**Values, principles, strategies, and frameworks underlying patient and public involvement in health technology appraisals and guideline development – a scoping review**

**Supplementary data**

**Table S1: Grey literature search**

|  |  |  |
| --- | --- | --- |
| Source | Search terms/techniques | Title and URL |
| Google | [framework involvement public OR patient](https://www.google.co.uk/search?as_q=framework+involvement&as_epq=&as_oq=public+patient&as_eq=&as_nlo=&as_nhi=&lr=&cr=&as_qdr=all&as_sitesearch=&as_occt=any&safe=images&as_filetype=&tbs=) | <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0164-0> How helpful are Patient and Public Involvement strategic documents - Results of a framework analysis using 4Pi National Involvement Standards (2019) *(five domains which are principles, purpose, presence, process and impact)* |
| [Framework for Patient and Public Participation in Public Health Commissioning](https://www.england.nhs.uk/wp-content/uploads/2017/01/ph-participation-frmwrk.pdf) (2017)https://www.england.nhs.uk/wp-content/uploads/2017/01/ph-participation-frmwrk.pdf |
| Public Involvement Impact Assessment Framework (PiiAF); <https://piiaf.org.uk/><https://piiaf.og.uk/documents/further-reading.pdf> |
| <https://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf> |
| [Public Involvement Framework (DoH Ireland last updated 2020)](https://www.gov.ie/en/collection/70a20b-public-involvement-framework/)  |
| [A Rough Guide to Public Involvement - Imperial College London](https://www.imperial.ac.uk/media/imperial-college/medicine/sph/ide/perc/PERCs-Rough-Guide-to-Public-Involvement---Jan-2020.pdf) (2020) |
| Proquest | (public involvement AND framework)AND PUBID(38894) ie “The Patient”https://www.proquest.com/results/5F18A0441B8043BDPQ/1?accountid=27428 | Messina, J., & Grainger, D. L. (2012). A pilot study to identify areas for further improvements in patient and public involvement in health technology assessments for medicines. The Patient, 5(3), 199-211.Dewar BJ. [Beyond tokenistic involvement of older people in research-a framework for future development and understanding](https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2702.2005.01162.x). J Clin Nursing. 2005;14(3a):48-53.Grant, S., Hazlewood, G. S., Peay, H. L., Lucas, A., Coulter, I., Fink, A., & Khodyakov, D. (2018). [Practical considerations for using online methods to engage patients in guideline development](http://dx.doi.org/10.1007/s40271-017-0280-6). The Patient, 11(2), 155. doi:http://dx.doi.org/10.1007/s40271-017-0280-6 |
| https://www.eu-patient.eu/ | Searched the listed projects | https://www.eu-patient.eu/search/?q=framework PE Toolbox new - PARADIGM (imi-paradigm.eu) |
| CADTH |  | CADTH Framework for Patient Engagement in Health Technology Assessment (June 2021)<https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment> Patient Involvement in Scientific Advice (July 2021)<https://www.cadth.ca/patient-involvement-scientific-advice>  |
| HTAi | Searched for ‘framework’ in resources | <https://htai.org/interest-groups/pcig/values-and-standards/>; <https://htai.org/interest-groups/pcig/resources/> <https://htai.org/interest-groups/pcig/projects/current-projects/> eg Patient participation at the organizational level in HTA (not individual HTAs) |
| <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00248-9> “Patients and public are important stakeholders in health technology assessment but the level of involvement is low – a call to action” (2021) |
| Kings Fund | Browsed topics | Topic dedicated to patient involvement:<https://www.kingsfund.org.uk/topics/patient-involvement>Patients as partners Building collaborative relationships among professionals, patients, carers and communities, 2016<https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Patients_as_partners.pdf>Joined-up listening: integrated care and patient insight, 2018<https://www.kingsfund.org.uk/publications/joined-up-listening-integrated-care-and-patient-insight?_ga=2.51954282.2141134226.1623842449-235412452.1600246417> |
| Kings Fund Library Catalogue (full list saved in Grey lit folder) |  | Participation : its impact on services and the people who use them, 2019<https://www.iriss.org.uk/resources/insights/participation-its-impact-services-and-people-who-use-them>Journal article:Ocloo J, Matthews RFrom tokenism to empowerment: progressing patient and public involvement in healthcare improvementBMJ Quality & Safety 2016;25:626-632.<https://qualitysafety.bmj.com/content/25/8/626.full>Health creation : how can primary care networks succeed in reducing health inequalities? 2021<https://thehealthcreationalliance.org/wp-content/uploads/2021/02/PCNs-workshop-series-report-FINAL-_-2-February-2021-.pdf> |
| National Association for Patient Participation | Browsed  | Building better participation : a guide to help patient participation groups and their GP practice work well[not available online without being a member] |
| National Survivor User Network | Browsed | Involvement for influence : 4Pi national involvement standards.<https://www.nsun.org.uk/projects/4pi-involvement-standards/> |
| NHS England |  | Framework for patient and public participation in primary care commissioning 2016<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/framwrk-public-partcptn-prim-care.pdf>Patient and public participation in commissioning health and care: Statutory guidance for clinical commissioning groups and NHS England, 2017<https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf> |
| Evidence Search | “patient involvement” research, "public involvement" research – used guideline, policy, evidence summary filters and date limit 2010 to date. Browsed first 100 results | Briefing Guide Effective Patient and Public Involvement, 2011RCGP Centre for Commissioning<https://www.rcgp.org.uk/policy/~/media/Files/CIRC/Effective_PPI.ashx>Public involvement in research: impact on ethical aspects of research, 2012INVOLVE, NIHR<https://www.invo.org.uk/wp-content/uploads/2012/06/INVOLVEevidenceresource.pdf>Briefing notes for researchers – public involvement in NHS, health and social care research, 2021NIHR (downloaded) <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371?pr=>Public involvement and engagement in research during the COVID-19 pandemic, 2020 Academy of Medical Sciences<https://acmedsci.ac.uk/file-download/77957062>Involving the public in healthcare policy An update of the research evidence and proposed evaluation framework,RAND Europe, 2010<https://www.rand.org/content/dam/rand/pubs/technical_reports/2010/RAND_TR850.pdf>THE DIVERSITY DIVIDEND? Does a more diverse and inclusive research community produce better biomedical and health research? 