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What factors determine the choice of public engagement undertaken by health technology assessment decision-making organizations?

Wortley, S., J. Street, W. Lipworth, K. Howard, H. Dickinson and S. Robinson (2016)

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Abstract

Purpose: Public engagement in health technology assessment (HTA) is increasingly considered crucial for good decision-making. Determining the “right” type of engagement activity is key in achieving the appropriate consideration of public values. Little is known about the factors that determine how HTA organizations decide on their method of public engagement, and there are a number of possible factors that might shape these decisions. This paper seeks to understand the potential drivers of public engagement choice from an organizational perspective.

Design/Methodology/: The published HTA literature is reviewed alongside existing frameworks of public engagement in order to elucidate key factors influencing the choice of public engagement process undertaken by HTA organizations. A conceptual framework is then developed to illustrate the factors identified from the literature that appear to influence public engagement choice.

Findings: Determining the type of public engagement to be undertaken in HTA is based on multiple factors, some of which are not always explicitly acknowledged. These factors include: perceived complexity of the policymaking issue, perceived impact of the decision, transparency and opportunities for public involvement in governance, as well as time and resource constraints. The influence of these factors varies depending on the context, indicating that a one size fits all approach to public engagement may not be effective.

Originality/value: Awareness of the various factors that might influence the type of public engagement undertaken would enable decision-makers to reflect on their choices and be more accountable and transparent about their choice of engagement process in eliciting public values and preferences in a HTA organization.

Keywords: public engagement, health technology assessment, decision-making

Introduction

Health technology assessment (HTA) is a multidisciplinary process, used by policy making bodies, to analyze and summarize information about medical, social, economic and ethical issues related to the use of a health technology (Banta 2003). Increasingly, public engagement has become an important component of this process. The term 'public', once mainly confined in this context to patients and consumer advocacy groups, is now understood to include 'ordinary' or 'lay' citizens who have not necessarily had contact with the relevant health services but have a 'stake' in the decisions made by policy makers by virtue of being members of the community (Mitton et al. 2009). There are a number of organisations worldwide that conduct or commission assessments of health technologies. These organisations (referred to collectively as HTA organisations—HTAOs) usually conduct some form of public engagement to guide their decisions about health technologies or to guide the recommendations they make to policy makers by whom they have been commissioned (Hailey and Nordwall 2006). Public engagement is seen as a means to increase the legitimacy of this advice and/or decision-making and ensure that decisions made are relevant to stakeholders, transparent, and responsive to relevant social values (Facey et al. 2010; Littlejohns et al. 2012; Nilsen et al. 2006).

The phrase 'public engagement' is used broadly in this context, to encompass a range of participative techniques aimed at supporting dialogue about values between groups and/or individuals—usually between decision-makers and interested parties outside the decision-making process. It extends from basic information provision to more complex methods of participatory deliberation and collaboration such as citizens' juries, consensus conferences and planning cells (Rowe and Frewer 2005). Many frameworks have conceptualized public engagement practices in public policy processes (Arnstein 2011; Harrison and Mort 1998; Head 2007; International Association for Public Participation (IAP2) 1999; Tritter and McCallum 2006). Most describe a continuum of engagement techniques characterized by increasing citizen influence, commitment and/or participation. Ideally, public engagement is underpinned by the principle that those affected by a decision have a right to be involved in the decision-making process. Often however the actual practice of engagement is perceived as a tokenistic effort on the part of decision-makers, or as a reactive process (House of Commons Public Administration Select Committee 2013), driven by public dissatisfaction about an impending decision. It therefore tends to follow that the greater the perception of dissatisfaction or conflict, the greater the 'push' for public engagement involving greater participation.

Given that there are a range of public engagement techniques, and that they arise from a variety of motivations, it is important to be able to understand how and why they evolve as they do. However, it remains unclear why HTAOs might choose one engagement type over another. Some authors have suggested that differences can be explained by the intended purpose of the engagement and perceived effectiveness of the type of engagement in achieving this purpose (Chafe et al. 2009). Others have argued that the choice of engagement type will vary depending upon the influence of other contextual factors, such as the nature and complexity of the technology, stakeholder interests, the potential impact of the technology on the population or budget, as well as the 'public' being asked (Canadian

Institutes of Health Research (CIHR) 2012; Degeling et al. 2015; Gauvin et al. 2010b; HIQA 2014).

