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# Consumer Involvement in Health Technology Assessment

A H F M R



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# Consumer Involvement in Health Technology Assessment

David Hailey



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**A H F M R**

ALBERTA HERITAGE FOUNDATION  
FOR MEDICAL RESEARCH

**HTA Initiative #21  
Consumer Involvement in  
Health Technology Assessment**

*Prepared by:  
David Hailey*

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## **FOREWORD**

Some of the material included here draws on a discussion paper prepared for a working group of the International Network of Agencies for Health Technology Assessment (INAHTA) to help in consideration of how the network might encourage more extensive involvement of patients in health technology assessment.

A general review of the topic is followed by a brief discussion on issues for the AHFMR Health Technology Assessment Unit (HTAU) to consider and possible future directions.

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## INTRODUCTION

Much of the activity and purpose of HTA is related to interaction with organizations and individuals with interests in the technologies that are being considered. The focus is often on stakeholders with major financial or operational responsibilities for health technologies, including government authorities, the manufacturing industry, health care professionals and the health insurance industry. Patients and their families or carers are an obvious key group with major interests in health technologies, but HTA has rarely involved them in the assessment process. In part, this may be associated with the linking of assessments to the needs of decision makers with specific responsibilities in the use and funding of health technology.

There seems a need for HTA to give more attention to the views of patients as a group that has immediate involvement with health technologies. Failure to do so may attract criticism of HTA providers and also lead to missed opportunities to improve assessments through taking account of additional perspectives and information.

Criticism may be pointed, as with this comment from a Canadian paper: "Health experts such as physicians, researchers and economists largely dominate HTA decision - making. This situation is antithetical to the belief that acceptable health decision - making requires a process that is transparent, not dominated by any particular interest and reflects the values of all users".<sup>1</sup> Also, citing Saltman & Figueras,<sup>2</sup> "...decisions related to health care priorities are essentially value judgements based on an individual's personal values. Therefore it is in the policy makers' best interests to ensure that all decision - making processes are open, transparent and *inclusive*".

There have been varying responses to patient participation from HTA agencies, not always well described, though details are available on initiatives taken in the UK by NICE and NCCHTA.

There is much material on the involvement of patients in planning and operation of clinical services and public health initiatives. Some useful general principles emerge from accounts of such efforts but there is relatively little directly touching on the situation typically facing AHFMR and other INAHTA members of routinely producing and disseminating technical advice for decision makers in health care, often with tight deadlines. There is more of an overlap with the literature on involving consumers with health research, including several papers relating to NHS - related research activities in the UK.

The position taken by assessment agencies on patient involvement in HTA will be influenced by their mandate and governance, and resources available; situations will vary and will often be contingent on the circumstances surrounding a specific technology. The following material presents some general issues and principles for consideration. The context does not always relate directly to HTA, but the various

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points raised should provide themes for discussion on patient participation in the HTA process.

The NCCHTA has taken “consumers” to mean “patients, carers, long-term users of services, organizations representing consumers’ interests, members of public who are the potential recipients of health promotion programs, and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.”<sup>3</sup> ‘Consumers’ has been used in the following discussion.

## PERCEPTIONS AND EXPECTATIONS

Various authors have identified reasons for involving consumers in the research process. Telford et al.<sup>4</sup> suggest the main reasons for involving consumers are because it:

- is a political imperative;
- is morally correct;
- benefits the research process.

It was suggested that consumers as citizens and owners of the NHS are entitled to have a voice about research issues in their health service.

Benefits to the research process arise as consumer perspectives complement the medical perspective; can highlight important issues of which researchers are unaware; and professionals cannot necessarily speak for consumers. There are potential benefits of consumers prioritizing the research agenda.

