# The Power of Community:

## Clinical Evidence for Transforming Healthcare Outcomes

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# Abstract

Pulmonary Arterial Hypertension (PAH) reveals important gaps in healthcare that many patients know all too well: long delays before diagnosis, short and infrequent clinic visits, difficulty accessing specialist care, and limited support for the emotional and practical realities of living with a lifelong condition. This article explores why patient communities are not "extra" support, but a vital part of care.

Drawing on real patient experiences, published research, and insights from the development of electronRx's respiratory monitoring technology, the article shows how patient communities provide something healthcare systems cannot: continuous, day-to-day support from people who truly understand what it is like to live with PAH. While doctors and nurses play an essential role, they are not available at 2am when symptoms change, anxiety rises, or questions appear. Patient communities fill that gap.

Through shared experience, communities help patients make sense of symptoms, manage treatments, stay active, and know when to seek medical help. Seeing others live well with PAH also helps counter fear and isolation, replacing "worst-case" expectations with realistic hope. Research shows that this kind of human support improves treatment adherence, physical function, emotional wellbeing, and reduces unnecessary hospital visits.

The article argues that digital health tools like electronRx work best when they support, not replace, these communities. By combining technology with human connection, care can become more continuous, more personal, and more effective. Recognising patient communities as a core part of care has the potential to improve quality of life and outcomes for people living with PAH and other long-term conditions.

# Introduction: Beyond the Clinic Walls

When Jenna first noticed her heart racing whilst caring for her six-month-old daughter in mid-2020, she embarked on a journey that would last three and a half years before she received her diagnosis of Pulmonary Arterial Hypertension (PAH). Three and a half years of dismissal. Three and a half years of being told it was "just anxiety." Three and a half years of watching her symptoms escalate, from elevated heart rate to chest pain, palpitations, and finally severe shortness of breath, whilst physicians insisted she simply needed to exercise more.

Halfway across Australia, Erin's story was different but disturbingly similar. Her mother had died of PAH when Erin was just five years old. This was not merely family history. It was the single most significant risk factor imaginable. Yet when Erin presented with textbook symptoms at age 16, she was repeatedly dismissed as "unfit" or "anxious."

Ultimately, Erin had to lie to her GP to secure a referral to a cardiologist. She claimed she was "due for a review" when she'd seen a cardiologist just seven months earlier. That deception saved her life. An echocardiogram immediately confirmed PAH, and she was referred to a centre of excellence the very next day.

But this article is not about diagnostic failures, critical though that issue is. It concerns what happens after diagnosis and the remarkable support infrastructure that patients have built when formal healthcare systems cannot provide what they need.

It's about why a WhatsApp group of 1,200 Australian PAH patients functions not as a social nicety, but as essential clinical infrastructure.

It's about understanding that patient communities provide something that even the most dedicated healthcare professional simply cannot: the lived experience of managing a condition 24 hours a day, 365 days a year, for decades.

It is about recognising that these communities improve clinical outcomes in measurable, evidence-based ways, enhancing adherence, functional status, psychological well-being, and healthcare utilisation, whilst reducing costs.

# Section 1: What Healthcare Professionals Cannot Provide, The Unique Value of Peer Support

## The Empathy Gap in Clinical Care

A systematic review published in npj Digital Medicine examining 29 randomised controlled trials (RCTs) across 16 countries found that healthcare interventions were most effective when they included " components with a strong human element" [1]. The review analysed remote patient monitoring technologies and concluded that technology alone, no matter how sophisticated, could not match outcomes achieved when human support accompanied technological tools [1].

However, the review didn't explicitly state that there are forms of human support that healthcare professionals, by the very nature of their role, cannot provide.

Consider what Erin told me when I asked about the primary value of their patient community: "The main thing people are going there for and how they feel supported is that we get it."

This seemingly simple statement carries profound clinical significance.

When a patient describes breathlessness to a pulmonologist, the physician draws upon textbook knowledge, clinical experience across many patients, and diagnostic algorithms. When a patient describes the same breathlessness to another PAH patient, the response comes from a fundamentally different place: I have felt exactly that. I know the terror of climbing stairs and not knowing if you'll reach the top. I understand the humiliation of having doctors dismiss your symptoms as anxiety.

Research published in Humanities and Social Sciences Communications emphasises that "doctor-patient communication is a pivotal element of clinical practice" [2]. Still, it acknowledges that "communication gaps between health professionals and patients, influenced by beliefs and expectations, risk giving rise to two errors that can compromise the therapeutic alliance: the concept of self-fulfilling prophecy and the nocebo effect" [2].

Patient communities solve this communication gap not through better medical communication, but through experiential communication, the kind that healthcare professionals, who have not lived with PAH, fundamentally cannot provide.

## The 24/7 Reality That Clinics Cannot Address

Jenna attends her specialist centre of excellence every six months. Six months. Consider what happens in the 181 days between appointments.

Symptoms fluctuate. New concerns arise. Medication side effects emerge. Exercise tolerance varies. Anxiety peaks at 2 AM when breathlessness worsens, and the clinic won't be open for another eight hours.

"Sometimes you will have times within those six months where you go, 'I feel like this could be flaring up,' or, you know," Jenna explains. "Yes, I can contact them, and I'm sure, you know, they will get you in if needed, but... having like a tool where you could sort of monitor that at a closer level could provide a bit of reassurance."

