World Medical
Journal

WMJ Interview with Experts in Patient Advocacy and Engagement

Clarinda Cerejo

Caitlin Rich

For this interview, Clarinda Cerejo and Caitlin Rich, hosts of the "Not Just Patients" podcast (https://notjustpatients.com/), describe the need to reinforce patient engagement and shared decision-making in physician–patient interactions. Their award-winning podcast aims to break barriers to meaningful patient involvement in healthcare, by challenging patient stereotypes, highlighting successful collaborations in healthcare, and sharing energising tales of turning adversity into advocacy. In this interview with Dr. Helena Chapman, the WMJ Editor in Chief, they comment on how their lived experiences and training facilitated their podcast leadership, describe systemic gaps in health systems, and propose how physicians can advance efforts to ensure physician-patient rapport and better quality of care.

Tell us more about the "Not Just Patients" podcast and how your collective roles as podcast co-hosts have created an inclusive and informed community.

Clarinda Cerejo: We started the "Not Just Patients" podcast in April 2024, shortly after we met at the Patient Expert Training programme run by the European Patients Academy for Therapeutic Innovation (EUPATI). During the programme, we learned about the value of patient involvement across various stages of the medicines development process. We started the podcast as a way to continue our learning and highlight for a broad audience the value that patient perspectives can add to all aspects of healthcare, even beyond medicines development. This mission holds deep significance for us, both as patients living with rare and chronic diseases, and as professionals working in healthcare communications and stakeholder engagement. The "Not Just Patients" podcast aims to break down barriers to meaningful patient involvement in healthcare. By talking about the barriers and opportunities to patient engagement from different stakeholders' lenses, we highlight the infinite possibilities for patients to bring value and create impact throughout the healthcare continuum.

Caitlin Rich: Patient engagement should be implemented across all facets of the healthcare system, and therefore requires collaboration from all stakeholders. The "Not Just Patients" podcast lives up to its name: it is for everyone, not just patients! Our guests and audience represent a diverse variety of stakeholders from across the healthcare ecosystem and around the world, including physicians; patient advocates; pharma representatives; regulatory, policy, medical publishing experts; and healthcare agency leaders. As hosts, we also bring our unique perspectives and experiences: I live in London and have been living with cystic fibrosis since birth, while Clarinda lives in Mumbai and was diagnosed with neuromyelitis optica spectrum disorder in her 20s.

While we interview globally recognised experts on highly technical topics, we break them down with practical advice and real-world examples, making each episode accessible and actionable for all. We recognise that no one expert holds all the answers on any topic, so while our guests share deep knowledge, the conversations are designed to spark reflection and challenge assumptions. We encourage listeners to share their stories, successes, and questions, fostering collective learning for everyone. While this journey started as a passion project to champion patient engagement, we have led this podcast for two years, releasing over 24 monthly episodes, ensuring steady audience growth, and receiving two business awards.

From the patient's perspective, can you describe three primary systemic gaps in health systems that challenge physician–patient rapport and quality of care?

Clarinda Cerejo: In my experience, some systemic and cultural issues can undermine shared decision-making from the outset. One gap is the inherent power imbalance between physicians and patients, where doctors are viewed as superior authorities. If physicians do not actively work to rebalance this dynamic, patients have little chance of achieving true parity. A second gap stems from the paternalistic "doctor-knows-best" attitude, which flows directly from the power asymmetry. When physicians overuse jargon or adopt a patronising or dismissive tone, even unintentionally, patients feel unwelcome to ask questions or voice differing opinions.

A third gap lies in viewing patients as cases, rather than unique individuals. With artificial intelligence (AI) and digital tools providing better on-demand access to medical information, patients can become more informed and willing to partner in their treatment decisions. However, not all patients want to be partners, which is why physicians must view patients as individuals and meet them where they are. As Dr. Victor Montori commented in one of our podcast episodes on shared decision-making, "Treating all patients with the same condition as *cases* rather than as *individuals* with distinct preferences and life circumstances does not allow physicians to see patients in high definition."

