

# **Involvement of consumers in the HTA activities of INAHTA members**

## **Report on a survey**

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In 2005 INAHTA members were surveyed to obtain information on what they did and what they avoided in involving consumers in the HTA process. The term ‘consumers’ was taken to include patients, carers, long - term users of services, organizations representing consumers’ interests, and members of the public. The survey findings are presented in a report which is available on the INAHTA website and in an IJTAHC article.

In 2010 a follow - up survey was undertaken. The intention was to obtain information on whether member agencies had changed their approaches in involving consumers in HTA since the earlier survey.

The questions used in the earlier survey were considered to still be appropriate and were used again for the 2010 survey form. The opportunity was taken to liaise with the HTAi Interest Group on Patient/Citizen Involvement in HTA on details of the survey. Following suggestions by the Interest Group, two items were added to the survey, covering the inclusion of consumer perspectives in assessments. Also, an option to share contact details with the HTAi Interest Group was included at the end of the survey.

The survey form was sent to members by the Secretariat in November 2010. Completed survey forms were returned by the following agencies:

AETS, AHTA, AHTAPol, ASERNIP-S, AVALIA-T, CADTH, CAHIAQ, CDE, CENETEC, CNHTA, CVZ, DACEHTA, DAHTA, DECIT, DHTA, Finohta, G-BA, GÖG, HAS, HIQA, HIS, HITAP, ICTAHC, IHE, LBI - HTA , MAHTAS, NETSCC, NHSC, NOKC, OSTEBA, SBU, UVT, and VASPVT.

## **Comparison of survey responses**

There were differences between the two surveys in the profile of responses, due to changes in the INAHTA membership and lack of response from some agencies that had participated in the earlier survey. In 2010 there were responses from 33 members, compared to 37 in 2005. Nineteen members (58%) participated in both surveys, and 14 had joined INAHTA since 2005. Distributions of responses by region are shown in Table 1.

Comparisons between the surveys for each of the questions are presented as the proportions of positive answers received.

**Table 1: Distribution of responses by region**

	2005, %	2010, %
Europe	68	67
Asia	3	15
Australasia	8	6
North America	16	6
Latin America	5	6

### **Involvement of consumers in HTA programs**

Details of the involvement of consumers in members' HTA programs are shown in Table 2. The proportions of agencies that involve consumers and of those intending to involve consumers in the future were higher than in 2005.

Comments were made by three agencies which had indicated that consumers were not involved in their programs:

\* Though we do not have consumers involvement in HTA so far, we are currently legislating for involving them in, and it is expected in the near future

\* Are searching how to introduce patients/consumers perspectives in health technology assessment's process.

\* We have some experiences with involving consumers in our HTAs, but have no process to do this on a regular basis. Consumers have been involved in different ways: doing the HTA, provided input on HTA protocols, or draft versions of the report.

**Table 2: Involvement of consumers, all agencies**

	2005, %		2010, %	
	YES	NO	YES	NO
Whether consumers are involved in some aspects of the HTA program.	57	43	67	33
Whether the agency intends to involve consumers in the future.	83	17	88	12

In 2010 all of the agencies that currently involve consumers in their programs intended to do so in the future, compared to 95% in 2005. In both 2010 and 2005, 64% of those agencies that did not involve consumers intended to do so in the future,

Of the four agencies in the 2010 survey that indicated they did not intend to involve consumers, two advised that this position might change:

- \* Our response to question 2 may change within the next years, depending on overall strategical considerations. At the moment no decisions on consumer involvement have been made.

- \* The Department of Medical Technology Policy at Ministry of Health is currently considering the the incorporation of consumer involvement in the HTA process. The results of your survey could be instrumental in this deliberation. We look forward to receiving your results soonest.

Four agencies provided comments on their involvement of consumers in the preparation of clinical practice guidelines:

- \* We haven't included in this survey about HTA, our Clinical Practice Guidelines (GPC). In our CPG we involve consumers in different aspects and moments:

- In the formulation of topics for assessment in a GPC.
- The consumers are contacted in order to provide opinion and preferences.
- To review protocols and/or drafts.
- We involve consumers organizations in the dissemination of the CPG materials.

- \* Consumers participate in some CPGs...

- \* We have only patients guidelines and in some evaluations we have taken the patients as consumers.

- \* Most of the activity in which we have worked with patients referred to their participation in the preparation of Clinical Practice Guidelines.

Three agencies noted difficulties in the involvement of consumers in their programs:

- \* The horizon scanning technology briefings we produce do not lend themselves to the addition of consumer opinions. Consumers are represented on the panels that consider the technology briefings and prioritise them for technology appraisal. The subsequent technology appraisal also includes consideration of consumers and the production of an 'easy-read/ understandable' version.

- \* We consider involving consumers important and relevant, but also time consuming.

- \* Patient involvement is not a routine activity, this is intended only to our major projects. Among barriers to expanding patients' involvement there are: time and resources constraints; difficulties identifying appropriate consumers.

## Details of consumer involvement

The following responses were obtained from those agencies that reported consumer involvement in their programs (21 in 2005 and 22 in 2010).

