# Supplementary Files

# Supplementary File 1

**Rapid Review: Grey literature search - PPI practices in HTA.**

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| --- | --- | --- | --- |
| **International** **HTA agencies** | **Search results** | **Identified links** | **Included links** |
| Canadian Agency for Drugs and Technologies in Health (CADTH)Canada<www.cadth.ca> | 184 | 02 | 01  <https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment> |
| The National Institute for Health and Care Excellence (NICE) United Kingdom  <www.nice.org.uk> | 29 | 02 | 01  <https://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/public-involvement-programme/patient-public-involvement-policy> |
| Health Technology Wales (HTW)  Wales, United Kingdom  <www.healthtechnology.wales> | 32 | 01 | 00 |
| Healthcare Improvement Scotland (HIS)  Scotland, United Kingdom  <www.healthcareimprovementscotland.org> | 111 | 04 | 00 |
| Health Technology Assessment International (HTAi)  <htai.org> | 93 | 03 | 01  <https://htai.org/interest-groups/pcig/values-and-standards/> |
| Adelaide Health Technology Assessment (AHTA)  Australia  <www.adelaide.edu.au/ahta> | 58 | 00 | 00 |
| Institute of Health Economics (IHE)  Canada  <www.ihe.ca> | 00 | 00 | 00 |
| Swedish Agency for Health Technology Assessment and Assessment of Social  (SBU)  Sweden  <www.sbu.se/en> | 07 | 00 | 00 |
| The Health Information and Quality Authority (HIQA)  Ireland  <www.hiqa.ie> | 20 | 00 | 00 |

Keys terms: “patient involvement”, “patient engagement”, “citizen involvement”, “POR”, “Patient-Oriented Research”, “PPI” and “Patient and Public Involvement”.

Translated from Silva, 2020.

# Supplementary File 2

**Rapid Review: Flow diagram of study selection process – PPI in HTA evaluation.**

1175 identified studies

MEDLINE/manual search (n=839)

Web of Science (n=336)

257 duplicates removed

900 publications excluded

918 publications screened against titles and abstracts

18 publications assessed for full text eligibility

03 publications included

15 full texts excluded

Keys terms: terms related to “health technology assessment”, “patient involvement” and “evaluation”.

The date of 2008 was chosen as the early limit because this review was based on a narrative review of the previous five years carried by Silva (2013)[[1]](#footnote-1), having its included studies also searched in the Web of Science (Clarivate Analytics) for cited references.

Manual search: Five international HTA organizations (Healthcare Improvement Scotland, Canadian Agency for Drugs and Technologies in Health, Adelaide Health Technology Assessment, *Agencia de Evaluación de Tecnologias Sanitarias*, and Agency for Care Effectiveness) and two relevant journals (Health Expectations: An international journal of public participation in health care and health policy and International Journal of Technology Assessment in Health Care).

Translated from Silva, 2020.

# Supplementary File 3

**Suggestions to improve PPI in the Brazilian HTA, received through group consensus activity in the workshop for patient representatives in Sao Paulo, 2017.**

