**Work Package 7**

**Deliverable 7.2**

**Framework for patient involvement in HTA**

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# Overarching principles for patient involvement throughout the medicines development cycle

* 1. The great majority of experts involved in the development and evaluation of medicines are scientists. There is an increasing need to understand what it is like to live with a specific condition, how care is administered and the day-to-day use of medicines and to draw on this experience and specific knowledge of patients in order to promote discovery of new effective drugs and improve their development and evaluation.
	2. Structured interaction between patients, their representatives and other stakeholders is necessary and allows the exchange of information and constructive dialogue at national and European level where the views from users of medicines can and should be considered.
	3. We recommend close cooperation and partnership between the various stakeholders including healthcare professionals’ organisations, patients’ and consumers’ organisations, academia, scientific and academic societies, regulatory authorities and health technology assessment (HTA) bodies and the pharmaceutical industry. Experience to date demonstrates that close cooperation with patients has resulted in increased transparency, trust and mutual respect between them and other stakeholders. It is acknowledged that their contribution to the discovery, development and evaluation of medicines enriches the quality of the evidence and opinion available.[[1]](#footnote-1).
	4. Existing codes of practice for patient involvement with various stakeholders do not cover the research and development (R&D) period. Where frameworks already exist, they have been written for use by a specific body (for example the European Medicines Agency, EMA). The EUPATI framework aims to support the development of patient involvement across the entire process of medicines development and evaluation.

	The framework is presented as four separate guidance documents covering patient involvement in:
* pharmaceutical industry-led medicines R&D
* ethics committees
* regulatory authorities
* health technology assessment (HTA).

Each guidance suggests areas where at present there are opportunities for patient involvement. This guidance covers health technology assessment (HTA).

# Scope of the HTA framework

* 1. This framework covers the interaction between Health Technology Assessment (HTA) agencies and patients in relation to medicines for human use. “Patients” can be individual patients or their carers, or representatives from patient organisations with expertise in relevant patient issues.
	2. The framework focuses on participation in the HTA process, and excludes the scientific collection of patient perspectives (i.e. it excludes quantitative and qualitative systematic research on the psychosocial impact of diseases and treatments).
	3. The framework has been developed by the European Patients’ Academy on Therapeutic Innovation (EUPATI). It draws together the outcomes of several research and consensus-building processes carried out by a variety of national and international organisations. It also draws on good practice examples from individual HTA agencies. These sources are referenced as they arise in the framework.
	4. This version of the framework has been approved by [to be finalised after the consultation].

# Rationale for the framework

* 1. HTA stands for **Health Technology Assessment**. The main aim of HTA is to inform decision making by health care policy makers. It is a systematic process that considers health technologies (such as medicines or medical devices) and can involve a review of:
* clinical effectiveness (how well a medicine will work in the local health system compared to the best standard of care)
* cost effectiveness (the long term costs and benefits of a medicine compared to the best standard of care)
* social and ethical impacts on the health care system and the lives of patients.
	1. The process advises whether or not a health technology should be used, and if so, how it is best used and which patients are most likely to benefit from it. Assessments vary, but most look at the health benefits and risks of using the technology. They can also look at costs and any other wider impacts that the technology may have on a population or on a society.[[2]](#footnote-2)
	2. HTA assesses international evidence but applies it to the local health care setting to understand the added value of a new medicine in that health care system. HTAs are performed at national, regional or hospital level.
	3. The importance of **patient involvement** in HTA is becoming widely recognised. Patients are directly affected by HTA decisions - they are key stakeholders, and have a democratic right to be involved.[[3]](#footnote-3) HTA agencies are “designed to serve as a bridge between the world of research and the world of decision-making [and as such] are meant to answer calls for **more informed, transparent and legitimate decisions and greater public involvement**”.[[4]](#footnote-4)
	4. **Patients can provide information and insight, about the impact of their condition and treatments on their daily lives that is not available elsewhere**. Patients are in a unique position to describe the outcomes that matter to them, to challenge presumptions about their health aspirations and to inform HTA processes about the potential positive or negative effects of new technologies - on their health and on their ability to live and work.

