

Good Practice Examples of Patient and Public Involvement in Health Technology Assessment

(Feb 2015)

Purpose of document

This document contains examples of the way in which HTA agencies involve patients and the public in HTA. The examples have been collected by the Patient Involvement and Education Working Group, part of HTAi's Patient and Citizen Involvement Interest Sub-Group, to help share good practice. The Working Group recognises that agencies take a variety of different approaches to engagement, but believes we can all learn from each other's work.

This document will be updated as further examples are submitted. To submit an example, please complete the Good Practice Template found at <http://www.htai.org/index.php?id=545> and return it to Ann Single, singlehaworth@gmail.com

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Agency for Health Quality and Assessment of Catalonia (AQuAS) – Catalonia, Spain

<p>Purpose & work of your organisation</p>	<p>AQuAS is a public entity of the Catalan Health Ministry with more than 20 years of history. AQuAS's role is to generate scientific and relevant knowledge for all the agents of the Catalan Health System to inform decision-making processes to contribute to the improvement of its quality, safety and sustainability.</p> <p>The AQuAS strategic lines are Observatory, Assessment and Innovation, using information and communication technologies as tools.</p>
<p>Type(s) of health technologies assessed by your organisation</p>	<p>Health technologies is taken to mean medical equipment and devices and drugs, ICT applications, as well as any type of health intervention, be it diagnostic, therapeutic, palliative, rehabilitation or organisational.</p>
<p>Purpose of your organisation's patient involvement</p>	<p>In general, to complete and enrich the professionals' perspective in the development of AQuAS's products and services</p> <p>Especially in CPG development, to take their expectations and relevant suggestions into account so the final guideline is more useful and accurate. AQuAS is already incorporating the perception, opinion and preferences of patients and carers (family and non-family) into the CPG it elaborates.</p>
<p>How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?</p>	<p>In CPG, AQuAS uses different strategies that are not incompatible amongst themselves:</p> <ul style="list-style-type: none"> - Research focused on patient/carers perspective to be incorporated into the CPG. When there is little or no published literature, an original qualitative study based on the most adequate techniques in each case (in-depth interviews, focus groups, etc.) should be carried out rigorously. Based on the results from such studies, we can ascertain the patients' and the carers' major concerns and these concerns should be addressed in the CPG. - Incorporating patients/carers as members of the drafting team developing the guideline. This is the most complex option entailing prior preparation and a certain knowledge level as well as communication skills both on the part of the professionals and the patients/carers involved throughout the entire process of CPG development. - Participating in the initial review of the CPG first draft and/or external revision. The objective here is to ensure that patient/carer criteria and experiences are included in the CPG (e.g. in the clinical questions and measurements of relevant results, etc.). This information might be very helpful for the preparation of the Annex "Information for patients" of the CPG. Moreover, and independently from the drafting team, patients/carers can participate in the external revision process of the CPG, both individually or through organised groups of people sharing a similar or the same health problem as the one covered in the CPG.

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<p>How are organisations representing the views of patients and/or carers involved in your HTAs?</p>	<p>AQuAS collaborates with the Patient Advisory Council (Consell Consultiu del Pacient), which represents all Catalan patients' associations and with concrete patients association. In GPC, patient and carers (family and non-family members) associations can be used as the initial point of contact to properly select the most adequate participant profiles.</p>
<p>How do you involve citizens?</p>	<p>In GPC, citizens carry out an external revision of the Annex "Information for patients".</p>
<p>What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?</p>	<p>In CPG, if they are members of the developing group, the same as health professionals (emails, drop box, verbal presentations, etc); if they are external reviewers, they fill specific templates out.</p>
<p>What support do you provide patients, carers, citizens and organisations to enable them to participate?</p>	<p>In CPG, any special attention. AQuAS provide the same support to patients, carers, citizens and organisations as health professional's members of the developing group.</p>
<p>How do you measure or evaluate the impact of the involvement?</p>	<p>In CPG, AQuAS doesn't measure or evaluate the impact of its involvement. AQuAS only tries to give assurance that they participate in all the steps of the project and agree with the final product (CPG, patient brochure, etc).</p>
<p>What are the main impacts of involvement in HTA witnessed by your organisation?</p>	<p>In CPG, the main impact of involvement witnessed by AQuAS is to remove barriers among all of us (members of AQuAS, health professionals and patients, carers, citizens and organisations representing the views of patients and/or carers). Some patients/careers facilitators have great interest in participating in these kind of projects, ability to learn quickly how to develop a guide, willingness to work in group even if it implied to work with health professionals.</p>
<p>How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?</p>	<p>In CPG, during the process AQuAS answers all their input and explains how it was used and its value to the project. Again, AQuAS treats the patients, carers, citizens and/or organisations the same way as the health professionals.</p>

