in both narcolepsy and other rare disease contexts.^{36,77}

Designing the Future: An Action Roadmap for the Next Decade

To deliver lasting change, narcolepsy advocacy must evolve from awareness-raising to building structural systems that drive equity and access. This requires more than storytelling, it demands system-level tools that prioritize measurement, inclusivity, and sustainability. Drawing from multi-condition support group models, we outline five key priorities to guide action across the coming decade.



Define and Adopt Standardized Outcome Metrics for Advocacy

Despite the strength of grassroots mobilization and compelling personal narratives in narcolepsy advocacy, there remains a notable gap in validated, standardized tools for assessing systemic impact. In contrast, fields like oncology and HIV have developed robust advocacy benchmarks, including metrics such as time-to-diagnosis, treatment initiation rates, policy uptake, and health equity gains.^{78,79} Rare disease groups are increasingly recognizing the importance of formalizing advocacy evaluation frameworks, especially in capturing dimensions such as stigma reduction, patient empowerment, and health system responsiveness.^{29,40} Developing such metrics for narcolepsy would enable more strategic planning, outcome tracking, and policy engagement.

In low-income countries (LICs), the feasibility of implementing standardized, quantitative advocacy metrics is often constrained by limited resources, weak health information systems, and a lack of specialist services. Therefore, alternative and context-adapted outcomes must be considered to ensure that advocacy efforts are both measurable and actionable. Recent evidence from global health and rare disease advocacy highlights several pragmatic approaches:

First, qualitative metrics, such as patient and caregiver narratives, focus group discussions, and community-based participatory research, can provide rich insights into advocacy impact, stigma reduction, and changes in health-seeking behaviors.^{39,64} Second, process indicators, including the number of peer support groups established, community awareness events conducted, or traditional leaders engaged, serve as practical proxies for advocacy reach and local engagement.^{15,32} Third, leveraging existing community health structures and primary care platforms for data collection, such as integrating narcolepsy awareness into routine health worker training or school health programs, can facilitate ongoing monitoring without overburdening local systems.^{80,81}

Additionally, digital solutions, such as mobile phone surveys or WhatsApp-based reporting, have shown promise in capturing advocacy outcomes in resource-limited settings, provided they are adapted for local language and technology access.^{71,72} Importantly, advocacy metrics in LICs should prioritize indicators that reflect the meaningful change for affected individuals and communities, such as increased symptom recognition, reduced stigma, improved referral pathways, and enhanced peer support participation, rather than relying solely on clinical or policy endpoints that may be unattainable in the short term.^{40,73}

By adopting a flexible, context-driven approach to outcome measurement, advocacy initiatives can remain responsive to local realities, foster community ownership, and generate actionable evidence to guide future efforts. This strategy aligns with recent calls in global health to prioritize implementation approaches that link essential services to sustainable health outcomes, particularly in the post-pandemic era.⁸⁰

Build Culturally Responsive and Youth-Led Advocacy Hubs

Evidence from adolescent support networks shows that youth-led models promote identity resilience, emotional coping, and social integration, particularly when peer leadership and shared lived experience are emphasized.^{21,73} To extend these benefits to marginalized and underrepresented communities, advocacy initiatives must prioritize the development of localized hubs that integrate cultural relevance, digital accessibility, and multilingual peer training. These structures are essential to ensuring equitable engagement and sustained impact, especially in underserved populations.⁶⁴

Integrate Narcolepsy into National and Global Rare Disease Registries

Many national registries still fail to explicitly list narcolepsy, weakening its visibility in prevalence data and limiting access to research funding and policy frameworks.¹³ As shown in other fields such as rheumatology and oncology, including narcolepsy in rare disease coding systems strengthens data visibility, enables research eligibility, and connects patients to institutional support pathways. Similar inclusion of narcolepsy would align with global calls to standardize rare disease surveillance and policy integration.²⁵

Establish Scalable Peer Mentoring Networks

Support groups in HIV and dialysis communities show consistent improvements in treatment adherence, mental health, and quality of life.^{78,82} Building on lessons from chronic illness communities, global peer mentoring platforms, delivered asynchronously and designed for mobile access, could extend similar benefits to narcolepsy patients, particularly in LMICs, where in-person resources are scarce.³³