The community provides that reassurance. At 2 AM, when the clinic is closed, and the emergency department seems excessive, a patient can post: "Has anyone else experienced..." Within minutes, responses arrive from people across Australia and different time zones who are managing the same condition.

This is not medical advice, and the community is clear about that. It's contextual validation: Yes, I've felt that. Here's what my doctor said. Here's when I called them. Here's when I waited it out.

A systematic review in npj Digital Medicine found that effective monitoring interventions reduced "risks of hospital admission/readmission, length of stay, number of outpatient visits" [3]. Patient communities contribute to this by providing the crucial triage function: whether this requires immediate medical attention or is normal PAH variation.

## The “Seeing Is Believing” Phenomenon

The Humanities and Social Sciences Communications paper introduces the concept of the “Bayesian brain”, the idea that “the brain does not perceive the world as it objectively is, but as it predicts it to be” [2]. The brain continually updates its predictions in response to new evidence, refining its model of reality through a process known as “active inference.”

For newly diagnosed PAH patients, the brain’s initial prediction is catastrophic. Jenna describes Googling PAH after her diagnosis and reading: “2-5 years to live.”

“So there I was sitting at home with my five-year-old, and I thought I’ve got two to five years to live and I’m not going to see her grow up.”

This prediction, I will die soon, I cannot function, my life is over, influences everything: treatment adherence, willingness to exercise, ability to work, relationships, and mental health.

Now, enter the patient community. Jenna encounters Erin, who has lived with PAH for 21 years before her transplant. She meets others who work, raise children, travel, and maintain active lives. The brain’s prediction updates: I can live with this. Quality of life may be possible. Perhaps there is hope.

This is not false reassurance; it’s evidence-based optimism. And it changes behaviour.

The paper emphasises that “positive beliefs and expectations communicated by healthcare providers can trigger a self-fulfilling prophecy, where patients experience better health outcomes simply because they believe in the effectiveness of their treatment” [2].

Patient communities amplify this effect through social proof. When Jenna sees 50 other patients reporting that exercise, whilst difficult, improved their functional capacity, she’s more likely to adhere to pulmonary rehabilitation. When she sees others managing medication regimens successfully, her own adherence improves.

The npj Digital Medicine review documented that interventions showing “positive outcomes in patient safety and adherence” were most successful [3]. Patient communities directly enhance adherence through constant, naturalised reinforcement of beneficial behaviours.

## The Motivation That Clinicians Cannot Sustain

During our conversation, I drew a crucial parallel between patient communities and fitness platforms. If we look at Fitbit, for example, or Strava or Whoop, they all have communities built into them. People interact and learn from one another. This comparison is clinically significant.

Fitbit doesn't work because of the technology alone. A study in the Journal of Medical Internet Research found that wearable fitness trackers achieve adherence and behaviour change primarily through social accountability, community challenges, and visible progress tracking [4]. Users who engage with the community features achieve dramatically better outcomes than those who use the device in isolation [4].

The same principle applies to patient communities managing chronic conditions.

When Jenna exercises, she shares her progress with the community. When she struggles, others encourage her. When she achieves milestones, walking further, reducing symptoms, and avoiding hospitalisation, the community celebrates.

Erin articulates this perfectly: "When I was at the peak of being unwell, it's not thinking that you have to do it all. Something is better than nothing, and taking that kind of imperfect action to try and keep yourself even 1% better."

This mindset of incremental improvement, of imperfect action, of getting 1% better, is precisely the psychological approach that drives adherence in fitness communities. And it's exactly what chronic disease management requires.

But there's a crucial difference. A healthcare provider can encourage exercise at each clinic visit every six months. The community reinforces it daily. A physiotherapist can explain the benefits of pulmonary rehabilitation in a 30-minute session. The community demonstrates those benefits through numerous lived examples that are constantly visible. A physician can prescribe medication and explain its importance. The community normalises the medication regimen, troubleshoots side effects, and provides accountability through casual check-ins: "Have you taken your meds today?"

The Humanities and Social Sciences Communications paper argues for "integrating a Bayesian interpretation of the human mind into healthcare" to "discourage reliance on a singular perspective, ensuring a broader understanding of patient needs" [2]. Patient communities provide that broader understanding, providing multiple perspectives, multiple experiences, and multiple models of successful disease management.

## Section 2: The Clinical Evidence, Why Communities Improve Outcomes

The question for healthcare professionals is straightforward: Does community support actually improve clinical outcomes, or is it merely emotional comfort?

The evidence is unequivocal: it improves outcomes.

### Adherence: The Foundation of Treatment Success

The npj Digital Medicine systematic review, analysing 29 RCTs across diverse patient populations, identified adherence as "a critical factor" in treatment success [1]. The review found that "interventions demonstrating positive outcomes in patient safety and adherence were most successful" [1]

Four studies in the review specifically examined adherence to medication or lifestyle prescriptions [1]. Blasco et al. reported statistically significantly higher rates of adherence to prescribed exercise routines amongst patients with moderate to severe COPD who received remote monitoring and support [5]. Geramita et al. similarly found a statistically significant lower risk of non-adherence to lifestyle requirements for patients enrolled in remote patient monitoring (RPM) interventions compared to those receiving usual care [6]. Riegel et al. observed a significant decline in median medication adherence amongst control group patients who were not monitored, compared to patients who were monitored [7]. Likewise, DeVito Dabbs et al. reported significantly higher odds of self-monitoring amongst lung transplant patients discharged with tracking technology [8].