2017University of Sheffield<https://wellcome.org/sites/default/files/the-diversity-dividend-briefing.pdf>Wellcome Monitor 2020 How the British public engage with health research, 2021[see section 4 – Involvement in health research]National Centre for Social Research<https://cms.wellcome.org/sites/default/files/2021-02/wellcome-monitor-2020-public-engagement_0.pdf>Public engagement, not just about the public, 2014INVOLVEhttps://www.involve.org.uk/sites/default/files/field/attachemnt/Public-engagement-not-just-about-the-public.pdf<https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>See also: on NIHRArts-based approaches to public engagement with research. Lessons from a rapid review, 2021RAND Europe<https://www.rand.org/content/dam/rand/pubs/research_reports/RRA100/RRA194-1/RAND_RRA194-1.pdf>The Biomedical Bubble Richard Jones and James Wilsdon July 2018 Why UK research and innovation needs a greater diversity of priorities, politics, places and people, 2018Nesta<https://media.nesta.org.uk/documents/The-Biomedical-Bubble.pdf>Effective patient and public involvement in the work of the medical royal colleges and faculties: A practical guide, 2018Academy of Medical Sciences<https://www.aomrc.org.uk/wp-content/uploads/2020/10/Patient_public_lay_involvement_guide_1020.pdf>Public Engagement in Health: A Literature Review, 2018Healthwatch England<https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/Healthwatch%20England%20Literature%20Review.pdf>NIHR July 2021 “Equal access to the knowledge table” Scoping exercise: Public & Community Involvement, Engagement & Participation in NIHR Applied Research Collaboration National Priority Consortium for Adult Social Care and Social Work<https://warwick.ac.uk/fac/sci/med/about/centres/arc-wm/research/social-care/co-production_adult_social_care_research_arcwm.pdf> |
| Healthcare Quality Improvement Partnership |  | Patient and public involvement in quality improvement, 2016<https://www.gloshospitals.nhs.uk/media/documents/HQIP_-_Patient_and_Public_Involvement_in_Quality_Improvement.pdf>Developing a patient and public involvement panel for quality improvement, 2016<https://www.hqip.org.uk/wp-content/uploads/pelerous_media_manager/public/253/Final%20Patient%20Panel%20Guide.pdf> |
| Health Quality Ontario | Searched terms patient/public/stakeholder/consumer involvement/engagement | Patient partnership section on website<https://www.hqontario.ca/Patient-Partnering> |
| INAHTA  | Searched terms patient/public/stakeholder/consumer involvement/engagement | Position statement (June 2021)Saved in Grey lit folder |
| WHO | Searched terms patient/public/stakeholder/consumer involvement/engagement | How can the impact of health technology assessments be enhanced? 2008<https://www.euro.who.int/__data/assets/pdf_file/0019/73225/E93420.pdf> |
| Monash Health | Searched terms patient/public/stakeholder/consumer involvement/engagement | Consumer, Carer and Community Partnerships Framework, 2019<https://monashhealth.org/wp-content/uploads/2020/02/Consumer-Partnerships-Framework-Feb-2019.pdf>Consumer Partnership in Industry: Are there lessons for Healthcare? A Literature Review, 2015<https://monashhealth.org/wp-content/uploads/2019/03/ConsumerPartnership_final-draft-distributed.pdf> |
| National Prescribing Service | Searched terms patient/public/stakeholder/consumer involvement/engagement | Involving consumers in our work<https://www.nps.org.au/about-us/services/involving-consumers-in-our-work> |
| Lutwig Boltzmann Institute of HTA (Austria) | Searched terms patient/public/stakeholder/consumer involvement/engagement | Involvement of Citizens and Patients in HTA-Processes – International Experiences and Good Practice Examples (2016)<https://eprints.aihta.at/1088/1/HTA-Projektbericht_Nr.86.pdf>Executive summary in English |
| Belgian Health Care Knowledge Centre (KCE) | Searched terms patient/public/stakeholder/consumer involvement/engagement | Patient involvement in policy research at KCE: process note (2021)<https://kce.fgov.be/sites/default/files/atoms/files/KCE_340_Proces%20Note_Patient_Involvement_Report2.pdf> |
| Haute Autorité de santé | Searched terms patient/public/stakeholder/consumer involvement/engagement | Supporting and encouraging public engagement in social and health care organisations (2020)<https://www.has-sante.fr/jcms/p_3201812/en/supporting-and-encouraging-public-engagement-in-social-and-health-care-organisations> |
| Health Information and Quality Authority | Searched terms patient/public/stakeholder/consumer involvement/engagement | Guidelines for Stakeholder Engagement in Health Technology Assessment in Ireland (2014)<https://www.hiqa.ie/sites/default/files/2017-01/HTA-Guidelines-Stakeholder-Engagement.pdf> |
| Irish Society for Quality and Safety in Healthcare (ISQSH), Health Care Informed (HCI) | Searched terms patient/public/stakeholder/consumer involvement/engagement | Now we're talking:a practical toolkit for public & patient involvement in healthcare (2009)<https://www.lenus.ie/bitstream/handle/10147/74413/Healthcare%20toolkit.pdf?sequence=1&isAllowed=y> |
| Medical Research Charities Group | Searched terms patient/public/stakeholder/consumer involvement/engagement | Developing a PPI Strategy: A Guide Practical advice on developing a patient and public involvement (PPI) strategy for research activities (2018)<https://www.lenus.ie/bitstream/handle/10147/623822/Developing_a_PPI_Strategy_-_A_Guide_MRCG_2018.pdf?sequence=1&isAllowed=y> |
| School of Nursing and Human Sciences, Dublin City University, Dublin 9 | Searched terms patient/public/stakeholder/consumer involvement/engagement | Patient engagement in the governance and development of national clinical effectiveness processes (i.e. clinical audit & guidelines): A systematic literature review and desk-top analysis (2016)<https://www.lenus.ie/bitstream/handle/10147/624708/PPI_FINAL-REPORT_08032016.pdf?sequence=1&isAllowed=y> |
| Swedish Agency for HTA | Searched terms patient/public/stakeholder/consumer involvement/engagement | A project on the involvement of organisations representing patients and service users in governmental knowledge based guidance (2019)<https://www.sbu.se/en/about-sbu/a-project-on-the-involvement-of-organisations-representing-patients-and-service-users-in-governmental-knowledge-based-guidance/> |
| Healthcare Improvement Scotland | Searched terms patient/public/stakeholder/consumer involvement/engagement | [Involving the public](https://www.healthcareimprovementscotland.org/about_us/involving_the_public.aspx) webpage |
| AHRQ | Browsed | Bennett WL, Pitts S, Aboumatar H, Sharma R, Smith BM, Das A, Day J, Holzhauer K, Bass EB. Strategies for Patient, Family and Caregiver Engagement. Technical Brief. (Prepared by the Johns Hopkins University Evidence-based Practice Center under Contract No. 290-2015-00006-I.) AHRQ Publication No. 20-EHC017. Rockville, MD: Agency for Healthcare Research and Quality; August 2020<https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/technical-brief-36-patient-family-caregiver-engagement.pdf> |
| AHRQ | Browsed | Discerning the Perception and Impact of Patients Involved in Evidence- based Practice Center Key Informant Interviews, Research White paper, 2017<https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/key-informant-interviews-research.pdf> |
| AHRQ | Browsed | Stakeholder Involvement in Improving Comparative Effectiveness Reviews: AHRQ and the Effective Health Care Program, Research Report, 2011<https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/stakeholder-engagement_research.pdf> |
| Institute for clinical and economic review | Searched terms patient/public/stakeholder/consumer involvement/engagement | A Guide to ICER’s Methods for Health Technology Assessment, 2020 (Chapter 4 – Stakeholder engagement)<https://icer.org/wp-content/uploads/2021/01/ICER_HTA_Guide_102720.pdf> |
| Institute for clinical and economic review | Searched terms patient/public/stakeholder/consumer involvement/engagement | Our patient engagement program [webpage]<https://icer.org/our-approach/methods-process/patient-engagement/> |