Caitlin Rich: First, although physicians endure years of gruelling, intense training in science, medicine, and clinical practice, they receive little instruction in key "softer skills" (e.g., communication, empathy, conflict management). It is encouraging to see growing education on these topics for medical students and practising physicians, but we still have a long way to go until it is ubiquitous. Second, consultations face strict time constraints with little flexibility to extend appointments. This makes it difficult for physicians to build rapport and trust, confirm patient understanding, field questions, and obtain a holistic view of patients' history and lifestyle. While systemic changes are not always feasible, tangible strategies can help overcome these time constraints. For example, physicians can ask patients to complete pre-appointment surveys, share resources for self-paced learning, and offer access to the wider clinical team (e.g., nurses, pharmacists, psychologists) for ongoing questions and concerns. Third, as physicians experience burnout, and patients experience emotional distress, this dynamic can create tension between physicians and patients, requiring empathy from both sides to bridge the gap.

Clarinda Cerejo and *Caitlin Rich:* Although we initially answered these questions independently, we recognise that our comments reflect our distinct cultural contexts and healthcare systems. These differences often arise in our podcast discussions, uniquely positioning "Not Just Patients" to highlight health inequities and compare patient engagement practices across regions.

How can physicians best evaluate patients' health and digital literacy to ensure their equitable access to care and understanding of medical information?

Clarinda Cerejo: Once again, it starts with meeting patients where they are. The best way for physicians to evaluate comfort levels is to ask patients whether they would like additional reading materials, whether they are comfortable reading in the consultation's language, and if they have access to a device for viewing online videos. Having accessible medical information tailored to grade-school (age 11-14 years) reading levels can be invaluable for addressing common patient questions and information needs. In countries where multiple languages are spoken, localising this material can further enhance its effectiveness.

In some of my own consultations, I have found it extremely beneficial when physicians have shared videos or photos directly on their computer screen and explained relevant details in real-time. This model offers an immediate education opportunity, allowing physicians to gauge patients' ability to comprehend, while opening up space for questions during the consultation. The key is avoiding a one-size fits-all approach and rather keeping various options available to best suit patients' needs.

Caitlin Rich: My advice is to treat every patient as an individual, ask questions, and listen attentively. Avoid assumptions based on stereotypes, such as assuming a person's tech-savviness from age or language fluency from appearance. Every consultation requires sharing a bare minimum of essential information so patients can understand their condition and follow health recommendations.

BACK TO CONTENTS

World Medical Journal

After sharing this information, invite further questions or deeper discussions on specific topics, as patients' responses will reveal comprehension levels and desired detail. At the end of an appointment, ask patients to repeat back the next steps, which will confirm if they fully understand the information discussed.

Remember that most people can only absorb limited information in one meeting, especially during emotional or distressing medical circumstances. Sending patients home with accessible resources to review at their own pace can be incredibly helpful. Patient organisations and advocacy groups often provide resources specifically designed for patients. Physicians can consider their patients' needs and prepare a range of resources with different topics, depths, and formats (e.g., larger fonts, child-friendly layout, multiple languages) for patients to choose from.

How can physicians' sustainable engagement in shared decision-making with patients in clinical practice improve patients' satisfaction, adherence to treatment, and overall health outcomes?

Clarinda Cerejo: Shared decision-making is the process whereby patients and physicians work together to make informed decisions related to patient care, considering the best available evidence alongside patients' values and preferences. As a science communication professional newly diagnosed with a rare disease, I was dismayed to find the scarcity of research publications on my rare disease. I brought all relevant research papers I could find to my medical consultations, expecting physicians to engage with me as someone deeply invested in the science behind their decisions. Unfortunately, I perceived that my actions made physicians uncomfortable, and I was frequently dismissed.

The physician I eventually chose as my primary consultant embraced my research-oriented mind, answered my questions thoroughly, and collaborated with me on treatment decisions. Now, 15 years later, I often share this interaction as life-changing, because it not only brought positive medical outcomes but also served as the pivotal event that led me to pursue patient advocacy. In this sense, my first experience of true shared decision-making had a profound, snowballing positive impact on my life.

Caitlin Rich: When I first left home for my university studies, I suddenly found the burden of managing all my treatments, alongside self-care, studying, and socialising, to be overwhelming. As a result, I avoided all treatments that required anything more than swallowing a pill. While it made life easier and more fun, my health declined over time, eventually leading to hospitalisation. My doctor scolded me and insisted that I resume all medications, while adding new treatments due to my worsened condition.