The pattern is clear: support structures improve adherence. But why do patient communities specifically enhance adherence in ways that standard clinical care does not?

Normalisation of treatment burden is the first mechanism. When patients see 1,200 others managing multiple medications, oxygen therapy, and exercise regimens, their own burden feels manageable rather than exceptional. Practical troubleshooting is the second. Communities share strategies for managing side effects, optimal timing for medications, dietary interactions, and travel logistics, and granular practical knowledge that clinicians often lack time to discuss.

Social accountability forms the third mechanism. Casual community interactions create gentle accountability. When someone mentions their exercise routine or medication adherence, others are implicitly reminded of their own. Finally, there are visible benefits. As Jenna noted about exercise: “I have noticed if I don’t move my body, then the next time that I do exercise, I can feel that I’ve deteriorated quite a lot.” The community amplifies this observation through collective experience, creating powerful motivation.

## Functional Outcomes and Quality of Life

The npj Digital Medicine review found that effective interventions “improved patients’ mobility and functional statuses” when proper support was provided [1]. Seven studies documented significant improvements in mobility using the six-minute walk test, the SF-36 and SF-12, and the modified Barthel Index [1].

Critically, the review noted: “RPM interventions have shown improvements in the mobility and functional statuses of patients in general.”

Patient communities function as continuous support structures that healthcare systems cannot match.

Consider Erin’s insight about pre-transplant management: “Movement is the most important thing. Otherwise, your outcomes are worse.”

This knowledge, that pre-transplant physical conditioning directly influences post-transplant survival, came from 21 years of lived experience, reinforced by community observation of others’ outcomes, and validated by medical teams. But it’s the daily community reinforcement that translates this knowledge into sustained behaviour change.

The Humanities and Social Sciences Communications paper emphasises that “incorporating psychosocial and cultural perspectives into healthcare practices” is essential for effectiveness [2]. It notes that “understanding patients’ cultural backgrounds, beliefs, and social contexts can significantly enhance the effectiveness of treatment plans and improve patient engagement and satisfaction.”

# Psychological Wellbeing and the Mind-Body Connection

The Humanities and Social Sciences Communications paper devotes substantial attention to "the interaction between mind and body" as "a critical factor in healthcare outcomes" [2]. The authors argue that "effective communication can harness this relationship to enhance patient care" through two key mechanisms [2].

The first is a self-fulfilling prophecy. Positive beliefs and expectations can trigger better health outcomes. When a community consistently reinforces that management is possible, that quality of life can be maintained, and that there is hope, these beliefs influence outcomes. The second is nocebo effect mitigation. Conversely, negative expectations deriving from the clinical encounter can produce adverse outcomes, known as nocebo effects. The paper cites research showing that exposure to a negative psychosocial context may exacerbate symptoms and anxiety [2].

Patient communities directly counteract the nocebo effect that can result from frightening diagnoses.

When Jenna was told she had "an incurable heart and lung condition" and then Googled to find "2-5 years to live," she experienced profound nocebo priming. Her brain's prediction: I will die soon. That prediction influences physiological stress responses, cortisol levels, inflammation, and ultimately disease progression.

The community provided immediate nocebo mitigation. Those statistics are outdated, they told her. Treatment has improved dramatically. Many of us have lived for decades. Look at Erin, 21 years and thriving.

The paper notes that "the relationship between mind and body is integral to understanding patient experiences and outcomes" and that "positive communication can strengthen the patient's belief in the treatment, thereby enhancing the placebo effect and improving physiological responses" [2].

Community support provides continuous positive communication that individual clinical encounters, limited to 15-minute appointments every six months, simply cannot sustain.

## Healthcare Utilisation and Cost Outcomes

The npj Digital Medicine review examined cost-related outcomes across 12 studies, finding “reduced risks of hospital admission/readmission, length of stay, number of subsequent follow-ups and non-hospitalisation costs” amongst patients receiving appropriate support [1].

The specific findings paint a compelling picture. Boriani et al. reported fewer in-hospital visits in the intervention group along with a markedly shorter median time from device-detected events to clinical decision-making [9]. Indraratna et al. found that patients who received remote monitoring had a lower risk of 30-day readmission [10]. Similarly, Weintraub et al. and Wintrich et al. observed reduced hospitalisations amongst patients monitored with technology [11,12]. Higgins et al. and Hindricks et al. reported significantly fewer post-surgical outpatient visits and unscheduled follow-ups, while Guédon-Moreau et al. found that mean non-hospitalisation costs per patient-year were substantially lower [13-15].

Patient communities contribute to these cost reductions through sophisticated self-triage.

Erin explained the practical reality: “We point each other in the right direction of centres of excellence, or if they can’t access those, which are generally all in the cities, if we know of any other clinics that do satellite clinics closer to them. We can also  help with recommendations for things like doctors and websites.”

This intelligence network prevents unnecessary emergency department visits when symptoms are typical PAH variation, whilst encouraging appropriate escalation when symptoms genuinely warrant urgent attention.

Moreover, the community addresses the “worried well” phenomenon. When a patient experiences a new symptom and asks, “Has anyone else felt this?”, responses like “Yes, that’s a known side effect of your medication, but mention it at your next appointment” provide reassurance that prevents anxiety-driven healthcare utilisation.

# Section 3: The Diagnostic Catastrophe That Creates Community Need

To understand why patient communities are essential, we must first examine the systemic failures that necessitate them.