| Canadian Medical Association | Browsed “Get Involved” and “Patient Voice”tabs on homepage | CMA’s patient engagement framework<https://www.cma.ca/sites/default/files/pdf/get-involved/Patient%20Engagement_Print.pdf> |
| SIGN | Browsed homepage and clicked on PPI tab | Section on website devoted to PPI<https://www.sign.ac.uk/patient-and-public-involvement/>Also:<https://www.sign.ac.uk/what-we-do/involving-patients-and-the-public/> |

**Table S2: Values identified by the scoping review**

|  |  |  |
| --- | --- | --- |
| Value | Mentioned in | Defined as |
| Capacity building | Hunter, 2018 CADTH Framework for Patient Engagement in Health Technology AssessmentEUPATI | Hunter, 2018: “Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.”CADTH Framework: “Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.”EUPATI: “Identify barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.” |
| Equity  | EUPATIHunter, 2018CADTH Framework for Patient Engagement in Health Technology Assessment | EUPATI: “Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.”Hunter, 2018: “Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with particular health issues, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.”CADTH Framework: “seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.” |
| Fairness  | EUPATIHunter, 2018CADTH Framework for Patient Engagement in Health Technology Assessment | EUPATI: “Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.”Hunter, 2018: “Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.”CADTH Framework: “Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.”  |
| Legitimacy  | EUPATIHunter, 2018CADTH Framework for Patient Engagement in Health Technology Assessment | EUPATI: “Patient involvement fosters the participation of those affected by the HTA recommendations and decisions. This contributes to the transparency, accountability and credibility of the decision-making process.”Hunter, 2018: “Patient involvement facilitates those affected by the HTA recommendations/decision to participate in HTA; contributing to the transparency, accountability and credibility of the decision-making process.”CADTH Framework: “Patient involvement facilitates those affected by the HTA recommendations and decisions to participate in the HTA, contributing to the transparency, accountability, and credibility of the decision-making process.” |
| Relevance | EUPATIHunter, 2018CADTH Framework for Patient Engagement in Health Technology Assessment | EUPATI: “Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.”Hunter, 2018: “Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.”CADTH: “Patients have knowledge, perspectives, and experiences that are unique and contribute to essential evidence for HTA.” |
| Transparency and openness  | CADTH Framework for Patient Engagement in Health Technology Assessment | CADTH: Not defined |

**Table S3: Principles identified by the scoping review**

|  |  |  |  |
| --- | --- | --- | --- |
| Principles | Setting | Definition (operationalization) | Author |
| Commitment to involving patients | Guidelines | Operates at strategic level within the organization and evidenced by a formal strategy, resource allocation, and established links to patient networks. | Bjorkqvist (2021) |
| Acceptance of patient involvement as part of the organizational culture | Guidelines | Establishment of a patient role, training opportunities, and a supportive environment to facilitate effective involvement in guideline production. | Bjorkqvist (2021) |
| Patient engagement and involvement in the relevant stages of guideline development | Guidelines | Involved throughout technical stages of guideline development (prioritizing questions and outcomes, disseminating and implementation).  | Bjorkqvist (2021) |
| Translating evidence to recommendations | Guidelines | Involve patients in framing questions, deciding on the most important outcomes, trained chair in expertise of psychology of small groups, manage power imbalances in committee, incorporation of lived experience | Harding (2011) |
| Optimizing the acceptability ofrecommendations to service users | Guidelines | Advising on the acceptability to patient groups of guidelinerecommendations both in terms of content and style; involve patients in discussions to resolve “grey” or scientifically uncertain preference sensitive decisions and include patient values and preferences to improve implementation of recommendations; explain evidence appraisal and recommendation formulation process throughout guideline development | Harding (2011) |
| Reconciling different types of knowledge | Guidelines | Assess the evidence base, produce decision support aids for use in appraising the evidence and making recommendations, and also highlighting recommendations that are particularly sensitive; outline techniques to enable communication about sensitive areas.  | Harding (2011) |
| Patient perspective | Guidelines and HTA | The perspective of patients is pivotal in health research, treatment guidelines, and the authorization of medicines | de Wit (2019) |
| Engagement | Guidelines and HTA | Capturing patients’ perspectives requires multiple forms of engagement that are complementary; the strategy should be tailored to suit different chronic diseases and contexts | de Wit (2019) |
| Transparency | Guidelines and HTA | Transparency for all stakeholders about the role of patients in the process facilitates participation and manages expectations from all perspectives | de Wit (2019) |
| Representation | Guidelines and HTA | Broad representativeness of patients’ perspectives in terms of demography, geography, disease severity and sample size must be ensured | de Wit (2019) |
| Multiple inputs | Guidelines and HTA | Involvement of at least two patient experts throughout the research, assessment and deliberation processes ensures that the patient perspective is preserved and increases the validity of the outcomes | de Wit (2019) |
| Support | Guidelines and HTA | Providing adequate information, support and feedback to patient representatives is key to effective engagement | de Wit (2019) |
| Expertise | Guidelines and HTA | Teaching researchers the knowledge and skills required to support public engagement should always be considered | de Wit (2019) |
| Resources | Guidelines and HTA | Productive participation always requires resources to be allocated to the process, with extra effort in time, money and energy | de Wit (2019) |
| Monitor | Guidelines and HTA | Continuous monitoring and measuring of interactions will be vital for refining procedures according to feedback | de Wit (2019) |
| Improving the relevance of assessments | HTA | n/a | Abelson (2016) |
| Strengthening the research and complementing the expertise of healthcare professionals and researchers | HTA | n/a | Abelson (2016) |
| Enhancing procedures, that is, the openness and inclusiveness of the decision process | HTA | n/a | Abelson (2016) |
| Purposeful | HTA | n/a | Abelson (2016) |
| Pragmatic | HTA | n/a | Abelson (2016) |
| Fair and equitable | HTA | “Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement“Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users | Abelson (2016) |
| Proportional | HTA | N/a | Abelson (2016) |
