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From Willingness to Action: Heterogeneous Patterns of Patient Participation in Chronic Disease Management

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Abstract. As aging speeds up and chronic diseases increase, patient engagement becomes more important. Many studies ignore different types of participation. This study combines the Health Belief Model and the Theory of Planned Behavior. It builds a framework about willingness and behavior. The study uses qualitative analysis. It finds four patterns: "Autonomous-Realization," "Behavior-Obstructed," "Externally-Driven," and "Passive-Disengaged." The results show that management outcomes do not depend only on willingness. They also do not depend only on strong intervention. Outcomes depend on personal ability and the environment. This study suggests a change from uniform intervention to differentiated governance. It stresses the need to improve self-management skills and support systems for different patient types.

Keywords: Chronic Disease Health Management, Patient Participation, Participation Willingness, Health Behavior, Typological Analysis

1. Introduction and literature review

Since 2000, China's aging demographic [1] and the rising prevalence of chronic non-communicable diseases (NCDs) [2] have intensified pressure on public health systems. Chronic diseases have evolved into major obstacles for "Healthy China 2030," with projections indicating case numbers could triple by 2030 without model optimization [3]. To address this, recent policies—including the "Implementation Plan (2025–2030)" and the Basic Medical and Health Care Law—emphasize shifting from treatment to health promotion and defining citizens as primary agents in health management. However, a significant gap remains between policy goals and practice, particularly regarding the sustainability of patient engagement.

Existing literature focuses on two core themes. First, the drivers and institutional foundations of health management, where aging [4], disease burden [5], costs [6], and "active health" governance [7] are supported by management networks [8], ICT [9], and self-management theories [10]. Second, operational models and mechanisms, such as family doctor services [11] and multi-agent collaboration [12]. While individual factors like self-efficacy [13], literacy [14], and willingness [15] are acknowledged, current research prioritizes institutional design over the patient participation process. Addressing this gap, this paper employs a participatory governance perspective to construct a typological model, revealing how participation willingness and health behavior shape management outcomes.

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2. Participation willingness and health behavior: an analytical framework

The Health Belief Model (HBM) posits that health behaviors stem from perceived threats, the assessment of benefits versus barriers, and self-efficacy [16]. Complementarily, the Theory of Planned Behavior (TPB) identifies behavioral intention as the central driver, shaped by attitudes, subjective norms, and perceived behavioral control [17]. Noting the theoretical intersection—particularly between self-efficacy and perceived behavioral control [18]—this study integrates both frameworks. We extract "participation willingness" and "health behavior" as core dimensions to construct a typological framework that systematically explains the heterogeneous participation patterns of chronic disease patients.

2.1. Conceptual definition

2.1.1. Willingness to participate

In long-term disease management, willingness means a patient's inner motivation. It comes from how the patient judges disease risk and personal ability. This willingness is different among patients. It can change even when patients have similar conditions. Patients with high willingness understand the seriousness of the disease. They believe they can handle problems in management. They also accept outside rules and turn them into inner goals. But an intention-behavior gap exists. Willingness alone cannot decide action. Some patients have strong intent but do not act. Some patients act because of outside pressure, even without inner motivation.

2.1.2. Health behavior

Health behavior means the daily actions that chronic disease patients take to control disease and improve life quality. This study uses the Health Belief Model and the Theory of Planned Behavior. It sees behavior as the direct result of health beliefs and intentions. High-level behavior shows long-term follow of medical advice. Patients put management into daily life. They control themselves without outside supervision. Health behavior is not a single action. It shows continuity, initiative, and compliance in health management.

2.2. Analytical framework

Drawing upon the Health Belief Model and the Theory of Planned Behavior, this study constructs a typological analysis framework centered on "Willingness to Participate" and "Health Behavior" (see Table 1). These two dimensions, which are both independent and interrelated, intersect to form four quadrants corresponding to four distinct patterns of health management participation. These patterns reflect the differentiated states of patients in chronic disease management. Specifically, "Willingness to Participate" characterizes the patient's subjective attitude and behavioral readiness, while "Health Behavior" reflects the actual execution of health management requirements in daily life. The different participation patterns exhibit significant variations in management stability, behavioral continuity, and the degree of proactivity. This framework aims to elucidate the intrinsic structural characteristics of chronic disease patient engagement, providing a theoretical basis for identifying participation patterns and formulating differentiated intervention strategies.