## The Pattern of Dismissal: Gender, Age, and Cognitive Bias

Jenna's diagnostic journey exemplifies multiple cognitive biases that affect the diagnosis of rare diseases.

The availability heuristic plays a significant role. GPs see anxiety frequently, PAH rarely. When symptoms could fit either pattern, the more common diagnosis is favoured. Gender bias compounds this. The Humanities and Social Sciences Communications paper notes that "communication gaps between health workers and patients, influenced by beliefs and expectations", often lead to diagnostic errors [2]. Young women reporting breathlessness, palpitations, and chest pain are frequently diagnosed with anxiety before organic disease is considered.

Then there's anchoring bias. Once Jenna was labelled with anxiety, subsequent presentations were interpreted through that lens. Antidepressants were prescribed, dosages increased, and additional anxiety medications added, all whilst PAH progressed unchecked.

Jenna's symptoms progressed from elevated heart rate to chest pain that radiated down her arm, which she described as "obviously concerning," to severe exercise intolerance. She was exercising five times weekly and deteriorating. Yet the response was: "It's probably just a case that you're unfit."

## The Knowledge Gap at the Primary Care Level

Both Jenna and Erin identified GP education as the critical intervention point for reducing diagnostic delays.

"I think it's the doctors," Jenna emphasised. "So that road to diagnosis is significantly shorter."

Erin, who has participated in medical education programmes about PAH, noted improvements at the specialist level: "Specialist cardiologists, they're actually recognising it now. They're doing well at that specialist level, but like I said, at the primary healthcare level, it's still, they're still so far behind."

The challenge is substantial. There are approximately 7,000 rare diseases. A GP cannot be an expert in all of them. Yet PAH presents with typical symptoms, breathlessness, fatigue, and chest pain, which could indicate dozens of conditions.

The 10-minute consultation becomes an impossible puzzle: identify zebras whilst expecting horses, all within severe time constraints, when diagnostic tests are expensive, and specialist referrals are rationed.

Jenna described being told, "It's going to be expensive to see a specialist." The implication: You don't look sick enough to justify the cost.

## The Lie That Saved a Life

Erin's story reveals the desperation that diagnostic failures create.

Despite a family history so significant it should have triggered an immediate investigation, Erin was dismissed for nine months. At age 16, experiencing "bad shortness of breath and chest pain," she "lied to a new GP" to secure a cardiologist referral.

"I said, I'm due for a review with a cardiologist because of my family history. I'd only seen a cardiologist about seven months before this."

That lie, a patient having to deceive her doctor to access appropriate care, saved her life. The echo confirmed the presence of PAH immediately, and she was referred to a centre of excellence the next day.

Should patients be required to deceive their physicians to obtain appropriate care? Absolutely not. Yet across the 1,200-patient community, similar stories are "all too common," as Erin notes.

## The Cost of Delay

Jenna’s reflection haunts every conversation about rare disease diagnosis: “I still sometimes wonder if I didn’t demand to go see that cardiologist, would I still be undiagnosed with a progressive illness? And I also sometimes wonder... had I been diagnosed earlier, would my disease not have progressed as far as it did if I were able to have access to treatment earlier?”

The Humanities and Social Sciences Communications paper emphasises that “the pitfalls of fragmented care and absent teamwork between healthcare professionals often result in a narrow medical perspective, which negatively impacts patient outcomes” [2].

For Jenna, the “narrow medical perspective” of a young mother with anxiety resulted in a three and a half year wait without treatment for a progressive, life-threatening condition.

When she was finally diagnosed, her right heart catheterisation showed median pulmonary artery pressures of 52 mmHg (normal is less than 20 mmHg). After six months on two oral therapies, her blood pressure decreased to 38 mmHg. After another year, they remained at 38 mmHg, improved from baseline, but were still severely elevated.

Would earlier diagnosis and treatment have prevented this level of disease progression? We cannot know. But the question is clinically and ethically significant.

# Section 4: What Patient Communities Actually Do, The Practical Reality

When I asked Erin to describe their community's function, her response was precise.

## The Knowledge Economy

"We point each other in the right direction of centres of excellence, or if they can't access those, which are generally all in the cities, and if we know of any other clinics that do satellite clinics closer to them. We can help with recommendations for things like doctors and websites. It's all just all-around support, really."

This is sophisticated healthcare navigation intelligence. The community collectively knows which centres of excellence have shorter wait times, which cardiologists have expertise in PAH, which satellite clinics offer which services, which telemedicine options exist, which specialists are accepting new patients, and which are worth the travel.

No formal healthcare system maintains this kind of real-time, patient-centred intelligence. Yet it's invaluable for patients navigating complex, fragmented care systems.

## Symptom Validation and Differentiation

When a patient describes a symptom to their doctor and the response is "I haven't heard of that," the patient is left wondering if they're "normal," as Erin puts it.

The community provides immediate context: "Half a dozen of them have felt the same thing."

This serves multiple clinical functions. First, distinguishing PAH symptoms from other causes. Is this breathlessness from PAH progression, medication side effects, anxiety, deconditioning, or an unrelated infection? The community's collective experience helps differentiate. Second, identifying medication side effects. Communities quickly recognise patterns. When multiple patients on a specific medication report similar experiences, that information feeds back to medical teams.