| Evidence informed | HTA | N/a | Abelson (2016) |
| Transparent | HTA | Not defined | Abelson (2016) |
| Engage early in the process | HTA | Involve patient advocacy organizations from the initial development of the framework, not only in a review capacity later down the road. Engage early and often; be persistent and continuous.  | Perfetto (2018) |
| Enhance outreach efforts to develop relationships with patient advocates  | HTA | Make it clear how patients can make contact to engage. Enhance outreach to patient groups to make initial contact easier.Provide incentive to work collaboratively (patient groups can use the data and analytic results, too). | Perfetto (2018) |
| Engage a range of patients and patient groups | HTA | Involve a range of patients to understand the varying needs. | Perfetto (2018) |
| Leverage patient-provided information and the data resources, and outreach mechanisms to collect information from patients | HTA | Use existing patient advocacy organization outreach mechanisms that patient groups have developed to gather information from patients. | Perfetto (2018) |
| Be Transparent | HTA | Adopt a clear timeline for the analysis and the conditions that must be met before the analysis is performed. Take a balanced approach; denying coverage should not be the intent.Provide redline changes to successive drafts so edits are readily apparent.Catalogue and make publicly available all suggestions received during an open-comment period.Provide/use an evaluation framework to triage the comments (e.g., what will be addressed immediately, in the short terms, long term, or cannot be addressed; a spreadsheet of concerns and how they have or will be addressed.Communicate, provide updates, personal outreach, and flexibility to enhance interactions. | Perfetto (2018) |
| Appreciate and accommodate patient community resource constraints | HTA | There is opportunity cost. Lengthen comment periods to the extent possible to accommodate the resource limitations of patient advocacy organizations | Perfetto (2018) |
| HTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients | HTA (General HTA process) | CADTH processes for patient engagement are explained in assessment protocols and/or program process documentation, and in the responsibilities of expert committee members. All are shared on CADTH’s website. This framework document reflection on how our activities meet or could better meet international values and standards provide CADTH’s broad strategy for patient engagement. | [CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| HTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA |  | CADTH appreciates the resource burden involved in providing regular patient input and contributing to ongoing calls for feedback.We do not provide funding to groups to prepare patient input, nor do we provide reviews of draft reports. We do provide patient and public committee members with honoraria and travel expenses equal to other committee members. | [CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| HTA participants (including researchers, staff, HTA reviewers, and committee members) receive training about the appropriate involvement of patients and consideration of patients” perspectives throughout the HTA process. | HTA (General HTA process) | Orientation training is received by CADTH reviewers and all committee members. We recognize the need for ongoing training of CADTH staff and committee members as methodologies for the integration of patient knowledge, perspectives, and experience change. | [CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA | HTA (General HTA process) | CADTH webcasts six to 10 lectures on HTA topics without cost each year, archiving past lectures at CADTH Lecture Series. We recognize the need to provide regular training specific to patient participation in HTA. | [CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them | HTA (General HTA process) | Published evaluations of patient engagement at CADTH include: SECOR 2012; Berglas et.al. 2016; Rosenberg-Yunger and Bayoumi 2017; and Rozmovitz et.al. 2018. CADTH also receives, reflects upon, and reviews, feedback shared directly with CADTH, adjusting processes and activities, as appropriate. | [CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA. | HTA (Individual HTAs) | CADTH uses email, Twitter, and Facebook to call for patient input and stakeholder feedback. Patient groups often circulate our call within their communities to gather input for CADTH. | [[CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment)](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| Clear timelines are established for each HTA, with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained | HTA (Individual HTAs) | Clear timelines for each milestone are indicated for the CADTH Common Drug Review and the CADTH pan-Canadian Oncology Drug Review assessments, and progress to timelines are regularly tracked and publicly updated.We are aware that advance notice for other assessments requesting feedback would be of value to all stakeholders. | [[CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment)](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA | HTA (Individual HTAs) | CADTH has a dedicated patient engagement team to support patient groups and individuals to contribute to assessments, and to support the incorporation of patient perspectives and experiences into assessments | [[CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment)](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| In each HTA, patients” perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported | HTA (Individual HTAs) | CADTH’s assessments, including patients’ perspectives and experiences gathered by literature review and/or patient input, are shared on our website. Recommendations and conclusions drawn by our three committees document key ideas deliberated on.We recognize a plain language description of the deliberations and evidence would improve understandability for a wider range of stakeholders, including the families who contributed to the submissions prepared by patient groups. | [[CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment)](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |
| Feedback is given to patient organizations that have contributed to an HTA, to share what contributions were most helpful and to provide suggestions to assist their future involvement. | HTA (Individual HTAs) | CADTH provides individual thank-you letters, which include feedback and suggestions for future involvement, to each patient group who contributes to the CADTH Common Drug Review and offers verbal or in-person feedback to patient group contributors to the CADTH pan-Canadian Oncology Drug Review.There would be value in extending the feedback offered to all who contribute insight, to all assessments including Optimal Use, Horizon and Environmental Scans, and Scientific Advice | [[CADTH](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment)](https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment) & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) |

**Table S4: Thematic analysis of principles**

|  |  |  |  |
| --- | --- | --- | --- |
| Principle theme | Authors | Setting | Definition |
