

Consumer participation in Health Technology Assessment: An overview of HTA agencies experiences by Marie Pierre-Gagnon (CAHTA, December 2004).

1. Introduction

Recently, the concept of “health consumer” has become central in policy debates over health care system’s orientations and priority setting. In a context of limited resources, rising demand for quality health services coupled with the rapid development of new and costly technologies, patients and the general public represent key partners who should be consulted regarding health care resources allocation. A growing number of organisations in the health care sector are now involving patients and citizens in decision-making processes. For instance, funding agencies have consulted consumers to identify and prioritise research topics (O’Donnell & Entwistle, 2004) and health technology assessment agencies are also concerned about public opinion in evaluating emergent health devices, procedures, or technologies (Pivik, Rode & Ward, 2004).

The International Network of Agencies for Health Technology Assessment (INAHTA) comprises 42 member agencies from 21 countries. Its purpose is to promote cooperation and information sharing among HTA agencies. An informal survey was conducted among INAHTA members to gather their experience with respect to consumer involvement in their activities. This document presents the results of the survey and proposes some orientations to advance research on consumer participation in HTA.

2. Definitions of concepts

In this section, we propose definitions of the key terms involved in the concept of health consumer involvement in decision-making.

Health consumer: “Patients, carers, long-term users of services, organisations representing consumers’ interests, members of the public who are the potential recipients of health promotion programmes (Hanley B. et al, 2000)”. Moreover, the NCCHTA (2004) specifies that these groups are asking for research for specific reasons, such as believing they have been exposed to potentially harmful circumstances, products or services or they have been denied products or services from which they could have benefited (NCCHTA, 2004). The NCCHTA also mentions that health consumers should not normally be a health practitioner, manager or researcher to avoid conflicts of interest. Furthermore, even if individual patient or citizen are considered, health consumers should be organised into networks, in order to maximize their input into HTA programmes (NCCHTA, 2004).

Participation: Citizen participation constitutes the basis of democracy. It is expected to energize the democratic system and result in more transparent government actions (Hidellage, 2004).

Involvement: “Consumer involvement incorporates the consumer perspective into the process of planning and decision-making” (Christensen & Rosen, 1994). It constitutes an extension of the idea of citizen participation in that it moves the voices of consumers into the planning and decision-making process of health services-delivery systems.

Health decision-making: Defined as the application of decision theory to clinical practice, to the management of care and to resource allocation (Chase, 1996). It is also seen as a decision process that is influenced by crisis situations, actuality issues, and the interests of various groups and organisations (CDCP, 2003).

3. Types of consumer involvement

Consumer involvement is gaining increasing attention among HTA agencies around the world. However, according to our survey, few agencies have actually implemented such processes and the degree of consumer involvement is highly variable. From the experiences reported, consumer involvement activities can be classified into the five following categories:

a. **Consumer-oriented publications and communications:**

The translation of HTA results into ‘layman’ language and its diffusion through communication channels that are accessible to consumers makes them aware of HTA activities and constitutes an indirect way to increase their involvement in further decision-making activities.

Example: The Australian Safety and Efficacy Register of New Interventional Procedures – Surgical (ASERNIP-S) has developed patient information leaflets which have been distributed to surgeons and peak consumer groups in Australia. These publications are short summaries of the systematic literature reviews, written in easy-to-read language for consumers and posted on the agency’s website.

b. **Review panels:**

A direct involvement of patient groups representative in the process of prioritising and refining research topics represents the recognition of consumer’s knowledge and expertise.

Example: The National Coordinating Centre for Health Technology Assessment (NCCHTA) has three different review panels and each one comprise two consumers. They participate to the meetings and are also consulted in the priority-setting process by means of vignettes. Consumers can also act as peer reviewers and comment the perspectives of patients or service users on research proposals. Their main contribution is to highlight issues that are important to patients or people using the services.

c. **Consumer representatives on committees:**

This constitutes an effort from HTA agencies to involve consumers as full partners in their decision-making processes. Consumer’s role on these committees can vary and scientific background can be a requirement.

