

From co-creation to compounding value: A new model of rare disease science communication in China

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SUMMARY: For the vast rare disease patient community in China, science communication is crucial for bridging the information gap. However, the traditional, expert-led knowledge distribution model has proven insufficient to address the dual challenges of resource scarcity and low efficiency in the rare disease field. This paper introduces a new science communication model derived from practice in China. With "Patient-Driven Co-Creation" as its core, this model's ultimate goal transcends traditional information dissemination, aiming to empower the entire ecosystem through systematic value creation. Through an analysis of the practical model of the *Wonder Sir* platform, this paper proposes for the first time the "Patient Compounding Value Model". This model demonstrates how intangible patient-lived experiences can be systematically transformed into tangible assets capable of driving scientific research, clinical optimization, and public policy, thereby providing a sustainable value-generation mechanism for the resource-scarce rare disease field.

Keywords: rare diseases, science communication, patient engagement, co-creation, China

1. Introduction

For the vast rare disease patient community in China, science communication is crucial for bridging the information gap and addressing systemic challenges. These challenges are pervasive, exemplified by a diagnostic odyssey averaging more than five years and extremely low awareness among clinicians (1,2). The core challenge confronting the rare disease community lies not only in the scarcity of information but, more fundamentally, in how to translate their unique lived experience into an effective force for advancing the entire ecosystem. While global discourse on patient engagement is intensifying, most practices remain confined to consultative or lower levels of involvement (3,4), lacking a systematic theoretical framework to guide and measure how deep patient participation can be converted into sustainably appreciating core assets. This theoretical void is particularly pronounced in low- and middle-income countries (LMICs) where resources are scarce (5,6).

These persistent systemic challenges themselves prove the insufficiency of the traditional knowledge distribution model followed by conventional science communication. This model, which presumes patients are passive recipients of information and aims to solve an information deficit, is inherently a unidirectional process

that consumes existing expert and institutional resources. This paper argues for a paradigm shift: from mere knowledge distribution to systematic value creation. Based on an analysis of the practice of *Wonder Sir*, a rare disease education and innovation platform in China (7), this paper introduces the "Patient Compounding Value Model". This theoretical framework elucidates how intangible patient experiences can be systematically transformed into tangible assets capable of driving scientific research, clinical optimization, and public policy. The core of the "Patient Compounding Value Model" is that it functions as a generative system that activates latent resources—the patients—to continuously create new assets.

2. Theoretical framework: The "Patient Compounding Value Model"

The "Patient Compounding Value Model" is philosophically rooted in the concept of coproduction, wherein the value of healthcare services is co-created by professionals and patients (8). The model comprises a driving engine ("Patient-Driven Co-Creation") and a value-transformation mechanism (the compounding growth of six core assets).

2.1. The engine: "Patient-Driven Co-Creation"

"Patient-Driven Co-Creation" serves as the core methodological engine for value transformation. It applies the foundational principles of Community-Based Participatory Research—such as recognizing the community as a unit of identity, building on community strengths, and fostering equitable partnerships (9,10) —to the rare disease context. Transcending unidirectional knowledge dissemination, "Patient-Driven Co-Creation" is a systematic process that empowers patients, transforming them from passive information recipients into active value co-creators (7).

The operational flow of this engine, exemplified by the creation of the "Born to Challenge" science communication comic series produced by *Wonder Sir*, has been presented as an innovative model at international conferences (e.g., World Orphan Drug Congress 2024, Boston, MA) and can be summarized in four stages (Figure 1):

(1) Strategic Framing & Community Consensus: The process begins with a clear strategic objective: to enhance public empathy through a layperson's perspective. Based on this, the platform proactively collaborates with patient communities, upgrading the engagement model from story collection to co-creation, thereby fundamentally acknowledging the expert status of the patient community.

(2) Multi-stakeholder Content Creation: Initiated by the community, a creative triangle comprising the protagonist, community representatives, and clinical

experts is formed. A pre-consensus on the script is achieved through in-depth interviews and joint reviews before production begins, ensuring accuracy, empathy, and efficiency.

(3) Embedded Expert Review: Clinical experts, recommended and invited by the patient community, are involved throughout the process from inception, establishing a trust-based, collaborative relationship rather than a traditional final-stage approval.

(4) Joint Dissemination & Asset Empowerment: The final output is jointly disseminated by the platform and the community. Crucially, all materials are provided royalty-free to the community, empowering them with sustainable tools. This act transforms dissemination from mere amplification into asset empowerment. (An English example of a science communication comic is available as Supplementary Figure S1, <https://www.irdrjournal.com/action/getSupplementalData.php?ID=280>).

2.2. The output: Compounding growth of the six core assets

The output of the "Patient-Driven Co-Creation" engine is not a one-off piece of content but the systematic generation of six cumulative and reusable core assets. The formation of these assets reflects the construction of social capital—features of social organization such as networks, norms, and trust that facilitate coordination and cooperation for mutual benefit (11). These assets can be categorized into three logically progressive tiers based on their nature and evolutionary stage, enabling a compounding growth of value (12). The hierarchical structure and compounding value growth of this model are illustrated in Figure 2.

