Insight Brief

Valuing the Patient Voice in Medicines Access Decisions — How Does Australia Compare?

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Across the world, the value and impact of patient voices are increasingly influencing Health Technology Assessments (HTAs). In Australia, this shift is transforming HTA by incorporating real-world experiences, preferences, and needs of patients, carers, and advocacy groups. As beneficiaries of the technology, the patient perspective is increasingly understood as critical to guide decision makers in determining the value of medicines.

This paper examines the use of consumer input and evidence across Australia and four international markets over a nine-year period, to benchmark Australia's position and identify opportunities to strengthen patient engagement in Australia's HTA policy and practice.

Defining the patient voice in Health Technology Assessment

Patient voice refers to the meaningful inclusion of consumer perspectives in HTA processes. This can take many forms but broadly falls into two key categories: consumer input and consumer evidence.

Both forms of engagement are essential for ensuring that HTA decisions reflect what truly matters to those affected by health technologies.

Consumer input

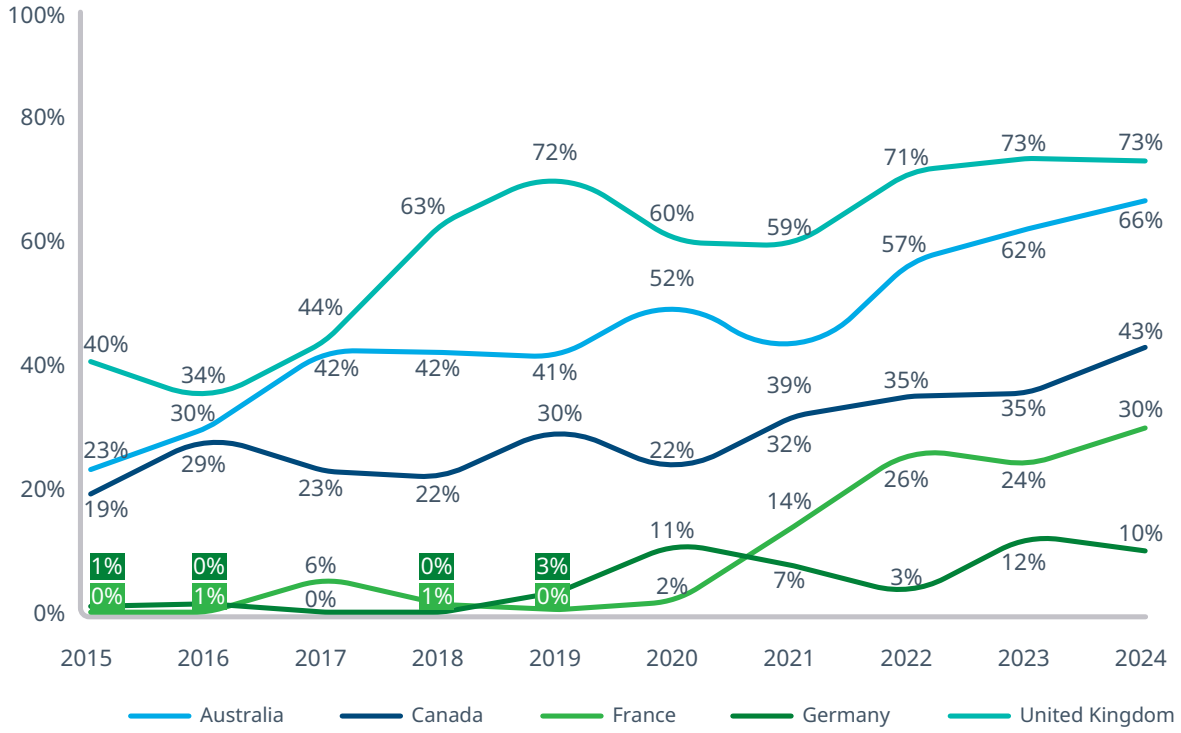
Consumer input refers to direct contributions from patients, families, carers, and advocacy groups — commonly in the form of written submissions to the HTA committee or statements in public hearings — sharing lived experiences and highlighting unmet needs.[1]