Example: The National Institute for Clinical Excellence (NICE) has three technology appraisal committees (technology appraisals, clinical guidelines and advice on safety and efficacy of interventional procedures) which include at least two lay members each. These lay members can be patients, carers or general public representatives. Consumer members work on an equal footing with other committee members. They play a specific role in bringing a patient or carer perspective to, and raising patient/carers issues at, meetings of the committee.

d. **Consumers committees:**

Some agencies have created specific entities to ensure the representation of the general public. One of the element to take into account is the representativeness of the committee by including citizen from various groups and backgrounds.

Examples: The NICE Citizen Council includes 30 people from diverse sectors and meets three times a year to discuss societal issues related to HTA activities.

e. **Punctual consumer involvement in HTA activities:**

Direct input from patients in an activity related to HTA has been obtained at some occasions by the majority of agencies. These punctual contributions can take diverse forms and consumers are involved as patients or representatives of the general public.

Example: Patients participation in the formulation of recommendations has been conducted by the Catalan Agency for Health Technology Assessment with respect to the definition of priority criteria for inclusion in waiting lists (Sampietro-Colom et al., 2004).

4. Results

An invitation to participate to an informal survey was sent by email to the member agencies of INAHTA. Of the 42 agencies involved in the network, 15 (36%) have replied to the invitation to participate. The countries for which we obtained information are the following: Australia, Canada, Denmark, England & Wales, Hungary, Israel, the Netherlands, Sweden, Spain, and the USA. Among the respondents, some countries had more than one HTA agency, thus we obtained information for a total of 15 agencies representing 10 different countries.

The longest experience in consumer involvement was reported from the NCCHTA of England and Wales. In 1998, a feasibility study was conducted to identify ways for increasing public participation in the agency's activities. Over the past five years, they have build a programme to involve consumers at different levels, such as participation to research priority-setting, commenting on vignettes in the light of consumers interests, and peer reviewing research proposals.

The NICE also provides a number of opportunities for patients, carers and the public to contribute to technology appraisals in England in Wales. The Patient Involvement Unit (PIU) constitutes the entity responsible for the management of all consumer participation activities. The PIU's mission is to develop and support opportunities for patient and carer involvement at different levels. Among its activities, the PIU is responsible for the identification of patients and carers organisations that may be interested in registering as consultees. The PIU also contributes to support these organisations and to provide the adequate training to their representatives.

Consumer involvement within NICE activities can take three major forms: 1) as an individual: participation to one of the three technology appraisal committees; 2) as a national patient or carer organisation (or as an individual): a role of consultee or commentator to react on relevant appraisal topics; and 3) as a member of the Citizens Council, that gathers 30 people who reflect a cross section of the population of England and Wales and uses deliberative techniques to consider societal value issues in health technology assessment. Finally, NICE technology appraisal guidance is also produced in a plain English version that is called 'information for the public' or IFP version.

A similar approach has been taken by the ASERNIP-S in Australia. Since 2002, the agency has two consumer representatives on their Management Committee. These representatives are also members of a multidisciplinary team, called the Consumer Information Group, set up after each review is completed to prepare the consumer information in plain English (ASERNIP-S, 2004).

The Centre Advisory Board of the Danish Centre for Evaluation and Health Technology Assessment (DACEHTA) has one representative for the Danish Consumer Council and one for the Council of Organisations for Disabled People. Thus, two out of 23 Board members represent health care consumers. The function of the Centre Advisory Board is, among other things, assessing and commenting on the strategic plans and proposals relating to the activities of the DACEHTA. It can submit its own proposals for activities and it is responsible for assessing the budgets in relation to specific activities with respect to the implementation of the National Strategy for Health Technology Assessment (DACEHTA, 2004).

Moreover, the DACEHTA involves – if relevant – a representative of the patient organisation concerned when carrying out an HTA on a specific technology or health care problem. The involvement can be as a member of the project group, a subgroup or as a member of the reference group for the project. The representatives give input into the projects and participate in communicating the results of the assessment.