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Table 1. Four modes of chronic disease patient participation in health management

		Health Behavior	
		High	Low
Participation Willingness	High	The Autonomous-Realization Type	The Behavior-Obstructed Type
	Low	The Externally-Driven Type	The Passive-Disengaged Type

2.2.1. The autonomous-realization type

The "Autonomous-Realization Type" shows a stable pattern of high willingness and high behavior. These patients have clear health goals and strong inner motivation. They can turn willingness into real action. They have good self-control and positive attitudes. They keep a proactive and lasting level of health management. They manage their health in an independent way. They make their own decisions about medicine, diet, exercise, and health checks. They also seek help from family, society, or doctors when needed. They use these resources to keep their management stable and effective.

2.2.2. The behavior-obstructed type

The "Behavior-Obstructed Type" manifests as a structural imbalance of "High Willingness–Low Behavior." Although patients exhibit a strong willingness to participate, their health behaviors are not effectively implemented due to insufficient action planning, low self-efficacy, or environmental barriers such as time constraints and financial limitations, resulting in a disconnection between willingness and action. In this mode, excessive perceived barriers or low self-efficacy undermine the capacity to translate intention into practice. Strengthening action planning, introducing external support, and establishing standardized execution mechanisms—such as phased goal setting and supervisory feedback—can, to a certain extent, bridge the structural rupture between willingness and behavior, thereby promoting the sustainability of health practices.

2.2.3. The externally-driven type

The "Externally-Driven Type" is characterized by "Low Willingness–High Behavior." Patients in this category demonstrate low intrinsic identification with health management; however, they maintain a high level of health behavior under the constraints of external forces, such as institutional requirements, social norms, familial pressure, or economic incentives. From the perspective of motivational structure, their behavior is governed primarily by external regulation, with subjective norms playing a dominant role in behavioral formation. While this mode exhibits strong execution in the short term, behavioral stability is highly contingent upon external drive mechanisms. Once supervision or incentives diminish, health behaviors are prone to relaxation or cessation, indicating a relative lack of internalization.

2.2.4. The passive-disengaged type

The "Passive-Disengaged Type" represents a dual deficit of "Low Willingness–Low Behavior." These patients generally lack clear health goals and behavioral impetus, hold negative attitudes toward health management, and fail to form stable behavioral practices. This state is frequently associated with structural constraints, such as insufficient economic resources, limited educational

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attainment, or low accessibility of health services. Consequently, the individual's health cognition remains unactivated, and perception of disease risk is inadequate, leading to a lack of motivation for action. Addressing this pattern requires institutional interventions to improve foundational support conditions—such as enhancing the accessibility of health services and information—to gradually reconstruct the connection between the individual and the health management system, thereby creating the basic prerequisites for participation.

3. Case analysis of chronic disease patient participation modes

Adhering to the principles of typicality and completeness, this paper selected seven chronic disease patients with varying baseline conditions as subjects for case analysis and comparison to interpret the four distinct health management modes. To ensure the reliability and validity of the study, data were primarily derived from semi-structured interviews with the patients themselves to enhance the sufficiency and accuracy of the cases.

3.1. Autonomous-realization type

In the Autonomous-Realization mode, the patient's willingness and action are highly synergistic. Such patients usually demonstrate a stable and sustained willingness to participate in chronic disease management and can effectively translate this willingness into systematic, long-term behavioral investment. Unlike passive execution or short-term coping, Autonomous-Realization patients often internalize health management as part of their personal life goals and value practices, forming a positive cycle in the long-term course of the disease accompanied by relatively stable health management outcomes.