# Introduction

* 1. The extent of patient involvement in HTA varies considerably between countries and regions in Europe. Commonly HTA is still focussed on quantitative evidence to determine clinical and/or cost effectiveness, although there are instances of active patient support. [[5]](#footnote-5),[[6]](#footnote-6),[[7]](#footnote-7)

* 1. The extent and nature of support for patients provided by HTA bodies, to optimise patient involvement in their processes, also varies a great deal.2, 6, [[8]](#footnote-8)
	2. The involvement of patients in HTA is determined at the national and regional level, and is not subject to any European legislation.
	3. HTA agencies and patient organisations have reported a positive impact of patient involvement on the processes and/or outcomes of HTA. Although systematic research into the impact of different approaches of patient involvement is scarce7, [[9]](#footnote-9), [[10]](#footnote-10) those case studies that are available make the impact of patient involvement explicit. Bodies such as HTAi and ISPOR are working to develop the evidence base.[[11]](#footnote-11), [[12]](#footnote-12)
	4. The HTA Core Model® (version 3.0) produced by EUnetHTA[[13]](#footnote-13) (a network of government appointed organisations, regional agencies and non-for-profit organisations that produce or contribute to HTA in Europe) provides a detailed technical guideline for HTA agencies, outlining the types and sources of evidence required for HTA. Patients and patient organisations are included as potential sources of evidence. The HTA Core Model® is aimed at professionals with HTA expertise and the topic of patient involvement in HTA processes more widely is outside its scope.
	5. There is therefore a need for a Europe-wide framework on patient interaction in HTA to promote good practice and to complement the work of EUnetHTA.
	6. **Objectives of the framework**
		1. The objectives of the framework are to ensure that the following **values** **are recognised**, and worked toward through the adoption of the recommended working methods (section 4) and suggested specific activities (section 5). The values, given in the table below, are one output of a consensus-building exercise by HTAi. Patient organisations, academia, HTA agencies and industry contributed to the exercise, which received input from 150 respondents in 39 countries. [[14]](#footnote-14)
		2. The values are:

|  |  |
| --- | --- |
| Relevance | Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA. |
| Fairness | Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement. |
| Equity | 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. |
| Legitimacy | Patient involvement facilitates those affected by the HTA recommendations/decision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process. |
| Capacity building | Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organisations to work together. |
|  |  |

# Recommended working methods

* 1. The working methods recommended **for HTA agencies and patient organisations** in this section arise from several sources. The primary sources are the set of quality standards from the HTAi consensus-building exercise, reviews of individual HTA agencies and the EPF survey of patient involvement in HTA in Europe.13, [[15]](#footnote-15), [[16]](#footnote-16), [[17]](#footnote-17), [[18]](#footnote-18), [[19]](#footnote-19), [[20]](#footnote-20) Specific patient involvement activities that are employed or planned by HTA agencies are given in section 6 “Suggested patient involvement activities”.

* 1. **General processes: advice for HTA bodies**
		+ HTA organisations should have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees, to effectively involve patients.
		+ HTA organisations should designate appropriate resources to ensure and support effective patient involvement in HTA.
		+ HTA participants (including researchers, staff, HTA reviewers and committee members) should receive training about appropriate involvement of patients and consideration of patients’ perspectives throughout the HTA process.
* Patients should be given the opportunity to participate in training to empower them so that they can contribute most effectively to HTA.
* Patient involvement processes in HTA should be regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve the processes.
* HTA organisations should work to align internal and external stakeholders on the objectives of patient input processes.18
* Patients and patient organisations should be given the opportunity to participate other than through making submissions[[21]](#footnote-21) to specific HTAs.18
* Frameworks should be developed to systematically incorporate patient input to HTAs. 18
* Systems for making written submissions should be easy to use by patients, patient organisations and experts, and appropriate support should be offered to individuals making submissions. 16
	1. **General processes: advice for patient organisations**
		+ Ensure those speaking on your behalf are trained in the nature of HTA, both its role in healthcare resource allocation and scientific and cost-effectiveness aspects.
		+ Where there are no or few patient involvement activities, approach HTA agencies pro-actively and suggest how patient involvement can be achieved through clear proposals.
		+ Understand the HTA processes: meet with HTA staff, follow guidelines and deadlines, use glossaries if available.
		+ Learn from the experience of other patient organisations and collaborate with them.
		+ Remain transparent: declare (publish) and diversify your financial support, and have a clear and explicit framework for cooperating with industry.
	2. **Individual HTAs: advice for HTA bodies**
		+ Proactive communications strategies should be used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA, including making public the criteria and processes they use to reach decisions.
		+ Clear timelines should be established for each HTA with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained.
		+ For each HTA, HTA organisations should identify a staff member whose role is to support patients to contribute effectively to HTA.
		+ In each HTA, patients’ perspectives and experiences should be documented and the influence of patient contributions on conclusions and decisions should be reported.
		+ Feedback should be given to patients who have contributed to an HTA, to share what contributions were most helpful and provide suggestions to assist their future involvement.
		+ The language used in documents and slide sets for each HTA should be accessible for the patients involved. 16