Tier 1: Social Assets - The Foundation of Value Creation

i) Narrative & Communication Assets: The capability to transform intangible lived experiences into tangible, scalable tools for empathetic communication. This asset is not merely content; it is the primary lever for building community identity, combating social stigma, and attracting external resources.

ii) Community Mobilization Assets: The aggregate social capital of a rare disease community, encompassing trust networks, shared identity, and the organizational capacity to mobilize individuals for collective action. This asset serves as the organizational infrastructure upon which all other assets are generated and transformed. Without robust community mobilization capacity, systematic data collection or biospecimen banking is inconceivable.

Tier 2: Knowledge Assets - The Transformation from Experience to Evidence

iii) Data Assets: Patient community-led, structured information collections that reflect the real-world panorama of a disease. Compared to traditional clinical trial data, this asset places greater emphasis on long-term,

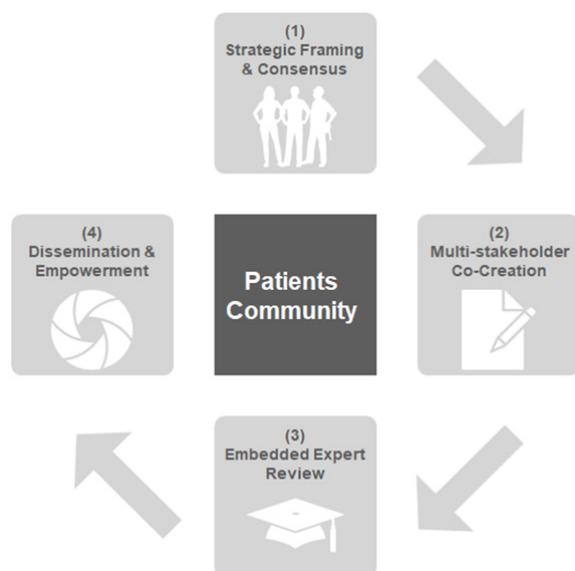


Figure 1. The "Patient-Driven Co-Creation" Process Model. The model illustrates a cyclical, four-stage process with the patient community as the central engine. The process begins with (1) Strategic Framing & Consensus to align goals, followed by (2) Multi-stakeholder Co-Creation to jointly develop content. (3) Embedded Expert Review ensures accuracy throughout the process. The cycle concludes with (4) Dissemination & Empowerment, where the output is transformed into a sustainable asset for the community, initiating a new cycle of value creation.

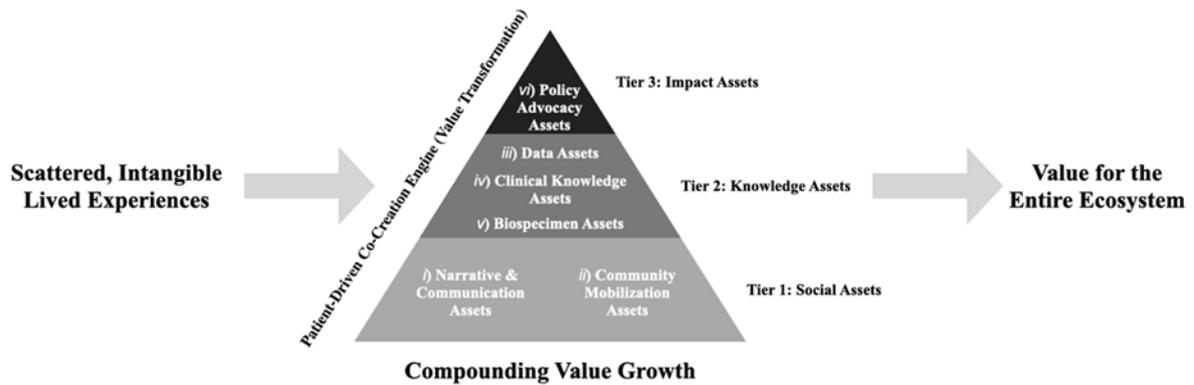


Figure 2. The "Patient Compounding Value Model". The model illustrates how the "Patient-Driven Co-Creation" engine transforms scattered, intangible lived experiences into tangible value for the ecosystem. This process demonstrates a compounding value growth, visualized as a pyramid of three hierarchical tiers. **Tier 1**, the foundation, consists of Social Assets: *i*) Narrative & Communication, and *ii*) Community Mobilization. These enable the creation of **Tier 2**, Knowledge Assets: *iii*) Data, *iv*) Clinical Knowledge, and *v*) Biospecimen. At the apex is **Tier 3**, Impact Assets: *vi*) Policy Advocacy, which leverages the lower-tier assets to drive systemic change.