| Transparency | de Wit (2019) | Guidelines and HTA | Transparency for all stakeholders about the role of patients in the process facilitates participation and manages expectations from all perspectives |
|  | Abelson (2016) | HTA | No operational definition |
|  | Perfetto (2018) | HTA | Adopt a clear timeline for the analysis and the conditions that must be met before the analysis is performed. Take a balanced approach; denying coverage should not be the intent.Provide redline changes to successive drafts so edits are readily apparent.Catalogue and make publicly available all suggestions received during an open-comment period.Provide/use an evaluation framework to triage the comments (e.g., what will be addressed immediately, in the short terms, long term, or cannot be addressed; a spreadsheet of concerns and how they have or will be addressed.Communicate, provide updates, personal outreach, and flexibility to enhance interactions. |
| Representation | de Wit (2019) | Guidelines and HTA | Broad representativeness of patients” perspectives in terms of demography, geography, disease severity and sample size must be ensured |
| Perfetto (2018) | HTA | Engage a range of patients and patient groups - Involve a range of patients to understand the varying needs. |
| de Wit (2019) | Guidelines and HTA | Multiple inputs- Involvement of at least two patient experts throughout the research, assessment and deliberation processes ensures that the patient perspective is preserved and increases the validity of the outcomes |
| CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520)Perfetto (2018)Perfetto (2018) | HTAHTAHTA | Communication strategy to reach patients – Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.Enhance outreach efforts to develop relationships with patient advocatesLeverage patient-provided information and the data resources, and outreach mechanisms to collect information from patients |
| Support/training for patients and orgs | de Wit (2019)Bjorkqvist (2021)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | Guidelines and HTAGuidelinesHTAHTA | Providing adequate information, support and feedback to patient representatives is key to effective engagementAcceptance of patient involvement as part of the organizational culture, which involves training opportunities and a supportive environment.Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA.For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA |
| Expertise and training for staff  | de Wit (2019)Harding (2021)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | Guidelines and HTAGuidelinesHTA | Teaching researchers the knowledge and skills required to support public engagement should always be consideredTranslating evidence to recommendations, which involves trained chair in expertise of psychology of small groups, manage power imbalances in committee, incorporation of lived experience. Therefore, expertise seems to be linked to training guideline staff to help achieve impactHTA participants (including researchers, staff, HTA reviewers, and committee members) receive training about the appropriate involvement of patients and consideration of patients” perspectives throughout the HTA process. |
| Types of patient engagement and involvement in the relevant stages of guideline development | Bjorkqvist (2021)Perfetto (2018)Harding (2011)Abelson (2016) | GuidelinesHTAGuidelinesHTA | Involved throughout technical stages of guideline development (prioritizing questions and outcomes, disseminating and implementation).Involve patient advocacy organizations from the initial development of the framework, not only in a review capacity later down the road. Engage early and often; be persistent and continuous. Optimizing the acceptability of recommendations to service users: Advising on the acceptability to patient groups of guideline recommendations both in terms of content and style; involve patients in discussions to resolve “grey” or scientifically uncertain preference sensitive decisions and include patient values and preferences to improve implementation of recommendations; explain evidence appraisal and recommendation formulation process throughout guideline development.Reconciling different types of knowledge: produce decision support aids for use in appraising the evidence and making recommendations, and also highlighting recommendations that are particularly sensitive.Strengthening the research and complementing the expertise of healthcare professionals and researchers |
| Resources | De Wit (2019)Perfetto (2018)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | Guidelines and HTAHTAHTA | Productive participation always requires resources to be allocated to the process, with extra effort in time, money and energyAppreciate and accommodate patient community resource constraintsHTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA |
| Including the patient perspective | De Wit (2019)Harding (2021)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | Guidelines and HTAGuidelinesHTA | Capturing patients” perspectives requires multiple forms of engagement that are complementary; the strategy should be tailored to suit different chronic diseases and contexts. The perspective of patients is pivotal in health research, treatment guidelines, and the authorization of medicines.Translating evidence to recommendations, which involves patient framing questions and deciding outcomesIn each HTA, patients” perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported |
| Incorporate PPI into organization’s strategy/commitment to involving patients | Bjorkqvist (2021)De Wit (2019)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | Guidelines Guidelines and HTAHTA | Operates at strategic level within the organization and evidenced by a formal strategy, resource allocation, and established links to patient networks.Capturing patients” perspectives requires multiple forms of engagement that are complementary; the strategy should be tailored to suit different chronic diseases and contextsHTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients |
| Feedback, review and evaluation of PPI | CADTHDe Wit (2019)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | HTA Guidelines and HTAHTA | Feedback is given to patient organizations that have contributed to an HTA, to share what contributions were most helpful and to provide suggestions to assist their future involvement.Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them.Providing adequate information, support and feedback to patient representatives is key to effective engagement.Continuous monitoring and measuring of interactions will be vital for refining procedures according to feedback.In each HTA, patients” perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported. |
| Timeliness (part of the principle “transparency”) | Perfetto (2018)CADTH & [EUPATI](https://learning.eupati.eu/mod/page/view.php?id=520) | HTAHTA | Adopt a clear timeline for the analysis and the conditions that must be met before the analysis is performed.Clear timelines are established for each HTA, with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained. |
| Improving the relevance of assessments | Abelson (2016) | HTA | n/a |
| Purposeful | Abelson (2016) | HTA | n/a |
| Pragmatic | Abelson (2016) | HTA | n/a |
| Fair and equitable | Abelson (2016) | HTA | Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement |
