

## Patients' Perspectives on Health Technology Assessment in 2009

### About this survey of patients' opinions on Health Technology Assessment

Health Technology Assessment (HTA) is a process by which governments (or the government-authorised insurers that pay for healthcare) try to assess the value of medicines, medical devices and other medical interventions in comparison with their costs.

This short survey represents a unique opportunity for patient groups across Europe to FIND OUT WHAT THEY COLLECTIVELY THINK ABOUT HTA TODAY, and to CLARIFY THEIR POTENTIAL CONTRIBUTION towards making HTA more equitable from the patients' perspective.

The survey results will be placed in the public domain. If you wish to be emailed a copy of the survey results upon publication (expected to be late 2009), please leave a contact email address at the end of the questionnaire.

The CLOSING DATE for the survey is Friday 30th October 2009. The survey has been commissioned by Hill & Knowlton, and is being administered by PatientView.

If you have any questions regarding the survey, please do not hesitate to contact:  
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## Patients' Perspectives on Health Technology Assessment in 2009

## Firstly, a few brief profiling questions

These simple profiling questions about your organisation will help the study understand the types of groups answering, and allow more sense to be made of the results.

**(A.) In what capacity are you answering?**

- As an individual member of my organisation.
- On behalf of my organisation.

**(B.) Would you like the survey's published report to mention your group's name?**

[You may tick more than one option, if relevant.]

- Yes, I would like my organisation's name to be included among the list of survey participants.
- Yes, I would like any of my comments to be quoted (and attributed to my organisation) within the text of the report.
- No, I would prefer my organisation to remain anonymous.

If "Yes", please note your organisation's name.

**(C.) In which European country is your organisation headquartered?**

[Please select a country from the menu below.]

**(D.) What is your organisation's main specialty/subject area?**

[Please select the MOST RELEVANT specialty from the menu below.]

**(E.) Approximately how many members does your organisation have?**

## Patients' Perspectives on Health Technology Assessment in 2009

### Your familiarity with Health Technology Assessment (HTA)

Please note that, in the questions below, "HTA" stands for "Health Technology Assessment".

**Question 1. Do you know which year your country introduced HTA processes as a way of assessing the value of medicines, medical devices, and other medical interventions compared with costs [Please tick only the MOST RELEVANT option.]**

**Question 2.**

**In your country, at what GEOGRAPHIC LEVEL or levels are decisions made about the reimbursement of medicines/medical devices (that is, whether a medical technology should be paid for by the national health system/insurer)?**

[You may answer more than one option, if you wish.]

- Decisions are made at European level.
- At national level.
- Regional level.
- Local level.
- I do not know.
- Not relevant in my country.

**Question 3.**

**Do you (your organisation) believe that HTA has made a POSITIVE or NEGATIVE contribution to public/patient health thus far in your country?**

- Mostly positive thus far.
- Mostly negative.
- Too early to say.
- My country has yet to institute an HTA system.
- I do not know.

Any comments about your answer?

**Question 4.**

**How FAMILIAR are you (your organisation) with the decisions made by HTA bodies about the availability of medicines/medical technologies in your country?**

- Very familiar.
- Quite familiar.
- Not familiar.
- We know nothing about this subject.

Could you describe the types of interaction (if any) that your organisation currently has with your country's HTA authority?

**Question 5.**

**How ACCOUNTABLE do you believe the following aspects of HTA activities/processes are in your country?**

[Please regard as a minimum standard of accountability: when the processes are in the public domain, and are transparent.]

	Very accountable.	Sometimes accountable.	Not accountable.	I do not know.
The LEVEL OF INDEPENDENCE that the HTA authority has from government.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether consideration is given to GOVERNMENT HEALTH POLICY when reaching an HTA decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The GOALS/OBJECTIVES of the HTA processes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COMPARISONS MADE during the HTA processes with other relevant medicines/technologies that are already available within the healthcare system.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The OUTCOME OF STAKEHOLDER CONSULTATIONS in the HTA processes, and their relative contribution to the final HTA decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CLINICAL EVIDENCE looked at in the HTA processes to determine whether a medicine/technology could be reimbursed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The ECONOMIC APPROACH taken in the HTA processes to determine whether a medicine/technology could be reimbursed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(And, if relevant in your country ...) The PRICE NEGOTIATIONS that take place with the manufacturer during the HTA process.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The FRAMEWORK by which the 'VALUE' of a product is assessed ('value' could include anything from the size of the patient population addressed by the medicine/technology, to a medicine/technology's safety profile, or whether the medicine/technology promotes a shift of treatment into primary care).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any comments about your answer?

