

# Patient Involvement

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## INAHTA POSITION

Patient involvement is recognised by INAHTA as an important and valuable element in the conduct of Health Technology Assessment (HTA).

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## SUPPORTING STATEMENTS

**WHO:** A “patient” involved in HTA<sup>1</sup> refers to anyone who is capable of communicating or conveying the lived experience of a health condition, healthcare technology (including preventive interventions) or using a healthcare system whether this is the individual themselves, someone speaking on their behalf, or a representative of a patient or other relevant organisation with collective experiential knowledge<sup>2</sup>.

**WHAT:** A variety of frameworks and terms exist to describe the concept of patient involvement in healthcare. INAHTA does not endorse any particular framework and recognizes the different terminology already used by agencies and the subtleties of translating terms between languages. Agencies may pursue a range of activities under the label of Patient Involvement and for this reason, providing a universal definition is challenging. The concept is most easily captured through examples. These include enabling and supporting patients:

- To have a role in the proposal, selection and prioritization of topics for HTA
- To provide input to the scoping process informing HTAs to ensure that the questions being considered are relevant to patients and address the outcomes that are important to them
- To provide their lived experience of the condition under study and the associated technology being evaluated such that this can be incorporated into the assessment and appraisal process
- To shape conclusions and recommendations to inform decision-making, such that the patient perspective, in the regional or national context, is appropriately incorporated
- To be involved in producing plain language summaries of assessments and appraisals that will be shared with the public, to ensure wider awareness and understanding of the work
- To respond to consultations on assessments and appraisals and to receive feedback on how their contribution has been used

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<sup>1</sup> Health Technology Assessment (HTA) is a multidisciplinary process that uses explicit methods to determine the value of a health technology at different points in its lifecycle. The purpose is to inform decision-making in order to promote an equitable, efficient, and high-quality health system.

<sup>2</sup> The involvement of family members, friends and formal and informal carers of patients is also valuable within the HTA process, but the focus of this statement is the patient themselves, and those acting on their behalf (for example in situations when the patient is a young child or has advanced disease).

- To participate in the decision-making structures and processes of HTA, such as assessment and appraisal committees
- To participate in facilitating the dissemination, implementation and adoption of HTA conclusions and recommendations
- To be actively involved in designing, reviewing and developing HTA processes, methods and resources<sup>3</sup>; and
- To participate in standing groups or other structures constituted to ensure patient involvement in the processes and outputs of an agency

**WHEN:** Patient involvement can take place at the following stages of the HTA process<sup>4</sup>, although not all of these will necessarily apply to all agencies at all times:

- Topic proposal, selection, including assessing the feasibility of conducting an HTA, and prioritisation
- Topic scoping
- Assessment and appraisal
- Drafting conclusions and recommendations
- Consultation on recommendations
- HTA committee<sup>5</sup> deliberations and decision-making processes
- Developing processes, methods and HTA resources<sup>3</sup>; and
- Dissemination, implementation and adoption of HTA conclusions and recommendations

**HOW:** To enable meaningful and active patient involvement in HTA processes and products, agencies should consider:

- Making explicit the expectations of both HTA agencies and participating patients regarding the level and objectives of involvement
- Identifying and developing methods to identify appropriate patients for meaningful engagement, ensuring a diversity of views are gathered
- Working closely with relevant topic-related external organisations and groups
- Providing clear, easily understood information and advice on patient involvement processes and opportunities
- Giving patients sufficient accessible information on the technology in question to enable their full understanding and hence participation
- Having a dedicated contact for patients within the agency
- Ensuring accessibility for patients to both physical and virtual meeting spaces or providing equivalent alternative arrangements
- Covering of expenses incurred by patients involved in the process
- Providing plain language summaries of HTA recommendations
- Having standard operating procedures for aspects of patient involvement in place where applicable
- Providing training sessions for patients and ensuring that the HTA agency staff they interact with have appropriate knowledge and skills for this work

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<sup>3</sup> Resources refers to outputs and products accompanying or relating to the production of the HTA. For example, budget impact templates, training material for agency staff, public partners or patient representatives, decision aids.

<sup>4</sup> The focus of this position statement is on the production of HTA reports and associated processes and outputs. Patient involvement may also take place within the other functions undertaken by HTA agencies such as providing scientific advice and post launch evidence generation but this is not covered here.

<sup>5</sup> The term 'HTA committee' is used to describe any group constituted by the agency that contributes to the production of their HTA outputs.

- Establishing a standing committee or advisory group for patient involvement to assure appropriate patient involvement in processes and promote best practice; and
- Having a conflicts of interest policy which is accessible and applicable to patients

The formats and approaches that HTA agencies may want to use, alone or in combination, when involving patients could include:

- Web forms, at events, or through email correspondence
- Workshops for patients or patient organisations
- Interviews, focus groups, Delphi panels and other preference elicitation methods
- Opening online fora
- Patients presenting to committees
- Use of templates to gather specific written information
- Patients sitting on assessment or appraisal panels, or methodology and process standing groups

**WHY:** Patient involvement is recognised by INAHTA as an important and valuable element in the conduct of HTA. INAHTA believes that:

- The processes and outputs of HTA concern patients either directly or indirectly, and therefore patients have a right to be involved. This is especially the case when HTAs are funded by public money
- Identifying what is important to patients in terms of their health care needs and the wider health care goals of society, helps ensure that HTA outputs are more responsive and of greater relevance to those needs and goals
- Involving patients in the production of HTAs helps to build patients' confidence in, and acceptance of, the processes and methods used, and thereafter the findings and related recommendations
- Involving patients in the production of HTA can improve the overall quality and can accelerate its translation into action. Patients can draw out messages from the evidence that might otherwise be missed, contribute to resolving ethical and social issues and provide intelligence on the national and local context not available from other sources.
- Relationships and linkages with formal and informal patient networks benefit both HTA agencies and patients, by encouraging dissemination and implementation of HTA products; and
- Involving patients and gaining an understanding of their views, perspectives and experiences leads to more informed decision-making both in HTA production processes and in drafting their related recommendations. This supports patient-centred decision-making within individual patient and clinician interactions

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## **WHY INAHTA HAS ISSUED THIS POSITION STATEMENT**

INAHTA wishes to highlight the importance of patient involvement and to support agencies in their efforts towards engaging effectively with patients to enable them to contribute meaningfully to HTA processes and outputs. This statement describes the different aspects of patient involvement in HTA and shares best practice.

HTA agencies may choose to include some, or all of these practices into their local processes, as appropriate.

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### **References:**

INAHTA website: <http://www.inahta.org/>

INAHTA Strategic Plan 2017-2020: <http://www.inahta.org/about-inahta/>

Publications by INAHTA member agencies relevant to this topic – *Under development, link to be added*

**Review cycle for statement:**

- This statement is to be reviewed by the INAHTA Board (or a task group established by the Board for this purpose) at the 1-year point since the release date.
- After the year 1 review, the statement is to be reviewed every three years by the Board (or task group designated by the Board).
- The objective of the review is to assess the value of the statement relative to the INAHTA strategic plan and any issues that have been raised by members in the use of the statement.

For more information about the INAHTA Position Statement Process, contact the INAHTA Secretariat at [INAHTA@ihe.ca](mailto:INAHTA@ihe.ca).