Third, recognising warning signs. The community collectively learns which symptoms warrant immediate medical attention and which can wait for scheduled appointments. Fourth, normalising disease experience. Knowing that others experience the same challenges reduces the psychological burden of feeling uniquely afflicted.

The Humanities and Social Sciences Communications paper emphasises that “the integration of cultural perspectives is particularly important in understanding patient behaviours, beliefs, and values, which can significantly influence health outcomes” [2].

The PAH patient community has developed its own “culture” of disease management, shared language, shared understanding, and shared norms that healthcare providers, despite their expertise, cannot fully access.

## Geographic Barriers and Community Solutions

For Australian PAH patients, geography compounds every challenge.

“You look at the size of Australia, you look at the population of Australia, and accessibility is a big problem because to get to those centres of excellence, a lot of people have to travel by plane,” Jenna explains. “Which can be a real struggle in itself, especially for those people who are on oxygen.”

Consider the compounding barriers. Distance means centres of excellence are in major cities, Sydney, Melbourne, Brisbane, Perth, whilst regional patients may be hundreds or thousands of kilometres away. Cost becomes prohibitive: “A lot of people with PAH may be too sick to work, so they can’t afford to fly to a centre of excellence to have regular monitoring.”

Physical burden compounds the problem. Air travel for oxygen-dependent patients involves complex logistics. Airlines have restrictions. Oxygen supplies must be arranged. The physical stress of travel can trigger symptoms. Time requirements make matters worse. A routine six-month follow-up appointment might require two days of travel, overnight accommodation, and significant expense.

The community addresses these barriers by sharing information. They tell each other which satellite clinics provide adequate care, how to navigate airline oxygen policies, which accommodation options are near hospitals, how to request bulk billing or financial assistance, and which local GPs are knowledgeable about PAH.

This intelligence transforms accessibility. Without it, regional patients face impossible choices between adequate care and financial ruin.

## Mental Health Support and the Emotional Labour of Chronic Illness

Jenna's post-diagnosis experience is emblematic: told she has "an incurable heart and lung condition," sent home, Googles PAH, reads "2-5 years to live."

"So there I was sitting at home with my five-year-old, and I thought I've got two to five years to live and I'm not going to see her grow up."

Healthcare systems often lack resources to address the profound psychological trauma of a serious diagnosis. A 15-minute consultation cannot process the existential terror, the grief for the life you expected, the fear of leaving your children, or the anxiety about disease progression.

The community provides what clinicians often cannot: time, empathy, hope grounded in lived experience, and permission to grieve whilst maintaining hope.

Research in Humanities and Social Sciences Communications emphasises that "integrating psychological support into medical treatment plans" is essential. The paper notes that "poor communication can increase stress and negative expectations, exacerbating the nocebo effect and worsening health outcomes" [2].

Patient communities provide continuous psychological support that healthcare budgets often cannot fund. This is not a replacement for professional mental health services when needed, but rather the ongoing, normalised emotional labour of living with chronic illness.

## Treatment Navigation and Advocacy

Both Jenna and Erin highlighted challenges accessing new therapies in Australia.

Jenna explained: "We do need to have access to them here in Australia, though, because they're no good being out there if we can't use them."

The community functions as an advocacy collective, pooling knowledge on which therapies are available overseas, which clinical trial opportunities are available, which lobbying pathways exist for medication approval, how to access compassionate use programmes, and which patient assistance programmes pharmaceutical companies offer.

This collective advocacy achieves what individual patients cannot. When 1,200 patients collectively lobby for access to medications, policymakers listen. When individual patients request it, they're often dismissed.

## The Practical Tips That Make Treatment Tolerable

Communities share granular, practical knowledge that enables treatment adherence.

Medication timing advice flows constantly. Take this one with food, that one on an empty stomach; this one causes insomnia, so take it in the morning. Side effect management strategies circulate. Ginger tea may help with nausea associated with this medication. Compression stockings may help with that side effect.

Exercise strategies are shared and refined. Start with five minutes, use breathing techniques taught in pulmonary rehab, and don't push through chest pain. Diet modifications get discussed. Low sodium really helps with fluid retention. These foods interact with your medications.

Travel tips facilitate the maintenance of treatment routines. How to pack medications, how to manage exercise routines when travelling, how to find oxygen suppliers in different cities, all this knowledge circulates continuously.

This knowledge is invaluable. It's the difference between treatment that's theoretically optimal but practically intolerable versus treatment that patients can actually sustain long-term.

# Section 5: The Biopsychosocial Model That Communities Naturally Provide

The Humanities and Social Sciences Communications paper argues for "a biopsychosocial approach that includes biological, psychological, and social dimensions" in healthcare delivery [2]. The paper notes that healthcare systems often fail to integrate these dimensions systematically, defaulting instead to biomedical reductionism [2].

Patient communities inherently provide this biopsychosocial approach.

## The Biological Dimension

Communities share information about disease progression patterns, treatment effects and side effects, symptom management strategies, which investigations are helpful, and how different patients respond to other therapies.

This collective biological knowledge, aggregated across 1,200 patients, provides insights that individual clinicians, who may see dozens of PAH patients, cannot match.

## The Psychological Dimension

Communities provide emotional validation and support. They offer anxiety reduction through shared experience. They provide hope through visible examples of successful management. They share mental health strategies for coping with chronic illness. They give permission to experience the full range of emotions: fear, grief, anger, frustration, and hope.