The question of which 'public' to include in public policymaking is a contentious issue in HTA and in health more generally (Martin 2012). In a recent review looking at public deliberation in public health and health policy research it was found that researchers use different 'publics' for different purposes (Degeling, Carter, & Rychetnik 2015). Patients, advocates or consumers, otherwise known as partisan groups, are often engaged as witnesses or experts on a specific matter whereas lay, non-partisan or disinterested citizens are more frequently asked to be involved in broader policy making decisions. This distinction between partisan and non-partisan participants is often unclear in reporting on public engagement (Martin 2012) (Degeling, Carter, & Rychetnik 2015) While some authors (Sarrami-Foroushani et al. 2014b) consider the question of 'which public' to be a factor in determining the type of engagement chosen by HTA agencies, the definition of 'publics' remains contentious. For this reason, we have chosen to use the term 'public/s' to refer to patients, consumers and advocacy groups, as well as citizens representing broader societal interests and use the terms 'targeted' and 'untargeted' (Rowe & Frewer 2005) (Sarrami-Foroushani, Travaglia, Debono, & Braithwaite 2014b) to indicate how individuals are selected for public engagement.

Framing of the research question

Our aim in conducting this review was to understand and theorize potential drivers behind the choice of public engagement type by HTAOs. We were particularly interested in understanding why, for some HTAOs, there appears to be a reluctance to undertake public engagement approaches that have been proposed by HTA stakeholder groups (Lopes et al 2015) or carried out by researchers in the field to address health technology policy questions. Recent research in this area indicates that members of the public want public engagement in decisions where uncertainties are present in the evidence, transparency is lacking and where 'value' (trade-offs between costs and benefits) is central to the HTA decision (Wortley et al 2016a).

As such the aim of this paper is not to describe how public engagement is conducted, or to determine how it should be conducted, but rather provide a framework that HTAOs might use to examine where and when they might use public engagement and what other factors they might consider, including the tensions and trade-offs inherent in their choice of method (Sarrami-Foroushani et al. 2014a). This should not only facilitate HTAO's internal decision-making process, but also enable them to be explicit about how they have reached their decisions, thereby opening dialogue, building trust and facilitating negotiation as to what modes of public engagement are desirable and possible. This may be particularly helpful for HTAOs in low or middle income countries where time and resources are lacking (Danko and Petrova 2014) yet public engagement is still desired.

Methods

The approach we used was based on interpretative hermeneutic analysis (Smith et al. 2009). This approach allows theory development through an iterative, and interpretive approach, acknowledging the lens of the researcher within the analytic process – as in this case all authors have worked in association with HTAOs and/or on projects relating to HTA decision-making.

Data are identified from a range of sources using expansive searches with constant review and reflection. While the strength of this method is in its interpretive and emergent nature, this method risks criticism based on the perceived lack of a systematic, reproducible and transparent process. We attempted to reduce this by following the methodologies described by others working in this field of theory generation, evidence synthesis and health (Pawson 2006, Finfgeld-Connett and Johnson 2013) and as outlined below.

As our perspective was from an organizational viewpoint, we used the Context-Management-Mechanism-Outcome (CIMO) Framework to refine the question (Denyer and Tranfield 2009) (Table 1).

Table 1: Question as defined by the CIMO Framework (Denyer and Tranfield 2009)

| | |
|---------------------|--|
| Context | Health Technology Assessment Organisations |
| Intervention | Public engagement |
| Mechanisms | Factors that determine choice of public engagement method - to be explored |
| Outcomes | Public engagement approaches undertaken |

Using the approach above we first identified (i) existing frameworks on public engagement. From these frameworks we undertook to identify (ii) public engagement frameworks from HTAOs or similar health organisations (iii) published literature examining factors of importance in HTA or evidence-based policy decision-making.

