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Bringing patient voices into HTA, health policy development in Asia

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Ruth Kuguru, Executive Director, Communications & Engagement, Novartis Asia Pacific, Middle East and Africa (APMEA) shares the continuing necessity for robust and fully validated Health technology assessment (HTA) processes

Health technology assessment (HTA) is recognised as a crucial stage in the introduction of new technology, new medicines, and new clinical practices. HTA gives evidence-based information to policymakers as well as a systematic appraisal of this evidence to establish the value of any new healthcare solution in terms of cost, quality, and most importantly, value to patients.

The growing recognition of the value of this kind of systematic assessment has been driven as much by the increasing importance of effective healthcare as by the need to contain healthcare costs, which are rising rapidly in line with aging populations and the associated burden of rising rates of cancer, cardiovascular disease, and other chronic illnesses.

Historically, HTAs have focused primarily on the clinical research-based efficacy of treatment and its cost, with less consideration given to the experiences and priorities of patients using it, or their families and caregivers. It is encouraging to see that healthcare organisations and public health authorities in Asia are increasingly recognising the need to bring patients' voices into assessment processes for new treatments. While this progress has been hugely positive, there is still an opportunity for policymakers to involve patients much more actively at every step of the decision-making process.

Patient experiences go deeper than data

While clinical trials and cost-benefit analyses remain crucial in the process of HTA decision-making, work commissioned for a forthcoming report from the independent think tank ACCESS Health - international due to be published in June has shown that better outcomes are achieved when patients feel the specific problems associated with their condition are fully understood by healthcare policymakers and providers — and that patients have been fully consulted about their treatment, understand its purpose and have given informed consent for its use.

A case in point is the treatment of psoriasis, an incurable chronic autoimmune skin disease. Beyond its severe physical symptoms, psoriasis also causes depression, anxiety, and low self-esteem, as well as social isolation and employment difficulties as sufferers, attempt to hide their condition.

These invisible effects of a health condition are often not reflected in data used to formulate healthcare policy and, if decision-makers consider patient concerns, they achieve vital insight into the wider impact of disease and what kind of care patients most value. It can often be difficult for policymakers to engage with patients on an individual level, and patient organisations are therefore obvious partners for policymakers, as they represent the collective experience of a particular disease.

Patients engaged in their own care report improved health, reduced healthcare use, and associated costs. They also enjoy higher quality care overall and fewer diagnostic or prescribing errors, the ACCESS report found.

As we move towards greater collaboration between policymakers and patient organisations, there are several important considerations for successful long-term partnerships.

Balancing breadth, depth, and efficiency in HTAs

When you consider that every healthcare system is different in terms of infrastructure, resources, and priorities and that every society has its own expectations and norms that may influence health decision-making, it is clear that there can be no one-size-fits-all model for patient engagement in HTA. This means that policymakers looking to implement HTA systems need to consider the unique attributes of the environment in which the system will operate.

A good first step in creating an HTA system that works is for organisations such as public health authorities and individual hospitals to form steering committees to investigate practice in other Asia Pacific HTA systems that have a high level of patient involvement. Australia’s Pharmaceutical Benefits Advisory Committee, for instance, invites public involvement in HTAs and conducts consumer hearings to obtain the full picture of the potential impact of any new intervention. In the Philippines, patients are considered vital data sources, and their opinions are sought through in-depth interviews, focus group discussions, and other methods to determine the implications of any proposed intervention.

It is also crucial for committees to consult key stakeholders from within the organisations involved in the HTA as well as from the wider healthcare ecosystem. An engagement model can then be developed and assessed with selected HTA projects to evaluate its efficacy so it can be refined where necessary.

Even when incorporating patient engagement in HTA, we see that efficiency continues to be of importance to healthcare systems. Taiwan has achieved this delicate balance by taking a holistic approach in involving patients while ensuring that their HTA process is streamlined. Their HTA framework includes two mechanisms for patient engagement. The Pharmaceutical Benefits and Reimbursement Scheme (PBRS) Committee supports Taiwan’s National Health Insurance Administration (NHIA) in designing reimbursement policies for new drugs. A month before the PBRS committee meets to discuss a new drug under evaluation, patients, caregivers, and patient groups are invited to submit opinions to an online platform. The results are summarised in a final report which is taken into consideration by the HTA committee. Patients are also invited to sit on these PBRS appraisal committees to further explain their perspective on managing the health condition addressed by the drug under review.

These initiatives are a significant step forward in the HTA process and it is hoped that more countries will follow Taiwan’s example in giving patients a voice when evaluating new healthcare technologies, protocols, and treatments that directly impact their lives.

Public opinion in the Asia Pacific region is also influencing the drive towards giving patients a greater say in new treatment appraisal processes. Opinion polls have shown support in Australia for patient involvement in HTA processes and the Korean Organisation for Rare Diseases recently conducted a public survey on attitudes to the provision of innovative cell and gene therapies for people with rare diseases who are often denied effective treatments because of cost. The survey revealed significant support for reimbursement of these treatments. The findings were highlighted at subsequent National Assembly policy seminars in Korea and even included in a presidential candidate's election pledge. Such initiatives are a useful tool for policymakers to understand the real views of the public on issues that may not affect them now but could be of huge significance if they or a family member happen to be diagnosed with a disease in the future.

Capability drives capacity and credibility What we hear from patient leaders are that the lack of information about decision-making processes and lack of opportunity for patient involvement have been barriers to identifying ways to make improvements. However, patient organisations can develop capabilities that will allow them to argue for a seat at the HTA table and maximise the benefits once they get there. A strong understanding of the local ecosystem and the views of other stakeholders will help ensure approaches and positions are adopted which will achieve a consensus leading to the greatest patient benefit.

United voices have the greatest impact and patient organisations in the same disease areas should collaborate as much as possible, prioritising the collection of integrated data through surveys, focus groups, and research to demonstrate the experience of an entire patient population which can then be presented to an HTA.

The Alliance and Partnership for Patient Innovations and Solutions (APPIS) were launched in 2021 as a collaboration between Novartis and patient organisations to enable targeted discussions around specific local needs, and support the growing capabilities and empowerment of patient organisations in the Asia Pacific and beyond. The ultimate objective is to bring patient organisations together to align on challenges and priorities and build strong partnerships that drive measurable benefits in healthcare.

Delegates at the recent APPIS 2022 Summit enjoyed a series of productive discussions on how to take forward these concerns. Initiatives such as APPIS provide a springboard for patient groups to consolidate their knowledge, skills, and networks to drive policy change. Health policy-shaping is also a category in the inaugural APPIS Innovator Programme, which supports patient organisations to scale initiatives and tools to improve healthcare outcomes for the people they represent. As more countries in the region join the healthcare drive to listen to patient voices, there will be a growing demand from patient groups for training opportunities offered by platforms such as APPIS.

Partners for a healthier future

Value, quality, and equity of access are important considerations for Asian countries as local systems respond to rising public expectations and evolving health requirements. There is a continuing necessity for robust and fully validated HTA processes, and a parallel growing need for patients to be at the heart of their own care and decisions that impact them. Collaboration should underpin all these efforts as we work towards a healthier future in Asia.