# Suggested patient involvement activities

* 1. Patient involvement can mean the involvement of **individual patients or carers**, or representatives from **patient organisations**. The term “**patient expert**” is used to describe someone who is an expert on relevant patient issues: they might be a patient or carer, and/or have a relevant role at a patient organisation.
	2. The suggested activities outlined in this section are examples of specific mechanisms to involve patients. They are all already practised (or planned) by one or more HTA agencies. They are drawn from publications from HTAi, EPF, INAHTA, individual HTA agencies and academic reviews. 5, 6, 7, 16, 17, 18 [[22]](#footnote-22)
	3. **General HTA process**

Aimed at HTA organisations, the activities listed here will help implement the recommended working methods for the HTA process in general. The list does not aim to be exhaustive but to provide initial ideas. **The information is summarised in a diagram on p12.**

* **Outreach and education**
* Write guidance on the different roles patients may take within HTA processes.
* Provide a single point of contact for patient involvement issues.
* Give presentations and training workshops for patient groups, about HTA and patient involvement.
* Evaluate and communicate about the impact patients have had to demonstrate that they can make a difference.
* Hold HTA meetings in public as far as possible.
* Provide a glossary in relevant language(s) of HTA-specific terms.
* Advertise forthcoming HTAs including alerting through regular bulletins, and **actively invite patient organisations** to take part.
* **Wider involvement**
* Include patients and those who represent them when consulting on potentially significant changes to HTA processes.
* Consider the use of participatory approaches, such as Citizen’s Jury[[23]](#footnote-23) or consensus conference methods, during development of HTA processes.
* Include patient experts as **lay members, or in addition to** **lay members**, **of HTA committees** not just as contributors to specific HTAs. Give these lay and/or patient members full voting rights.
* **Resources for patients**
* Provide “sitting fees” for patients attending meetings, plus reimbursement for travel, accommodation and other expenses incurred. Acknowledge that some people may not be able to accept these if they are in receipt of state benefits.
* Offer one-off payments to patient organisations for each HTA they contribute to.
* Help to organise the logistics of patient participation, including travel and/or accommodation.
* Support the development of peer support groups for patients involved with individual HTA bodies.
	1. **For individual HTAs**

The activities listed here are again aimed at HTA organisations, to help implement the recommended working methods for individual HTAs. The list does not aim to be exhaustive but to provide initial ideas. **This information is summarised in a flow chart on p14.**

* **Identifying and prioritising which technologies to assess**.
	+ Develop a system for individual patients, carers or patient organisations to nominate technologies for HTA.
* **Scoping (developing a framework for an individual HTA)**
* Consult with patient organisations on the draft scope using templates for **written submissions**.
* Invite patient organisations to oral **consultation meetings** to take part in discussion on the HTA scope.
* **Assessing and developing recommendations/guidelines**
	+ - Invite **patient organisations to nominate patient and clinical experts** to attend HTA committee meetings.
		- Invite **written submissions** from individual patients/carers and patient organisations to form part of the evidence base considered by the committee.
		- Provide templates, guidance documents and telephone support for those completing written submissions, and preparing to act as patient experts at meetings.
		- Invite oral submissions from individual patients/carers at committee meetings i.e. **personal testimony**.
		- Provide easy to read summaries of documentation sent out ahead of individual HTAs.
		- Develop an **exit questionnaire** for patients/carers and patient experts attending meetings, to be issued after each HTA, and feed results into the overall review of patient involvement.
* **Reviewing and disseminating HTA outcomes**
	+ - **Summarise patient input** in HTA outcome documents, and how it was used in reaching the final recommendation. When suggestions from patient groups were not included in the final recommendation, provide a properly justified written explanation.
		- Provide **lay language** versions of HTA outcome documents.
		- Invite written comment on **drafts of HTA outcomes** from patients/carers and patient organisations taking part in the HTA, and from others who did not take part.
		- Develop and disseminate a clear system for patients/carers and patient organisations to appeal HTA decisions.
		- Involve patients in the review of patient involvement processes.

Suggested patient involvement activities for general HTA processes

Invite patients to nominate patient & clinical experts to attend HTA meetings.

