
RESEARCH REPORTS

Survey on the involvement of consumers in health technology assessment programs

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Objectives: The aim of this study was to obtain information from members of the International Network of Agencies for Health Technology Assessment (INAHTA) on their involvement of consumers (patients, carers, and related organizations) in their programs.

Methods: A questionnaire for a survey was developed and sent to member agencies in October 2005.

Results: Of the thirty-seven agencies that provided responses, 57 percent involve consumers in some aspects of their HTA programs and 83 percent intend to involve consumers in the future. Summaries of HTA reports that are intended to be easily understood by consumers are prepared by 49 percent of the agencies, and 36 percent involve consumers in dissemination of HTA material.

Conclusions: Most INAHTA members involve consumers in some aspects of their programs, although not always routinely. Involvement seems likely to increase in the future.

Keywords: Health technology assessment, Patients, Consumer participation

The focus of health technology assessment (HTA) is often on organizations and individuals with major financial or operational responsibilities for health technologies. Patients and their families or carers also have interests in health technologies, but less attention has been given to involving them in the HTA process (1). The International Network of Agencies for Health Technology Assessment (INAHTA) has considered how to encourage more extensive involvement of patients in health technology assessment. A survey of its members was undertaken to obtain information on what they do and what they avoid in involving patients in their programs. In this article, we present the main findings from the survey. Further details are available on the INAHTA Web site (www.inahta.org).

METHODS

A questionnaire for the survey was developed by an INAHTA working group and was sent to member agencies by the INAHTA Secretariat in October 2005. In the questionnaire, the term “consumers” was used to include patients, their carers, long-term users of services, organizations representing consumers’ interests, and members of the public who are the potential recipients of health promotion programs.

RESULTS

Thirty-seven member agencies responded to the survey and provided details using the questionnaire, a 90 percent response rate. Agencies that responded were IECS

(Argentina); ASERNIP-S, MSAC (Australia); ITA (Austria); KCE (Belgium); AETMIS, AHFMR, CCOHTA, MAS (Canada); DACEHTA, DSI (Denmark); CEDIT, HAS (France); DAHTA (Germany); FinOHTA (Finland); HunHTA (Hungary); ICTAHC (Israel); CVZ, ZonMw (The Netherlands); IMSS (Mexico); NZHTA (New Zealand); NOKC (Norway); AETS, AETSA, AVALIA-T, CAHTA, OSTEBA, UETS (Spain); CMT, SBU (Sweden); CRD; IAHS; NCCHTA, NHSC, NHS QIS (UK); and AHRQ, VATAP (USA). Twenty-one agencies (57 percent) indicated that consumers were involved in some aspects of their HTA programs, and the remainder that there was no such involvement.

Current Involvement of Consumers

The following responses were obtained from the twenty-one agencies that reported consumer involvement in their programs.

Types of Consumer Involved in Programs.

Twenty agencies (95 percent) involve consumer or patient organizations in their programs and ten (48 percent) 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 percent) reported that contact was made by invitation from the agency. Fourteen indicated that contact involved acceptance of requests from consumers for assessment of specific topics; and for five agencies, contact was in response to publicity on forthcoming assessments.

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

Avoidance of Consumer Involvement. Most of the agencies (16 of 21, 76 percent) indicated that consumer involvement is not avoided in some types of assessment that they undertake. Five agencies gave details of assessments where consumer involvement is avoided. These assessments included those in which there is no added value or benefit from the involvement of consumers, brief summaries of evidence on health technologies, briefing notes on the accuracy of diagnostic tests and horizon scanning products.

Use of Consumers in the Formulation of Topics for Assessment. Fourteen agencies (67 percent) involve consumers in the formulation of assessment topics. All of them consider suggestions made by consumers. Eight agencies (38 percent) make use of consumer input to the prioritizing process, and six (29 percent) seek comment from consumers in refining the scope and nature of HTA projects. Six agencies indicated there is more detailed involvement of

Table 1. Agency Intentions for Future Consumer Involvement

	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 ($n = 14$) ^a	9 (64%)	5 (36%)
All agencies	29 (83%)	6 (17%)

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

consumers in development of the HTA protocol, for example, through participation in committees.

Preparation of Assessments. Fourteen agencies (67 percent) 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 percent) indicated that this strategy is used sometimes. Twelve agencies (57 percent) use consumers to review protocols and/or draft HTA reports. Six agencies indicated that this approach is used sometimes and four that it is used routinely.

Future Involvement of Consumers

All agencies that responded to the survey were asked to indicate whether they intended to involve consumers in the future. The thirty-five responses received are summarized in Table 1.

Consumers and Dissemination of HTA

Agencies were asked whether they prepared summaries or versions of HTA reports that are intended to be easily understood by consumers. A breakdown of the thirty-six responses received is given in Table 2. Of the agencies that prepare such

Table 2. Preparation of HTA Summaries for Consumers by HTA Agencies

	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 ($n = 15$) ^a	5 (33%)	10 (67%)
All agencies	17 (49%)	19 (51%)

^a One agency did not respond to the question. HTA, health technology assessment.

Table 3. Agency Involvement of Consumers in the Dissemination of HTA

	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 ($n = 12$) ^a	3 (25%)	9 (75%)
All agencies	12 (36%)	21 (64%)

^a No responses from four agencies. HTA, health technology assessment.

summaries, eleven provide information in newsletters or similar format, thirteen use one or two page summaries, four use more detailed consumer summaries, and four prepare “consumer versions” of HTA reports.

Agencies were also asked whether they involved consumer organizations and/or individual consumers in the dissemination of HTA materials. The responses received are shown in Table 3. 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.

Evaluation of Consumer Input

Eight agencies have undertaken appraisal of consumer involvement in their programs. Five had 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.

CONCLUSIONS

The results of the survey give a summary of experiences of a group of HTA agencies that are primarily concerned with providing advice to decision makers in the public sector. 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 involve consumers in some aspects of their HTA programs, although not always routinely. Approximately one 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.

POLICY IMPLICATIONS

The involvement of consumers by many INAHTA agencies and the reported intention to increase such participation offer the potential to broaden the perspective of assessments and of the advice provided to decision makers. The trend toward broader consumer involvement is still in its early stages. The INAHTA agencies, like other HTA organizations, face practical difficulties related to demands on consumers, resource considerations, and influence on the timeliness of HTA advice (1).

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