Patient A, a 58-year-old female living in Hangzhou, Zhejiang, is a retired administrative staff member from a state-owned enterprise (SOE). She suffers from hypertension and Type 2 diabetes, with a disease duration of 12 years. At 46, a unit physical examination revealed high blood sugar (prediabetes); three years later, she was diagnosed with Type 2 diabetes complicated by hypertension. She has systematically carried out health management for 9 years."I had just retired when I was diagnosed. At the time, I felt the sky was falling—my retired life ended before it began. But I'm not one to give up. I used to manage union activities at work, so I thought, can I use that same energy to manage this disease?" (Interview Record: HZ2025091803)

Patient A's health management behavior exhibits significant endogenous drive, constantly externalizing into social action during practice. Her internal motivation initially stemmed from fear of the disease and unwillingness to yield, subsequently evolving into a reconstruction of self-worth and lifestyle. "At first, it was fear, then competitiveness. Now, I feel it's a new lifestyle, even a 'new job'." (HZ2025091803) On this basis, her health behavior expanded from individual self-management to supporting and leading others. As a "five-star volunteer" at the "Sugar Friends Club" (Diabetes Support Group) of the Municipal People's Hospital, Patient A has long participated in and organized patient activities, establishing multiple WeChat groups for patients to share diet, exercise, and monitoring data, forming continuous positive supervision for group members. "I set up three WeChat patient groups myself. Every day I share 'today's meal plate' in the group and urge everyone to 'post their step count'." (HZ2025091803) Although she faced skepticism and friction from her family initially, as her health and mental state continued to improve, this resistance transformed into support. "Seeing my body get better and my spirits higher than before retirement, they went from opposing to supporting me." (HZ2025091803) In Patient A, health management not only achieved

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the effective conversion of willingness to behavior but also became embedded in her social role and daily life, serving as a crucial pillar for long-term sustainability.

Patient B, a 58-year-old male, formerly a laid-off worker, currently lives in Wuhan. Starting with joint swelling and pain at age 42, he spent three years visiting multiple medical institutions before being diagnosed with rheumatoid arthritis at 45. The disease duration is now 15 years. During his illness, Patient B underwent high-intensity treatment and management involving standard medication, physical therapy, and folk remedies for 12 years, but disease control remained suboptimal."My body has really been dragged down by this disease. It hurts like hell, and my joints are deformed. Fifteen years... I went from a man who could carry a hundred pounds of cargo to this... I've been to countless hospitals, taken countless Chinese and Western medicines, money thrown into a bottomless pit. I'm more active than anyone in wanting to cure it, but this disease just doesn't reason with you." (HB2025092205)

Patient B's health behavior exhibits coexistence of endogenous and exogenous drives. Endogenous motivation comes from pain caused by the disease and physical limitations—a natural reaction of the self-protection mechanism; exogenous motivation stems from family emotional support—a social force maintaining behavioral continuity. "I'm the one hurting; how could I not want to treat it? My wife and kids watch me every day, finding folk remedies for me. I can't let them down." (HB2025092205) However, continuous medical seeking consumed vast amounts of money and time without achieving expected therapeutic effects. Instead, Patient B's economic and psychological pressure increased daily, and his decision-making gradually shifted from rational thinking toward emotional and random directions, leading to "desperate medical seeking." "I spent almost all my pension on medical bills. I've seen every local hospital, and now I go to the provincial capital regularly. I do whatever the doctor says; I do rehabilitation exercises even when sweating from pain. But it feels like the doctors are out of options too, just swapping the same few drugs. The patient group says all sorts of things; I tried some recommended medicines and ended up with abnormal liver function." (HB2025092205)

Although both Patient A and Patient B possess high participation willingness and high health behavior, Patient B's outcomes are far less satisfactory. The root cause is not Patient B's willingness, but the mismatch between the health management system's resource support response capabilities and the patient's subjective initiative. While the patient is encouraged to be a health manager, the accessible medical system fails to provide sustainable resource responses in terms of medical level, information accessibility, and decision support. "For twelve years, the more seriously I 'managed,' sometimes the greater the disappointment felt. I'm very lost now, don't know who to trust. I'm really afraid that one day the money will run out, or my spirit will be ground down, and I'll give up. Unless I find a medicine or method that actually works for me, giving me a little hope, I can persist. Now I'm just holding on by sheer will." (HB2025092205)

3.2. Behavior-hindered type

Behavior-Hindered patients possess the willingness for health management but struggle with implementation. Subjectively, they usually have high participation willingness, clearly recognize disease risks, and agree with the importance of health management. They are willing to cooperate with medical advice in attitude, yet frequently encounter obstacles in actual action. Health behaviors appear intermittent, low-intensity, or even difficult to initiate. Their predicament stems not from a lack of willingness but more from low self-efficacy, strong realistic situational constraints, or a lack of clear, executable action paths. This leads health management to stagnate at the level of "wanting

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to do but unable to do," forming a state of high willingness, low behavior, and limited management effectiveness.