Invite written submissions & 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.

Exit questionnaire

Summarise how patient input was used in assessment, as part of HTA outcome report.

Provide easy-to-read versions of HTA outcome report & invite patients to comment.

Establish system for patients to appeal HTA decisions.

Patient involvement activities

HTA procedure

Allow patients to nominate health technologies for assessment.

Suggested patient involvement activities for individual HTAs

Invite patient organisations to comment on draft scope: via templates & at consultation meetings.

Resources

**International**:

[www.htai.org/interest-groups/patient-and-citizen-involvement/resources/for-patients-and-patient-groups.html](http://www.htai.org/interest-groups/patient-and-citizen-involvement/resources/for-patients-and-patient-groups.html)

**National**:

[www.nice.org.uk/about/nice-communities/public-involvement/develop-nice-guidance](http://www.nice.org.uk/about/nice-communities/public-involvement/develop-nice-guidance)

www.scottishmedicines.org.uk/Public\_Involvement

# Appendix 1 Resources

**International and country-specific resources for HTA agencies and patients**

|  |
| --- |
| **International** |
| **Author** | **Resource** | **Date** | **Notes** |
| Recommendations |
| HTAi | Values and Quality Standards for Patient Involvement in HTAhttp://www.htai.org/fileadmin/HTAi\_Files/ISG/PatientInvolvement/v2\_files/Info/PCISG-Info-ValuesandStandards-30-Jun14.pdf | 2014 | Outcome of international 18-month consensus building project. |
| EPF | Patient involvement in HTA in Europe. Results of the EPF survey.http://www.eu-patient.eu/globalassets/projects/hta/hta-epf-final-report2013.pdf | 2013 | Includes recommendations for HTA bodies and for patient organisations. |
| Good practice examples |
| HTAi | Good Practice Examples of Patient and Public Involvement in Health Technology Assessmenthttp://www.htai.org/fileadmin/HTAi\_Files/ISG/PatientInvolvement/EffectiveInvolvement/Good\_Practice\_Examples\_Feb\_2015.pdf | 2014 |  Summary of approaches taken by HTA bodies, including several EU countries/regions. Includes some hints and tips for others. |
| Patient templates |
| HTAi | Patient group submission template for HTA of medicinesFollow link from: <http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement/resources/for-patients-and-patient-groups.html>  | 2014 | Includes brief guidance for patient groups. |
| **International** |
| **Author** | **Resource** | **Date** | **Notes** |
| Patient templates cont. |
|  | Patient group submission template for HTA of health interventions (not medicines)Follow link from: http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement/resources/for-patients-and-patient-groups.html | 2015 | Includes brief guidance for patient groups. |
|  | Completing a patient group submission template: guidance for patient organisations.http://www.htai.org/fileadmin/HTAi\_Files/ISG/PatientInvolvement/v2\_files/Resource/PCISG-Resource-GuidanceandChecklist-Dec14.pdf | 2015  | For HTA bodies to adapt to their needs and those of their community. |
| Education aimed at patients |
| EUPATI | EUPATI Patient Expert Training CourseToolbox for education in medicines development.https://www.eupati.eu/ | 2015 | The training course takes new trainees each September/October.The training course and the online toolbox include HTA educational material for patients and patient representatives. |
| EURORDIS | Webcasts and slide presentations from annual summer school:<http://www.eurordis.org/training-resources> |  | Includes a session on HTA. |
| HTAi | Introducing HTA to patients and patient organisations. www.htai.org/webinars/pcisg-intro-hta/ | 2013 | Video and slide presentation. |
| HEE | Understanding health technology assessment.http://www.htai.org/fileadmin/HTAi\_Files/ISG/PatientInvolvement/EffectiveInvolvement/HEEGuideToHTAforPatientsEnglish.pdf | 2008 | Booklet available in English, Spanish, Mandarin, Italian, Polish, Swedish, Greek |
| **International** |
| **Author** | **Resource** | **Date** | **Notes** |
| Education aimed at other stakeholders (not patients) |
| EUnetHTA | Training for stakeholders.<http://www.eunethta.eu/events> |  | This weblink includes information as it becomes available. |
| ISPOR | HTA training programme:<http://www.ispor.org/education/EducationIndex.asp> |  |  |