Consumer evidence

Consumer evidence is patient-based research, including qualitative studies, patient-reported outcomes, and real-world evidence, often published in peer-reviewed journals and co-designed with patients and sponsors.[1]

Consumer input: *Across benchmark markets, an average of 44% of drug HTA submissions in 2024 included consumer input — in Australia this reached 66%.*

Figure 1: Percentage of Health Technology Assessment submissions with consumer input by country



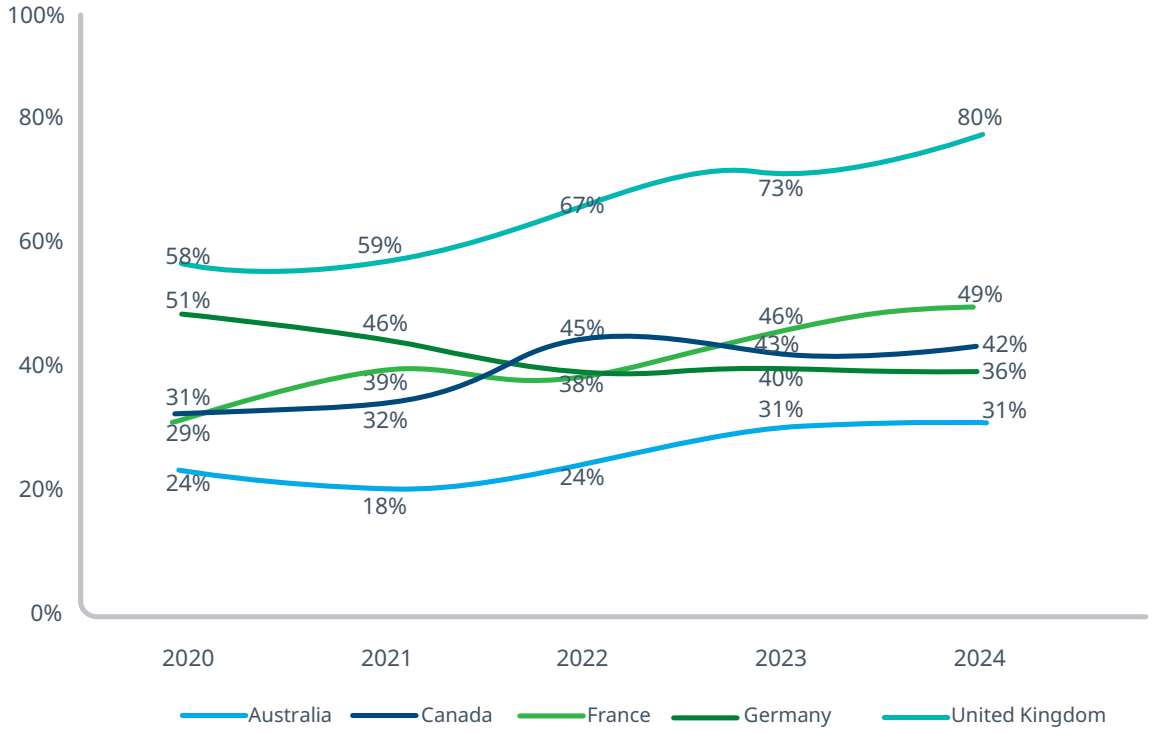
Source: IQVIA HTA Accelerator, March 2025 (Based on 10,364 submissions in 5 countries from 2015 to 2024)

The United Kingdom remains the global leader in embedding consumer input into HTA submissions, with Australia following closely behind. Both markets have demonstrated a strong upward trend over the past decade. Canada has shown steady growth in consumer engagement since 2015, while France's progress is primarily within the last five years. Germany is gradually adopting more patient-centred approaches; however, it is lagging behind other key HTA markets, with consumer input only exceeding 10% of submissions in the past two years. Despite the presence of formal mechanisms, participation pathways are less "open-door" than other markets, and the combination of a historically technocratic, expert-led model and less resourced patient advocacy groups contributes to Germany's lower rates of consumer input.