To identify relevant literature we searched the following databases: MEDLINE, MEDLINE In-Process & Other Non-Indexed Citations, EMBASE, Sociofile and DARE and HTA (CRD) from Jan 1999 to March 2014. The choice of time period reflects the relatively recent emergence of public engagement themes in HTA discourse (Banta and Jonsson 2009). The construction of the search strategy was an iterative and divergent process (Booth et al. 2013), informed by our analysis and interpretation consistent with a hermeneutic approach (Boell and Cecez-Kecmanovic 2014). Text words related to public engagement and participation [e.g. deliberation, patient*, public] were combined with Medical Subject Heading [MeSH] terms relating to HTA [e.g. 'evidence based medicine', 'biomedical technology assessment', etc.] and MESH terms encompassing health policy decision making. Google scholar, websites of international HTAOs, and the Health Technology Assessment International (HTAi) interest subgroup on Patient and Citizen Involvement in HTA Interest Sub-Group were also searched using a pearl-growing method (Ramer 2005) and text words from the search. Reference lists of all included studies were also searched for potentially relevant studies. Searching ceased once it was determined that no new concepts were being identified in the literature (Finfgeld-Connett and Johnson 2013).

Key concepts and findings were extracted from the relevant studies, along with author information, purpose of the article, perspective and evidence source. These data were placed in a table, with similar concepts grouped together. The data were then interpreted, discussed between two of the authors before being further reordered and revised following reflection among all authors. Table 2 outlines the key concepts and inferences made from the studies.

Table 2: Key concepts from the literature on factors appearing to influence the choice of public engagement: decision-makers' perspectives

| Frameworks of public engagement | Frameworks of public engagement in settings Health/HTAOs | Published studies reporting on factors of importance in HTA or evidence-based policy decision-making. | Proposed term for framework and implications for choice |
|--|--|---|---|
| External Factors | | | |
| <i>'Complexity of the information to be understood by participants'</i> (Robinson 2003) | Complexity of the topic <i>'dependent on the research questions, quality and quantity of evidence'</i> HIQA (2014) Complexity of the issue (CIHR 2012) Purpose of the HTA HIQA (2014) | Purpose of the decision-making (Dobrow, 2004) Characteristics of technology (Gauvin 2010) Quality and uncertainty of evidence (Guindo 2012) Clinical effectiveness (Stafinski 2011) Cost effectiveness (Stafinski 2011) | Perceived complexity of policymaking issue – higher level of participation/involvement as complexity increases (Robinson 2002, HIQA 2014, CIHR 2012) |
| <i>Inherent risk in situation (e.g. potential for social and environmental impacts'</i> (Robinson 2003) Public impact of the topic (IAP2) | Sensitivity of the topic <i>'related to public and patient interest in disease, technology, historical context and whether opinions are divided'</i> HIQA (2014) Impact or level of public interest, conflict, or controversy (CIHR 2012) | Demographic and epidemiologic characteristics of a disease/severity and burden of disease (Dobrow, 2004) (Stafinski 2011) Impact of the disease targeted by intervention (Guindo 2012) Health outcomes and type of health benefit (Guindo 2012) The interests of stakeholders involved (Gauvin 2010) Political factors. (Dobrow, 2004), (Guindo 2012) Availability of alternatives (Stafinski 2011) Cost to society (budget impact) (Stafinski 2011) Cost to patient (Guindo 2012) Patient preferences (Stafinski 2011) | Perceived impact of decisions on stakeholders – higher level of participation/involvement as impact increases (Robinson 2002, HIQA 2014, CIHR 2012) |
| Internal Factors | | | |
| | Timeframe of the HTA HIQA (2014) Internal capacity (CIHR 2012) Cost implications (CIHR 2012) | Timeliness (Stafinski 2011) | Time and resources – More time and costs available able to have higher level of participation/involvement (HIQA 2014, CIHR 2012) |
| | Need for input from specific stakeholders HIQA (2014) | Role of participants in a decision-making process (Dobrow, 2004) Process employed to arrive at a decision (Dobrow, 2004) The agency's institutional context (Gauvin 2010) (Guindo 2012) The HTA community's ideas regarding health technologies, HTA, and public involvement (Gauvin 2010) | Transparency and opportunities for public involvement in governance |

Existing frameworks used to guide choice of public engagement type

We identified two main frameworks that are used, referred to, and/or adapted by those describing and evaluating public engagement HTA. The Rowe and Frewer framework (2005) (Rowe & Frewer 2005) describes three broad types of engagement: communication, consultation, and participation. In the framework, the three types are differentiated based on the direction of flow of information between participants and the 'sponsor' (in this case, the HTAO). Subtypes of engagement methods are based on other factors, such as selection of participants, facilitation of participation and framing of responses with techniques for each subtype listed.

