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An International Survey of the Public Engagement Practices of Health Technology Assessment Organizations

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ABSTRACT

Objectives: Many jurisdictions are moving toward greater public involvement in health technology assessment (HTA) processes. This study aims to provide a broad, cross-sectional indication of the extent and methods of public engagement in HTA, with a focus on which public are engaged, by what mechanisms, and the purpose of public engagement. **Methods:** An international Web-based survey of 217 organizations involved in HTA was undertaken. Contact e-mail addresses for targeted organizations were identified from the Internet. **Results:** Individuals from 39 (18%) of the contacted organizations completed a survey. The majority (67%) of responding HTA organizations undertake public engagement activities, predominantly involving lay representatives of organized groups (81%), and to a lesser extent individual patients/consumers (54%) or citizens/community members (54%). For organizations undertaking public engagement, mechanisms based on communication or consultation were the most common, although some organizations have used or intend to use participatory approaches, particularly the Citizens' Jury (8%) or Consensus Council (20%) methods. Respondents identified with a number of rationales and barriers for undertaking public engagement. **Conclusions:** This survey provides further insight into the public engagement approaches that are used by HTA organizations in practice. In particular, it suggests a limited adoption of participatory methods to date, and interest in the use of social media. Study findings require further confirmation, due to limitations related to survey response. There is considerable opportunity for further research into pragmatic, robust, and meaningful approaches to public engagement to strengthen HTA policy and decision-making frameworks. An agenda for future research evolving from the survey responses is proposed.

Keywords: decision making, health policy, health technology assessment, public engagement.

Introduction

In an evolving era of patient-centered health care, many jurisdictions are moving toward greater patient and public involvement in health technology assessment (HTA) processes and decision making [1,2]. The involvement of patients and the public in HTA can provide a unique perspective, balancing the views of health care professionals, service providers, and industry [3,4], promote transparency and fair decision making [5], and legitimize the HTA process [4,6]. HTA processes and decision making have a direct impact on the choice of interventions and services that are funded through scarce public health care resources and are therefore available to be accessed by current or future patients. HTA is fraught with challenging and sometimes conflicting social values and ethical factors to be considered alongside technical information and expertise to inform decision making [7], and the decisions made as a result of HTA processes frequently apply across a wide population.

This article reports the findings from an international Web-based survey of organizations involved in HTA, with the aim of exploring the extent and methods of public engagement in HTA processes and decision making. The article starts by briefly reviewing the literature on public engagement in the HTA setting. The survey methods and scope are then described. The survey results are presented, and the implications for HTA organizations that may be developing public engagement processes or considering doing so are discussed, along with some potential limitations of the study and recommended future research directions.

What Do We Currently Know of Public Engagement Experiences in the HTA Setting?

A number of frameworks for public engagement in HTA have been proposed [2,8–15]. Some have concentrated largely on the involvement of patients [10,11] or consumers [2,14], but others have focused on involving the general public [9,11–13], of which patients or consumers may be a subset. Aspects of public engagement including who to involve, how to engage them, and for what purpose have been identified as relevant considerations by several

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Conflicts of Interest: The author is not aware of any conflict of interest related to this research study.

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researchers [9,11]. Our knowledge of the application of these frameworks or the extent of public involvement in HTA in practice, however, is limited. A recent systematic review of the scientific literature confirmed that there are few published examples of experiences involving patients and the public in HTA [16]. Nevertheless, available studies do suggest an increasing interest in involving the public in HTA processes and decision making, particularly in the United Kingdom and Canada [16–18]. In an early pilot study undertaken in 2001, Oliver et al. [17] found that consumers were willing and able to play an active role in HTA priority-setting processes, concluding that consumers made a unique contribution to the HTA program (UK). The UK National Institute for Health and Clinical Excellence has developed extensive policy and processes around patient and public involvement in HTA and has established a Citizens' Council. The National Institute for Health and Clinical Excellence's Citizens' Council was arguably an innovative approach in the HTA setting at the time of its inception in 2002 [19] and has been sustained over nearly a decade to guide social value judgments in decision making [20]. More recently, there have been several published reports originating from Canada of the use of a Citizens' Council or Citizens' Jury approach to engage the public to develop priority-setting criteria [18] or explore the "reasonableness" of waiting for more evidence before funding innovative health technologies [21]. Distinct from the general public, patients with experience of a condition can potentially provide useful insights into the lived experience for specific technologies under assessment [4,22].