The Humanities and Social Sciences Communications paper emphasises that "managing patient expectations and reducing anxiety through clear communication can significantly enhance health outcomes" [2].

Community support achieves this through naturalised, continuous positive communication that clinical encounters cannot sustain.

## The Social Dimension

Communities address social isolation from having a rare disease. They address relationship challenges by teaching patients how to explain PAH to family, friends, and employers. They provide practical support, can help with childcare during appointments, and understand workplace accommodations. They support social identity, helping patients redefine themselves beyond being a “PAH patient.”

Research shows that social isolation negatively impacts health outcomes across numerous conditions. Patient communities directly combat isolation by creating connections around shared experiences.

## The Integration That Systems Lack

The Humanities and Social Sciences Communications paper argues that “the future of healthcare requires an integrative approach that combines technological advancements, continuous professional development, cultural competence, holistic health models, interdisciplinary collaboration, and patient empowerment” [2].

Patient communities embody several of these elements. They provide patient empowerment, shifting the locus of control from passive recipients of care to active disease managers. They demonstrate cultural competence, understanding the lived culture of PAH management, the daily realities that textbooks don’t capture. They exemplify holistic health models that address biological, psychological, and social dimensions simultaneously.

The paper emphasises that “healthcare providers can create a more integrated and effective treatment plan” when these dimensions are addressed [2]. Patient communities do this naturally, filling the gaps left by formal systems.

## Section 6: The Fitbit Parallel, Why Community-Driven Accountability Works

During our conversation, I drew a parallel between patient communities and fitness platforms. If we look at Fitbit, for example, or Strava or Whoop or any of these products that are out there, they all have communities built into them. People interact and learn from one another. This comparison deserves deeper exploration because it reveals why community support succeeds where individual motivation often fails.

### The Social Accountability Mechanism

Research on fitness tracker adherence consistently shows that devices are most effective when users engage with community features.

The mechanisms are precise. Visible progress matters. When Jenna exercises and shares progress, even casually mentioning it, she's more likely to maintain the behaviour. Comparative performance creates aspirational targets. Seeing others achieve milestones creates goals to work towards. Supportive encouragement reinforces behaviour. Community celebration of achievements strengthens commitment.

Gentle pressure plays a role, too. Not wanting to be the only one not participating creates accountability. Practical tips improve strategies. Learning what works for others enhances personal approaches.

These exact mechanisms apply to the management of PAH. The difference is that for PAH patients, the stakes are not fitness goals but functional capacity, disease progression, and survival.

### Incremental Improvement and the "1% Better" Philosophy

Erin's articulation of the community ethos is remarkable: "When I was at the peak of being unwell, it's not thinking that you have to do it all. Something is better than nothing, and taking that kind of imperfect action to try and keep yourself even 1% better."

This is precisely the mindset that drives successful behaviour change in fitness communities, now applied to chronic disease management.

The Humanities and Social Sciences Communications paper notes that "illness expectations can impact symptoms and disease progression through two distinct pathways: a behavioural route and a non-behavioural avenue” [2]. The behavioural route involves “adherence to treatment and lifestyle modifications such as physical activity.” [2]

When communities normalise incremental effort, it’s acceptable if you can only manage five minutes of exercise today; they reduce the psychological barrier to starting. Perfect becomes the enemy of good, and patients who might otherwise do nothing because they can’t do “enough” instead do something.

This incremental approach, reinforced daily through community interaction, creates sustained behaviour change that clinical exhortations to “exercise regularly” simply cannot achieve.

## Celebration of Non-Scale Victories

Fitness communities celebrate “non-scale victories”, being able to climb stairs without breathlessness, having more energy, sleeping better, rather than focusing solely on weight or numerical targets.

PAH communities do the same. Celebrations include walking further in the six-minute walk test, reduced oxygen requirements, ability to play with grandchildren, return to work, avoidance of hospitalisation for another year, and stable pressures on right heart catheterisation.

These celebrations serve multiple functions. They reinforce that disease management is working. They provide hope to others who are struggling. They create social bonds around shared achievements. They generate positive emotions that counter disease-related depression.

The Humanities and Social Sciences Communications paper emphasises that “positive communication can strengthen the patient’s belief in the treatment, thereby enhancing the placebo effect and improving physiological responses” [2].

Community celebrations are ongoing forms of positive communication that sustain hope and adherence.

## The Power of Visibility: Seeing Others Succeed

One of the most potent aspects of fitness communities is visibility. You see others achieving goals similar to yours, making those goals feel attainable.

For patients with PAH, this visibility is transformative.

Jenna meets Erin, who has lived with PAH for 21 years. Not 2-5 years, as the Google search predicted, but 21 years, including working, thriving, ultimately receiving a successful transplant, and now thriving post-transplant.

This is not an anecdote; it's social proof. It updates the brain's Bayesian prediction from I will die soon to Long-term survival is possible. Quality of life is achievable. I can do this.

Research on self-efficacy, the belief in one's ability to succeed, shows that "vicarious experience," or observing others like oneself succeed, is one of the four key sources of self-efficacy. The others are mastery experience, verbal persuasion, and physiological states.

Patient communities provide all four. They offer vicarious experience through seeing others manage successfully. They facilitate mastery experience by providing a platform for sharing your own successes. They deliver verbal persuasion through encouragement from others. They help with physiological states by teaching patients to interpret symptoms accurately.

Enhanced self-efficacy improves adherence, which improves outcomes, which further enhances self-efficacy, a virtuous cycle that communities sustain.