Royle and Oliver, in discussing the NCCHTA program, note that NHS policy encourages active consumer participation in all stages of a program: identifying and prioritizing research topics, commissioning, conducting and reporting research, and getting findings into use.<sup>3</sup>

There seems a widely – held perception that consumer involvement in health research can provide benefits. A view from the perspective of the Cochrane Collaboration is that:

‘Consumer involvement provides a unique perspective, valuable because individuals have first hand experience with a health condition, as patients or carers. It can ensure that Cochrane reviews that are done to cover a broad range of questions and reviews are relevant and made accessible to those most affected by the condition..... One of the roles of consumers on the review teams is to raise the difficult questions others may not have considered or do not give priority to; and challenge ideas, suggestions with which they do not feel comfortable.’<sup>5</sup>

Suggested benefits for US breast cancer research of including consumer reviewers in scientific merit reviews included themes of the consumer as a survivor, advocate and educator of others with breast cancer and the community, and these aspects informing the researcher perspective.<sup>6</sup>

A survey of UK public and voluntary organizations that fund research found reasons given for attempting to involve consumers in decisions on what research is funded included:

- to ensure research is of relevance and importance to people;
- consumers seen as having right to be involved;

- involvement might improve quality and legitimacy of the organization's decision making processes.<sup>7</sup>

A paper on consumers and genetic testing suggests that one way to avoid discrimination against under-represented individuals is to involve them in policy making; they can share valuable experiences and perspectives as input to policy.<sup>8</sup>

These generally positive perceptions are further informed by advice and opinion on the practicalities and problems of consumer involvement. O'Donnell & Entwistle in their survey of UK funders of health - related research found that some thought consumer involvement possible in any kind of research project, while others were less keen. All respondents thought the appropriateness of particular forms of consumer involvement could vary across different types of project.<sup>9</sup> Indicators of good involvement were that consumers should make a difference; have some real power in the whole process; and that the research process might be altered according to consumer responses.

But in practice, judgments could be made on the basis of:

- types, numbers of consumers involved
- whether consumer involvement was credible or feasible,
- whether consumers had been named as co - applicants in a research proposal
- whether initial contact was already made
- training, personal and financial support for consumers
- cost and appropriateness of cost for consumer activities
- concerns as to whether researchers would actually do what they proposed, whether consumers would have "real" involvement.

## CHALLENGES

These points lead to consideration of potential difficulties with consumer participation. Comments in the literature on challenges associated with consumer involvement have some common themes:

### *Interaction of consumers and researchers*

- It takes time to develop productive working relationships; those in the relationship need to trust and value opinions, expectations of others.<sup>5</sup>
- Possibly unfavorable responses from scientists to consumers as advocates.<sup>10</sup>

### *Availability of resources*

- Resources, including infrastructure support at the editorial base, limits the support that the base can provide.<sup>5</sup>
- Success depends on degree of enthusiasm from individual consumers and staff; further support for staff is needed (turnover, general unfamiliarity with the consumer side).<sup>3</sup>
- Additional administrative and financial costs.<sup>7</sup>

### *Identifying a reasonable consumer position*

- Consumers do not all hold the same point of view, but it is not possible to canvass all consumers before making a decision. Priorities of individuals vary depending on values, expectations, motives, environment and culture. And by contact with the health care system.<sup>5</sup>
- In discussion of genetic testing issues<sup>5</sup> it was suggested that there was under-representation of consumers on advisory committees - and when they are on these "members do not represent a plurality of views."
- Quick identification of appropriate consumers is a challenge.<sup>3</sup>

### *Technical demands on consumers*

- The consumer as reviewer and the degree of scientific preparation possible for a review meeting.<sup>10</sup>
- Lack of knowledge/power/credentials of consumers regarding health care and policy options.<sup>11</sup>
- Consumers having difficulties with understanding proposals.<sup>7</sup>
- Skills and support.<sup>12</sup>

### *Training and education*

- A lack of education and training specific to consumer participation.<sup>1</sup>

### *Nature and extent of consumer representation*

- Difficulty defining which consumers should be involved.<sup>11</sup>
- Lack of representation; difficulty reaching marginalised populations.<sup>1</sup>
- Methodological problems about how to get the patient perspective as patients are not an homogenous group.<sup>13</sup>
- Appointments of consumer representatives lacked openness, could affect credibility of individuals.<sup>13</sup>
- Identifying appropriate consumers to participate.<sup>7</sup>