**Question 6.**

**(A) Are you (your organisation) AWARE of the following activities related to HTA?**

[You may tick more than one option, if you wish.]

	Aware when in my country.	Aware when at European level.	My group has been directly involved in such work.	Not aware.	I do not know.
Consultations about HTA's PRIORITIES (that is, which technologies should be reviewed).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consultations on the MERITS of a medicine/technology as judged from the PATIENTS' PERSPECTIVE.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discussions about HTA METHODOLOGY.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discussions as to how European countries can CO-ORDINATE their HTA processes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CONFERENCES on HTA subjects (particularly when regulators are present).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research about the IMPACT of HTA ON PATIENTS.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The work of MEDEV (Medical Evaluation Committee), a working group of the European Social Insurance Platform.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The work of the European Network of Health Technology Assessment (EUnetHTA), a pan European HTA mechanism.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**(B) Do you think that patients should participate in the European HTA mechanism?**

- Yes.
- No.
- I do not know.

Would you like to comment on your answer?

**(C) It is currently proposed that for patients to be meaningfully involved in the European HTA mechanism, a consultation with all stakeholders once a year will be sufficient.**

**Do you agree or disagree that one yearly meeting is sufficient to take properly account of patients view?**

- Yes.
- No.

If no, how frequently do you believe patients should be consulted in a pan-European HTA mechanism?

**Question 7.**

Can you (your organisation) indicate which of the following statements is TRUE or FALSE from the patient perspective in your country?

Please select one option in each box below.

HTA is a complex process LITTLE UNDERSTOOD by patients.	<input type="text"/>
HTA is the ONLY LOGICAL APPROACH for rationing the use of medicines/medical technologies.	<input type="text"/>
HTA remains the province of academics and clinicians, and has SO FAR EXCLUDED other stakeholders (including patient groups).	<input type="text"/>
HTA authorities accuse patient groups of being in the pocket of pharma/industry — which is WHY patient groups are NOT INVOLVED in the HTA processes.	<input type="text"/>

Any comments about your answers?

**Question 8.**

What RIGHTS (if any) do patients (or patient groups) have to appeal against an HTA decision in your country?

[You may tick more than one option, if you wish.]

- The (legal) right to APPEAL AGAINST an HTA decision within a limited time period.
- The right to COMPLAIN ABOUT an HTA decision, and have that decision REFERRED FOR REVIEW.
- The right to PUBLICLY LOBBY against an HTA decision.
- Although (in principle) patients in my country have the right to appeal against an HTA decision, FEW DO SO.
- I am NOT AWARE of any rights in my country to appeal against an HTA decision.

Any comments about your answers?

**Question 9.**

Has your organisation EVER CHALLENGED the HTA authority in your country to secure patient access to a new medicine/medical technology?

- Yes.

[You may tick more than one option, if you wish.]

- The (legal) right to APPEAL AGAINST an HTA decision within a limited time period.
- The right to COMPLAIN ABOUT an HTA decision, and have that decision REFERRED FOR REVIEW.
- The right to PUBLICLY LOBBY against an HTA decision.
- Although (in principle) patients in my country have the right to appeal against an HTA decision, FEW DO SO.
- I am NOT AWARE of any rights in my country to appeal against an HTA decision.

Any comments about your answers?

**Question 9.**

Has your organisation EVER CHALLENGED the HTA authority in your country to secure patient access to a new medicine/medical technology?

- Yes.
- No.
- We intend to.
- I do not know.

If "Yes"/"We intend to" could you describe how your organisation did/plans to do this?

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## Patients' Perspectives on Health Technology Assessment in 2009

## HTA and the pharmaceutical industry

## Question 10.

Has your organisation BEEN INVOLVED WITH any of the following industry discussions on how to improve HTA health outcomes for patients?