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Tips for others	Spanish handbook about patients/carers in the development of CPG: http://www.guiasalud.es/emanuales/pacientes/documentos/manual_pacientes.pdf
Other	International initiatives about patients/carers in the CPG topic: - NICE (National Institute for Health and Clinical Excellence, UK) (http://www.nice.org.uk/getinvolved/patientsandpublic/patientandpublichomepage) - SIGN (Scottish Intercollegiate Guidelines Network, UK) (http://www.sign.ac.uk/patients/index.html). - GIN (Guidelines International Network): GIN-Public (http://www.gin.net/activities/gin-public)

Person completing the template: Maria-Dolors Estrada (destrada@gencat.cat)

Position: Researcher of AQuAS and coordinator of its Guideline Clinical Practice (CPG) group

Date completed: 24 April 2014

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Agency for Health Technology Assessment – Poland

Purpose & work of your organisation	Governmental institution in service for Minister of Health
Type(s) of health technologies assessed by your organisation	Drug technologies (90%), non-drug technologies (10%)
Purpose of your organisation's patient involvement	Providing patient's point of view in HTA process at analytical assessment level as well as at appraisal level
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	Individual patients may provide their opinions through patients organisations
How are organisations representing the views of patients and/or carers involved in your HTAs?	<ol style="list-style-type: none"> 1. Providing written opinion to AOTM; 2. Providing oral opinion to Transparency Council; In the former case the opinion is given on demand of AOTM analytical staff, in the later – patient's organisations apply for hearing
How do you involve citizens?	In addition to above <ol style="list-style-type: none"> 3. Public consultations in the process of assessment of reimbursement submissions are in place, when Applicant HTA Analysis as well as Agency's Verification Analysis are published on Agency's website for 7 days. Every citizen may pass her/his opinion provided that she/he fills Declaration of Conflict of Interest
What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	<ol style="list-style-type: none"> 1. Completing template sent by AOTM 2. Verbal presentation of the opinion at Transparency Council meeting 3. Completing template placed on website (1-3 are relevant to possibilities of providing opinion by patient/public described above)
What support do you provide patients, carers, citizens and organisations to enable them to participate?	Under the process of analytical assessment patient organisations relevant to the subject are sought and asked for their opinions

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How do you measure or evaluate the impact of the involvement?	No means
What are the main impacts of involvement in HTA witnessed by your organisation?	Not assessed
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	No feedback provided
Tips for others	No suggestions
Other	

Person completing the template: Anna Zawada (a.zawada@aotm.gov.pl)

Position: Director of the Department of Transparency Council

Date completed: 1 April 2014

Good Practice Examples of PPI

Australian Department of Health and Ageing

Prostheses List Committee and its Clinical Advisory Groups and panel of Clinical Experts – Australia

NB As this information was provided prior to the development of a standard template some sections have not been completed.

<p>Purpose & work of your organisation</p>	<p>Under the Private Health Insurance Act 2007 private health insurers are required to pay benefits for prostheses on the Prostheses List for which an insured person has appropriate cover; that is provided as part of hospital (or hospital substitute) treatment, and for which a Medicare benefit is payable for the associated professional service.</p> <p>Private health insurance payments are tax deductible by Federal Government.</p>
<p>Type(s) of health technologies assessed by your organisation</p>	<p>Implanted medical devices, i.e. ‘prostheses’. The product should be surgically implanted and purposely designed to do one of replace an anatomical body part, combat a pathological process, or modulate a physiological process; or be an essential single use aid for implanting the product or critical to the continuing function of the implanted product for that person.</p>
<p>Purpose of your organisation’s patient involvement</p>	<p>The consumer representatives:</p> <ul style="list-style-type: none"> - have the ability to raise consumer issues - are reflective of Australian community values - consider consumer impact – including with innovative products, and complex issues.
<p>How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?</p>	<p>Consumer representatives sit on each of the Prostheses List Advisory Committee (PLAC) and the Clinical Advisory Committees that provide clinical advice to PLAC. The committees have independent chairs. The aim is to provide balanced, informed recommendations on what products should be on the Prostheses List, and the associated benefits [ultimately to the Health Minister].</p> <p>The consumer representatives are nominated through the Consumers Health Forum, the national peak consumer organisation (non-disease based, members made up of patient and health consumer/community organisations) and have a community network they interact with. They have some ‘technical’ knowledge and are also generally patients in the area they represent (e.g. orthopaedic, urogenital, cardiac, vascular).</p> <p>The consumer representatives are there to provide expert input and advice</p>