### *Time demands and remuneration*

- Time commitment of representatives, especially those sitting on committees, linked with issues re remuneration.<sup>13</sup>
- Time constraints.<sup>1</sup>
- Resources – time and money.<sup>12</sup>
- Challenge for consumers in working to tight timetables.<sup>3</sup>
- Lack of time and payment.<sup>11</sup>
- Whether and how much consumers should be paid.<sup>7</sup>

### *Matching consumer information and information from researchers and the literature*

- Perception by some of a lack of concordance between issues that consumers regard as important and those in which research has been conducted.<sup>5</sup>
- Affected individuals may believe health professionals overemphasize impairment rather than social factors as defining characteristics of disability.<sup>8</sup>
- Nature of evidence: an area where patient participation and EBM meet head on and where there is potential for conflict. Concern about methodology used to balance qualitative and quantitative evidence and also the role of cost. A question of how credible evidence from the patient perspective would be to those from scientific backgrounds and where it ranked in traditional hierarchies of evidence.<sup>13</sup>

### *Consumer impact on discussion and decisions*

- Importance of the lay perspective; whether scientific debate gets softened. Process issues: efficient use of panel's time; consumer input on funding decisions.<sup>6</sup>
- Tokenism.<sup>13</sup>
- Attempts to involve patients from the start, but not sure what to 'do' with patient representatives or how to involve them.<sup>13</sup>

- 
- Lack of procedures on how to select and integrate into health policy decision making; lack of understanding how consumers affect the health care system through these involvement mechanisms.<sup>11</sup>
  - Patient groups .....are concerned about how their evidence is handled, weighed and valued; .....challenges on how to handle evidence from disparate sources ....consumer groups feel that others have more influence.<sup>1</sup>
  - Conceptual problems still in defining relevant 'publics' and with using public attitudes to inform policy decisions. Mechanisms for involvement in policy but limited empirical evidence to evaluate which of these is best for a particular policy situation.<sup>8</sup>
  - Possible "distortion" of funding decisions due to consumer biases.<sup>7</sup>
  - Absence of good quality research to show that consumer participation makes a difference.<sup>7</sup>

## APPROACHES TO INVOLVING CONSUMERS

Telford et al.<sup>14</sup> have suggested the following principles for involvement of consumers in research. They note that the value and utility of the principles have yet to be established and will almost certainly need to be further developed and refined. Also, work is needed to establish how transferable they are to different research methodologies and models of consumer involvement.

| Principle  | Indicator(s)  |
|--|---|
| Roles of consumers agreed between researchers and consumers involved in the research   | Roles are documented  |
| Researchers budget appropriately for costs of consumer involvement   | Researchers applied for funding; consumers reimbursed   |
| Researchers respect differing skills, knowledge and experience of consumers  | Include consumer contribution in research reports and papers  |
| Consumers offered training and personal support  | Needs agreed between consumers and researchers; access to training; mentors available to provide support  |
| Researchers ensure they have necessary skills to involve consumers in research process   | Ensure their own training needs are met   |
| Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research | Consumers gave advice on how to recruit and how to keep participants informed   |
| Consumer involvement is described in research reports  | Acknowledge involvement; give details of how consumers involved   |
| Research findings are available to consumers in formats and in language they can easily understand                                 | Disseminate to consumers in appropriate formats, language. Consumers involved in research gave advice on choice of methods used to distribute research findings |

### Collaboration with consumer and patient groups

In 2002 the Cochrane Collaboration had 49 Collaborative Research Groups (CRGs) with more than 200 consumers involved; about half of the consumers were associated with patient or consumer groups. Interaction with consumer and patient organizations has been seen as a practical approach to involving the consumer in medical research. Such organizations may be able to act as a focus for consumer interest, knowledge and opinion and provide useful contacts.<sup>5</sup>

However, “not all consumers want to assume an advocacy or policy making role and consumer organizations may not exist in some areas. Links to consumer organizations go some way towards representation, but members of those may not be representative of all people with a particular condition.”