Unfortunately, behaviour change is not that simple, and I lacked time in my daily schedule to manage all treatments, continue my academic routine (e.g., studying, socialising), and recommended health behaviours (e.g., adequate sleep, physiotherapy, exercise, consuming over 3000 calories a day). Although I agreed to adhere to these recommendations, I was unable to follow through. During my next consultation, I was honest about my situation with a different physician I already trusted, and together, we developed a care plan that incorporated the most important treatments while suiting my lifestyle. This physician invited a nurse and psychologist to discuss habit stacking to support behaviour change, switched me from a nebuliser (requiring 15 minutes, refrigeration, and cleaning) to a portable inhaler (taking 2 minutes before brushing my teeth). Though not the absolute best treatment per data guidelines, it improved adherence (*some* medication vs *none*) and health outcomes significantly.

As demonstrated by my own personal experiences, shared decision-making empowers patients with the knowledge, confidence, skills, and motivation to manage their own health. This is particularly important for chronic conditions, where care must seamlessly integrate into daily life over the long-term. If you would like to learn more about shared decision-making from the physician and patient perspectives, I highly recommend two "Not Just Patients" episodes: one with Victor Montori (physician perspective) and one with Estelle Jobson (patient perspective), offering practical tools for individual and systemic implementation.

How can physicians empower the global community to collectively address patient engagement and advocacy efforts?

Clarinda Cerejo: Physicians have a powerful and unique role in the healthcare ecosystem. Among all healthcare stakeholders–drug manufacturers, hospital administrators, payers, and policymakers–physicians are the

BACK TO CONTENTS

ones who have maximum direct and meaningful access to patients. In fact, as their perspectives are often used as a proxy for patient perspectives, they hold significant power to influence patient engagement and advocacy across multiple levels.

The beauty of patient engagement and advocacy lies in its flexibility, differing in scale and form based on objectives and available resources, from in-clinic to community and then to global engagement. First, in-clinic engagement and advocacy require that physicians see the patient as a whole person, ask the right questions and actively listen, simplify complex medical information, and encourage shared decision-making. Second, community advocacy and engagement might involve activities like sharing more patient stories, raising awareness of healthcare issues (via podcasts, lectures, social media, editorials, blogs), reducing stigma through seminars at schools and workplaces, and supporting local advocacy efforts (e.g., amplifying messages on social media, donating to advocacy groups, participating in fundraiser events). Finally, national and global advocacy and engagement incorporate partnering with patient authors for research publications, integrating patient voices into programming for medical conferences, serving on regulatory committees that matter to patients, and becoming involved in international projects (e.g., World Health Organization, United Nations) related to meaningful patient engagement.

Although physicians often refrain from engaging in patient advocacy due to perceived time and resource constraints, advocacy is inherently scalable and can be adapted to available capacity. Notably, in-clinic efforts can be just as powerful as global advocacy. What matters most is for physicians to leverage their strengths and skills to try and bring more patient voices into rooms where they have influence.

Caitlin Rich: As a first step, physicians can explore patient engagement and advocacy efforts in their own space. They can research patient advocacy organisations and events related to their disease expertise, region, or interests, learn about their activities, and identify how they might become involved. They can review advice on supporting patient care and then implement one small change in their clinical practice and monitor improvements. They can explore ways to support patient engagement beyond the clinic; patients can (and should!) also be invited to help shape research, regulations, reimbursement, policy, and healthcare systems. “Not Just Patients” episodes are available on a range of healthcare topics if any health professional would like to learn more.

Once health professionals gain experience in patient engagement and advocacy, they can share insights with their peers. For example, what did they do, why did they do it, and what was the impact? Their stories and example scan motivate and empower others. Change at a personal level can drive change at the department level, and then locally, regionally, nationally, and ultimately worldwide.

AI Disclosure Statement

The authors confirm that no artificial intelligence tools were used in the preparation of this manuscript.

Authors

Clarinda Cerejo
Co-host, “Not Just Patients” podcast
Mumbai, India
clarinda.cerejo@gmail.com

Caitlin Rich
Co-host, “Not Just Patients” podcast
London, United Kingdom
caitlin169@hotmail.com