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	<p>from a consumer/patient perspective.</p> <p>Patient or patient organisation submissions are not a part of this process.</p>
<p>How are organisations representing the views of patients and/or carers involved in your HTAs?</p>	<p>Consumers are witnesses to the process and thinking, particularly during committee meetings, and:</p> <ul style="list-style-type: none"> • Observe how decisions are made and the effectiveness of communications • Determine if fair process is followed, without conflicts of interest being evident • Check that the developed recommendations are well considered and clear, the rationale and reasoning can be followed (and is recorded), e.g. by seeking clarification and reality check the recommendations, as required • ‘Check’ the consistency of decisions re use of evidence; influence poor decisions • Provide ‘corporate memory’ • Prompt and check process <p>The consumer representatives have a vested interest in the prosthesis being both effective and safe, in the short and longer term. They can relate to the impact and consequences if that is not the case.</p> <p>The consumer representative provides one avenue for reporting back to the committees any reports they receive of safety concerns and also demands for financial payments to meet costs of prostheses.</p> <p>They are witnesses to the process and can contribute to discussion on the evidence provided for a product to be recommended to go on the prostheses list is sufficient (or not) and work toward managing uncertainties. In this way they address societal values, ethical and legal issues.</p> <p>For innovative products, in particular, these and organisational/financial aspects are important. Sustainability of the health system for the public is important and good use of private health funds is important.</p>

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How do you involve citizens?	See above
What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	
What support do you provide patients, carers, citizens and organisations to enable them to participate?	<p>A Secretariat that provides papers, arranges travel; and are there to talk with consumer representatives to ensure that they know what they are doing and to discuss any issues with them. They may talk with the consumer when they first join a committee.</p> <p>Sitting fees.</p> <p>Travel and accommodation, as required.</p> <p>Provide time-limited funding to Consumers Health Forum (CHF) to enable meetings between CHF, the consumer representatives and a Government representative.</p>
How do you measure or evaluate the impact of the involvement?	
What are the main impacts of involvement in HTA witnessed by your organisation?	People on the committees are constantly reminded and become or are aware of patient issues and perspectives (as active participants in their care)
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	

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Tips for others	<ul style="list-style-type: none">• Provide induction for new consumer members• Have a chairperson who is 'comfortable' with consumers• Be respectful of each other at all times• Provide sitting fees, travel and accommodation, as required• Provide opportunities to discuss 'clinical evidence'• Identify consumer/patient representatives who have the ability to raise consumer issues in a balanced manner, are reflective of Australian community values, and can consider the consumer impact of any decisions and recommendation including with complex issues and uncertainties.
Other	www.health.gov.au/internet/main/publishing.nsf/content

Person completing the template: Janet Wale (socrates111@bigpond.com)

Position: Consumer representative on the Prosthesis List Advisory Committee

Date: August 2012

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Canadian Agency for Drugs and Technologies in Health (CADTH) – Canada

NB As this information was provided prior to the development of a standard template some sections have not been completed.