NCCHTA has identified consumers through directories of consumer organizations, the Internet for particular health conditions, and personal contacts. They sought organizations with a high consumer profile: consumer led, national groups with local networks.

In the UK, Jones et al.<sup>10</sup> conducted a survey on the role of health consumer groups in representing user, carer and patients’ interests nationally. Groups believed their main purpose was to provide services rather than to influence policy. However, most were engaged in policy activity. There were difficulties in choosing priorities because of resource pressures; as a consequence some chose not to attempt to influence policy.

Some were concerned at the implications of getting funding from statutory and commercial sources. There were fears that this could undermine their independence and possibly also distort priorities, shift away from core functions.

There was a wide range of membership and structure; and a range of motivations and activities by members. Jones et al. provided a typology:

- Formal alliance organizations: membership consisted of other autonomous organizations e.g. Genetic Interest Group.
- Population – based groups; representing all patients or a specific population subgroup – e.g. Action for Sick Children (range of medical conditions, more concerned with generic issues like access and rights).
- Condition – based groups e.g. National Childbirth trust.

Details of approaches to involvement of the public in the NHS HTA programme are available through the NCCHTA website<sup>15</sup> and include several help sheets for consumers.

### **Other structures**

NICE has put in place councils that include consumers to assist it in its work. The NICE website<sup>16</sup> gives the following details:

*“The Citizens Council : The Citizens Council brings the views of the public to NICE decision-making. The 30 members of the Citizens Council, drawn from all walks of life and reflecting the make up of the population in England and Wales, give their views on the social values which should underpin NICE's work. The Council meets twice a year and provides advice in response to a specific question of importance to NICE.*

*The Partners Council:* Individuals nominated by patient groups, health professional bodies, academic institutions, NHS management, healthcare quality organisations, industry (companies producing drugs, devices and diagnostic equipment) and trade unions sit on the Partners Council to provide NICE with the views of a range of organisations that have an interest in our work.”

The NICE website also gives details of its approaches to communicating with and involving patients and carers.<sup>17</sup>

More elaborate proposals to increase consumer involvement have been made. Sleath and Rucker have suggested creation of a centre for studying and improving consumer participation in health policy decision making.<sup>11</sup> Pivik et al., considering HTA in Canada, suggest that focus would be placed on involvement versus consultative strategies, with the most feasible type of involvement based on current practices involving consumer participation on a decision – making committee.<sup>1</sup> They propose a consumer involvement model for HTA in Canada with a federally - funded independent HTA consumer organization. This would include a health consumer network; development of a national data base to include health consumer knowledge, interests, skills and expertise; coordination of selection for HTA committee; provision of training and educational support.

### **Operational considerations**

A King’s Fund rapid appraisal of Health Improvement Programs (HImPs) in London raises some general issues.<sup>18</sup> There were generally positive views from those interviewed for the appraisal, but also perceptions of challenges, some of which can be considered in terms of HTA:

- Tension re defining partnerships, working within a system versus engaging in local activities.
- Forums for stakeholders were “a good way to meet people, but not really where work is done.... involving all stakeholders requires an immense amount of time and effort.”
- Resources: “..health authorities were meant to link HImPs to their annual service and financial framework; but most found resources consumed by acute health services and other priorities already identified. Many faced budget cuts, discussing what to ration rather than what new to implement.”
- Measuring progress: Needs to be some demonstration of progress – many aims and objectives of health improvement will take years to achieve. Need to demonstrate some “quick wins”.

## INVOLVEMENT OF CONSUMERS IN HTA FUNCTIONS

### Formulation of HTA questions

In the Cochrane Collaboration, consumers have been involved throughout the review process. In the breast cancer group example give by Ghersi<sup>5</sup>, with priority setting two consumers are on the editorial committee, and can be approached directly by other consumers.

Lomas et al.<sup>19</sup> argue for a central role for health system managers and policymakers in setting priorities – they know the system and are those who will apply or ignore research findings. Helping them to identify priorities increases their sense of ownership. These authors suggest a “Listening Model” based on principles of linkage and exchange between funders and researchers and the research’s potential users. Both sides need to listen to each other.