A Survey of International Practice

While there is some limited information available on public engagement practices around HTA in the peer-reviewed literature, anecdotal observations and the recent review by Gagnon et al. [16] suggest that organizational practices often occur in policy environments and do not necessarily infiltrate the peer-reviewed literature, remaining diverse and difficult to synthesize. A previous survey of the International Network of Agencies for Health Technology Assessment (INAHTA) member organizations around the involvement of consumers in HTA was undertaken in 2005 [23] and updated in November 2010 [24]. Findings suggest that approximately half of the organizations responding involve consumers in some aspect of their programs, with little change from 2005 to 2010. A recent summary of the peer-reviewed and gray literature and Web sites of selected organizations by Menon and Stafinski [22] explored the potential roles for patients and the public in HTA and coverage decision making, concluding that many of the HTA agencies in developed countries have established mechanisms for seeking input from patients or the public. While this survey and the review explore the extent of public engagement [23,24] and approach to public engagement by selected organizations [22], less is known about the public engagement methods used across a broad range of organizations.

This article reports the findings from an online international cross-sectional survey of organizations involved with HTA processes or decision making. Specifically, the survey aims to provide further insights into three important considerations for public engagement in HTA processes or decision making [9]: which public are engaged, why they are engaged, and what mechanisms are used for engagement?

Methods

Ethical clearance was provided by the Griffith University Human Research Ethics Committee. The online survey was undertaken between September and November 2010. Organizations, groups, agencies, or committees (herein the term "organization" is used to represent all these categories) involved in HTA processes or decision making were identified from the Web by using a search (September 2010) of membership lists, or in the case of ISPOR the Directory of HTA Organizations, available at the Web sites of the following umbrella organizations:

- INAHTA http://www.inahta.org/
- European Network for Health Technology Assessment (EuNetHTA) http://www.eunethta.eu/Public/Home/
- International Society for Pharmacoeconomics and Outcomes Research (ISPOR) http://www.ispor.org/
- International Information Network on New and Emerging Technologies (Euroscan) http://www.euroscan.org.uk/

To ensure a comprehensive coverage of HTA organizations, an additional manual search was undertaken via Google to identify contacts at further organizations indicated from the literature to undertake HTA processes or decision making but not included in the above Web sites [25–29]. A total of 264 e-mail contact addresses were retrieved for a named contact where available, otherwise a generic e-mail for the organization. Where more than one e-mail address was available, all were retained to maximize potential response. Two individuals contacted the research team after the mailing of the original survey invite and requested an additional survey invite. Therefore, a total of 266 e-mail invites were sent to e-mail addresses across 217 HTA organizations. The e-mail invite briefly introduced the purpose of the survey, provided a link for the completion of the survey, and asked that the recipient forward the invite on to the most appropriate person to complete the survey in his or her organization, if this was not he or she. Two e-mail reminders were sent to e-mail addresses that had not yet responded at fortnightly intervals.

The survey was pilot tested in a group of university researchers with expertise in HTA prior to the main data collection. The survey commenced by providing an information sheet, and some background questions on the scope of the HTA organization including a request to indicate whether the HTA organization undertakes any form of public engagement activity. This was followed by the main body of the survey, which consisted of a number of questions around which public are engaged, what mechanisms are used for engagement, the rationale for engaging the public, an indication of whether the public engagement activities have been evaluated, and challenges that had been faced when engaging the public. Finally, respondents were given the opportunity to provide feedback on the survey. A copy of the survey instrument is provided in Appendix A in Supplemental Materials found at doi: 10.1016/j.jval.2012.09.011.

The survey adopted Mitton et al's definition of "public" [30] and Rowe and Frewer's typology of public engagement mechanisms [31]. Respondents were told that for the purpose of this survey, "public" includes ordinary or lay citizens who are members of the general public, members of social interest groups (but not as health professionals), patients, or consumers [30] and "engagement" includes any process or attempt to support communication, consultation, or participation with/by the public [31]. Furthermore, respondents were provided with definitions for "communication" (a one-way transfer of information, from the HTA organization to the public), "consultation" (the provision of information from the public to the HTA organization, but without formal interaction or discussion), and "participation" (negotiation and/or discussion with the public) [31].

Questions included in the survey instrument were selected to ensure coverage of the study objectives and were informed by the existing literature [9,30–32]. The majority of questions were closed-ended (including individual and tabled multiple-choice