Purpose & work of your organisation	A pan-Canadian health technology agency, funded by Health Canada, the provinces and territories. <i>CADTH supports informed decisions by Canadian health care decision makers by providing impartial, evidence-based research and advice on drugs, medical devices and other health technologies.</i>
Type(s) of health technologies assessed by your organisation	<p>The CADTH Common Drug Review (CDR) is a pan-Canadian process that includes an objective, rigorous review of a drug’s effectiveness and safety, its cost-effectiveness (or value for money) compared with other available therapies, as well as patients’ perspectives on the drug. This information is used by the Canadian Drug Expert Committee (CDEC) — a CADTH advisory body — to make formulary listing recommendations to Canadian publicly funded drug plans (except Quebec).</p> <p>Patient: Someone with a health condition who receives a service Public: Citizens interested in healthcare system efficiency and fairness</p>
Purpose of your organisation’s patient involvement	
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	<ul style="list-style-type: none"> • Two public members are appointed to the 13-member Canadian Drug Expert Committee (CDEC) to directly represent the broad public interest, and not any specific interest, group or organisation. They present the patient group input at the CDEC meetings. The public members have full voting rights. • Patient groups contribute patient perspectives via the CADTH Patient Input Process. • Input is collected via on-line submissions, requested at the beginning of the drug submission review process to help inform the review protocol and is included in review report in summary and where applicable. The patient group input is also shared in full with reviewers and CDEC. <ul style="list-style-type: none"> ➤ Information is sought on: Impact of condition and current

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	<p>treatment on patients</p> <ul style="list-style-type: none"> • Issues and outcomes of importance • Benefits and adverse effects • Unmet needs <ul style="list-style-type: none"> ➤ Experience with or expectations for new drug ➤ Additional Information <ul style="list-style-type: none"> • Patient input is presented by public members, used in deliberations and reflected in the CDR Recommendations & Reasons and Recommendations published and is publically available on-line.
How are organisations representing the views of patients and/or carers involved in your HTAs?	
How do you involve citizens?	See above
What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	
What support do you provide patients, carers, citizens and organisations to enable them to participate?	<ul style="list-style-type: none"> • Orientation for reviewers and Canadian Drug Expert Committee members • Information and support for patient groups <ul style="list-style-type: none"> • Webinar at launch for patient groups & industry • Written information and guidance on website • Presentations at national patient umbrella group meetings and to academia • In-person workshop for patient groups
How do you measure or evaluate the impact of the involvement?	Findings from a series of qualitative surveys of different stakeholders, undertaken in the fall of 2011 and early 2012 show that majority of stakeholders understand CADTH's Patient Input process, were satisfied with guidance document and the template for patient group input.

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	CADTH needs to further align all stakeholders on purpose, value and credibility of soliciting patient group input as evidence and to continue to communicate achievements to date.
What are the main impacts of involvement in HTA witnessed by your organisation?	For every CDR drug submission that is reviewed, the number of patient groups providing Input is stated along with a summary of the information received in the publicly posted CDEC Recommendations & Reasons for Recommendation document. If an insight or outcome highlighted by patients has substantially contributed to the CDEC listing recommendation it is noted within the CDEC Recommendations and Reasons for Recommendation.
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	
Tips for others	<p>Key elements of meaningful patient input are to:</p> <ul style="list-style-type: none"> • Engage patient groups <ul style="list-style-type: none"> • Need to identify and reach them • Empower patient groups <ul style="list-style-type: none"> • Explain how our process works • Describe what type of information is needed and how it is used • Describe how and when to submit • Educate all stakeholders, including patient groups, industry, CADTH reviewers and the expert committee members • Acknowledge how patient group input is used CDR reviews and CDEC recommendations in publicly posted documents
Other	

Person completing template: Elaine MacPhail (elainem@cadth.ca)

Position: Senior Advisor, Programs

Date completed: June 2012

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Centre for Drug Evaluation (HTA) - Taiwan

Purpose & work of your organisation	The purpose of HTA in Taiwan is to provide quality assessment of medical technologies in a timely manner to support decision making regarding listing and pricing in National Health Insurance Administration (NHIA) in Taiwan.
Type(s) of health technologies assessed by your organisation	The reports prepared by CDE include reviews of evidence on clinical effectiveness, reviews of economic evaluations, and cost-utility analyses.
Purpose of your organisation's patient involvement	As greater consumer and patient involvement in purchasing decisions is expected, the 2 nd Generation of the National Health Insurance (NHI) Act of Taiwan, which just took effect this year, provides the right and opportunity for the insured (consumer) and patients to get involved with the listing decision for pharmaceuticals and medical devices.
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	It is still focused on the patient representative chosen from the patient groups, at current proposed model, opinions from other patients or the public via website, like other countries do, are not included.
How are organisations representing the views of patients and/or carers involved in your HTAs?	In the era of the 2 nd generation NHI (National Health Insurance), two pluralistic appraisal committees, namely the Expert Meeting and the PBRS (Pharmaceutical Benefit and Reimbursement Standard) Joint Meeting. After the Expert meeting has made their preliminary recommendation regarding listing and pricing, the PBRS Joint meeting will reconsider it and make the final decision. If an appeal against the PBRS Joint meeting final decision (normally an appeal against prior rejection) is submitted, experts or one patient representative may be invited to present their viewpoints in the PBRS Joint meeting. The patient representative would be chosen from the patient groups of the indication under review registered in the Ministry of the Interior.
How do you involve citizens?	Each PBRS Joint meeting comprises of 29 representatives of payers (n=3), insured (n=3), health care providers (n=13), manufacturers (n=3), government (n=2), and experts (n=5). The insured are recruited from national foundation or association of consumers, workers and farmers.