Several surveys and reviews have been conducted to determine the extent and type of public engagement currently practiced by HTAOs (Hailey & Nordwall 2006; Menon and Stafinski 2011b; Whitty 2013). The most recent of these (Whitty 2013) applied Rowe and Frewer's (Rowe & Frewer 2005) typology, and found engagement techniques based on communication, typically provision of information on a website, and consultation (focus groups and discussion documents) were the mainstay of HTA public engagement strategies. Consultation was undertaken in either an untargeted manner or by using a targeted/partisan selection of particular participants by HTAOs. Only a small proportion of agencies undertook participatory approaches (Whitty 2013), however there appears to be a growing interest in these methods (HIQA 2014; Menon & Stafinski 2011b; Mitton, Smith, Peacock, Evoy, & Abelson 2009) – particularly deliberative methods such as consensus panels and citizens' juries (Bombard et al. 2011; Facey, Boivin, Gracia, Hansen, Lo Scalzo, Mossman, & Single 2010; Watt et al. 2012).

Apart from the assessment framework of Rowe and Frewer (Rowe & Frewer 2005), discussed above, another frequently used and adapted framework for evaluating engagement is the 'Spectrum of Public Engagement' developed by the International Association for Public Participation (IAP2) (International Association for Public Participation (IAP2) 1999). This framework outlines the different types of engagement (inform, consult, involve, collaborate, empower) that organizations can undertake to engage stakeholders/communities. The further to the right on the Spectrum, the greater the influence the community has on decision-making. The IAP2 Spectrum presents a continuum of levels of engagement where the most appropriate engagement format is selected depending on the topic (International Association for Public Participation (IAP2) 1999). One of the limitations of the IAP2 Spectrum is the lack of guidance given to direct this selection. The selection decision, according to Hardy (2015) can be viewed as a process of negotiation between the organization and community. This may be influenced by the culture and structure of the organization, as well as internal pressures, for example time and financial costs, and issues relating to the nature and complexity of the actual topic (Canadian Institutes of Health Research (CIHR) 2012; Corporate Consultation Secretariat 2000). The IAP2 Spectrum is currently under review because of these debates in the public engagement field. Some authors (Robinson 2003) (Praxis group 2012) however have adapted the Spectrum to make explicit some of these factors in driving selection of engagement, namely the inherent risk (impact) and complexity of information which needs to be understood by the participants. This can also be applied to the field of HTA which will be discussed below.

Analysis of factors

From analysis of the data, we propose that there are four main drivers that influence the choice of public engagement process undertaken by HTAOs (Table 2). These relate to both content of the HTA itself; which we refer to as the ‘complexity’ and ‘impact’ of a topic – external to the organisation - as well as other internal factors associated with the HTAO. These internal factors include the time and resources available to the HTAO and the existent organizational culture, structure and processes of the HTAO - labelled ‘transparency and opportunity for public involvement in governance’. These latter factors are rarely made explicit in public engagement frameworks, yet are just as influential in determining when and how engagement is undertaken (Gauvin et al. 2010a).

Factors influencing the choice of public engagement type undertaken by HTAOs:

Perceived complexity of the policymaking issue

Existing public engagement frameworks suggest that as a decision becomes more complex, a different type of engagement may be sought (Canadian Institutes of Health Research (CIHR) 2012; International Association for Public Participation (IAP2) 1999; Robinson 2003). While some could argue that in an HTA the content, and the associated deliberations, are always complex, the literature appears to indicate that there is a spectrum of complexity. Where a particular HTA is seen to sit on this spectrum is often driven by factors such as the characteristics of the technology under review, the research question, and the type, quantity and quality of the evidence available (HIQA 2014). For example, medical tests (screening, diagnostic tests, co-dependent technologies) are often considered complex due to the type of evidence available, the quality of this evidence, and the subsequent assumptions that need to be made when transforming this evidence for use in an economic model assessing final health outcomes (Merlin et al. 2013). This is in contrast to a situation where a technology is already considered standard practice and/or where there is a large body of good quality evidence showing a consistent effect.