Reform Policy and Insurance Frameworks to Reflect Narcolepsy as a Disabling Condition, When Appropriate in Context

The classification of narcolepsy as a disabling condition varies significantly across global health and legal systems. In some countries, formal recognition provides access to income support, insurance coverage, and workplace accommodations. In others, however, the label of “disability” may be misunderstood, stigmatized, or legally ambiguous, particularly where frameworks are rigid or under-resourced. Effective advocacy must, therefore, balance the benefits of formal recognition with sensitivity to cultural attitudes and legal variability, ensuring strategies are both globally informed and locally grounded.

Movements in oncology and autoimmune disease advocacy demonstrate that framing illness in terms of functional impairment, rather than diagnosis alone, can resonate across diverse legal and insurance systems^{48,83,84} For narcolepsy, this means highlighting the real-world impact of symptoms on daily functioning, including education, employment, and social participation. Embracing this shift can strengthen payor engagement and policy reform while preserving sensitivity to cultural and legal contexts. Table 2, provides a comprehensive implementation framework for the five priority actions, detailing supporting evidence from other conditions, anticipated implementation challenges, and specific measurable outcomes for each initiative. Figure 2 complements this framework by illustrating the sequential progression of these priorities, highlighting their interconnected nature within the advocacy ecosystem. The structured visual representation

Table 2 Comprehensive Implementation Framework for Narcolepsy Advocacy Priorities

Priority Action	Supporting Evidence from Other Conditions	Implementation Challenges	Measurable Outcomes/Metrics
Develop Standardized Outcome Metrics	The American Heart Association's policy implementation framework demonstrates how structured metrics improved advocacy impact assessment ^{34,37} Rare disease patient organizations using standardized metrics showed enhanced funding opportunities and policy influence ²⁹	Limited baseline data; Resource constraints for data collection; Lack of consensus on priority indicators	Time-to-diagnosis reduction (months); Percentage of patients receiving guideline-concordant care; Media sentiment analysis scores; Validated quality of life measures
Build Culturally Responsive and Youth-Led Advocacy Hubs	Successful cultural adaptation in epilepsy advocacy across Africa demonstrated improved community engagement through local leadership and contextual framing; ¹⁵ Youth-led models in adolescent support networks promoted identity resilience and emotional coping ²¹	Digital divide limiting access; Language barriers; Cultural stigma variations; Limited youth engagement infrastructure	Number of culturally adapted resources developed; Geographic distribution of advocacy hubs; Youth leadership representation percentage; Digital engagement metrics across regions
Integrate Narcolepsy into Rare Disease Registries	The European Reference Networks' registry integration efforts demonstrated improved data visibility and research eligibility for rare diseases; ³¹ India's National Policy for Rare Diseases framework shows how registry inclusion enhances policy recognition ³⁰	Data privacy concerns; Interoperability challenges between systems; Varying diagnostic criteria across regions	Number of registries explicitly including narcolepsy; Percentage increase in research studies including registry data; Policy documents referencing registry data

(Continued)



Table 2 (Continued).

Priority Action	Supporting Evidence from Other Conditions	Implementation Challenges	Measurable Outcomes/Metrics
Expand Scalable Peer Mentoring Networks	HIV support groups showed consistent improvements in treatment adherence and mental health; ⁷⁸ Digital peer support platforms in rheumatic diseases demonstrated enhanced patient care and outcomes ⁷³	Volunteer sustainability; Quality assurance of peer support; Technology access inequities; Maintaining engagement	Number of active peer mentors; Geographic/demographic reach; Participant-reported outcomes (treatment adherence, quality of life); Retention rates in mentoring relationships
Reform Policy and Insurance Frameworks	The Public Policy Advocacy Actions Checklist documented successful policy reform strategies across three states; ⁸⁴ Rare disease advocacy groups achieved policy recognition through strategic stakeholder engagement ^{31,32}	Varying healthcare systems; Political resistance; Limited economic incentives; Competing health priorities	Number of policy documents recognizing narcolepsy; Insurance coverage expansion metrics; Workplace accommodation policy adoption; Healthcare cost reduction for patients