| ISPOR | Regional Chapters’ activities:<http://www.ispor.org/RegionalChapters> |  | Most regional ISPOR chapters are national. They provide a range of training and education opportunities. |
| Contact information for HTA bodies |
| HTAi | List of HTA bodies worldwide:http://vortal.htai.org/?q=about/producers\_and\_networks |  |  |
| INAHTA | Contact information for HTA bodies worldwide:http://www.inahta.org/our-members/ |  |  |
| Glossaries |
| INAHTA/HTAi | Glossary of HTA terms:HTAglossary.net |  | Web-based glossary available in English, French, Spanish and German.Updated periodically.http://htaglossary.net/HomePage |
| HTAi | HTAi consumer and patient glossary:<http://www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/v2_files/Resource/PCISG-Resource-ENGLISH-PatientandConsumerGlossary-Oct09.pdf><http://www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/v2_files/Resource/PCISG-Resource-GREEK-PatientandConsumerGlossary-Oct09.pdf> | 2009 | Glossary (pdf). Available in English and Greek. |
| **International** |
| **Author** | **Resource** | **Date** | **Notes** |
| Surveys |
| EPF | Patient involvement in HTA in Europe. An interim report on EPF's survey with HTA agencies in Europe.<http://www.eu-patient.eu/News/News-Archive/Patient-involvement-in-health-technology-assessment-in-Europe---An-interim-report-on-EPF-survey-with-HTA-Agencies/> | 2011 |  |
| EPF | Patient involvement in HTA in Europe. An interim report on EPF's survey with decision makers in Europe.<http://www.eu-patient.eu/globalassets/projects/hta/report-hta-survey_decision-makers_final.pdf> | 2011 |  |
| EPF | Patient involvement in HTA in Europe. An interim report on EPF's survey with patient organisations across Europe.<http://www.eu-patient.eu/globalassets/projects/hta/epf-report_hta-survey_po.pdf> | 2011 |  |
| INAHTA | Involvement of consumers in the HTA activities of INAHTA members.<http://www.inahta.org/wp-content/uploads/2014/04/INAHTA_Survey_Consumer-Involvement_2011.pdf> | 2011 | Comparison of repeat survey of HTA agencies in 2005 and 2010. |
| Industry reports |
| Deloitte / Eli Lilly | Enhancing Consumer Involvement in Medicines Health Technology Assessment. | 2009 |  |
| **Regional templates and guides, available online (Europe)**  |
| **Body** | **URL or document title** | **Notes** |
| INVOLVE(UK) | Payment and recognition for public involvement.http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/ | Written for patient involvement in general research, but contains useful pointers for payment and recognition generally. |
| IQTIG(Germany) | http://www.iqtig.de | Legal text and guidelines for patient participation in HTA. |
| NICE(England) | <http://www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance> | Comprehensive set of templates, factsheets and guides for patients/carers and patient organisations. |
| NICE(England) | Confidentiality agreement for stakeholders taking part in HTAs.https://www.nice.org.uk/get-involved/stakeholder-registration/confidentiality-agreement |  |
| SMC (Scotland) | <http://www.scottishmedicines.org.uk/Public_Involvement/> | Submission form and guidance document for patient organisations. |
| **Evaluations of individual HTA bodies**  |
| **Body** | **URL or document title** | **Notes** |
| CADTH(Canada) | CADTH Patient Input Process Review. Findings and Recommendations<https://www.cadth.ca/sites/default/files/pdf/2012_SECOR_Patient-Input-Review_e.pdf> | Review published 2012.  |
| NICE(England) | Technology Appraisal Patient Expert Survey 2012 Report<http://www.nice.org.uk/media/default/About/NICE-Communities/Public-involvement/Public-involvement-programme/Patient-expert-TA-report-final-1.pdf> | Survey of patient involvement in NICE HTAs. |
| SMC(Scotland) | The Scottish Medicines Consortium and public attitudes to the provision of medicines for the NHS in Scotland. 2015 http://www.scottishhealthcouncil.org/publications/gathering\_public\_views/public\_attitude\_to\_medicines.aspx#.VZKh3vlVhBc | Remit not restricted to patient involvement in HTA. |
| **Case studies of patient involvement** |
| **Body** | **Document title** | **Notes** |
| NICE (England) / SMC (Scotland) | Patient involvement in NICE technology appraisals.  | Authored by Amis L. In “Patients, the public, and priorities in healthcare”. Edited by Peter Littlejons and Michael Rawlins. Oxford: Radcliffe. 2009. |

# Appendix 2 Abbreviations

AOTM Agency for Health Technology Assessment (Poland)