According to Plsek and Greenhalgh (2001) complexity is also intertwined with issues around uncertainty. It is uncertainty that has proven to be one of the greatest challenges for decision makers in HTA, particularly with the current pace of innovation and the rise of personalized medicine for which trials are often small and evidence of safety and efficacy often uncertain (Grutters et al. 2015). From a policy-maker’s perspective, decisions often need to be made regardless of the level of evidentiary certainty. In such situations of uncertainty, opportunities are seen to exist for other sources of evidence, such as public perspectives, values and preferences, to influence and legitimize processes (Sharma et al. 2015). For complex decisions, public engagement therefore needs to facilitate understanding - often through the consultation and/or deliberation of the uncertainties inherent in the assessment.

Perceived impact of decisions on stakeholders

Perceived impact relates to the size of the perceived effect of a decision on the community that it will impact, and is often framed in terms of the ‘sensitivity’ of a topic (HIQA 2014) to the interests of the stakeholders involved (Gauvin, Abelson, Giacomini, Eyles, & Lavis 2010b). The studies we reviewed suggest that characteristics of both the disease and the technology can determine the perceived impact of a decision (Dobrow et al. 2004; Gauvin,

Abelson, Giacomini, Eyles, & Lavis 2010b;Stafinski et al. 2011b). This includes the number of people in the intended population to be impacted by the technology, the characteristics of the population (e.g. age), the perceived benefit of the technology, the availability of other diagnostic or therapeutic options, and the cost of the technology – both to the individual and society (Dobrow, Goel, & Upshur 2004;Stafinski et al. 2011a). In a recent report from the Ontario Health Technology Advisory Committee (OHTAC), it is recommended that public engagement should be “proportional to the nature and purpose of the technology, size and demographics of the targeted patient population, and disease incidence and prevalence” (OHTAC Public Engagement Subcommittee 2015, p.15) i.e that more participative approaches are needed for high impact topics.

High impact topics are those most likely to require trade-offs and/or about which stakeholders have strongly held beliefs. Population screening is one example of a high impact HTA (Dobrow, Goel, & Upshur 2004;HIQA 2014): potentially large numbers of individuals are involved and there is complex trade-off of costs, risks and benefits (Rychetnik et al. 2013). Some pharmaceuticals also exhibit these characteristics; trastuzumab for recurrent/ metastatic breast cancer, ivacaftor for cystic fibrosis (O’Sullivan, 2013) and ipilimumab for advanced melanoma (PBAC 2012) have all demonstrated efficacy and potential for substantial health gain but are high cost. In such circumstances the literature suggests that deliberative or participatory approaches are most appropriate to allow the public’s perspectives, values and concerns to be fully explored and understood when topics are sensitive (Watt, Hiller, Braunack-Mayer, Moss, Buchan, Wale, Riitano, Hodgetts, Street, & Elshaug 2012;Whitty et al. 2014) thereby reducing potential conflict around a decision (Rychetnik, Carter, Abelson, Thornton, Barratt, Entwistle, Mackenzie, Salkeld, & Glasziou 2013).

Transparency and opportunities for public involvement in governance

This factor relates to the environment in which a decision is made, and captures the organizational culture, processes (transparency) and structure of the HTAO. For many HTAOs, fulfillment of the opportunity for governance involves simply giving a public representative –typically a consumer advocate - a ‘seat’ or voice at the decision making table. Both Whitty (2013) and Menon & Stafinski (2011a) found that individual citizens were more likely than patients or consumer representatives to be included in development of HTA processes (for example the Citizens Council at National Institute of Health and Care Excellence - NICE). The reverse was true for processes around specific technology decisions where patients or partisan groups were consulted and engaged more frequently. It has been suggested that this may be because partisan groups can provide an efficient and publicly visible route to consider issues (Kahane et al. 2013). Many countries have undertaken significant training and education activities to support and strengthen patient and patient advocate involvement in HTAs (Consumers Health Forum 2013;EUPATI 2014;pan-Canadian Oncology Drug Review (pCODR) 2013;Patient Access to Cancer care Excellence (PACE) 2014). These internal processes often also serve as promoters of transparency and demonstrate commitment to other values required for effective public engagement (HTAi 2014). Other studies have also noted the importance of the role of stakeholders in internal organizational processes (Martin 2008), based on the idea that stronger internal processes will enable individuals’ greater influence in decision-making (International Association for Public Participation (IAP2) 1999) (Gauvin et al. 2014). Clark and Weale (2012) also acknowledge the importance of these types of process values in health care decision-making. However rather than enabling influence, Clarke and Weale (2012) see participation and transparency as a

way of promoting greater trust and confidence in the system and ultimately legitimacy in the decision

