



ISPEP Voice 2 Value Study | Access and Reimbursement

Patient voice in health technology assessment

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Problem Statement

Need for Patient Voice: While patient input and the role of Patient Advocacy Groups (PAGs) in Health Technology Assessment (HTA) submissions have grown, their impact has rarely been quantified. This case study fills that gap by offering measurable insights into patient input and PAG involvement with HTA in Canada, serving as a foundational framework for similar assessments globally.

Objectives

1. Quantify the impact of PAG contributions on HTA outcomes in Canada
2. Demonstrate the value of investing in early, structured patient engagement to enhance eventual HTA submissions.

Methodology

Patient input was analysed across 611 Canadian HTA submissions from 2014 to 2023, focusing on:

- The impact of patient input on reimbursement decisions
- The increase in patient input prevalence
- The trend towards collaboration among PAGs

Results (Outcomes and Impact)

Activation of Patient Voice

Patient input in HTA submissions rose from 18% in 2014 to 95% by 2023, highlighting a significant activation of the patient voice in drug reimbursement decision-making. In 65% of cases with positive reimbursement outcomes, patient input was included, compared to 56% for negative outcomes. While this is a correlation, further research would be helpful in exploring any potential causative relationship here so the impact of patient voice in HTA submissions may be more clearly defined.

Collaboration

There has been an increase in collaborative patient input submissions, with an average of two PAGs involved per submission. Fostering more collaboration across various communities helps ensure that patient perspectives are more diverse and representative.

Triple Win

- **Patients:** Gain access to new therapies that are better-aligned with their needs
- **Pharma:** Achieve improved reimbursement outcomes with high-quality patient input submissions
- **Society:** Canadian reimbursement recommendations now better incorporate patient needs

Return on Investment

By not engaging PAGs early in the drug development process, pharma companies increase the risk of poorly-informed patient input submissions from PAGs contributing to unfavourable reimbursement outcomes. Proactive engagement with PAGs could help reduce this risk, potentially leading to cost savings by minimizing the likelihood of delayed or negative public insurer decisions.

Lessons Learned

PAGs will be involved in HTA submissions, regardless of pharma engagement. Pharma's objective should therefore be to support PAGs to optimize their submissions by investing in early scientific education, involvement in evidence generation, and capacity building.

Looking Ahead

This case study highlights the potential to expand similar analyses across global Health Technology Assessment (HTA) bodies. By understanding regional variations in patient/PAG involvement in HTA, pharma companies can tailor their engagement strategies to maximize the impact of patient input, regardless of the local environment.

Behaviour Change

Pharma needs to shift towards proactive engagement with PAGs early in drug development, ensuring that PAGs are educated on the therapy and HTA process and actively involved in real-world evidence generation. This approach leads to more informed patient input submissions that align with payer decision-making criteria.

Conclusion

PAG involvement in Canada's HTA process is here to stay, with patient input becoming an integrated part of the submissions. By investing early in patient engagement, pharmaceutical companies can help equip PAGs with the scientific knowledge, real-world evidence generation opportunities, and patient input collection skills that HTA assessor's value in making reimbursement decisions. This early support ensures that PAGs can gather meaningful insights from their communities, leading to stronger and more informed HTA submissions.