Patient C, a 52-year-old male living in a minority village in western Yunnan, is a villager primarily engaged in farming. Five years ago, during a clinic visit by township health workers, he was found to have elevated blood pressure and diagnosed with mild hypertension. Although prescribed medication, his adherence was intermittent, and strictly speaking, health management practices were not sustained."The medical team came down that year and said I had high blood pressure. I didn't take it too seriously. Many people in our village have it; it doesn't hurt or itch. Just sometimes my head gets a bit dizzy." (Interview Record: YN2025081706)

Patient C's willingness is mainly driven by external factors, specifically the connection between social emotions and family responsibility. Long-term follow-ups by the village doctor and remote concern from his children constitute the primary sources of his health consciousness. "The village doctor is good; she comes to my house every now and then, telling me, 'Uncle, take your medicine, or you'll have a stroke and burden your kids.' My kids work in Kunming and call to remind me too. In my heart, I want to do it; I can't be a burden to them." (YN2025081706) This external drive created a strong sense of health responsibility but failed to translate effectively into stable behavioral practice.

At the level of health behavior implementation, Patient C's main obstacles lie in realistic conditions and lifestyle limitations. Geography and labor rhythms restrict the regularity of medical visits and medication: "The medicine was prescribed, but when I get busy, I forget. A trip to the township health center takes most of the day on mountain roads, delaying work in the fields." (YN2025081706) Furthermore, the inertia of traditional dietary habits and lifestyle acts as hidden resistance to behavioral change: "I stopped smoking and drinking, but I still eat heavy salt. I'm used to it." (YN2025081706) Despite low behavioral execution, the patient's blood pressure control remains within an acceptable range, largely due to his good physical foundation, regular physical labor, and peaceful psychological state. "Last check-up, the village doctor said I controlled it okay. Maybe it's because I'm open-minded, work a lot, and have a good foundation." (YN2025081706)

Patient D, a 48-year-old male living in an old industrial zone in Northeast China, was formerly a frontline worker in an SOE. Two years ago, unit physicals revealed blood sugar abnormalities, confirmed as diabetes with fatty liver. Initially, he fully recognized the severity and developed a strong willingness for health management."The factory wasn't doing well, and I took a buyout last year. I felt suffocated, so I drank a bit. After finding out about the diabetes, I was terrified. I really wanted to manage this problem well." (Interview Record: HLJ2025110307)

Patient D's willingness has a dual drive: internal need for livelihood continuity and physical function maintenance—"I'm only 48, I still have to find work, my body can't collapse" (HLJ2025110307); and external influence from family pressure and emotional factors—"My wife fought with me a lot over this." (HLJ2025110307)

However, behaviorally, Patient D's practice is chronically limited by social structural constraints. Financial straits and environmental scarcity became core obstacles to implementation. "I want to exercise, but there's no decent park nearby. I want to eat healthy, but healthy vegetables are expensive." (HLJ2025110307) Multiple pressures of real life weakened the patient's self-control, leading to recurrent emotional behaviors. "Job interviews didn't go well; when I'm in a bad mood, I want a drink. Once I drink, blood sugar goes up. I know it's wrong, but I can't control it." (HLJ2025110307) In doctor-patient interactions, Patient D understands medical advice well but lacks situational support and psychological adjustment mechanisms. "Doctors just say 'you must quit drinking.' I understand the logic, but who understands my difficulties? I feel tied hand and foot by

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life, willing but powerless." (HLJ2025110307) Consequently, he is trapped in a vicious cycle of "determination—setback—self-blame/giving up—determination again."