Time and resources (financial and knowledge)

Time constraints are often not explicitly acknowledged as a factor in choice of method of public engagement, but this is often implicitly understood (Gauvin, Abelson, & Lavis 2014) (Irvin and Stansbury 2004). Indeed, some recent publications acknowledge the impact of the time on public engagement choice (e.g. OHTAC Public Engagement Subcommittee 2015). A common criticism of the HTA process is the time it takes to produce reports and to make policy decisions (Drummond et al. 2008;McGregor 2006). It has been estimated that two to three weeks (HIQA 2014) need to be added to completion time each time a decision making committee meets. Public engagement is seen to substantially increase the time required (Ford et al. 2012) and many view public participation in the HTA process as a trade-off between engagement and timeliness (Stafinski, Menon, McCabe, & Philippon 2011b).

Public engagement also involves a financial cost to the HTAO. There is little in the literature on this aspect of public engagement (Burns et al. 2014;Pizzo et al. 2015), but it is highly likely that cost would be a factor in decision-making about methods of public engagement. This is reflected in the fact that deliberative methods such as citizens' juries, which involve substantial costs, (Watt, et al 2012) are often reserved for complex or substantive issues (Abelson et al. 2003b). The Agency for Healthcare Research and Quality's (AHRQ) Effective Health Care Program (EHCP) (Carman KL et al. 2013a), for example, recently undertook a randomized controlled trial where the decisions of four groups using deliberative methods (Brief Citizens' Deliberation, community deliberation, Online Deliberative Polling®, Citizens' Panel) were compared to those of a control group. As well as reporting effectiveness outcomes, the costs of directly holding each deliberative method was reported. Costs ranged from US\$45,000-\$82,800 depending on the number of engagement groups and methods. Similar findings were reported in an Australian study which reported costs for deliberative strategies between AUD\$90 500-\$93 040 (Watt, et al 2012). While these costs are dwarfed by the public money that potentially will be expended on a new technology it doesn't mean that the HTAO has adequate resources to commit to pursue these activities.

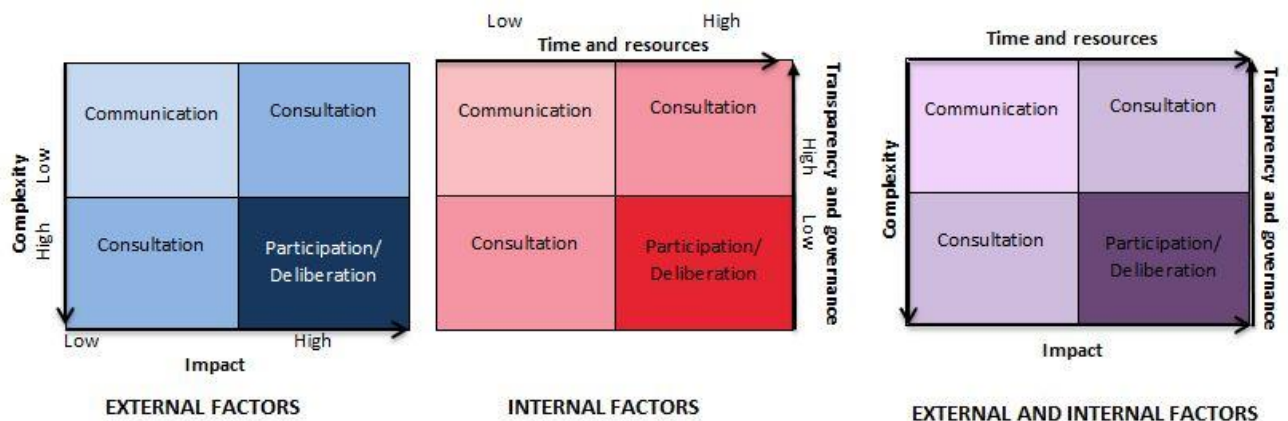
Most HTAOs also undertake public engagement activities themselves, rather than engaging expert external groups (Whitty 2013). The type of engagement will therefore be dictated by skills, knowledge and preferences of the HTAO (House of Commons Public Administration Select Committee 2013). For example, a HTAO may be more likely to use focus groups rather than a quantitative preference assessment method, such as a discrete choice experiment, simply because of familiarity with the methodology. Such a situation is suggested in the study by Whitty (2013) which indicated that use of online consultation documents is by far the most prevalent approach to public engagement undertaken by HTAOs.