### Types of consumer involved in programs

In both surveys, 95% of agencies reported involving consumer or patient organizations in their programs. Large minorities in the surveys also involved individual consumers (48 % in 2020 and 45% in 2005). One agency reported use of a board of laymen.

### Bringing consumers into contact with the HTA process

Invitation from the agency remained the most frequently used method of bringing consumers into contact with the HTA process (Table 3). Compared to the 2005 survey, fewer agencies accepted requests from consumers on specific topics, while contact with the HTA process in response to publicity on forthcoming assessments was more common.

**Table 3: How consumers are brought into contact with the HTA process**

	2005, %	2010, %
Invitation from the HTA agency	90	91
Accept requests from consumers on specific topics	70	59
Response to publicity on forthcoming assessments	25	45

### Training for consumers

As in the previous survey, only a small proportion of agencies provide a training process for consumers who are involved in HTA programs (19% in 2005, 23% in 2010).

### Avoidance of consumer involvement

As before, a minority of agencies indicated that they avoided consumer involvement in some types of assessment that they undertake (24% in 2005, 23% in 2010).

Five agencies gave details of assessments where consumer involvement is avoided (Table 4). As in 2005, horizon scanning and brief reports were areas where consumers were not involved. One agency advised: “We have no specific exclusions but consumer engagement has not been formally implemented in all of our processes.”

**Table 4: Assessments where consumer involvement is avoided**

2010	2005
<p>1. Commercial in confidence evaluation of pharmaceuticals</p> <p>2. Assessments we do on behalf of some other organisations</p> <p>3. Usually consumers are excluded from the HTA reports (either full or mini-HTA). But consumers participate in some CPG and reports about prioritization of healthcare services or in defining quality of care indicators</p> <p>4. Rapid assessments - Technology Review reports and Information Brief</p> <p>5. Assessments in which there is no added value or benefit from the involvement of consumers or rapid reports that summaries evidence on specific health technologies</p>	<p>1. Those in which there is no added value or benefit from the involvement of consumers</p> <p>2. HTA scoping reports – which are not developed as HTAs; and Evidence Notes – which are brief summaries of evidence on particular health technologies</p> <p>3. There are no consumer members on the commissioning board; consumer comment is not sought on briefing notes (at the topic prioritisation stage) for topics solely focussed on the diagnostic accuracy of diagnostic tests</p> <p>4. Horizon scanning</p> <p>5. Most of them, because the patient issue is not important</p>

**Use of consumers in the formulation of topics for assessment**

In 2005, 67% of agencies involved consumers in the formulation of assessment topics. In 2010 the proportion was 55%. One agency does not generally seek consumers’ input but involves them in a few projects regarding the assessment of treatments for psychiatric diagnoses.

Approaches used by agencies are shown in Table 5. In the 2010 survey the proportion of agencies that considered consumers’ suggestions was lower than in 2005, while that for each of the other (more detailed) approaches was higher.

**Table 5: Approaches used by those agencies that involve consumers in the formulation of assessment topics**

	2005, %	2010, %
Consider suggestions made by consumers, including loosely-specified health technology topics	100	83
Use consumer input to the prioritizing process	57	67
Seek comment from consumers in refining the scope and nature of HTA projects	43	54
More detailed involvement in development of the HTA protocol, e.g. participation in committees	43	58

## Preparation of assessments

Responses on involvement of consumers in the preparation of HTA reports are summarized in Table 6. In 2010, higher proportions of agencies contacted consumers or used them for interpretation of data and in drafting reports. Similar proportions in each survey used consumers to review protocols or reports. Routine involvement was higher in the 2010 survey for the first two types of task and lower for the third.

**Table 6: Involvement of consumers in preparation of assessments**

	2005, %		2010, %	
Consumers contacted to provide information or opinion on the technology being assessed	67	Sometimes: 79 Routinely: 21	86	Sometimes: 67 Routinely: 33
Consumers used to provide input to analysis/ interpretation of data or to drafting of some sections of HTA reports	10	Sometimes: 100	59	Sometimes: 62 Routinely: 38
Consumers used to review protocols and/or drafts of HTA reports	57	Sometimes: 60 Routinely: 40	59	Sometimes: 86 Routinely: 14 33

## Dissemination of HTA

### Summaries for consumers

All agencies were asked whether they prepared summaries or versions of HTA reports that are intended to be easily understood by consumers. In the 2010 survey 59% of agencies provided such material compared with 49% in 2005. The majority of those that provided summaries of reports also involved consumers in their programs (84% in 2010 and 71% in 2005).

Proportions of agencies that provide different types of summary are shown in Table 7.