# Section 7: What Healthcare Professionals Must Do Now

The evidence is clear. The mechanisms are understood. What should healthcare professionals actually do with this knowledge?

## Prescribe Community Connection as Part of Treatment

When diagnosing PAH, or any rare disease, clinicians should say: “Along with medications and regular monitoring, I strongly recommend you connect with the patient community. They provide support and practical knowledge that I, as your doctor, simply cannot.”

Make this as routine as prescribing medication. Provide contact information for established communities. Facilitate introductions where possible.

The npj Digital Medicine review found that interventions with “a strong human element” achieved better outcomes [1]. Community connection is that human element.

## Create Feedback Loops with Communities

Communities possess collective wisdom that individual clinicians cannot match, so mechanisms must be developed to disseminate this knowledge back to medical teams.

Regular town hall-style meetings where community representatives share common concerns, patterns they’ve observed, and gaps in care can help inform practice improvements.

When multiple patients report a pattern, a previously unknown medication side effect, or a particular symptom cluster that predicts deterioration, investigate it. Don’t dismiss it as “anecdotal.”

The Humanities and Social Sciences Communications paper emphasises “the importance of integrating diverse perspectives to prevent one viewpoint from dominating” [2]. Communities represent that diversity.

## Educate Primary Care Aggressively

Both Jenna and Erin identified GP education as the single most critical intervention for reducing diagnostic delays.

Medical schools, postgraduate training programmes, and continuing medical education must systematically address the recognition of rare diseases. The specific pattern-recognition skills matter. Young women with unexplained breathlessness should prompt consideration of PAH before assuming anxiety. Symptoms that worsen despite treatment require reconsideration of the diagnosis. A family history of a rare disease must be taken seriously, even in young, otherwise healthy patients. Exercise intolerance disproportionate to deconditioning demands investigation for cardiopulmonary causes.

Develop decision-support tools that prompt consideration of rare diseases when specific symptom clusters are observed.

The Humanities and Social Sciences Communications paper notes that "training healthcare providers in cultural competence" is essential [2]. Understanding rare disease culture, the diagnostic odysseys, the dismissal, and the desperation is part of that competence.

## Address Geographic Barriers Systematically

For countries like Australia, with vast distances and concentrated expertise, the current model, requiring patients to travel to capital cities, is unsustainable.

Solutions include expanded telemedicine for routine follow-up, satellite clinics with specialist video consultations, training regional cardiologists in PAH management basics, mobile clinics for remote areas, and financial support for travel when an in-person assessment is essential.

Patient communities already identify many of these solutions. Healthcare systems need to implement them systematically.

## Integrate Communities into Care Pathways

Rather than viewing communities as peripheral to care, formally integrate them into care.

At diagnosis, provide a structured introduction to patient communities, for example, through a “buddy system” in which newly diagnosed patients are paired with experienced community members. During treatment, recognise community participation as part of the therapeutic plan, equivalent to pulmonary rehabilitation or psychological support. During care transitions, use community support during vulnerable periods, such as hospital discharge, initiation of new medications, and episodes of deterioration.

The npj Digital Medicine review found that interventions including “personalised care, self-management and patient education” alongside technology achieved the best outcomes[1]. Communities provide all three.

## Research Community Impact Rigorously

We need robust research on how patient communities influence clinical outcomes. Questions include what the adherence differential is between community-connected and isolated patients, how functional outcomes differ over time, what the healthcare utilisation pattern differences are, whether community-connected patients have different rates of hospitalisation, what the cost-effectiveness of facilitating community connection is, and which community engagement patterns predict the best outcomes.

The Humanities and Social Sciences Communications paper emphasises “the need for more economic evaluations and implementation studies” [2]. Studying community impact systematically would provide the evidence base for formal integration into care pathways.

## Advocate Alongside Communities

When communities identify barriers, medication access, funding issues, and geographic challenges, healthcare professionals have a duty to advocate alongside them.

Our conversation concluded with a commitment: we would document patient experiences, present them to policymakers, and push for change. Every healthcare professional working with patients with rare diseases should make similar commitments.
The Humanities and Social Sciences Communications paper notes that "future research should explore whether incorporating intervention components with a strong human element alongside the deployment of technology enhances the effectiveness" of healthcare interventions [2].

Patient communities are that human element. But they function despite, not because of, formal healthcare structures. It's time to change that.

# Section 8: The Broader Implications, Beyond PAH

Whilst this article focuses on PAH, the principles apply to rare diseases and chronic conditions more broadly.

## The Rare Disease Landscape

There are approximately 7,000 rare diseases[16]. Collectively, they affect about 300 million people globally [16]. For each condition, similar patterns emerge: diagnostic delays averaging 5-7 years for rare disease diagnosis, dismissal of symptoms, knowledge gaps in primary care, geographic access barriers, limited research due to small patient populations, and feeling isolated and misunderstood.

For each rare disease, patient communities exist. They serve identical functions: emotional support, practical knowledge sharing, advocacy, and gap-filling in formal healthcare.

## Chronic Disease Management More Broadly

The principles extend beyond rare diseases to common chronic conditions, diabetes, heart failure, COPD, chronic pain, and mental health conditions.

The npj Digital Medicine review examined interventions across diverse conditions: coronary disease, COPD, post-surgical patients, postpartum women, neurological conditions, cancer, and COVID-19 [1]. Across all conditions, “interventions demonstrating positive outcomes in patient safety and adherence” included strong support elements [1].