Development of a framework

Using the previously described literature on theoretical frameworks of public engagement (International Association for Public Participation (IAP2) 1999; Robinson 2003;Rowe & Frewer 2005) and the four factors that we have identified that appear to influence the choice of approaches public engagement , we developed a framework to conceptualize potential reasons for the extent and type of public engagement currently undertaken by

HTAOs. The framework applies Rowe and Frewer’s broad engagement types (Rowe & Frewer 2005) (Figure 1). It also borrows the matrix concept developed by Robinson (2003), based on the IAP2 Spectrum (International Association for Public Participation (IAP2) 1999), that acknowledges the external factors of complexity and impact and adds the internal factors:- transparency and opportunities for involvement in governance in the HTA process and time and resource constraints of the HTAO. The framework suggests that each of these factors exists along a spectrum or continuum and varies depending on the question.

Figure 1: Simplified process showing the development of the conceptual framework of factors influencing public engagement choice



Application of the framework

The upper quadrants of the framework identify the types of public engagement that might be most appropriate for technologies where the complexity of the decision is relatively low, and where there are already good opportunities for the public to be involved in the HTA decision-making process. Engagement options in these situations vary from information provision to targeted consultation depending upon the time and resources available to the HTAO and the likely impact of the decision. The lower quadrants indicate the types of public engagement that might be appropriate for more complex assessments or ones where there are limited opportunities for public involvement in the HTA process. Similar to the upper quadrants, decisions about public engagement methods would also vary from left to right depending upon time and resources and the perceived impact of the decision. An example of an HTA in the lower quadrants is the 2009 assessment of colorectal cancer screening tests by the Ontario Health Technology Advisory Committee (OHTAC) (Medical Advisory Secretariat 2009). As previously mentioned, screening is often considered to be complex and of high impact. A public representative was not part of the OHTAC and so the Committee drew upon both an evidence report (Ontario Health Technology Advisory Committee 2009) and the views expressed by the Citizens Reference Panel of Health Technologies.

In many circumstances the key factors will cross opposing quadrants. A likely scenario is where there is a more complex HTA (due to uncertainties in the evidence) with potential for high impact, the HTAO has limited time and resources but the HTAO has put in place some opportunities for engagement at the governance level. In these circumstances the HTAO must make a trade-off between the factors. A recent example of such a scenario is that of

ipilimumab, reviewed by the Pharmaceutical Benefits Advisory Committee (PBAC) in Australia (PBAC 2012). This was a highly complex HTA of high impact, but subject to tight deadlines. Opportunities for involvement in governance were available (consumer representative on committee) as well as targeted consultation (solicited patient stories). However in Australia timeliness has often taken precedence over extended public consultation (Department of Health and Ageing 2009). In such circumstances, the HTAO takes a risk: that the final decision does not cause public dissatisfaction and erosion of confidence and trust in the process leading to the public engaging with the media (Street et al. 2011) in the hope of reopening the dialogue with the HTAO (Peoplepledge 2011) and policy makers.

Discussion

At the moment judgments regarding whom and when to engage, and the method of engagement are dictated by the particular health care organization. There is very little research published identifying the factors that influence HTAOs choice of engagement method, so it is difficult for agencies to place their decisions in a broader context or learn from others. In particular, there is little information on which HTAOs can draw with respect to the ways in which internal pressures such as time and resources or their own organizational culture may influence their choice of public engagement process. According to some authors, public engagement in health care suffers from limited conceptualization and a lack of evidence on the most effective method to engage the public (Christiaens et al. 2013; Litva et al. 2002) (Haywood et al. 2014). However these issues are currently receiving greater attention (OHTAC Public Engagement Subcommittee 2015) with some significant efforts to integrate evaluation into public engagement in HTA decision-making (Dipankui et al. 2015) and reflect on potential barriers and enablers.