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What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	None have been implemented yet.
What support do you provide patients, carers, citizens and organisations to enable them to participate?	So far, we have provided practical support for patients and carers to enable them to participate by online HTA reports since 2011 and translate HTA reports into an understandable format. We also provided patients/carers workshop about the laws and regulations of listing and reimbursement of NHI in Taiwan and international conference which supply global HTA experiences to encourage them to join the decision making process. In the future, we will have specific team to offer advice and support to patient and carer organisations that take part the PBRS meeting.
How do you measure or evaluate the impact of the involvement?	None yet.
What are the main impacts of involvement in HTA witnessed by your organisation?	N/A
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	N/A

Person completing the template: Grace Hui-Min Wu (hmwu320@cde.org.tw)

Position: Researcher

Date completed: 12 December 2013

Good Practice Examples of PPI

Federal Joint Committee (G-BA) - Germany

Purpose & work of your organisation	The Federal Joint Committee (G-BA) is the highest decision-making body of the joint self-government of physicians, dentists, hospitals and health insurance funds in Germany. It issues directives for the benefit catalogue of the statutory health insurance funds for more than 70 million insured persons and thus specifies which services in medical care are reimbursed by the GKV. In addition, the G-BA specifies measures for quality assurance in inpatient and outpatient areas of the health care system.
Type(s) of health technologies assessed by your organisation	Drugs, diagnostic and therapeutic methods/procedures, psychotherapy, disease management programs
Purpose of your organisation's patient involvement	Nationwide advocacy groups that represent patient interests or facilitate self-help for people in Germany who are chronically ill or have disabilities are entitled to take part in discussions and submit petitions. Patient groups and the people they represent reflect the rich diversity of patient and self-help organizations in Germany. They are supposed to provide patient's views and experiences into the consultation process. Further information: http://www.english.g-ba.de/structure/patient/
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	Patients can propose topics for consultation, they are involved at all levels of decision-making, i.e. in all available committees. They cannot vote but they may agree or disagree.
How are organisations representing the views of patients and/or carers involved in your HTAs?	See above
How do you involve citizens?	The Patient Involvement Act sets forth the criteria an organization must fulfil to be recognized by the Federal Ministry of Health (BMG) as a leading nationwide advocacy group. Besides, every citizen can use his/her right for (written or oral) statements.

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<p>What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?</p>	<p>Verbal presentations, working papers, written proposals, sometimes public relations</p>
<p>What support do you provide patients, carers, citizens and organisations to enable them to participate?</p>	<p>The patient involvement specialist team supports patient representatives in matters of organization and content in exercising their right to take part in discussions and submit petitions in accordance with the German Social Code, Book Five, section 140f, paragraph 2. Currently there is a staff of 5 persons available for this purpose.</p>
<p>How do you measure or evaluate the impact of the involvement?</p>	<p>We don't</p>
<p>What are the main impacts of involvement in HTA witnessed by your organisation?</p>	<ul style="list-style-type: none"> - Patients submit proposals for consultation - Patients enrich discussions and bring in their perspectives
<p>How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?</p>	<p>Not applicable</p>

Person completing the template: Matthias Perleth (matthias.perleth@g-ba.de)

Position: Head, Department of Methodological Advice

Date completed: 31 July 2013

Good Practice Examples of PPI

National Institute for Health and Clinical Excellence (NICE) - England and Wales

NB As this information was provided prior to the development of a standard template some sections have not been completed.