A large majority of persons from two medical clinics who participated in an Australian survey felt that priority setting decisions on medical interventions should be informed by the preferences of more than one group (e.g. doctors, health service managers, patients and the general public).<sup>20</sup>

NCCHTA used consumers in advisory panels on prioritization; comment on vignettes-summaries of research need; and as peer reviewers of research proposals. It was found that review of research proposals was technically demanding for consumers. The approach was changed to ask questions from a consumer’s perspective first, before scientific merit and cost; also consumers are free to ignore questions they do not feel able to answer. Guidelines for consumers were developed.<sup>3</sup>

Vignette topics were rarely repeated, contact between program and consumer tends to be one off, giving little opportunity to learn and benefit from experience. Panel meetings on priority were difficult for consumers due to speed of discussion and unfamiliarity with material. This improved with more meetings and use of a mentor system that was developed for new panel members.

### Preparation of assessments

In the Cochrane breast cancer group, all protocols and completed reviews are refereed by at least one consumer.<sup>5</sup> Changes such as consumer – oriented outcome inclusion, and more appropriate language have been made as a result. Seven consumers were involved in design and conduct of systematic reviews, and provided input on identifying trials and hand searching journals and conference proceedings.

The NCCHTA found similar difficulties to those with review of research proposals in consumer review of reports. Consumers were not always able to review. Reasons included no payment being available for reports of less than 200 pages; the technical nature of a report; or the topic of a report not being in line with the policy of a consumer

organization. Consumer review of final reports was abandoned because of the disproportionate effort required.<sup>3</sup>

The NCCHTA website mentions that the first projects formally encouraged to actively involve service users as members of the research team started work in early 2004. The HTA programme will be monitoring the progress of this initiative to check what is feasible and to develop or direct research teams and service users to appropriate support.<sup>15</sup>

## **Dissemination of HTA findings**

Two aspects to be considered are the dissemination of HTA material in a form that consumers will read and understand; and involving consumers in the dissemination process.

### *Summaries for consumers*

Several agencies have given consideration to preparation of summaries or versions of HTA reports that will be accessible to consumers, both in hard copy and through their websites. For example, ASERNIP-S prepares detailed consumer summaries, SBU publishes booklets that are available in pharmacies, clinics and hospitals, and NICE has comprehensive versions of guidance for patients and their care-givers. Succinct information is also provided through newsletters by a number of agencies.

Lay synopses have been introduced as part of Cochrane reviews, most drafted by the Cochrane Consumer Network; they are published on the network web pages and in paper form. Some CRGs use these synopses as a basis for articles in consumer organization newsletters. Consumers are involved in lay translation of materials, including proof reading newsletters, and assisting in compilation of brochures and synopses targeting a consumer audience.<sup>5</sup>

Development and use of information material for patients by the NHS CRD has been described by Entwistle et al.<sup>21</sup> Patients' versions "aim to present people facing a decision about their health care with relevant research – based information in an accessible form". Those wanting more detailed information are encouraged to ask for copies of the health professionals' version, talk with health professionals or in some instances to contact consumer health information services. Leaflets were produced with the intention that they would be deliberately given to people by health professionals involved in their care. This had potential advantages of patients having someone to discuss their concerns with, and health professionals would be less likely to feel threatened. A disadvantage is that patient access to health information is controlled by health professionals.

Consumer – focused information from HTA agencies varies considerably in scope from one-paragraph summaries to quite lengthy reports. Resources required, impact of such

publications on assessment staff and accessibility to the consumer are all important considerations.

Preparation of longer documents for consumers will be demanding and effort spent on these will need to be balanced by consideration of likely impact. An easier option, with possibly more immediate influence, is to develop consumer publications from executive summaries in HTA reports, paying attention to use of appropriate language and inclusion of explanations of technical terms.