HTAOs will also need to demonstrate a genuine commitment to public engagement. Engagement that is perceived to be token, and/or undertaken to give legitimacy to a decision already made, can erode trust in the process. There are some reports that trust in the health care system has been slowly declining (Gille, Smith and Mayes, 2014). With the increasing focus on developing patient centered care, improvements have been observed in attitudes towards engagement (Forsyth et al 2016)- however this needs to be embedded within organizational structures that promote transparency and inclusiveness. HTAOs should also take note of studies that are focused on asking what the public want in relation to engagement (Wortley et al 2015) to inform discussions as to whether and how engagement should take place within an HTAO.

Our framework does not suggest a hierarchy of effectiveness of engagement methods; indeed research on the comparative effectiveness of the different types of engagement and the use in different 'publics is lacking. (Mitton, Smith, Peacock, Evoy, & Abelson 2009; OMara-Eves et al. 2013). A Cochrane review of consumer involvement in healthcare policy (Nilsen, Myrhaug, Johansen, Oliver, & Oxman 2006) identified one trial where two deliberative techniques were compared to a consultative approach (Abelson et al. 2003a). No definitive conclusions could be reached due to methodological limitations (Nilsen, Myrhaug, Johansen, Oliver, & Oxman 2006). The randomized trial conducted by the AHRQ EHCP cited earlier (Carman KL et al. 2013b) found each deliberative method was effective in increasing knowledge; however community deliberation and citizens' panel techniques may be more appropriate for more complex topics. Other similar research projects are ongoing

(Gagnon et al. 2012) and our understanding of strengths and weaknesses of different public engagement approaches is likely to improve with the increasing interest in patient centered policymaking and practice (Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI 2012)). This also applies to our understanding of the use of multiple publics (Martin 2012).

It is increasingly recognized that traditional methods of public engagement may become increasingly ineffective as HTAs become more complex and publics simultaneously become more informed and demand more representation (Abelson, Forest, Eyles, Smith, Martin, & Gauvin 2003b; Street et al. 2008). There has, for example, been growing interest in recent years in applying novel quantitative methods to incorporating the values of patients and the community in HTA decision-making. This includes models of value based pricing (Garner 2010; Linley and Hughes 2012) as well as the use of multi-criteria decision making (MCDA) and discrete choice experiments (Adunlin et al. 2014; Danner et al. 2011). Such approaches, if implemented in HTA, could see public engagement focused on developing relative weights for criteria around the complexity and impact of an HTA (Linley & Hughes 2013). This could potentially lead to more transparent and systematic public engagement processes (Dowie et al. 2015; Tony et al. 2011). It could also capture many of the benefits of directly incorporating preferences and social values into decision-making whilst avoiding the time delay and cost associated with undertaking additional public engagement.

Given these complexities, it will be crucial to determine what factors are important to the relevant 'publics' in determining the type of engagement undertaken by HTAOs. It may be that in some circumstances the public are happy not to be involved in decision making (Litva, Coast, Donovan, Eyles, Shepherd, Tacchi, Abelson, & Morgan 2002; Lomas 1997) or that they have an unexpected preference regarding the most appropriate mode of engagement. Few published studies are available on this topic (Wortley et al 2016b). While this paper touches on some of these issues - it is from an organizational perspective and relies on interpretive analysis. Further studies, analysis and evaluation are needed in this area to determine public preferences around engagement as well as the features that facilitate public engagement in decision-making (Emery et al 2105). Having this information will assist us in choosing engagement methods, improving transparency and thereby effectively integrating social values into the HTA decision-making process.

Conclusions

There is no universal or ideal approach to public engagement into HTA processes. While multiple methods exist, HTAOs have tended to focus on a limited range of approaches. Four main drivers appear to guide the choice of engagement type used by contemporary HTAOs. The dictates of these factors are rarely explicitly acknowledged by HTAOs. Rather, engagement is simply framed as an imperative with little consideration given to whether engagement is desired by the public, which publics should be included, whether the chosen approach is appropriate to achieve the intended outcome, or how engagement should be tailored for particular technologies. This is an unsatisfactory state of affairs, and there is a need for greater understanding of what methods 'work' best in particular situations, development of new methods of engagement to account for increasing complexity, and greater understanding of how the various 'publics' themselves want to participate in HTA.

Competing Interests

The authors declare they have no competing interests

Author contributions

SW drafted the manuscript and undertook the data analysis. KH, JS, WL reviewed and edited the paper and KH formally supervised the process and provided input throughout the stages. All authors read and approved the final manuscript.

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