Gijong An – Representative, Korea Alliance of Patients Organisations



Developing an innovative medicine and ensuring patients can access it are two very different things

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Drawing on his personal experience as a caregiver and more than two decades of patient advocacy, Gijong An, representative of the Korea Alliance of Patients Organizations (KAPO), discusses how patient voices have shaped healthcare policy and legislation in South Korea. He also addresses barriers to accessing innovative medicines, the need for stronger patient representation in healthcare decision-making and the importance of patient-centred clinical research.

Could you share the personal background that led you into patient advocacy and explain the mission and values of the Korea Alliance of Patients Organisations (KAPO) today?

I studied law at university and was preparing for the Korean Bar Examination. My goal was to become a lawyer who could help socially disadvantaged people. However, my life took a different direction in 2001, when my wife was diagnosed with chronic myeloid leukaemia (CML). At the time, an innovative targeted cancer therapy called Gleevec (imatinib) had just become available. However, its monthly cost ranged from KRW 3 million to KRW 6 million, making it difficult for many patients to access. My wife’s diagnosis motivated me to join campaigns to secure National Health Insurance coverage for Gleevec and reduce its price. Eventually, I gave up my plans to become a lawyer and dedicated myself to patient advocacy.

In 2005, I began working as a patient advocate at the Korea Leukaemia Patients Organisation. On February 4, 2010, I co-founded the Korea Alliance of Patients Organisations (KAPO) with several other patient organisations.

KAPO's core mission is to "build a patient-centred healthcare environment by fostering solidarity across diseases, ideologies, and national borders to improve the conditions under which patients live with and fight their illnesses and to advance their rights."

We pursue this mission through three core values.

First, patient-centredness. Patients should be respected not simply as recipients of medical treatment, but as individuals with rights who actively participate in healthcare decisions.

Second, solidarity and the public interest. We seek to build solidarity beyond individual disease groups, considering the health and well-being of all patients and the long-term sustainability of the National Health Insurance system.

Third, we aim to translate patients' real-life experiences and voices into meaningful changes in healthcare policies, systems and legislation.

Ultimately, the patient movement is about building a society in which everyone can access appropriate care and have their rights protected.

Looking back at campaigns such as the "Patient Shouting Café" and the passage of the Patient Safety Act, which initiatives have had the greatest impact on patient rights in South Korea?

Over the past 20 years, one of the greatest achievements of the patient movement in South Korea has been showing that patients' experiences and voices can drive changes in national policies and legislation.

One notable example is the "Patient Shouting Café", launched on June 27, 2012. It is a healthcare communication platform built around three elements: Shouting, where patients share their grievances and experiences of harm; Healing, where participants offer empathy and support; and Solution, where experts and patient organisations propose ways to address the issues raised.

At the first event, the mother of a young boy named Jong-hyun, who had died following a vincristine chemotherapy medication error, called for measures to prevent similar incidents. Her

appeal became an important catalyst for the Patient Safety Act, enacted in 2014 and commonly known as “Jong-hyun’s Law.”

Other cases have also prompted important institutional changes. The case of a child named Ye-gang Jeon contributed to the introduction of automatic commencement of medical dispute mediation in serious cases, including deaths. The case of a child named Jae-yoon Kim led to mandatory reporting of serious patient safety incidents.

Another important case involved So-yeon Park, a patient with stage IV lung cancer who spoke out in 2014 about the cost of Xalkori, a targeted cancer therapy priced at approximately KRW 10 million per month. In 2015, Xalkori was included in the National Health Insurance coverage system through the Risk-Sharing Agreement (RSA) scheme, significantly reducing patients’ financial burden.

More recently, the Patient Basic Act was enacted and promulgated on April 28, 2026. It aims to improve patients’ treatment experiences and protect their safety and rights. Scheduled to take effect on April 29, 2027, it provides a legal foundation for protecting patient rights, ensuring patient participation in policymaking and promoting comprehensive national patient policies.

The most important development is that patients are no longer simply recipients of protection and support. They are becoming active participants in shaping healthcare policies and institutions. The greatest achievement of the Patient Shouting Café has been demonstrating that patients’ voices can genuinely change South Korea’s healthcare system and legislation.

How effectively are patient representatives now integrated into national healthcare decision-making bodies, including those under the Ministry of Health and Welfare (MOHW), the Health Insurance Review and Assessment Service (HIRA) and the National Health Insurance Policy Deliberation Committee?

Compared with the past, opportunities for patient organisations to participate in national healthcare policymaking have expanded considerably. I currently serve on the Health and Medical Services Policy Deliberation Committee and the Public Participation Committee for Medical Innovation, both under the Ministry of Health and Welfare. In these roles, I represent patients’ perspectives. I also participate in various committees operated by the Health Insurance Review and Assessment Service (HIRA).

I served on the National Health Insurance Policy Deliberation Committee from 2015 to 2024. Since 2025, Eun-young Lee, a KAPO board member, has represented consumers among the insured representatives on the Committee. However, having a seat at the table does not necessarily mean that patients' experiences and voices influence actual policy decisions.

The Committee consists of 25 members representing the government, healthcare providers, insured individuals and experts. Within this structure, direct participation by patient organisations remains limited.

Currently, only civic and consumer organisations can nominate members. Patient organisations cannot nominate their own representatives. As a result, KAPO participates as a consumer organisation rather than as a patient organisation.

Furthermore, patients' experiences and unmet medical needs are not adequately reflected in HIRA's reimbursement assessments of new medicines or in drug price negotiations conducted by the National Health Insurance Service (NHIS).

I believe three areas require particular attention.

First, patient representation must be formally guaranteed on major healthcare policy and reimbursement decision-making bodies.