The Swedish Council on Technology Assessment in Health Care (SBU) involves a group of five citizen participants (with academic training, although not medical/nursing), plus a journalist chairman, which meets 2-3 times yearly. Their tasks are twofold: 1) active participation in the initial phase of projects by giving their opinion about protocols of projects, including relevance of main questions, additional consumer issues which should be covered, ethical issues (such as conflicting issues, or priority-setting issues), issues related to patients' family situation. Sweden has started an HTA Program in Psychiatry we had meetings with Patient's organizations in priority discussions about what areas to take up. They were also involved in conferences where the reports were presented.

In addition, the SBU has implemented a strategy to ensure effective dissemination and implementation of its recommendations based upon local and regional involvement. To do so, the SBU has organized a network of local “ambassadors” throughout Sweden. These people are not health consumers but clinicians. However, their role is one of opinion leaders in their community and their aim is to influence local practices in accordance with the evidence. They use the findings from SBU reports to influence clinical policy and practice at the regional and local levels.

In Spain, few experiences of consumer involvement in HTA activities have been conducted to date. The Andalusian HTA Agency (AETSA) has consulted patient representatives during its investigation of decision support systems for shared decision-making (Hermosilla & Briones, 2002). At the Catalan HTA Agency (AATRM), a significant experience has been conducted with respect to patient involvement in the development of set of criteria to determine priority in waiting lists for different surgical procedures (Sampietro-Colom et al., 2004).

In 1999, Israel has involved consumers in the process of adding new technologies to the national health basket (Shani et al., 2000). The Minister of Health set up a public committee in which health consumer representatives were involved. The committee had to appraise various technologies on clinical, economic, social, ethical and legal dimensions based upon analyses from HTA experts. Then, the public committee had to make its recommendations on which health technologies should be given priority for inclusion in the list of national health services. This was an isolated experience, but the results present a pragmatic model to integrate health consumers' perspective in priority-setting for the inclusion new health technologies.

In Canada, a growing interest is present to further involve consumers in HTA. According to a recent study, health consumer groups representing various disease or illness conditions in Canada reported a desire for greater involvement in HTA, and provided feedback on mechanisms for facilitating their participation (Pivnik et al., 2004). Nevertheless, Canadian experience in health consumer involvement remains limited. The Canadian Coordination Office for HTA (CCOHTA) is currently funding a project to develop a model for consumers involvement in HTA, based upon the UK's NCCHTA experience. Furthermore, the Swedish model of "ambassadors" is also being implemented in Canada (AHFMR, 2004a). The HTA Unit of the Alberta Heritage Foundation for Medical Research (AHFMR) has recently published a report on consumer-oriented HTA publications (AHFMR, 2004b). According to their review of HTA agencies' experience with respect to publication of consumers versions of scientific reports, only 9 (out of the 48 surveyed) have produced such summaries. The AHFMR is now implementing a model to provide consumer summaries of their reports. The model will involve consumers in the review and writing of the summaries.

In the United States, the Center for Medicaid and Medicare Services is currently launching a project at to increase public (patients and advocates) participation in coverage policy development. The other responding agency from the USA, the Veteran Affairs, did not have experience of direct consumer involvement in its activities. However, an indirect public participation is done through the work of an expert panel that is set up according to the specific topic of assessments they are asked to undertake.

In Australia, consumers involvement within the ASERNIP-S is concentrated in the production and dissemination of information. Consumers are not yet consulted on priority-setting. Consumer participation is sought after in the publication and dissemination processes of recommendations. The ASERNIP-S staff prepares a first draft which is circulated to other members of the group (consumers and surgeons) for comments. Consumer representatives provide their input into the preparation of all ASERNIP-S consumer information, including submissions to the publications of peak consumer organisations in Australia, such as Consumers' Health Forum.