**Table 7: Types of summary prepared for consumers**

	2005, %	2010, %
Information in newsletters or similar format	65	47
Brief one/two page summaries	76	53
More detailed consumer summaries	24	39
'Consumer versions' of HTA reports	24	26

Three agencies provided details of other approaches used to inform consumers:

- \* In the CPGs there are specific recommendations adapted for consumers or specific CPG for patients and consumers. There isn't a specific strategy of dissemination addressed to the consumer but the information provided by the agency is available for free in the website
- \* The Canadian Expert Drug Advisory Committee recommendations and reasons for recommendation document that includes a brief overview of the drug reviewed and some discussion is made available as a consumer version.
- \* HTA network briefs

### **Involving consumers in dissemination**

In the 2010 survey 42% of agencies involved consumer organizations and/or individual consumers in the dissemination of HTA materials, compared with 33% of agencies in 2005. One agency advised: “..have to say NO at this point but we currently have several projects running that, when the reports are done, will involve patient organizations in the dissemination of the HTA materials.” Approaches used by the agencies are shown in Table 8.

**Table 8: Approaches used to involve consumers in dissemination of HTA**

	2005, %	2010, %
Use of other organizations to distribute HTA materials	75	69
Advice in newsletters or other publications of consumer organizations	75	46
Presentation of advice at public meetings, seminars	67	77

### **Evaluation of consumer input**

In 2010 19% of agencies that involved consumers in their programs had undertaken appraisal of such involvement, compared to 29% in the 2005 survey. Of the four agencies that provided responses in the 2010 survey, one recorded numbers of reports where there has been consumer input, three noted the type of consumer input, and three considered the influence of consumer input on product quality and relevance. None of them had considered the potential for conflicts of interest to influence consumer opinions. One agency reported use of a survey of consumers involved with the organization. Another advised that “ The patient input initiative is still relatively young so we have not done an evaluation yet but all of the above measures will be part of our evaluation.”



## **Consumer perspectives in assessments**

In response to the additional questions in the 2010 survey 17 (52%) of agencies advised that their HTA reports consider consumer – reported attitudes and preferences, and 13 (39%) that their reports include a section that assesses patient/consumer perspectives. One agency commented “We involve/focus on patient relevant outcomes in our assessments (besides standard clinical relevant outcomes).”

## **Other comments**

- \* Is there any agency who utilises media to disseminate the information from HTA reports to consumers. If yes, how was it done?
- \* We look very much forward to the results of this survey, to learn from other organisations’ experiences.
- \* Continues to explore ways of making patient input more meaningful for patients/consumers as well as for the agency and participating drug programs
- \* Consumer involvement in the agency has a legal base (§ 140f Social Code Book V), confined to representatives of independent patient organisations on a federal level; they have no voting rights but can actively participate in all committees and express their opinions.
- \* In 2010 the agency established a Lay Advisory committee of 12 members of the public from across the province chaired by a retired journalist. The committee meets twice a year to provide advice to the agency on its research publications and programs. In a day long meeting the committee is presented with overviews by staff on selected publications and health technology assessments. At the most recent meeting the committee acted as a focus group reviewing some dissemination tools designed for the public ( a comic book and an online video) associated with guidelines developed for the effective management of chronic pain and provided feedback. We also consult with them on topics for future research that might be of interest to the general public.
- \* Consultation is the type of patient involvement used in our HTA activities: individual patients are consulted to gather evidence about their perspectives, experiences, or preferences about technologies, clinical procedures, or healthcare services.

## **Conclusions**

As in the previous survey, reported involvement of consumers in HTA varied among INAHTA members, reflecting differences in responsibilities and administrative arrangements. Any comparison of the two surveys is somewhat tentative, given the differences in response profiles, but there appear to be similarities in their results.

Of the agencies that provided responses, 67% involve consumers in some aspects of their HTA programs, although not always routinely, a higher proportion than that in the 2005 survey. . As in 2005, a large majority of agencies intend to involve consumers in the future. This includes a majority of those that do not currently involve consumers in their programs. Several agencies noted their involvement of consumers in the preparation of CPGs.

Similar findings were reported on types of consumer and how they are brought into contact with the HTA process. Consumer or patient organizations are the most

common type of contact, though large minorities of agencies in each survey also involve individuals. Invitation by the HTA agency is the most common contact mechanism. A majority of agencies accept requests on specific topics, while response to publicity on future assessments remains less common, though more frequent than reported in 2005. Only a few INAHTA members have a training process for consumers.

As in 2005, most agencies do not avoid involving consumers in some types of assessment. Comments in the 2010 survey from members who have restrictions on types of assessment, or on any involvement with consumers, point to practicalities in their programs that make these necessary. Time and resource constraints, requirements of rapid/ horizon scanning assessments and projects undertaken in confidence all present challenges for wider patient involvement.

In 2010, fewer agencies used consumers in formulation of topics for assessment, though their use in more detailed approaches, such as involvement in the prioritisation process, was higher.

A much higher proportion of agencies in 2010 used consumer input to data analysis or drafting sections of HTA reports. Similar proportions of agencies in each survey (a small majority) used consumers to review of protocols or reports. Evaluation of consumer input to HTA programs remains uncommon.

In 2010 there was an increase in the proportion of agencies that provide summaries of HTA reports for consumers, and also in the proportion that involve consumers in dissemination.

The additional items included in the 2010 survey indicated relatively limited inclusion of consumer perspectives in assessment reports.

Overall, the 2010 survey suggests that there is a trend to increased involvement of consumers by the INAHTA agencies in their programs, continuing the generally positive response found in the earlier survey.