Whatever the approach taken, points to consider will include:

- Authorship: medical writers; external experts; HTA authors
- Language: literacy level; style
- Determining content: writer + authors of report; steering groups; consumer groups
- Format: e.g. Text with headings; Questions and Answers
- Review of material: HTA authors; HTA management; consumers; external experts
- Timing: release with HTA report; after distribution of HTA report
- Length and graphic design
- Method and scope of distribution

### ***Involving consumers in dissemination***

The Cochrane Collaboration has found it useful if consumers with an editorial role have a constituency with whom they can communicate; this may be easier to identify if the CRG has established relationship with existing consumer organization. Advantages are the ability of such organizations to access a wide range of individuals with experience in the condition being investigated and for those individuals to have access to the rest of the Cochrane collaboration.<sup>5</sup>

Woolf and Henshall note that in Britain public participation in implementation of HTA findings has not been straightforward.<sup>22</sup> There are technical problems in presenting information in a format that is understandable by readers as well as being factual and balanced. It is unclear whether all British patients want this information or if they desire a more active role in decision making. Public attitudes to HTA are often unfavourable when assessment leads to a denial of access to health services.

## POINTS FOR CONSIDERATION IN DEVELOPING CONSUMER PARTICIPATION IN HTA

Several general points have been suggested for consideration by the INAHTA agencies. Those that seem immediately applicable to AHFMR are as follows.

- Are there guiding principles for patient participation in HTA that might be helpful?

*Transparency and accessibility of HTA procedures and products should continue to be furthered by the HTA Unit. The Unit should keep in touch with discussion and outputs of the INAHTA and HTAi groups.*

- Why get involved with consumer participation:
  - a - political or administrative directives?
  - b - pressure from patient groups, lobbyists?
  - c - to support basic rights of consumers?
  - d - to generate a warm inner glow?
  - e - consumer perspectives and input can improve HTA products?
  - f - consumer involvement can increase the influence of HTA and improve health care decisions?
  - g - consumer involvement can give wider publicity to HTA organizations?

*Several of these may well be applicable to AHFMR. It is suggested that items e and f may be particularly appropriate as a focus. Improvement of the HTA products and their influence is a more positive rationale than "pressure driven" incentives.*

- What is the audience/ clientele for consumer - related HTA activities?

*There has been a clear consumer focus with some HTAU products that relate to specific patient groups. This is an area that deserves further consideration, having regard to consumer needs in the province.*

- How are consumers to be differentiated and/or targeted?

*Experience within the AHFMR program suggests some possibilities for Alberta; practicalities would need to be thought through.*

- Should there be consumer involvement in all assessments? If not, what types of assessment should be excluded?

*Some types of consumer involvement would be hard to contemplate for the urgent, short term HTA products that form a significant part of the HTAU work program. Involvement in longer term projects would be more realistic, subject to consumer availability and ability to inform the HTA process.*

- Where do requests for assessments come from? Should consumer groups form part of this process?

*Most of the requests to the HTAU come from the health ministry or regional health authorities. However, the Unit has always accepted approaches from other bodies, or individuals, so that suggestions for assessments by consumers could be considered. Involving consumers in requests from government organizations is a topic that would need further debate, though their input in informing and refining HTA questions would be an option for longer projects.*

- If a consumer makes a request to an HTA program, what options are available for a response?

*The HTAU has had a long experience in handling consumer requests, which have in the main been for general information on particular technologies. Responses are provided to all requests; in some cases these responses have been as short reports. Follow up of a request by an HTA is an option and was undertaken, for example, in response to an approach from the Alberta Consumers' Association.*

- To what extent should consumer input modify the scope and approach of an assessment?

*This difficult issue would require further discussion; the topic, questions asked and availability of pertinent information would all be important considerations.*

- How will consumers be identified, briefed, trained when timelines are short?

*For some HTAU projects, it may be too difficult to meet such requirements. Development of training packages might be an option, but resources would be needed.*

- If consumers are to be involved, can the proposed method of involvement be sustainable?

