

INAHTA survey on involvement of consumers in HTA

At the 2005 Annual Meeting it was agreed that it would be useful to survey INAHTA members to obtain information on what they do and what they avoid in involving patients in the HTA process.

A questionnaire for the survey was developed by the Working Group on Impact of HTA and was sent to members by the INAHTA Secretariat in October 2005. Thirty seven members responded to the survey and provided details using the questionnaire, a 90% response rate.¹

In the questionnaire, the term ‘consumers’ was used to include patients, carers, long – term users of services, organizations representing consumers’ interests, and members of public who are the potential recipients of health promotion programs.

A. Involvement of consumers in HTA programs

Members were asked whether consumers were involved in some aspects of their HTA program.

- 21 agencies (57 %) responded “YES”
- 16 agencies (43)% responded “NO”

B. Details of consumer involvement

The following responses were obtained from the 21 agencies that reported consumer involvement in their programs

Types of consumer involved in programs

Twenty agencies (95 %) involve consumer or patient organizations in their programs and 10 (48 %) involve individual consumers. One agency reported use of focus groups and another that involvement of consumers is not consistent as it depends on the technology and the issues surrounding it.

Bringing consumers into contact with the HTA process

Nineteen agencies (90%) reported that contact was made by invitation from the agency. Fourteen agencies indicated that contact involved acceptance of requests from consumers for assessment of specific topics; and five agencies showed that contact was in response to publicity on forthcoming assessments.

Training for consumers

Four of the agencies (19%) have a training process for consumers who are involved with their HTA programs.

¹ Agencies that responded were AETMIS, AETS, AETSA, AHFMR, AHRQ, ASERNIP-S, AVALIA-T, CAHTA, CCOHTA, CEDIT, CMT, CRD, CVZ, DACEHTA, DAHTA, DSI, FinOHTA, HAS, HunHTA, IAHS, ICTAHC, IECS, IMSS, ITA, KCE, MAS, MSAC, NCCHTA, NHSC, NHS QIS, NOKC, NZHTA, OSTEBA, SBU, UETS, VATAP and ZonMw.

Avoidance of consumer involvement

Most of the agencies (16/21, 76%) indicated that consumer involvement is not avoided in some types of assessment that they undertake.

Five agencies gave the following details of assessments where consumer involvement is avoided:

1. Those in which there is no added value or benefit from the involvement of consumers.
2. HTA scoping reports – which are not developed as HTAs; and Evidence Notes – which are brief summaries of evidence on particular health technologies.
3. There are no consumer members on the commissioning board; consumer comment is not sought on briefing notes (at the topic prioritization stage) for topics solely focused on the diagnostic accuracy of diagnostic tests.
4. Horizon scanning.
5. Most of them, because the patient issue is not important.

Use of consumers in the formulation of topics for assessment

Fourteen agencies (67%) involve consumers in the formulation of assessment topics. All of them consider suggestions made by consumers.

Eight agencies (38%) make use of consumer input to the prioritizing process and six (29%) seek comment from consumers in refining the scope and nature of HTA projects. Six agencies indicated there is more detailed involvement of consumers in development of the HTA protocol, for example through participation in committees, though one agency noted that this applies in some selected projects.

Preparation of assessments

Fourteen agencies (67%) indicated that consumers are contacted to provide information or opinion on the technology being assessed and the condition(s) that it is used for. Three agencies do this routinely, in one case as part of a broader advisory panel.

Use of consumers to provide input to analysis/ interpretation of data or for drafting of some sections of HTA reports is less common. Two agencies (10%) indicated that this is done sometimes.

Twelve agencies (57%) use consumers to review protocols and/or draft HTA reports. Six indicated that this is done sometimes, and four that it is done routinely, in one case as part of a broader advisory panel.

C. Future involvement of consumers

All agencies that responded to the survey were asked to indicate whether they intended to involve consumers in the future. Breakdown of the 35 responses received was as follows:

| | Intend to involve consumers in the future? | |
|---|--|---------|
| | YES | NO |
| Agencies that currently involve consumers (n = 21) | 20 (95%) | 1 (5%) |
| Agencies that do not currently involve consumers (n = 14) * | 9 (64%) | 5 (36%) |
| All agencies | 29 (83%) | 6 (17%) |

*One agency did not respond to the question and another provided a comment that was not directly related to it.