| Proportional | Abelson (2016) | HTA | n/a |
| Evidence informed | Abelson (2016) | HTA | n/a |

**Table S5: Frameworks identified by the scoping review**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Author | Setting | Description | Framework component | Operational definition |
| Hunter (2018) | HTA | EUPATI framework: stage-based approach to PPI with activities at each stage | Identifying and prioritizing | No definition |
|  |  |  | Scoping | No definition |
|  |  |  | Assessing | No definition |
|  |  |  | Reviewing and disseminating | No definition |
| Abelson (2016) | HTA | Framework based on 4 elements and integrated into the stages of HTA development: topic selection, scoping, evidence-based analysis, drafting recommendations, professional and public consultation, assessment of comments, post review and recommendation | 1. Guiding principles and goals for public and patient involvement (PPI) in HTA also mapped onto the stages of HTA development  | Six *principles* that should guideHQO’s approach to public and patient involvement: (i) purposeful;(ii) pragmatic; (iii) fair and equitable; (iv) proportional; (v) evidence-informed; and (vi) transparent Linked to these principles is a set of *operational goals*PPI will be strengthened and supported: focus on quality, accountability, legitimacy and transparency, increase awareness of HTA.PPI efforts will be informed by evidence (where possible), best practice in the absence of evidence, and sound principles.Evaluation is to be embedded into all aspects of HQO’s PPI activities given the lack of a strong evidence base in this area and given HQO-OHTAC’s emphasis in this area.PPI efforts will support and, in turn, be supported by HQO’s decision making framework, which includes a specific emphasis on the incorporation of social values and ethics into the evidence-review process |
|  |  |  | 2. The establishment of a common language to support PPI efforts | The “what” of PPI was established by adopting three commonly cited levels of involvement: communication, consultation, and participation |
|  |  |  | 3. A flexible array of PPI approaches – this includes activities and strategies for each HTA stage  | There is no one-size-fits-all approach to PPI. Rather, the choice of method should be considered in the context of each HTA stage and matched to the motivation for incorporating societal and/or patient perspectives into the process, and the relevant societal and/or patient values at stake.  |
|  |  |  | 4. On-going evaluation of PPI to inform adjustments over time. | Evaluation of basic formative evaluation metrics to determine whether the intended goals of the PPI activities are being achieved, including basic process and impact measures such as numbers and types of consultations, how different types of PPI input are being used in the various stages of the HTA process, and the resources required to carryout relevant activities. In future, more quasi-experimental research can be conducted.  |
| Björkqvist, 2021 | Guideline development | EVOLVE framework – stage-based approach to support PPI in guideline development | Panel membership | Selecting the key stakeholder |
|  |  |  | Prioritize questions | Discussing and selecting the most important clinical questions |
|  |  |  | Developing the scope of guideline | Agreeing the guideline scope |
|  |  |  | Formulate questions | Defining the questions for systematic review |
|  |  |  | Choose Outcomes | Selecting the most important outcomes for patients |
|  |  |  | Assess certainty of evidence | Providing patients’ preferences to help develop the strength of recommendations |
|  |  |  | Write guidelines | Wording the guideline to make it clear and unambiguous. Highlighting patient preferences clearly in guidelines. |
|  |  |  | Review draft guidelines | Reading over and commenting on guidelines |
|  |  |  | Actively disseminate guideline | Publicizing finalized guidelines to patient organizations, clinicians and policy makers. Developing patient information, patient versions of guidelines and patient decision aids. |
|  |  |  | Instigate update | Taking part in deciding when guidelines need to be updated.  |
| Armstrong, 2017 | Guideline development | Staged-based approach to support PPI in guideline development and during three levels: developer, guideline specific, and development end.  | Patients can assist in topic nomination (step 1) | Identify topics that are important to patients, caregivers, and the community. Propose topics to be investigated. |
|  |  |  | Topic prioritization (step 2) | Solicit feedback on relevance and priority of topics.Discuss the urgency of addressing topics. |
|  |  |  | Guideline development group selection (step 3) | Help ensure that the GDG composition is both representative and trustworthyAssess conflicts of interest of panel members from patient perspective |
|  |  |  | Patients’ opinions may be incorporated when framing the question (step 4) | Ascertain questions” relevance and usefulnessAssess “real-world” applicabilityIdentify outcomes of relevance to patients, caregivers, and the communityIncorporate other aspects of treatment |
|  |  |  | Creating an analytic framework and research plan (step 5) | Help refine or expand scope of topicIdentify potential harms associated with the questions posedProvide a “reality check”Verify logic of analytic frameworkSupplement with additional factors not documented in the literatureDiscuss proxies for a specific concept (e.g., whether test scores and school performance are interchangeable)Suggest additional search termsInquire about potential confounding factorsIdentify particular populations of interest and/orimportant multimorbidity to consider in search |
|  |  |  | Conducting the systematic review and conclusion formation (step 6) | Assist with critical appraisal of studies andevidence synthesisAssess believability of resultsSuggest alternative interpretations of evidence |
|  |  |  | Development of recommendations (step 7) | Assist in translating evidence-based conclusionsinto meaningful, clear, and respectful recommendationsAssist in ensuring that recommendations foster partnership between physicians, patients and familiesDescribe variability in patient preferencesHelp make recommendations easy to understandProvide input when there are gaps in the evidenceIndicate which recommendations are counterintuitive (e.g., so that additional explanation can be provided) |
|  |  |  | Dissemination and implementation (step 8) | Endorse guidelines from patient perspective (either individually or in representation of patient groups)Assist in developing patient- and family-level summaries of systematic review findings and guideline recommendationsAssist in developing patient decision aidsIdentify barriers to implementation and possible solutionsFacilitate engagement of other patients in disseminationImprove legitimacy and trustworthiness of guideline process such that recommendations are more likely to be implemented |
|  |  |  | Patients can help determine when guidelines need updating (step 9) | Identify when public or stakeholder views have changed such that a guideline requires update or reaffirmation |
|  |  |  | Evaluating methods and impact of patient engagement (step 10) | Identify if patients were engaged in a meaningful way.Suggest options for improvement in future engagement strategies |