*An important issue for AHFMR. If further consumer involvement is to be pursued, then any mechanisms that were introduced would need to be realistic as routine components of the HTA program.*

- Should agencies further develop links with consumer and other organizations as a step towards greater patient participation?

*This is an area that AHFMR might consider, building on existing contacts and other potential consumer sources from within the province.*

- How is anecdotal input matched to approaches such as systematic reviews?

*A complex issue that will need detailed consideration. Liaison with the INAHTA and HTAi groups may be helpful in developing perceptions and approaches.*

- What weight is given to consumer input on HTA analysis, synthesis?

*Again, a complex issue. Likely to vary with the nature of the HTA topic and the question that is being addressed. But consumer input, when it is available, should be clearly stated and addressed in HTA reports.*

- How might the effectiveness of consumer involvement on HTA be described and measured?

*This will be an important issue if consumer involvement is increased. There will be a need for reassurance that such involvement is producing benefits that match the resources committed both by the HTA program and by consumers. Information would be needed to inform possible ways to improve efficiency or to address any difficulties. As a start, HTAU project leaders might prepare concise summaries of any consumer involvement in the preparation of various HTA products and to what extent the assessments had benefited from such input.*

Some summary points on HTAU involvement with consumers is provided in the following table, which identifies past experience, difficulties associated with wider involvement and possible ways forward.

### AHFMR experience and potential in involving consumers in HTA

| HTAU experience  | Difficulties in involving consumers  | Possible future directions   |
|--|--|--|
| <b>Formulation of HTA questions</b>  |  |  |
| Consumers have been consulted in development of some HTA projects. Has depended on the topic and scope of the assessment.  | Time constraints -many of the Unit's projects are carried out in response to urgent requests.  | For longer projects, seek consumer input in developing specification. Perhaps seek comment on proposed approaches etc.<br><br>Consider broadening scope of literature searches to cover publications on consumer perspectives. |
| <b>Preparation of assessments</b>  |  |  |
| <i>Analysis and drafting:</i><br>Little involvement to data; occasional information input on selected topics   | As suggested by the review material, there would be formidable difficulties for most HTAU projects; issues include identification of suitable individuals, training and integration with other assessment input and timing. Also, might be a difficult process to sustain. | Consider usefulness and feasibility for selected topics.<br><br>At start of assessment identify groups that might assist (e.g. patient groups, Consumers' Association).  |
| <i>Review of draft HTA products:</i><br>Little input to date. Occasional feedback on specific topics.  | Potential for delay in the review process, identification of well – informed reviewers.  | As above, identify potential consumer reviewers near the start of the project.   |
| <b>Dissemination</b>   |  |  |
| <i>Summaries for consumers:</i> The Unit routinely prepares one page summaries of its HTA reports.<br><br>Further information on assessments is provided through the newsletter. | More elaborate approaches would need further resources (financial and personnel). historically, little scope for additional activities given the size of the program.  | Further develop approaches using links with other areas of AHFMR.  |
| <i>Consumer involvement:</i> Has occurred with some HTA reports, for example through   | Possible difficulty in identifying organizations and individuals that are able and willing to assist effective dissemination.  | More active search and follow up during and after preparation of reports and summary material.   |

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## CONCLUSIONS

In principle, the involvement of consumers in HTA can provide benefits through improving quality and relevance of assessments and the dissemination of their findings. Consumers are clearly key stakeholders in any debate over health care technologies. Their input and awareness of HTA approaches and findings are important. However, there are various practical difficulties for HTA programs in achieving increased consumer participation. Demands on consumers themselves, resource considerations and influence on the timeliness of HTA advice are examples of areas where there may be no easy solutions.

The HTA program at AHFMR may have opportunities to increase the level of consumer participation in its activities. Realizing these may not be easy, given resources available to the HTA Unit, the nature of its workload and the availability and expertise of potential consumer representatives.

It will be valuable for the HTAU to keep closely in touch with the initiatives that are now being pursued by INAHTA and the HTAi interest group and to contribute to their discussions. Also, practical approaches to further consumer involvement in Alberta HTA should be kept under consideration and put in place as circumstances permit.

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