D. Dissemination

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. Breakdown of the 36 responses received was as follows:

| | Prepare easy to read HTA summaries? | |
|---|-------------------------------------|-----------|
| | YES | NO |
| Agencies that currently involve consumers (n = 21) | 12 (57%) | 9 (43%) |
| Agencies that do not currently involve consumers (n = 15) * | 5 (33%) | 10 (67%) |
| All agencies | 17 (49%) | 19 (51%) |

*One agency did not respond to the question

Of the agencies that prepare such summaries, 11 provide information in newsletters or similar format, 13 use brief one/two page summaries, 4 use more detailed consumer summaries and 4 prepare 'consumer versions' of HTA reports.

Comments from agencies that currently involve consumers were as follows:

1. Language of HTA executive summary made readable and understandable for lay persons
2. Planning to start with consumer versions occasionally
3. We intend to produce consumer summaries in the future
4. A direct line for consumers is currently being developed
5. Two page summaries of all HTA reports are written with the intent that they could be understood by consumers, but we do not target these specifically to consumers.
6. Ad hoc use of consumer/ patient newsletters

Comments from agencies that do not currently involve consumers were as follows:

1. Information on our website
2. An e- bulletin that summarizes our findings and recommendations is sent to our mailing list (anyone can join the mailing list). Each full report has a summary on our website.
3. Sometimes for all YES, but intend to do more, we are gathering experiences for the moment.

Involving consumers in dissemination

Agencies were asked whether they involved consumer organizations and/or individual consumers in the dissemination of HTA materials. Breakdown of the 33 responses received was as follows:

| | Involve consumers in dissemination of HTA materials? | |
|---|--|----------|
| | YES | NO |
| Agencies that currently involve consumers (n = 21) | 9 (43%) | 12 (57%) |
| Agencies that do not currently involve consumers (n = 12) * | 3 (25%) | 9 (75%) |
| All agencies | 12 (36%) | 21 (64%) |

*No responses from four agencies

Nine agencies used other organizations to distribute HTA materials, nine presented advice in newsletters or other publications of consumer organizations and eight presented advice at public meetings and seminars. Three agencies commented as follows:

1. All of the above occasionally if consumer organizations wish us to disseminate findings through them; not systematically.
2. All, but only sometimes
3. Sometimes for all YES, but intend to do more, we are gathering experiences for the moment.

E. Evaluation of consumer input

Eight agencies, six of which currently involve consumers, have undertaken appraisal of consumer involvement in their programs. Five have noted the type of consumer input, four record numbers of reports where there has been consumer input, four had considered the influence of consumer input on product quality and relevance, and three had considered the potential for conflicts of interest to influence consumer opinions. Other points made by four agencies were:

1. Survey of users in 2003
2. This will be an area of future development
3. A survey on satisfaction with the direct line to consumers.
4. Just in the forthcoming period (let's say one year) we will design a new procedure to involve patient groups and/ or citizens' representatives in our appraisal activities. have characteristics of an appraisal organization rather than performing assessments ourselves.

Other comments from agencies

One organization involves consumers through patient advocacy groups in the peer review process. Another agency states that they have involved consumer/patients in connection with developing or collaborating on clinical practice guidelines. It was reported that lack of time and resources were the reasons for not preparing consumer material based on HTA reports. A reason reported by another respondent for not involving consumers in the agency's work was that patient organizations are not very well organized in their country. One member has a continuing consumer panel of lay persons used as a sounding board for the agency's assessment protocols and communication of results.

Conclusions

Involvement of consumers in HTA programs varies among INAHTA members, as would be expected given the diversity of mandates and administrative arrangements for the various agencies. A majority of agencies involve consumers in some aspects of their HTA programs, though not always routinely. About a third of those that do not involve consumers intend to do so in the future.

Involvement of consumer or patient organizations is the most common approach; invitations by the HTA agency and acceptance of requests from consumers have both been used. Only a few members have a training process for consumers.

Several agencies involve consumers in topic formulation, preparation of assessments and review of protocols and reports. Input to data analysis or drafting sections of HTA reports is uncommon.

Fewer than half the agencies currently provide summaries of HTA reports for consumers and only a third involve consumers in dissemination. Evaluation of consumer input has been considered by only a few agencies.

David Hailey
Margareta Nordwall
January 2006