	Yes, directly.	In association with other patient groups.	No involvement.	I do not know.
EFPIA (European Federation of Pharmaceutical Industries Associations).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUCOMED (European Medical Technology Industry Association).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With my country's national pharmaceutical/medical-device tradesbody (association).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With local pharmaceutical/medical-device company employees.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With specific nationally-based pharmaceutical/medical-device companies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Could you name any pharmaceutical organisations that your group has had direct contact with on the subject of HTA?

## Question 11.

Pharmaceutical/medical-device companies and patient groups all try to ensure that patients get access to innovative medicines (and all are increasingly looking for ways to work together to transmit the views of patients to HTA authorities).

Have you any suggestions as to how patient groups and pharma/medical device companies COULD WORK TOGETHER EFFECTIVELY on HTA issues?

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The way forward

Question 12.

Do you (your organisation) believe that HTA (as the process is applied today) is **INAPPROPRIATE** in any of the circumstances listed below?

HTA, as currently practised, is not appropriate when applied to ...

	Strongly agree.	Agree.	Disagree.	Strongly disagree.	I do not know.
Treatments for <b>RARE DISEASES</b> (since these will always be costly).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>LIFE-SAVING</b> treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatments that produce dramatic improvements in patients' <b>QUALITY OF LIFE</b> .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New methods of drug delivery that significantly improve patients' <b>COMPLIANCE</b> to treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical interventions that involve <b>ETHICAL/MORAL ISSUES</b> (for instance, in-vitro fertilisation [IVF], or medicines originating from stem-cell research).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Could you comment on your answers?

Question 13.

The HTA processes rely heavily on **CLINICAL EVIDENCE** to reach a decision whenever they assess any medicine/medical technology.

Which of the following additional factors do you (your organisation) believe HTA **SHOULD TAKE INTO ACCOUNT** when assessing the value of a medicine?

[You may choose more than one option, if you wish.]

- Improvements in patients' **QUALITY OF LIFE**.
- Impact on the **CARERS** of patients.
- The ability of patients to **RETURN TO WORK**.
- The ability of patients to **LIVE AN INDEPENDENT LIFE**.
- The range of **CHOICES OF SIMILAR** medical interventions within a therapeutic category.
- The **SIZE** of the patient population addressed.
- Whether the **METHOD OF ADMINISTERING** the medicine/medical technology to the patient is an advance on what went before.

Any other? (Please specify.)

Question 14.

HTA has an important role to play in ensuring that healthcare systems are sustainable, and **NOT CRIPPLED BY RUNAWAY COSTS**. Therefore, HTA has the inevitable effect of **LIMITING** the **THE LEVELS** of medical interventions available.

Given the above, could you indicate which of the following statements you **AGREE OR DISAGREE** with?

	Strongly agree.	Agree.	Disagree.	Strongly disagree.	I do not know / have no view.
All citizens, no matter in which European country they live, should have access to the <b>SAME CHOICES</b> of prescription medicines/medical technologies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If national healthcare systems pay for all available medicines, <b>NOT ENOUGH MONEY WILL REMAIN</b> to provide patients with other important medical interventions (such as surgery, medical devices, and public-health measures).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Governments/insurers that pay for healthcare <b>NEED TO BE ABLE TO MAKE CHOICES</b> between various medicines/medical technologies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The HTA process should be combined with the drug/medical-device approval process. So, if a medical technology is approved, it is <b>AUTOMATICALLY REIMBURSED</b> .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is <b>IMPOSSIBLE TO HAVE A TRUE IDEA</b> of the value of a medicine/medical device until that technology is widely used by patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What do you (your organisation) believe should be the **ROLE** of Health Technology Assessment (HTA) in our society?

Question 15.

Finally, can you suggest any ways in which HTA authorities might be persuaded to take **GREATER ACCOUNT** of patients' views?

That concludes this survey on HTAs.

Thank you for taking part.

If you would like to be emailed the survey results when published (expected to be late 2009), please leave an email address here (you do not have to leave your name or any other details).

Upon leaving this questionnaire, you will be taken to the PatientView website.