It is evident that within the multiple influence mechanisms of chronic disease management, individual endowment and living ecology play important latent roles. Although Patient C lacked systematic management behavior, he maintained a relatively stable health status through the combined effects of natural labor, social support, and psychological balance. As he stated: "If the village doctor could deliver medicine to my house every month, or if my son were home watching me eat it, I could definitely persist. As it is now, it's all luck and God's blessing." (YN2025081706) Conversely, Patient D's continuously poor outcomes were not due to lack of willingness or knowledge, but because individual agency was eroded by structural dilemmas. Economic instability, insufficient environmental support, and fragile social networks jointly led to his status of high willingness, low behavior, and poor outcomes. As he said: "Unless I find a stable job and feel settled, or have a partner to exercise with and supervise me, it's unlikely. Relying on myself alone is too hard." (HLJ2025110307)

3.3. Externally-driven type

Despite lacking positive participation willingness, Externally-Driven patients are pushed by outside factors to participate in health management. They typically possess high behavioral execution and good health outcomes, but this does not stem from individual cognition of the disease or a sense of self-health responsibility. Instead, it relies mainly on the continuous propulsion of family members, medical institutions, or institutional arrangements. In practice, they demonstrate health behaviors under supervision, reminders, or mandatory requirements from others. Once external constraints or incentives weaken, health management may be interrupted or regress; behavior exhibits obvious "task-based" or "directive-based" patterns.

Patient E, a 35-year-old male living in Shenzhen, works as a programmer. Three years ago, his company's annual physical revealed significantly high uric acid levels. Due to a fast-paced work life and lack of obvious symptoms, he lacked an intrinsic sense of crisis regarding this diagnosis but entered a standardized treatment process following the "red-flagged" results and HR reminders."Company physical found high uric acid. I didn't feel anything, but the report was red, and HR specifically reminded me to pay attention." (Interview Record: GD2025113008)

Patient E's willingness is almost entirely driven by external factors. He does not consider himself "truly sick" nor actively learns related knowledge; his willingness stems from work requirements, institutional guarantees, and potential risk avoidance. "I really don't feel like I'm sick. But the company has commercial insurance, reimbursements, and I'm afraid a gout attack might affect work. It's for work and convenience, basically." (GD2025113008)

Behaviorally, Patient E is highly dependent on professional directives. He strictly adheres to medication and follow-ups and uses the company gym regularly, but the behavior feels more like "completing a task" than active participation. "I registered, took whatever the doctor prescribed, and went back when told. The company has a gym; I go two or three times a week, mainly for neck stress relief, lowering uric acid is incidental. I rely heavily on doctor's orders and physical data; I won't actively learn about the disease myself. For three years, all actions have been based on 'tasks', like finishing a project I don't want to do but must." (GD2025113008) Thanks to high compliance, his uric acid is well-controlled, and health results remain ideal.

However, the sustainability of this mode relies heavily on the continued existence of the task mechanism and external environment. As Patient E stated: "As long as there are annual company physicals and medical insurance policies don't change, I'll continue this process. If I change jobs one

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day and lose these benefits and pressure, I might ignore it unless the body gives a serious warning." (GD2025113008) His health behavior is not truly solid and may enter a management void at any time if institutional support is withdrawn.

3.4. Passive-disengaged type

Patients in the Passive-Disengaged mode generally lack health participation willingness at the subjective level, having vague cognition of disease risks and health management values. At the action level, they fail to form stable health behavior practices, often remaining outside the health management system for extended periods. Their passivity is not simply a result of personal choice but stems more from structural factors such as resource scarcity, information isolation, and insufficient institutional accessibility. These factors make it difficult for individuals to access effective health information, medical services, and social support networks. Consequently, patients neither form the intrinsic motivation to participate nor possess the realistic conditions to implement management, resulting in a state of low willingness and low behavior, leading to continuous accumulation of health risks.