Purpose & work of your organisation	The independent UK organisation responsible for providing national guidance on promoting good health and preventing and treating ill health
Type(s) of health technologies assessed by your organisation	Medications, diagnostics, medical devices, procedures
Purpose of your organisation's patient involvement	<ul style="list-style-type: none"> - To develop fair, transparent, accountable and effective procedures for patient/public involvement - To ensure that patient/public perspectives are represented in NICE processes and products <p>Core principles of all NICE guidance</p> <ul style="list-style-type: none"> • Comprehensive evidence base • Expert input • Patient and carer involvement • Independent advisory committees • Genuine consultation • Open and transparent process • Equalities considerations • Regular review
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	<p>Scoping, development, consultation, publication, implementation support</p> <p>Levels of involvement</p> <ul style="list-style-type: none"> • Consultation with patient and voluntary organisations/charities • Patient/carer evidence and views (submission*) • Patient/carer experts (personal testimony) • Lay members (part of decision making – minimum 2, often 3, sometimes 6 – patient experiences!) of committees/developmental groups • Patient/public versions of NICE guidance • Citizens Council (societal values) <p>*We find that patient evidence is most useful when presented as a summary that balances positive and negative views</p>

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<p>How are organisations representing the views of patients and/or carers involved in your HTAs?</p>	<p>See above</p>
<p>How do you involve citizens?</p>	<p>See above</p>
<p>What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?</p>	
<p>What support do you provide patients, carers, citizens and organisations to enable them to participate?</p>	<ul style="list-style-type: none"> • Have PPI Policy • Patient & Public Involvement Programme (PPIP) <ul style="list-style-type: none"> – 12 members of staff – Advise NICE on methods for involving patients, carers and the public – Identify patient and public participants (organisations and individuals) – Provide information, training and support to patients and lay people who engage with NICE (as individuals or organisations) • 4x Masterclass workshops (2012-13) for patient/carer organisations (asked them what they wanted to be included) <ul style="list-style-type: none"> – Intro to NICE (rated 4.25 out of 5) – Intro to Health Economics – Intermediate Health Economics – Preparing for a Technology Appraisal • Induction and training for lay members and Chairs

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	<ul style="list-style-type: none"> • Patients Involved in NICE (PIN) – peer support group <p>Ad hoc, informal support</p>
How do you measure or evaluate the impact of the involvement?	Individual examples collated
What are the main impacts of involvement in HTA witnessed by your organisation?	<p>Information provided:</p> <ul style="list-style-type: none"> - The personal impact of their condition - Outcomes patients want the technology to help with - The impact of a technology on outcome, symptoms, physical & social functioning, quality of life - Impact on family, friends and employers - Ease of use, side effects and costs of the technology - Patient preferences - Subgroups who might benefit more/less from the technology - Challenges to professional or researcher views - Areas needing further research
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	
Tips for others	<ul style="list-style-type: none"> - Commitment to PPI at all levels in organisation - PPI policy - Committed resource - specialist staff - Lay members <ul style="list-style-type: none"> ▪ At least 2 ▪ Full voting rights, equal members, paid - Balancing patient/carer vs. public

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	<ul style="list-style-type: none">- Balancing individuals vs. organisations vs. society- Explain how input was used, feedback- Plain language, no jargon (and glossaries!)
Other	

Template completed by: Lizzie Amis (lizzie.amis@nice.org.uk)

Position: Patient and Public Involvement Programme

Date completed: June 2012

Good Practice Examples of PPI

Osteba – Basque Country

Purpose & work of your organisation	Informing decision making process for the Basque Health System (public system) and the Spanish Health System
Type(s) of health technologies assessed by your organisation	All of them
Purpose of your organisation's patient involvement	Include all the stakeholders perspectives in our assessments from the beginning
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	Submissions, participating on committees and free submission of information when a new project starts. We incorporate patients in CPG elaboration as well.
How are organisations representing the views of patients and/or carers involved in your HTAs?	We prefer to involve individual patients and caregivers than patients' associations.
How do you involve citizens?	They have the chance of free submission of information when the project starts. No involvement of citizens in the overall process.
What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	Completing information template.
What support do you provide patients, carers, citizens and organisations to enable them to participate?	Explaining the HTA process and its implications in general and at our country level.

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How do you measure or evaluate the impact of the involvement?	We don't measure it.
What are the main impacts of involvement in HTA witnessed by your organisation?	The implications for outcomes definition and measurements.
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	We provide them the report for its consideration and reviewing before its publication. It is similar to other stakeholders.