continuous quality of life, disease burden, and patient-reported outcomes, offering a unique and indispensable perspective for understanding natural history and evaluating real-world treatment effectiveness.

iv) Clinical Knowledge Assets: An experiential knowledge system, accumulated and validated by the patient community through long-term practice. It includes non-pharmacological intervention techniques for specific symptoms, side-effect management strategies, and nuanced observations of treatment responses not found in textbooks. This knowledge is crucial for optimizing clinical practice guidelines and developing more patient-centric therapeutic approaches.

v) Biospecimen Assets: The collective capacity of a community, built on trust and mobilization, to provide well-characterized, ethically sourced biospecimens for research. The value of such specimens extends far beyond the biological material itself, as they are linked to the rich data and clinical knowledge assets held by the community, offering researchers an invaluable specimen-data-knowledge triad.

Tier 3: Impact Assets - The Driver of Ecosystem Change

vi) Policy Advocacy Assets: The ability of a community to leverage its accumulated assets to engage with policymakers, transforming its role from passive recipients to active co-creators of policy. When a community can present its own narratives, data, and knowledge in policy discussions, it evolves from being a mere supplicant to an evidence-based participant in the policy agenda-setting process.

2.3. A compelling case: The Lesch-Nyhan syndrome community

The efficacy of the "Patient Compounding Value Model" is compellingly demonstrated by the trajectory of the Chinese Lesch-Nyhan Syndrome (LNS) Association. The model was initiated by a high-impact Narrative &

Communication Asset—a science communication article on LNS (13). This asset acted as a lighthouse, connecting several isolated families on the day of its publication and leading directly to the formation of China's first LNS patient WeChat group, marking the birth of the first Community Mobilization Asset. The significance of this step lies in its use of emotional resonance to transform atomized, powerless individuals into a collective with a shared identity (14).

This community container then began to precipitate value. Through internal communication, members systematically generated and accumulated Data Assets and Clinical Knowledge Assets. For instance, caregivers collectively identified patterns and intervention strategies for the self-injurious behaviors characteristic of LNS—experiential knowledge that even top specialists had not observed. This knowledge represents an invaluable scientific clue for understanding the disease's core mechanisms. Subsequently, the community independently produced the "Survey Report on the Current Status of Chinese Patients with Lesch-Nyhan Syndrome (2021)" and the "100 Questions and Answers on Lesch-Nyhan Syndrome handbook", formally converting dispersed experiences into structured knowledge assets. This step marked the community's evolution from a peer support network into a knowledge production hub (15,16).

Ultimately, this rich foundation of social and knowledge assets empowered the community to make a decisive leap. It has grown into the world's largest LNS patient cohort, possessing significant potential to build a Biospecimen Asset. More importantly, it has begun converting its internal value into external Impact Assets. The community leader, as the sole representative of a single-disease patient community from China, attended the 2024 World Orphan Drug Congress and hosted an exhibition booth, engaging with executives from top pharmaceutical companies and leading researchers, thereby gaining international recognition.

This recognition is not merely honorary; it signifies that the community has earned a seat at the table for dialogue with top-tier global resources, marking its emergence onto the global stage as a professional and equal partner (14).

3. Discussion and Conclusion

The "Patient Compounding Value Model" proposed in this paper offers a novel, operational framework for conceptualizing and measuring the true value of patient engagement, elevating patients from passive research subjects to active co-builders of the ecosystem. Unlike Western models, which are often driven bottom-up by politically powerful Patient Advocacy Groups such as NORD in the US and EURORDIS in Europe (17,18), the rare disease ecosystem in China is predominantly constructed through top-down state guidance, with stakeholders participating as collaborative partners (19). While this collaborative partner model may possess less direct political influence than its Western counterparts, its high degree of alignment with national strategy affords it a unique efficiency in mobilizing centralized resources and rapidly advancing specific agendas.

As the practice of *Wonder Sir* demonstrates, a professional third-party platform plays a crucial role as infrastructure and an enabler in this model (7). Its true advantage lies not in the volume of content it produces unidirectionally, but in its pioneering and validation of the replicable "Patient Compounding Value Model", which systematically empowers patient communities to create value for themselves. This enabling role represents a fundamental transcendence of the traditional knowledge distribution model.

The central tenet of the "Patient Compounding Value Model" is that science communication should be elevated from a mere promotional activity to essential infrastructure for ecosystem-building. Against the backdrop of global sustainability challenges in the rare disease field (20), this model, originating from China and rooted in low-cost digital platforms, demonstrates high replicability in resource-constrained environments (5,6). It thus offers an innovative and sustainable solution for other LMICs facing similar challenges. We therefore propose that global health policymakers and funding agencies consider shifting investment from traditional information-dissemination programs to supporting and cultivating such value-creation infrastructures that can systematically generate, manage, and transform patient value. Such an investment shift would not only endorse a new model but would also represent a strategic commitment to a more equitable, effective, and human-centered future for global health.

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