Patient F, a 70-year-old male living in an agricultural county in central Henan, is a typical "left-behind" elderly person. Diagnosed with hypertension eight years ago while accompanied by children to the county hospital, he has failed to take medication regularly despite his children purchasing and mailing it. Sustained health management behavior is virtually non-existent."Getting old, who doesn't have a headache or fever? The kids are out in the big cities; I'm fine on my own. Dizziness? Sleep it off." (Interview Record: HEN2025122409)

Patient F's health willingness is nearly zero; his attitude lacks both internal drive and effective external incentives. A weak perception of disease risk, a sense of alienation from the modern medical system, and intergenerational communication barriers constitute the psychological foundation of his "low willingness." "I'm not sick, why take that stuff? Hospitals are for when you have a big disease. The kids tell me to go look, but I'm hard of hearing, can't hear what they say." (HEN2025122409)

Behaviorally, Patient F has almost no health management practice. He has formed no stable habits regarding regular check-ups, regular medication, or dietary control. "Never verify, never take medicine. The village cadre gave out free medicine, I forgot to eat it. I like salty food, love pickles." (HEN2025122409) Notably, despite long-term non-management, his health results are relatively good, with high blood pressure but mild symptoms. This may be related to strong physical tolerance formed by long-term manual labor, stability of a simple diet, and a peaceful psychological state. "My neighbor, an older brother, also had high blood pressure and passed away last year. I feel that was just his time." (HEN2025122409)

Patient G, a 60-year-old male, lives alone in a remote pastoral area in western Gansu. With a history of cough and asthma for over twenty years, symptoms worsened ten years ago. Five years ago, he was diagnosed with pulmonary heart disease and diabetes at the county hospital. However, constrained by structural factors such as remote geography, inconvenient transportation, and poverty, he has received almost no continuous treatment or management."Been wheezing for over ten years; diabetes was tagged on. Kids are married and far away. I'm alone; living is just waiting out the days." (Interview Record: GS2025081210)

The disease, in his narrative, has transformed from a "problem" to "fate," a background of life to be passively endured. Patient G possesses almost no effective health management willingness; internal and external drives are both missing. He has no hope for improvement, lacks trust in

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medical resources, and actively avoids family support. "Can't be cured, waste of money. Kids have it hard too, don't want to trouble them. This is my fate, I accept it." (GS2025081210)

Behaviorally, Patient G's health behavior is nearly completely interrupted. He cannot persist in regular follow-ups, medication, or basic monitoring. "It takes hours to get to the county hospital; I wheeze too much to stand it. Medicine is too expensive, can't afford it. I don't understand what the doctors say either." (GS2025081210) Accessibility barriers, economic burden, communication difficulties, and social isolation have completely detached him from the formal health management path. "Now I just endure it when it's bad, one day at a time. In five years, I only went to the clinic for a shot when the pain was unbearable." (GS2025081210)

It is evident that under the Passive-Disengaged mode, major hidden dangers exist. Patient F believes his status is not problematic—"I'm fine as I am. Unless I fall in the field and can't get up, maybe then I'll go. Making me take medicine every day like city people, I can't stand that constraint." (HEN2025122409)—but essentially, his good health result is a temporary physiological homeostasis rather than a management achievement. Conversely, the sustainability of Patient G's health management is practically zero. He does not expect improvement and lacks hope for the future. "No conditions for it. Unless the government sends a doctor to live in my house and medicine is free, maybe I'd try. But as it is, I see no end." (GS2025081210) In this group, individual willingness and behavior are exhausted, and their health status relies entirely on external structural intervention.

4. Conclusion and implications

From the perspective of participatory governance, this paper integrates the Health Belief Model and the Theory of Planned Behavior to construct a typological analysis framework centered on "participation willingness - health behavior", and through multi-case comparative analysis, systematically reveals the internal differentiation logic of chronic disease patients' participation in health management and its governance implications.

Our findings reveal that engagement is not a linear translation of willingness into action but manifests in four distinct patterns: Autonomous-Realization, Behavior-Obstructed, Externally-Driven, and Passive-Disengaged. These patterns demonstrate that high willingness does not ensure high engagement, and behaviors sustained solely by external pressure lack long-term stability. Consequently, disparities in management effectiveness stem fundamentally from these divergent participation patterns.

Theoretically, this study transcends assumptions of patient homogeneity; empirically, it elucidates the generative mechanisms of engagement. We propose a paradigm shift from "uniform intervention" to "typological governance." This approach advocates for differentiated strategies—ranging from capacity building to safety-net accessibility—tailored to specific participation types. Future research should employ longitudinal and quantitative methods to validate the distribution and dynamic transformation of these patterns.

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