



# Level of Patient Involvement in Health Technology Assessment (HTA) Agencies:

## A Systematic Literature Review by Alira Health

Annabel de María<sup>1</sup>, Nerea Blanqué-Catalina<sup>2</sup>, Chus Castillo<sup>3</sup>, María Miralles<sup>4</sup>, Giulia Perini<sup>5</sup> and Marta Aguado<sup>6</sup>

<sup>1</sup>Patient Engagement Vice President, Alira Health; <sup>2</sup>Global Market Access Vice President, Alira Health; <sup>3</sup>Global Market Access Director, Alira Health; <sup>4</sup>Associate Consultant, Alira Health; <sup>5</sup>Patient Engagement Associate Consultant, Alira health; <sup>6</sup>Global Market Access Medical Editor, Alira Health



## INTRODUCTION

HTAs play an important role in the process of market access for new medicines<sup>1-4</sup>. Structures, methodologies and processes differ from one country to the other, but a common factor is present in all of them: awareness of the importance of including the patient's voice is essential<sup>5-8</sup>.

Engaging with patients during this process allows them to describe their experience and relevant aspects impacting their quality of life regarding the assessed product, providing the experts with valuable evidence on a patient's perspective<sup>1,2</sup>.

However, while the patient's voice is increasingly being included in the evaluation, patients still perceive that there is a long way to go before their opinion has a real impact on decision-making<sup>1,3,8</sup>.

## OBJECTIVE AND METHODOLOGY

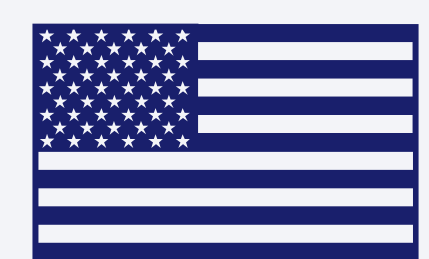
To characterize the level of current patient involvement in health technology assessment (HTA) in the European, US, and Canadian HTA agencies, Alira Health conducted a systematic literature review of articles published in English between 2016 and 2021 on HTA and patient engagement.

## RESULTS

**Patients have roles at the different steps of the HTAs in several countries; however, their participation is dissimilar during the process and several countries are still barely involving patients<sup>3,7</sup>.**



In Europe, there is an increasing awareness of the benefits of patient engagement in HTA. This is determined at the national and regional levels and is not subject to any European legislation. Consequently, the extent of the patient presence in HTA varies considerably between countries and regions in Europe. NICE in the U.K. and SMC in Scotland offer one of the most formalized and structured European approaches to involvement, where patients participate in meetings, workshops, or committees. In most cases, patients do not have voting rights<sup>3,7,8</sup>, with some exceptions, including Spain, with the Catalan HTA agency, AQuAS<sup>9,10</sup>.



In the U.S., patient participation in value assessment has increased and improved considerably since the National Health Council (NHC) launched a Value Initiative in 2016 to support its patient-advocate membership in this regard<sup>11</sup>.



In Canada, CADTH invites patients to share their perspective in different ways. For instance, in pCODR, which assesses cancer drugs, three patient members with voting rights sit on the Expert Review Committee. For its pioneering role, CADTH has gained international recognition as a leader in the area of patient involvement<sup>5, 12, 13</sup>.



## CONCLUSIONS

Although the level of patient involvement in HTA is increasing, there is still too much heterogeneity between different agencies. The integration of patient preferences is expected to contribute to better decision-making and to increase uptake, adherence, and patient satisfaction. However, there are some methodological and procedural issues that remain unresolved.

1. Facey KM. As health technology assessment evolves so must its approach to patient involvement. *J Comp Eff Res.* 2019;8(8):549–54.
2. Scott AM, Wale JL. Patient advocate perspectives on involvement in HTA: An international snapshot. *Res Involv Engagem.* 2017;3(1):1–17.
3. Wale JL, Thomas S, Hamerlijnck D, Hollander R. Patients and public are important stakeholders in health technology assessment but the level of involvement is low – a call to action. *Res Involv Engagem.* 2021;7(1):1–11.
4. Huls SPI, Whichello CL, van Exel J, Uyl-de Groot CA, de Bekker-Grob EW. What Is Next for Patient Preferences in Health Technology Assessment? A Systematic Review of the Challenges. *Value Heal.* 2019;22(11):1318–28.
5. Berglas S, Jutai L, Maclean G, Weeks L. Patients' perspectives can be integrated in health technology assessments: An exploratory analysis of CADTH common drug review. *Res Involv Engagem.* 2016;2(1):1–13.
6. Wale JL, Sullivan M. Exploration of the visibility of patient input in final recommendation documentation for three health technology assessment bodies. *Int J Technol Assess Health Care.* 2020;36(3):197–203.
7. Stewart J, Clifton E, Macpherson K, Angelova N, Morrison G. Scottish Health Technologies Group: enhancing patient engagement. *Int J Technol Assess Health Care.* 2021;37(e21):1–6.

8. Hunter A, Facey K, Thomas V, Haerry D, Warner K, Klingmann I, et al. EUPATI guidance for patient involvement in medicines research and development: Health technology assessment. *Front Med.* 2018;5(SEP):1–10.
9. Consell Consultiu de Pacients. Departament de Salut [Internet]. [cited 2021 Sep 21]. Available from: [https://salutweb.gencat.cat/ca/ambits\\_actuacio/per\\_perfiles/Consell\\_pacients/el\\_consell\\_pacients/](https://salutweb.gencat.cat/ca/ambits_actuacio/per_perfiles/Consell_pacients/el_consell_pacients/)
10. Àmbit. 2017;
11. Perfetto E, Harris J, Al. E. Emerging good practices fro transforming value assessment: Patients' voices, Patients' values. *Value Heal.* 2018;386–93.
12. Mercer RE, Chambers A, Mai H, McDonald V, McMahon C, Chan KKW. Are We Making a Difference? A Qualitative Study of Patient Engagement at the pan-Canadian Oncology Drug Review: Perspectives of Patient Groups. *Value Heal.* 2020;23(9):1157–62.
13. Bidonde J, Vanstone M, Schwartz L, Abelson J. An institutional ethonographic analysis of public and patient engagement activities at a national health technology assessment agency. *Int J Technol Assess Health Care.* 2021;37(e37):1–7.