| Toledo - Chavarri (2019) | HTA | Development of a framework of PPI implementation based on the stages of HTA development | Phase 1: Identification and prioritization of technologies to be evaluated | Prioritize the technologies to be evaluated according to the values and preferences of patients and/or citizens as a whole. |
|  |  |  | Phase 2. Setting objectives, scope of assessment and problem definition | Identify the affected population and subgroups that could benefit from the technology and add and prioritize outcomes of interest to patients. |
|  |  |  | Phase 3. Evidence review | Obtain evidence related to experiences of living with the disease, values and preferences of care options, experiences of using the technology, expectations, needs (for information and support), and acceptability of the technology.Obtain evidence related to the impact of disease and technology on health outcomes, physical and social function, quality of life in real contexts, and economic impact for patients. |
|  |  |  | Phase 4. Elaboration of recommendations | Adapt the wording of the recommendations to consider perspectives, values, and preferences of patients and improve transparency. |
|  |  |  | Phase 5. Review and presentation ofthe allegations | Assess the quality of the evaluation and level of completeness of the information and the reliability and relevance of the report in the local context. |
|  |  |  | Phase 6. Dissemination of HTA results | Increased dissemination of results with patient friendly versions |
| Gagnon (2015) | HTA | User involvement in HTA at a local level based on the stages of HTA development | Submitting requests | Get suggestions from patients about assessment needs, during the topic selection phase. |
|  |  |  | Prioritizing topics | Get the patients’ perspectives about priority topics, during the topic selection phase. |
|  |  |  | Drawing up an evaluation plan | Seek the patients” perspectives concerning the refinement of the question, including dimensions to be evaluated, to improve the plan’s accuracy and applicability, during the evaluation phase. |
|  |  |  | Collecting evidence (literature), collecting new data or contextualization | Obtain information on the impact of the technology assessed, the context of its implementation and/or about the patients” needs, views or preferences, during the evaluation phase. |
|  |  |  | Final report and recommendations | Obtain information on the impact of technology and the context of its implementation to improve the accuracy, applicability and adoption of recommendations, during the analysis and synthesis phase. |
|  |  |  | Development of material | Obtain information material adapted to the patients or relatives, during the dissemination phase. |
|  |  |  | Communication and dissemination of results | Promote information sharing, accountability and autonomy with respect to patients/ Encourage implementation, acceptability and adoption of recommendations, during the dissemination phase. |
| Wortley (2016) | HTA | Framework of factors influencing choice of public engagement in HTA mapped onto three types of participation: communication, consultation and participation.  | Complexity | When decisions are more complex, different public involvement strategies are needed. There is a spectrum of complexity, which is influenced by characteristics. Of the HTA, research question, type, quantity and quality of the available evidence and certainty of the evidence.  |
|  |  |  | Perceived impact of decisions on stakeholders | Impact on stakeholders relates to the size of the perceived effect of a decision on the outcomes, known as “sensitivity”. Characteristics of the disease and the technology can determine perceived impact, including number of people to be impacted by the technology. Public engagement should be proportional to the nature and purpose of the technology. High impact topics could include deliberative and participatory approaches to allow discussion.  |
|  |  |  | Transparency and opportunities for public involvement | Transparency and opportunities include being involved in the meetings to promote greater trust, confidence and legitimacy in the process.  |
|  |  |  | Time and resources | The impact of public engagement on HTA development is seen as a trade-off between engagement and timeliness of the guidance. Financial cost of public involvement needs to be taken into consideration.  |

**Table S6: Strategies supporting PPI in guideline development**

|  |  |  |
| --- | --- | --- |
| Guideline development stage | PPI Strategy | Author |
| Topic nomination | Directly solicit topic nominations from public.Solicit topic nominations from patient advocacy groups.Review priorities published by patient advocacy groups.Review research on patients’ priorities and needs. | Armstrong (2017) |
| Topic prioritization | Survey patient groupsReview research on patients’ priorities and needsEngage patients on guideline committees determining priorities | Armstrong (2017) |
| Guideline development group selectionPanel membership | Review proposed panel members’ conflicts of interestApprove proposed panel with ability to suggest changesDirectly engage patients, caregivers and advocates on selection of guideline development group membersN/a | Armstrong (2017)Björkqvist (2021) |
| Developing the scope | No specified PPI strategy | Björkqvist (2021) |
| Framing the questionPrioritize questions | Perform focus groups on identified guideline topics.Review existing research on patients” priorities and opinions.Solicit public comment on guideline topics prior to formalization of questions.Ask stakeholders to suggest materials about patient preferences that are not formally published (“grey literature”).Survey patients to rate importance of proposed outcomes.Post draft research plan for public comment/review.Directly engage patients, caregivers and advocates on GDGs.N/a | Armstrong (2017)Björkqvist (2021) |
| Formulate questions for systematic review | No specified PPI strategy | Björkqvist (2021) |
| Creating an analytic framework and research plan | Review existing research on patients’ priorities and opinionsSurvey patients to rate importance of elements of proposed frameworkPost draft research plan for public comment/reviewPerform focus groupsDirectly engage patients, caregivers and advocates on GDGs | Armstrong (2017) |
| Choose Outcomes | No specified PPI strategy | Björkqvist (2021) |
| Conducting the systematic review and conclusion formation | Solicit feedback on draft evidence review from guideline development group lay participants even if they did not participate in analysis of evidencePost draft evidence review for public commentDirectly engage patients, caregivers, and advocates on GDGs | Armstrong (2017) |
| Development of recommendations | Review existing research on patients’ preferencesPost draft recommendation statements for public commentPerform focus groupsDirectly engage patients, caregivers and advocates on GDGs | Armstrong (2017) |
| Assess certainty of evidence | Providing patients’ preferences to help develop the strength of recommendations | Björkqvist (2021) |
| Write guidelines | Wording the guideline to make it clear and unambiguous. Highlighting patient preferences clearly in guidelines. | Björkqvist (2021) |