Notes: This table presents a detailed roadmap for operationalizing the five priority advocacy actions, including supporting evidence from other conditions, implementation challenges, and measurable outcomes. The framework provides practical guidance for advocacy organizations to translate strategic priorities into actionable initiatives with defined metrics for evaluation and success.

facilitates knowledge translation across multidisciplinary stakeholders involved in narcolepsy care pathways. These complementary resources establish both the theoretical foundation and methodological approach for implementing evidence-informed advocacy strategies, with quantifiable indicators to assess intervention efficacy and longitudinal outcomes across diverse healthcare systems.

Reclaiming Sleep: A Call to Expand the Advocacy Imagination

Narcolepsy advocacy offers a compelling lens through which to reimagine what a more just, inclusive, and patient-powered sleep field could look like. The fragmented pathways to diagnosis, persistent stigma, and lack of representation in health systems make narcolepsy a critical case study in redesigning care for chronic sleep disorders.

The next era of advocacy must prioritize structural transformation, embedding patient voice into research, expanding policy frameworks, and ensuring culturally grounded care delivery. Peer support infrastructures, rare disease registries, and insurance reforms are not peripheral; they are essential components of health equity for sleep disorders.^{13,25,33}

Sleep, like pain or fatigue, is often medicalized without being humanized. Advocacy grounded in lived experience challenges this by shifting focus from compliance to collaboration, from surveillance to solidarity. And as patient-led efforts grow across chronic illness communities, narcolepsy offers the sleep field a compelling template for what equitable, systems-aware, and digitally inclusive advocacy can look like. Reclaiming sleep, then, means more than fixing clinical gaps. It means rebuilding trust, reshaping systems, and reaffirming that rest, like justice, is something everyone deserves access to.

Conclusion

This perspective advances the Stigma-to-Structure Advocacy Framework as a central, evidence-based model for transforming narcolepsy advocacy from fragmented awareness campaigns to coordinated, equity-driven action. By bridging patient narratives with systemic reform and aligning with global health equity goals, this framework provides a strategic roadmap for addressing persistent disparities in diagnosis, care, and social participation.

Looking ahead, the next critical step is to pilot the Stigma-to-Structure Advocacy Framework in diverse healthcare settings, particularly in low- and middle-income countries and underrepresented regions, to assess its adaptability, effectiveness, and scalability. Collaborations with national and international sleep societies, patient organizations, and policy stakeholders will be essential to integrate the framework into clinical guidelines, rare disease registries, and health policy platforms.

Sustained, cross-sector collaboration among patients, clinicians, policymakers, and community leaders is vital to dismantle stigma and ensure that all individuals with narcolepsy have access to timely, effective, and compassionate care.



Figure 2 Strategic Roadmap for Advancing Narcolepsy Advocacy. This figure presents a structured, sequential approach to the five priority actions proposed to transform narcolepsy advocacy: (01) developing standardized outcome metrics, (02) building culturally responsive and youth-led advocacy hubs, (03) integrating narcolepsy into rare disease registries, (04) expanding scalable peer mentoring networks, and (05) reforming policy and insurance frameworks. The numbered format and visual pathway reflect the strategic progression from measurement to systemic change, providing a clear guide for advocacy stakeholders.

Future advocacy must be guided by measurable outcomes, a commitment to global inclusion, and a willingness to innovate, setting a new standard for patient-powered transformation in sleep medicine.

Data Sharing Statement

No new data was generated for this paper. Data sharing is not applicable to this article.

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Author Contributions

Ahmed S. BaHammam: Lead: Conceptualization, Writing – original draft preparation, Writing – review and editing, and Supervision.

Lindsay Jesteadt: Conceptualization, Writing – original draft preparation, Writing – review and editing, Supervision.

Hamza Dhafar: Conceptualization, Writing – original draft preparation, Writing – review and editing.

Amir Sharafkhaneh: Conceptualization, Writing – original draft preparation, Writing – review and editing, Supervision.

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