AQuAS Agency for Health Quality and Assessment of Catalonia

CEDIT Hospital based Health Technology Assessment Agency (Paris, France)

EPF European Patients Forum

EUnetHTA European network for Health Technology Assessment

EUPATI European Patients’ Academy on Therapeutic Innovation

FOPH Federal Office of Public Health (Switzerland)
G-BA Federal Joint Committee (Germany)

HTAi Health Technology Assessment international

IQTIG Institute for Quality Assurance and Transparency in Healthcare (Germany)

ISPOR International Society for Pharmacoeconomics and Outcomes Research

IQWiG German Institute of Quality and Efficiency in Healthcare

ISPOR International Society for Pharmacoeconomics and Outcomes Research

NICE National Institute for Health and Care Excellence (England)

Osteba Basque Office for Health Technology Assessment

SBU Swedish Council for Technology Assessment

SMC Scottish Medicines Consortium

1. Adapted from the EMA framework http://www.ema.europa.eu/docs/en\_GB/document\_library/Other/2009/12/WC500018013.pdf [↑](#footnote-ref-1)
2. HTAi “Completing a patient group submission template: guidance for patient organisations.” 2015. [↑](#footnote-ref-2)
3. HTAi “Patients’ perspectives in health technology assessment: A route to robust evidence and fair deliberation.” IJTAHC 2010. [↑](#footnote-ref-3)
4. Gauvin F-P et al. “”It all depends”: Conceptualizing public involvement in the context of health technology assessment agencies”. Social Science and Medicine 2010. [↑](#footnote-ref-4)
5. HTAi “Patients’ perspectives in health technology assessment: A route to robust evidence and fair deliberation.” IJTAHC 2010. [↑](#footnote-ref-5)
6. EPF “Patient Involvement in Health Technology Assessment in Europe. Results of the EPF Survey.” 2013 [↑](#footnote-ref-6)
7. INAHTA “Involvement of consumers in the HTA activities of INAHTA members. Report on a survey.” 2011 [↑](#footnote-ref-7)
8. HTAi “Good practice examples of Patient and Public Involvement in Health Technology Assessment. 2014 [↑](#footnote-ref-8)
9. Menon D, Stafinski T. “Role of patient and public participation in health technology assessment and coverage decisions.” Expert review pharmacoeconomics and outcomes research. 2011 [↑](#footnote-ref-9)
10. Gagnon M-P et al. “Involving patients in the early stages of health technology assessment (HTA): a study protocol.” BMC Health Services Research. 2014 [↑](#footnote-ref-10)
11. http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement/resources.html [↑](#footnote-ref-11)
12. http://www.ispor.org/sigs/PatientCentered/PC\_EngagementInResearch.aspx [↑](#footnote-ref-12)
13. EUnetHTA Joint Action 2, Work Package 8. HTA Core Model ® version 2.1 (Pdf); 2015. Available from http://www.corehta.info/BrowseModel.aspx. [↑](#footnote-ref-13)
14. HTAi “Values and Quality Standards for Patient Involvement in HTA.” 2014 [↑](#footnote-ref-14)
15. EPF “Patient Involvement in Health Technology Assessment in Europe. Results of the EPF survey.” 2013 [↑](#footnote-ref-15)
16. NICE “Technology Appraisal Patient Expert Survey 2012 Report.” 2014 [↑](#footnote-ref-16)
17. SMC & Scottish Health Council “The Scottish Medicines Consortium and public attitudes to the provision of medicines for the NHS in Scotland”. 2015 [↑](#footnote-ref-17)
18. SECOR “CADTH Patient Input Process Review.” 2012 [↑](#footnote-ref-18)
19. Australian Government Department of Health and Ageing “Review of health technology assessment in Australia.” 2009 [↑](#footnote-ref-19)
20. Messina J, Grainger DL. “A pilot study to identify areas for further improvements in patient and public involvement in health technology assessments for medicines. “ The Patient. 2012. [↑](#footnote-ref-20)
21. **Some HTA bodies invite patients to submit information and views to specific HTAs, either verbally or in writing. These are called “submissions”.** [↑](#footnote-ref-21)
22. Whitty JA “An international survey of the public engagement practices of health technology assessment organizations.” Value in Health. 2013. [↑](#footnote-ref-22)
23. Citizen’s Jury method is explained at http://www.methods.manchester.ac.uk/medialibrary/docs/citizensjuries.pdf [↑](#footnote-ref-23)