Second, Patient Experience Data and Patient-Reported Outcomes (PROs) should be meaningfully incorporated into policy and reimbursement decisions.

Third, greater support for education and research is needed to help patient organisations participate in policymaking with the necessary expertise and independence.

With the Patient Basic Act scheduled to take effect in 2027, mechanisms for patient participation, including a Patient Policy Committee, must also be implemented effectively. Policies designed to serve patients should never be decided without them. We must move beyond simply listening to patients and ensure they participate as equal partners in healthcare policymaking.

From the patient's perspective, what are the main barriers delaying access to life-saving medicines during pricing and reimbursement negotiations, and what reforms are urgently needed?

My wife’s experience with Gleevec in 2001 taught me that developing an innovative medicine and ensuring patients can access it are two very different things. More than 20 years later, the problem persists. Innovative medicines receive approval from the Ministry of Food and Drug Safety (MFDS), yet patients may still be unable to access them because they are not covered by National Health Insurance.

I see three major barriers.

First, current methods of assessing clinical value and cost-effectiveness do not adequately reflect the circumstances of patients with rare and serious diseases.

Second, negotiations between the government and pharmaceutical companies, as well as reimbursement decisions, can take too long.

Third, there are insufficient mechanisms to ensure affordable access between regulatory approval and inclusion in the National Health Insurance reimbursement system.

The most urgent reform is to expand a system based on the principle of “patient access first, followed by evaluation and settlement.” Under this approach, patients with serious or rare diseases who have no alternative treatments, or for whom existing therapies are ineffective, could access new medicines following an assessment of clinical evidence and medical necessity. Prices could then be evaluated or adjusted based on actual treatment outcomes and the financial impact on the healthcare system.

On October 1, 2026, KAPO held a press conference outside the National Human Rights Commission of Korea. We launched a campaign calling for an “Expedited National Health Insurance Listing System for New Medicines Directly Related to Saving Lives.”

Earlier, on January 5, 2022, the National Human Rights Commission of Korea had issued an opinion recommending that the Minister of Health and Welfare accelerate National Health Insurance coverage for life-saving medicines. The Commission proposed that the MFDS and HIRA conduct their reviews simultaneously for medicines directly related to saving lives. This would allow eligible patients to receive treatment immediately after regulatory approval and market launch, using provisional prices covered by National Health Insurance while the formal reimbursement process is completed.

Since 2023, the government has been pursuing a pilot programme allowing marketing authorisation applications, reimbursement evaluations and drug price negotiations to proceed simultaneously. The existing Risk-Sharing Agreement (RSA) scheme should also be used more

actively. However, reasonable pricing proposals from pharmaceutical companies and appropriate risk-sharing arrangements are essential to maintaining the financial sustainability of National Health Insurance.

At a recent Patient Shouting Café event focusing on treatments for Crohn’s disease, we again saw how reimbursement delays can prevent patients from accessing medicines that have already received regulatory approval. Patients respond differently to treatments. Therefore, access to new medicines is about more than expanding therapeutic options. For some, it can mean extending their lives or continuing a treatment that works. Time is critical for patients with serious illnesses. We must minimise situations in which patients lose valuable treatment opportunities because of delays in reimbursement assessments and price negotiations.

South Korea has become a major global hub for clinical trials. How important are clinical trials for Korean patients, and how can global pharmaceutical companies better incorporate patient perspectives into trial design and ensure continued access to investigational treatments after trials end, including through Expanded Access Programs?

My wife’s experience with chronic myeloid leukaemia and Gleevec has given me a deep appreciation of the importance of clinical trials and innovative medicines for patients with serious diseases.

Clinical trials can be particularly valuable for patients who do not respond to existing treatments or have limited options. They may offer an opportunity to access an investigational treatment. Of course, clinical trials are designed to evaluate the safety and efficacy of new medicines, so therapeutic benefits cannot be guaranteed. Patients must receive sufficient information and participate voluntarily, with a clear understanding of the potential risks and benefits. Global pharmaceutical companies should go beyond simply recruiting Korean patients for clinical trials. They should recognise patients as partners in developing new medicines.

I believe three areas deserve particular attention.

First, patients and patient organisations should be involved from the earliest stages of clinical trial design. Research should consider not only clinical endpoints, such as survival rates and disease progression, but also outcomes that matter to patients. These include symptom improvement, quality of life and the ability to maintain daily activities. Patient-Reported Outcomes (PROs) should

be used more extensively. Researchers should also consider the practical burden of hospital visits and the financial costs of participating in clinical trials.

Second, the rights and safety of clinical trial participants must be protected. Patients should not be unfairly burdened with the costs of examinations and medical services required for research purposes. Clear explanations, voluntary informed consent, personal information protection and appropriate compensation for clinical trial-related injuries are also essential.

Third, patients who benefit from an investigational treatment should have the opportunity to continue receiving it after a clinical trial ends. Patients with serious or rare diseases who have no alternative treatments should not be forced to discontinue an effective treatment simply because a trial has concluded. Post-Trial Access arrangements should therefore be considered from the outset of clinical trial planning.

Where appropriate, legally permitted mechanisms such as the Expanded Access Program (EAP), which allows investigational medicines to be used for therapeutic purposes, should also be available. The government and pharmaceutical companies should work together to ensure continuity of treatment, particularly when delays in National Health Insurance reimbursement occur after a medicine receives domestic regulatory approval.

South Korea has developed considerable expertise in the global clinical trial sector. The next step is to move beyond the scale of patient recruitment and build a genuinely patient-centred research environment. Patients' experiences and perspectives should be reflected throughout the process, from research design to continued access to treatment after clinical trials end.

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