In 2024, 66% of Australian HTA submissions included consumer input, reflecting a strong culture of engagement supported by an active and mature network of patient advocacy groups and well-defined pathways for consumer participation in PBAC processes. This is especially pronounced in assessments for oncology, musculoskeletal, and central nervous system therapies. Orphan drug and cost-effectiveness submissions also showed a higher proportion of consumer input. The UK's leadership is driven by structured and institutionalised pathways for patient organisations and experts to contribute to HTA submissions.[2]

***Consumer evidence:** When compared to international benchmarks, Australia demonstrates the lowest uptake of consumer evidence in HTA, with only 31% of submissions incorporating it.*

Figure 2: Percentage of HTA submissions with consumer evidence by country



Source: IQVIA HTA Accelerator, March 2025 (Based on 10,364 submissions in 5 countries from 2015 to 2024).

While the use of consumer evidence is increasing globally, the pace of adoption varies. The UK continues to lead with 80% of health technology submissions including consumer evidence in 2024. This is followed by France and Canada with 49% and 42% of submissions respectively.

In 2024, only 31% of Australian HTA submissions included consumer evidence, the lowest among benchmark markets. The government-initiated HTA Policy and Methods Review determined that the key barriers to consumer evidence integration were the absence of standard guidelines for consumer evidence preparation and limited transparency regarding the influence of consumer evidence on HTA decision making.[3]

What does this mean for Australia?

Globally, the patient voice is increasingly being used to support market access decision-making, with the UK leading that way in both consumer input and evidence.

Australia demonstrates a strong culture of consumer engagement, however, consumer evidence is underutilised compared to the benchmark markets.

The Federal Government is increasingly prioritising consumer engagement and evidence in HTA processes, with anticipated policy reforms aimed at improving accessibility, strengthening support for consumer engagement, and enhancing transparency. These reforms are expected to provide clearer guidance for consumer evidence and input submissions, alongside the development of an HTA stakeholder engagement framework.[1,3]

This presents an opportunity for increased early collaboration between industry and patient advocacy groups to develop robust consumer evidence, including RWE to integrate into HTA submissions and outcomes.

About IQVIA

Who we are:

IQVIA is a global provider of advanced analytics, commercial strategy advisory services, and clinical research services to the life sciences industry. With a presence in over 100 countries, we have deep expertise in supporting life sciences industry and governments as they navigate the challenges of bringing new therapies and technologies to market. Leveraging our global expertise, IQVIA provides services on best-practice case studies to help adapt for a rapidly evolving healthcare landscape.

Our collaboration with Patient Advocacy Groups

In Australia, IQVIA works closely with Patient Advocacy Groups (PAGs) to improve health outcomes by accelerating medicines development and fostering impactful partnerships across patient communities. Our broad range of capabilities support diverse PAG needs, including:

- Patient-centred, informed, end-to-end drug development
- Expertise and innovation in real-world evidence, data, genomics, and AI/ML
- Facilitation of non-competitive collaboration across industry, patient organisations, and academia
- Support for income generation through commercialisation and reimbursement strategies
- Engagement with policymakers and Health Technology Assessment agencies

References

1. Department of Health, Disability and Ageing, “Enhance HTA: An Enhanced Consumer Engagement Process in Australian Health Technology Assessment”, 2024.
2. G. Arianna, “How are patient input considered in HTA? A thematic document analysis of NICE ultra-rare disease appraisals”, *The European journal of health economics*, Vol.26 (6), p.945-968, 2025.
3. Department of Health, Disability and Ageing, “Health Technology Assessment Policy and Methods Review — Final report”, 2024.