For all chronic conditions, community support provides normalisation of the disease burden, practical management strategies, social connections that reduce isolation, hope through visible examples of successful management, and motivation and accountability.

## The Mental Health Parallel

Mental health communities for conditions such as depression, anxiety, bipolar disorder, and eating disorders demonstrate particularly powerfully why peer support provides what clinicians cannot.

A therapist, no matter how skilled, has not experienced the condition they’re treating. They can empathise, but cannot say: I know exactly how this feels because I’ve lived it.

Peer support in mental health achieves outcomes that complement professional care. The same principle applies to physical health conditions.

## The Healthcare System Transformation Required

The Humanities and Social Sciences Communications paper argues that “the future of healthcare requires an integrative approach”, including “patient empowerment” and “interdisciplinary collaboration” [2].

Patient communities embody patient empowerment. Recognising and integrating them represents an essential healthcare system transformation.

But this requires fundamental shifts. We must move from paternalism to partnership, acknowledging that patients, collectively, possess expertise that complements clinical knowledge. We must shift from individual to community, recognising that optimal care addresses not just the individual patient but their social context. We must transition from episodic to continuous care, recognising that six-monthly appointments cannot provide the constant support that chronic illness requires. We must move from a biomedical to a biopsychosocial approach, addressing biological, psychological, and social dimensions simultaneously.

The paper emphasises that "healthcare systems that recognise and integrate these communities will deliver better care. Systems that ignore them will continue to fail patients" [2].

## Conclusion: A Fundamental Rethinking of Support Infrastructure

When I asked Jenna and Erin why they contacted electronRx, the answer was revealing. They had heard about our respiratory monitoring technology, indeed. But more than that, they were encouraged by the fact that we were "people sharing stories and being invested," as Jenna put it.

Patients with chronic conditions are exhausted by healthcare systems that see them as collections of symptoms to be managed rather than as whole human beings navigating complicated lives.

They're exhausted by being told "I haven't heard of that" when they describe symptoms.

They're exhausted by being dismissed, delayed, and disbelieved.

They're exhausted by fragmented care where no one sees the whole picture.

And they're exhausted by well-meaning healthcare professionals who prescribe exercise, medication adherence, and lifestyle changes without understanding the monumental daily effort required to actually live with a chronic condition.

Patient communities exist because formal healthcare systems have failed to address these realities.

However, the evidence shows that communities don’t just provide comfort; they improve clinical outcomes.

They improve adherence to medication and lifestyle prescriptions through normalisation, accountability, and practical troubleshooting. They improve functional status through motivation, shared strategies, and the “1% better” philosophy that makes incremental progress achievable. They enhance psychological well-being by combating the nocebo effect, providing hope grounded in lived experience, and creating social connection that reduces isolation. They reduce healthcare utilisation by enabling appropriate self-triage, preventing anxiety-driven emergency visits, and facilitating access to optimal care.

And they do all of this whilst providing something that even the most dedicated healthcare professional simply cannot: the lived experience of managing a condition 24 hours a day, 365 days a year, for decades.

The Humanities and Social Sciences Communications paper concludes that “the adoption of a comprehensive, multidisciplinary approach to patient treatment and the incorporation of patient preferences into treatment decisions can enable continuous learning amongst healthcare professionals, ultimately contributing to a truly patient-centred healthcare system” [2].

Patient communities are a patient-centred approach. They’re not peripheral to care, they’re central to it.

The question for healthcare systems is straightforward: will we continue to let communities function despite formal structures, or will we finally recognise, respect, and integrate them into the care we provide?

For Jenna and Erin and 1,200 other PAH patients in Australia, and for the 300 million people globally living with rare diseases, and for the billions managing chronic conditions, the answer matters profoundly.

As I told Jenna and Erin at the end of our conversation: “If we can help you, I think it makes, yeah, it gives a sense of purpose, doesn’t it, in life? You know, why do I wake up at five in the morning every day to do this stuff?”

The answer is simple: because patients deserve better. Because diagnostic journeys of three and a half years represent preventable suffering. Because communities of 1,200 patients shouldn’t have to exist as a workaround for healthcare system failures, they should be recognised as the essential clinical infrastructure they are.

The evidence supports it. The lived experience demands it. The outcomes prove it.
It’s time to act.

This article was informed by two podcast conversations with PAH patients Jenna Mazor and Erin Baker recorded in November and December 2025, research published in Humanities and Social Sciences Communications (2025) on integrating psychological and mental health perspectives in disease management (Grosso, F.), and a systematic review in npj Digital Medicine (2024) on remote patient monitoring interventions (Tan, S.Y., Sumner, J., Wang, Y., & Yip, A.W.).

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## About The Author

Dr Bipin Patel is CEO of electronRx, a Cambridge-based healthcare technology company developing remote respiratory monitoring solutions. With over 30 years in healthcare innovation, Dr Patel and his team have spent the last seven years focused on creating accessible, smartphone-based respiratory monitoring technology,"a Fitbit for lungs", to empower patients and clinicians managing chronic respiratory diseases.

electronRx's mission is to make continuous respiratory monitoring available to hundreds of millions of people globally, removing geographic and financial barriers to quality care. The company's technology uses AI-powered analysis of smartphone recordings to provide clinically meaningful respiratory data without requiring complex equipment or forced breathing maneuvers.

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