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| **Groups** | **How can we do it together?** |
| Group 1 | Include a seat at Conitec for specialist representative in rare diseases |
| Conitec proactivity in clinical research for rare diseases |
| Anvisa and Conitec collaboration to support greater agility on health technology registration |
| Provide mechanisms to monitor health technologies’ clinical effectiveness after reimbursement decision-making (performance assessment) |
| Conitec phone support (direct line) for public and patients |
| Group 2 | Review criteria for rare diseases HTAs |
| Transparency on Conitec’s HTA criteria |
| Participation |
| Video explaining how to get involved with public consultation |
| Include a seat at Conitec for specialist representative in rare diseases |
| Patient representatives’ participation in the committee meetings, according to theme under assessment |
| Include a seat at Conitec for specialist representative in chronic degenerative diseases |
| Group 3 | Patient representatives’ participation in the committee meetings, according to theme under assessment |
| Disclosure committee meeting agenda earlier |
| Broadcast committee meetings |
| Notification of new content at Conitec’s website (search engine by area of knowledge) |
| Tutorial step by step on how to get involved with public consultation, focused on patients |
| Promote at least two annual workshops including medical associations |
| Group 4 | More clarity and transparency on recommendation reports |
| Clarify information about Conitec’s role (to recommend and not to decide) |
| Enable public participation during committee meetings or broadcast the committee meetings (to improve transparency of Conitec's work, ensuring the possibility of participation/interaction with the public) |
| Clarify cost-effectiveness and budget impact analysis, to make clear the decision is not always about costs |
| Analysis of patient engagement in the Brazilian HTA processes (history of patient participation at the committee meetings) |
| Keep open communication with public and promote more events like this |
| Share workshop suggestions summary with participants |
| Clarify the role of the horizon scanning of new and emerging technologies and who requests it to help us to understand whether this impacts the reimbursement decision-making and public consultation |
| Inform which medicines will be assessed in the future so that patient groups can plan for the public consultation |
| Group 5 | Link to tutorial “Understanding the incorporation of health technologies  into SUS: how to get involved” in the public consultation forms |
| Improve public consultation forms (less-technical language to avoid ambiguity) |
| Broadcast the committee meetings and option for external web conference participation |
| Clarify cost-effectiveness and budget impact analysis in the plain language summaries of recommendation reports |
| Create an area to provide support for patient and public HTA requests |
| Participation of patient groups throughout the clinical guideline’s elaboration process |
| Group 6 | Public committee meetings (including deliberation on recommendation) |
| Exclusive way for HTA topic proposals from Civil Society Organisations |
| Provide more details on the plain language summaries of recommendation reports |
| Create a permanent forum between Conitec and patient groups (virtual) |
| Create specific patient committees within Conitec |
| Provide a meeting scheduling channel for patient groups (like the Brazil's National Health Surveillance Agency does) |
| Request information from patient groups to get patient perspectives/opinion |
| Group 7 | Create specific channel (e-mail) for patient groups request/receive information |
| Expand time for discussion in events like this (for example: two days or more) |
| Promote meetings with medical societies |
| Receive clinical guidelines from civil society organizations to contribute as information for the HTA process |
| Participation of civil society organizations in the HTA (effectively) |
| Amplify contact with health bloggers. Promote meetings to better capture public perspective |
| Patient groups should be authorised by Conitec/Anvisa to add their institutional links on websites |
| Accelerate clinical guidelines development after reimbursement decision-making |
| Improve public consultation forms |
| Provide support for HTA topic proposals from patient groups |
| Let us be a voice, not an echo! |
| Group 8 | Plain and positive language |
| Disclosure committee meeting agenda earlier and provide online support for public |
| Broadcast the committee meetings (similiar to Anvisa procedure) |
| Simplify registration to submit inputs through public consultations |
| Improve Conitec’s website navigation |
| Review of Conitec’s representation parity |
| Re-design public consultation form Likert-scale (provide ‘comment’ section) |
| Improve interaction through social media, email and website |
| Transparency on Conitec’s HTA process and methods |
| Capacity building/Events by specific diseases and related groups and more collaboration/partnership |
| Patient groups should be authorized by Conitec to add its link on their websites |
| Share workshop suggestions summary with participants |
| Group 9 | Strengthen the public representation in the committee |
| Web participation – Chat |
| Continuous capacity building for SUS users (patient groups) on how to get involved with public consultation |
| Web conferences for the public on Conitec duties, and laws, with wide dissemination |
| Wider communication via mainstream media, as well as print-out materials explaining Conitec’s HTA processes and public involvement approaches |
| Conitec’s technical support |

Translated from Silva, 2020. Data transcribed and translated from collected and archived material.

Summary (graphic facilitation document) available from: <http://conitec.gov.br/images/pdf/evento/Apresenta%C3%A7%C3%A3o_ata-dinamica.pdf>

1. Silva AS, Marcondes WB, Elias FTS. *O envolvimento do público no processo de Avaliação de Tecnologias em Saúde: experiências mundiais e proposições para sua ampliação no Brasil*. Escola Nacional de Saúde Pública Sergio Arouca, Rio de Janeiro; 2013. [↑](#footnote-ref-1)