Person completing the template: Iñaki Gutiérrez-Ibarluzea (Osteba7-san@ej-gv.es)


Date completed: 24 April 2014

Good Practice Examples of PPI

Scottish Medicines Consortium - Scotland

Purpose & work of your organisation	SMC advises Health Boards in NHS Scotland and their Area Drug and Therapeutics Committees on the clinical and cost-effectiveness of all new medicines.
Type(s) of health technologies assessed by your organisation	All new medicines and all new indications/licence extensions and new formulations of established medicines.
Purpose of your organisation's patient involvement	<ol style="list-style-type: none"> 1. Ensure that the patient experience informs SMC decision making, advice and recommendations. 2. Raise awareness of the role of SMC amongst the general public, voluntary sector organisations and health charities. 3. Monitor , evaluate and develop SMC's involvement processes
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	Voluntary groups and health charities are invited to submit written evidence to SMC in the form of a Patient Interest Group (PIG) Submission. Three public members are appointed to the SMC committee to represent the public interest and not any specific interest or organisation. They present the PIG input at the SMC meetings. The public members have full voting rights.
How are organisations representing the views of patients and/or carers involved in your HTAs?	<ol style="list-style-type: none"> 1. SMC considers written evidence from patient interest groups alongside the evidence from the submitting pharmaceutical company. 2. PIG submissions are seen as an integral part of SMC evaluation process 3. PIG evidence presented by one of three Public Partners at monthly SMC meeting.
How do you involve citizens?	<p>Efforts are made to raise awareness and understanding of the SMC through process through:</p> <ol style="list-style-type: none"> 1. Information stands at appropriate conferences and events. 2. Presentation to local groups 3. Comments facility on SMC Website

Good Practice Examples of PPI

<p>What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?</p>	<p>1. Written evidence using Patient Interest Group (PIG) Template and Guidance Notes</p> 
<p>What support do you provide patients, carers, citizens and organisations to enable them to participate?</p>	<ol style="list-style-type: none"> 1. Dedicated member of staff 0.5WTE (Public Involvement Officer) 2. Practical support in form of: <ul style="list-style-type: none"> • Free monthly E- alert facility- provides information on forthcoming submissions and latest SMC advice • Written guidance notes • Telephone and 1:1 support to complete PIG submission • Feedback • PIG Submission workshop / training • Briefing Note summarising the SMC advice emailed to ALL submitting Patient Interest Groups. 3. Information updates to wider Public facing Involvement structures.
<p>How do you measure or evaluate the impact of the involvement?</p>	<p>An evaluation of stakeholder engagement carried out in 2005 found that awareness of SMC and its processes by public partners was limited, with 41% of public partners indicating that they were aware of SMC and 33% aware of its patient involvement processes and website. Encouragingly, those who had engaged with SMC had a generally positive view of their involvement.</p> <p>One of the actions following this evaluation was the establishment of a part-time Public Involvement Officer post with the aim of increasing awareness of, and involvement in, the work of SMC amongst people who use NHS services and their carers.</p> <p>Quantitative :</p> <ol style="list-style-type: none"> 1. Number of PIG submission received (as a proportion of new medicines assessed); 2. Data base of Patient Interest Groups (increasing annually); 3. Number of Patient Interest Groups supported per month; 4. Percentage of positive decision with/out PIG submission;

Good Practice Examples of PPI

	<p>Qualitative</p> <ol style="list-style-type: none"> 5. Annual survey of Patient Interest Groups: feedback utilised to make improvements to PIG involvement processes; 6. Post Workshop/training Evaluation forms 7. Testimonials/comments from PIG
What are the main impacts of involvement in HTA witnessed by your organisation?	<ol style="list-style-type: none"> 1. Affects the decision and advice issued by SMC. 2. PIGs provide valuable insight into the 'burden' of illness and the impact living with a condition or illness has on an individual or group of individuals' quality of life. 3. Adds weight to or cast doubt on the QOL data presented by pharmaceutical companies.
Tips for others	<ol style="list-style-type: none"> 1. Patient involvement requires investment in resources both personnel and time. 2. Patient Interest Group should be given sufficient notice in order to collate supporting evidence 3. Practical educational support in the form of 1:1 support, writing workshops, learning logs and aide memoirs have proven to be useful.