| Review draft guidelines | Reading over and commenting on guidelines | Björkqvist (2021) |
| Dissemination and implementationActively disseminate guideline | Consult patients, caregivers, and advocacy groups regarding barriers to dissemination and implementation and identifying solutions.Directly engage patients, caregivers and advocates in development of lay summaries and patient decision aids.Engage individuals and advocacy groups in dissemination strategies.Publicizing finalized guidelines to patient organizations, clinicians and policy makers. Developing patient information, patient versions of guidelines and patient decision aids. | Armstrong (2017)Björkqvist (2021) |
| Updating | Solicit patient views regarding when guidelines need updating (e.g., on websites)Include patients in formal review of evidence regarding guideline currency | Armstrong (2017) |
| Evaluating methods and impact of patient engagement | Provide feedback regarding engagement experience.Discuss feedback from participating patients (e.g., verbal, survey). | Armstrong (2017) |

**Table S7: Strategies supporting PPI in health technology assessment**

|  |  |  |
| --- | --- | --- |
| HTA development stage | PPI Strategy | Author |
| Submitting requests | Consultation: collecting information and suggestions from patients using various methods such as phone calls and websites. This involves “Specialists”: patients (including their relatives and representatives) directly affected by the technology that is being evaluated | Gagnon (2015) |
| Topic selectionPrioritizing topicsIdentifying and prioritizingIdentifying and prioritization of technologies to be evaluated | General public: website description of topic selection process; polling/surveysPatients: Horizon scanning (e.g., analysis of traditional and social media, focus groups, surveys); Advisory committee representationPatient organizations: Stakeholders meetings/A Delphi process (every 2-3 years)Participation: actively involve patients in the HTA process, through representation on committees or a citizen’s jury devoted to prioritizing topics. This involves “Generalists”: patients who represent all current or potential service users, who may be represented, for example, by members of the Users’ Committee.No definitionForms for the identification of technologies to be evaluated on the Web; Surveys; Stakeholder meetings or Delphi processes (every 2-3 years); Patient representation on the Agency’s Advisory Committee; Popular jury. | Abelson (2016)Gagnon (2015)Hunter (2018)Toledo – Chávarri (2019) |
| ScopingScopingSetting objectives, scope of assessment and problem definition | Patient organizations: Submissions (targeted and web)Patients: Social media analysis; interviews and focus groups; committee representationInvite patient organizations to comment on draft scope: via templates & consultation meetingsNo definitionQualitative literature review; Revision of the protocol; Direct Participation in the Expert Panel or Development Group; Experience forms, values, and preferences; Interviews/focal groups; Analysis of patient association Web sites and other Internet sources. | Abelson (2016)Hunter (2018)Toledo – Chávarri (2019) |
| Assessing | Invite patients to nominate patient & clinical experts to attend HTA meetings; Invite written submissions and personal (oral) testimony from patients; Provide patients with easy-to-read document summaries, templates, written guidance, telephone support; Issue exit questionnaires to review patient involvement. | Hunter (2018) |
| Drawing up an evaluation plan | Participation: actively involve patients in the HTA process, by involving their representatives in a workgroup with various stakeholders, a separate group, or an ad-hoc committee. This involves specialists or generalists. | Gagnon (2015) |
| Collecting evidence (literature), collecting new data or contextualization | Consultation: collect data from patients using qualitative or quantitative methods, such as focus groups, interviews, analysis of blogs, questionnaires, time trade-off survey, or discrete choice questionnaire. This involves specialists. | Gagnon (2015) |
| Evidence-based analysisEvidence review | Patient organizations: submissionsPatients: Surveys, social media analysis, primary qualitative research/synthesis; committee representation e.g., expert panel.Direct Participation in the Expert Panel or Development Group; Evidence synthesis (qualitative or quantitative studies); Analysis of Web sites, blogs, and social networks; Surveys; Interviews/focal groups; Experience forms, values and preferences. | Abelson (2016)Toledo – Chávarri (2019) |
| Draft recommendationsElaboration of recommendationsFinal report and recommendations | Broader public: explicit discussion of how social/patient values were considered in review; Patients: Expert panel consultation with priority populations.Direct Participation in the Expert Panel or Development Group; Discussion groups / Citizens panel; Wiki.Participation: actively involve patients in the HTA process, through a workgroup with various stakeholders, a separate group, or an ad-hoc committee. This involves specialists. | Abelson (2016)Toledo – Chávarri (2019) Gagnon (2015) |
| Assessment of commentsReview and presentation of the allegations | Authors of public comment submissions: web posting of public comments and relevant actions taken; face to face meetings to discuss and address concerns.Draft review (online or offline); Direct Participation in the Expert Panel or Development Group; Review Forms; Public consultation | Abelson (2016)Toledo – Chávarri (2019) |
| Development of material | Consultation: Through focus groups and consultation of experts about information material. This involves mainly specialists.Participation: By involving patients” representatives in the development and dissemination of information material. This involves mainly specialists. | Gagnon (2015) |
| Post review and recommendationReviewing and disseminatingCommunication and dissemination of resultsDissemination of HTA results | Broader publics: multimedia dissemination or reportPatients: lay review of plain language summaryPatient organizations: Targeted dissemination to high priority groupsSummarize how patient input was used in assessment, as part of HTA outcome reportProvide easy-to-read versions of HTA outcome report and invite patients to comment.Establish system for patients to appeal HTA decisions.Information: Inform patients about HTA results and recommendations, through the dissemination of a report and recommendations to patients using various means such as leaflets, a website etc. This involves specialists.Publication on the Web and active and passive dissemination; Revision of the patient version. | Abelson (2016)Hunter (2018)Gagnon (2015)Toledo – Chávarri (2019) |
| On-going evaluation of PPI to inform adjustments over time. | Evaluation of basic formative evaluation metrics to determine whether the intended goals of the PPI activities are being achieved, including basic process and impact measures such as numbers and types of consultations, how different types of PPI input are being used in the various stages of the HTA process, and the resources required to carry out relevant activities. In future, more quasi-experimental research can be conducted.  | Abelson (2016) |