5. Discussion

As illustrated from our exploratory review, consumer involvement in HTA can take various forms. However, among the HTA agencies that have introduced such programs or activities, few have performed a formal evaluation of their effects on patient satisfaction, decision-making processes, empowerment, health outcomes, etc.

An evaluation of patient/carer participation in guideline development committees was conducted by the NICE Patient Involvement Unit (NICE, 2004). Despite their satisfaction with the process, patients and carers have pointed out some weaknesses that needed to be addressed. For instance, a better training and further support from the organisation were deemed necessary. Furthermore, a greater involvement in the definition of the scope as well as in the organisation of committee's meetings was expected. Finally, the need to provide patients and carers with research skills and with information about other patient/carer organisations perspectives was identified.

With respect to consumer-oriented publications, the experiences conducted so far seem satisfactory. According to ASERNIP-S, involving consumers on review panels plays a specific role in bringing a patient or carer perspective to, and raising patient/carer issues at, meetings of the committee. Furthermore, links formed between evaluators and consumer or

carer organisations facilitate the transfer of information. Other informal evaluation made by HTA agencies staff indicates that including a consumer perspective in their publications ensures that the information produced is relevant to the needs of the consumer.

In the light of these observations, different avenues exist to enhance health consumer participation at different levels of decision-making. Additionally, all responding agencies showed a great interest in this topic and many are currently planning and developing strategies to increase the role of patients and the general population in their activities. All the responding agencies have also manifested their desire to get more information about activities related to consumer involvement among other HTA agencies, showing a great interest for sharing knowledge and experiences in this field. Therefore, collaborations should be promoted through the International Network of Agencies for Health Technology Assessment in order to facilitate information exchange and to share about successful experiences of consumer involvement in HTA activities.

6. Limits of the study:

This study was conducted as an exploratory informal survey aimed at gathering recent information about consumer participation in HTA activities among the members of the Network of Agencies for Health Technology Assessment. Participation was rather low among agencies (15 out of 42). This result could be explained by the fact that only one message presenting the survey was sent by email. Also, some agencies informed us that they have had some experience in involving consumers in their activities, but that they did not have any documentation in English about it. HTA agencies should be encouraged to disseminate their experiences in involving consumers in decision-making, for instance by a contribution to a special edition of a scientific journal on this topic. Furthermore, agencies that have responded to our survey are likely to be the ones that have already implemented citizen participation mechanisms or that are actually considering this possibility. Thus, additional information should be obtained from national agencies of countries where citizen participation has not been experimented to ensure a valid portrayal of the current situation. In order to carry on this work, a formal survey should be conducted, including a short structured questionnaire which HTA agencies could complete about their experience with consumer participation, their intention to carry out such activities as well as the perceived benefits and pitfalls associated with it.

7. Conclusion

This study constitutes, together with other similar work (AHFMR, 2004), one of the efforts currently aimed at exploring possibilities to further involve consumers in health policy-making. Citizen and patient participation to setting research priorities and health technologies appraisal are among the methods that have been proposed to increase consumers' involvement in health matters. However, this study highlights that, with a few exceptions notably in England and Wales, Sweden and Australia, HTA agencies have not yet implemented formal mechanisms to integrate the perspective of patients and the general population in their activities. Despite a wide recognition of the need for involving consumers, carers and/or members of the public in HTA activities, a majority of agencies have not included such procedures in their programme so far.

Based upon an informal survey among INAHTA members as well as a consultation of HTA agencies' websites, we found only a handful of examples reporting consumer involvement, but these appear as promising experiences. Unfortunately, there is no evidence of the effects of consumer involvement in HTA activities since little formal evaluation has been conducted

by the few agencies that have introduced such programmes. Nonetheless, some agencies have implemented successful programmes and further efforts to involve consumers in HTA activities could be adapted from these models. More research is needed in order to develop our knowledge about the diverse mechanisms to increase health consumers' participation in health technology assessment and priority-setting and their effects on the health care system as well as on individual and population health outcomes.

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