Person completing template: Linda McGlynn (linda.mcglynn@alliance-scotland.org.uk)

Position: Public Involvement Officer

Date completed: 20 May 2013

Good Practice Examples of PPI

The Israeli Center for Technology Assessment in Health Care - Israel

Purpose & work of your organisation	ICTAHC is an applied research unit in the field of health technology assessment for health services. ICTAHC was founded in 1992 and serves as a supportive research center to the Israeli Ministry of Health (MOH) in general and to the Director of Technology and Infrastructure in particular, regarding health policy and decision-making processes of health technologies.
Type(s) of health technologies assessed by your organisation	A wide range of health technologies submitted for consideration for public funding through the National List of Health Services (NLHS) annual updating mechanism.
Purpose of your organisation's patient involvement	Patient groups are consulted when relevant especially for feedback on patient preferences and issues regarding the implementation of certain new technologies.
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	Patients, patient groups and associations are able to submit new technologies for consideration in the annual updating process.
How are organisations representing the views of patients and/or carers involved in your HTAs?	When relevant, patient groups take part in the consultation process eg in the case of CF treatment.
How do you involve citizens?	As above
What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	Patients, patient groups and associations submitting new technologies for consideration use the standard template on the MOH site.

Good Practice Examples of PPI

What support do you provide patients, carers, citizens and organisations to enable them to participate?	There are 4 representatives of the public in the Public Committee which decides on the technologies to be funded in updates to the NLHS.
How do you measure or evaluate the impact of the involvement?	
What are the main impacts of involvement in HTA witnessed by your organisation?	
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	In cases when patients, citizen or patient groups have been part of the HTA process they are given feedback.

Person completing the template: Nina Hakak (ninah@gertner.health.gov.il)

Position: Information Specialist

Date completed: 9 January 2014

Good Practice Examples of PPI

Dutch Health Care Institute - Netherlands

Purpose & work of your organisation	<ul style="list-style-type: none"> • Advising on reimbursement for basic health care insurance package (HTA, for this task the form is completed) • Stimulating patients, insurers and professionals to develop quality standards together; • Disclosure of transparent health care information to citizens; • Advising on development of health care professions
Type(s) of health technologies assessed by your organisation	All kinds of technologies ie helping aids, pharmaceuticals, medical devices, surgical interventions and so on
Purpose of your organisation's patient involvement	To learn more about patients experiences and interests. Working together on issues to receive more support and understanding for our reports.
How are individual patients and/or carers involved in your HTAs (eg submissions, participating on committees, etc)?	Patients are recruited through patient and consumer organisations and not as individuals. Nevertheless, they operate on individual title.
How are organisations representing the views of patients and/or carers involved in your HTAs?	We invite patient and consumer organisations to participate in an interactive process of assessment and appraisal. So there are several moments that their input can be collected. In the end we ask the board of these organisations to reflect on the concept advice before the final appraisal is done
How do you involve citizens?	Not on individual HTAs. More in general topics which may be discussed with the public; such as the use of cost effectiveness in reimbursement decision.
What processes or tools are used by the individual patients, carers, organisations and/or citizens to provide input (eg completing templates on website, verbal presentations, etc)?	Verbal presentations, reactions in writing and in the appraisal committee parties have a right to ask for speaking time

Good Practice Examples of PPI

What support do you provide patients, carers, citizens and organisations to enable them to participate?	On special occasions we reimburse travel expenses. In general we don't have any special policy to support patients participation
How do you measure or evaluate the impact of the involvement?	No special measure or evaluation in this respect.
What are the main impacts of involvement in HTA witnessed by your organisation?	More understanding of the complexity of the problem and of the arguments.
How do you provide feedback to the patients, carers, citizens and/or organisations on how their input was used and its value to the HTA?	Organisations that are consulted receive a reply on their input. In this reply we tell what we did and did not with their arguments.
Tips for others	Involving patients is important but has its problems. How do you keep your independency and how can you manage high expectations and hope? We're now confronted with these issues and in the middle of dealing with them.
Other	We provide courses for patient and consumer organisations our work and our methodology. This helps them to understand more and it helps us to receive "higher quality" input.

Person completing the template: Jacqueline Zwaap (jzwaap@zinl.nl)

Position: Secretary of Appraisal Committee

Date completed: 26 January 2015