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Jackie Street, Tania Stafinski, Edilene Lopes and Devidas Menon

Defining the role of the public in Health Technology Assessment (HTA) and HTA-informed decision-making processes

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**DEFINING THE ROLE OF THE PUBLIC IN HEALTH TECHNOLOGY
ASSESSMENT (HTA) AND HTA-INFORMED DECISION-MAKING PROCESSES**

Running Title: Defining the public in HTA

Authors

Jackie Street, PhD, BSc., Grad.Dip.PHC, Australian Centre for Health Engagement, Evidence and Values (ACHEEV), University of Wollongong

Tania Stafinski, PhD, Director, HTPU, Health Policy and Management, School of Public Health, University of Alberta,

Edilene Lopes, B.Comm, Grad.Dip.Sc.Comm, MPhil. School of Public Health, University of Adelaide

Devidas Menon, MHSA, PhD, BSc, Health Policy and Management, School of Public Health, University of Alberta,

Corresponding author: Dr Jackie Street, Australian Centre for Health Engagement, Evidence and Values (ACHEEV), School of Health and Society, Bld 15 142, University of Wollongong, Wollongong, NSW, 2522, Australia.

Tel: +61 242528269

Email: streetj@uow.edu.au

Abstract:

Objectives: The terminology used to describe community participation in health technology assessment is contested and frequently confusing. The terms patients, consumers, public, lay members, customers, users, citizens and others have been variously used, sometimes interchangeably. Clarity in the use of terms and goals for including the different groups is needed to mitigate existing inconsistencies in the application of patient and public involvement (PPI) across HTA processes around the world.

Methods: We drew from a range of literature sources in order to conceptualize i) an operational definition for the 'public' and other stakeholders in the context of HTA and ii) possible goals for their involvement. Draft definitions were tested and refined in an iterative consensus-building process with stakeholders from around the world.

Results: The goals, terminology, interests and roles for PPI in HTA processes were clarified. The research provides rationales for why the role of the public should be distinguished from that of patients, their families and caregivers. A definition for the public in the context of HTA was developed: A community member who holds the public interest and has no commercial, personal or professional interest in the HTA process

Conclusions: There are two distinct aspects to the interests held by the public which should be explicitly included in the HTA process: the first lies in ensuring democratic accountability and the second in recognising the importance of including public values in decision-making.

Keywords: Health technology assessment; methodology; community participation; patient participation

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Introduction

It has been 50 years since Arnstein published her seminal paper, “A ladder of citizen participation” (1). It aimed to distinguish between *citizen control* and empowerment and *citizen consultation* and levels of ‘tokenism’. Some forty years later, Tritter and McCallum (2) published a critique of Arnstein’s model, suggesting that her emphasis on power undermined the potential of involvement processes. Tritter and McCallum explored the involvement of users of healthcare in healthcare decision-making, focusing on aspects of effective involvement that Arnstein’s model did not consider (Arnstein’s “missing rungs” (2, p.161)).

From ‘citizens’ to ‘users’, Tritter and McCallum’s paper reflected a neoliberal shift in citizen involvement to that of “future service users” and “potential patients” (2, p.160). The shift emerged from the notion that markets could improve health service provision by “giving [patients] purchasing power - i.e. making them *customers* of primary care services” (emphasis in the original text) (3, p.95). The term ‘user’ employed by Tritter and McCallum (2) is consistent with ‘consumer’, the term preferred in Australian government circles.

Debate over terminology continued. Coulter suggested that it was “easy to stumble into semantic minefields when writing about patient engagement” (4, p.8), and rejected the use of alternative terms to ‘patient’. However, in many countries, the term fell out of use in a context which saw service delivery as operating within a market. The term ‘citizen’, on the other hand, suggests a reciprocal arrangement with the state in which individuals have both rights and responsibilities. It also carries notions of nationality and may be seen to exclude non-citizen residents. While the term ‘citizen’ includes patients, in recent years “public and patient” or

simply “public” involvement has mostly engaged those presenting patient and/or carer perspectives. (5)

Public and patient involvement in HTA and HTA-informed decision-making, at least initially, appears to have been undertaken with relatively little attention to the roles these groups might play. Boothe suggests that, without any clear goals, the inclusion of public members in the Canadian Drug Expert Committee was a response to demands by patients groups “and a reluctance on the part of experts in agencies responsible to involve patients directly on the committee” (6, p.639). She also documents how our iterative engagement (7), described in this paper, sparked intense reflection and debate amongst researchers, agencies and patient communities (6) with one ministry official commenting, “they’re working on trying to make a conceptual distinction between patient and public...I find that really hard to draw, except at the extreme case” (6, p.640). As of November 2019, there is no definition of ‘public’ provided in the glossary of Health Technology Assessment international (8) or HTA Glossary.net although there are definitions of patient, consumer, user, advocate and patient representative (see Table 1). In the main, the definitions describe the type of individual involved and not the interests that they represent. To date, in many cases, the distinction between ‘public’ and ‘patient’ or ‘consumer’ has failed to penetrate the working processes of HTA and HTA decision-making. A summary of public and patient involvement across countries is provided in Supplementary Table 1.

Implications for health technology assessment (HTA)

The lack of clarity in the use of these terms has resulted in their inconsistent application across HTA processes around the world. Health technology assessment (HTA) is a multidisciplinary process through which governments compare new health technologies with existing publicly

funded medicines, services and devices. It is based on a systematic evaluation of safety, effectiveness, cost-effectiveness and social, ethical and legal factors. It supports decisions on which technologies to fund and, in some cases, which ones not to fund (9, 10).

The past ten years have seen increasing demand for patient and public involvement (PPI) in HTA and HTA-informed policy decision-making (11, 12). This has stemmed from a broader move towards patient centred care in all health systems, a focus on patient empowerment and the associated collectivisation of patient voices in patient organisations and lobby groups (12). Also, a desire to address a ‘democratic deficit’ in representative democracies has emerged. Democratic deficit refers to a point at which the public becomes disaffected with governments and political matters because they are not aligned with public aspirations (13). In general, stakeholders, including clinicians, industry, HTA agencies and government departments, have responded favorably to patient involvement in HTA processes. Patient involvement supports a broad panel of objectives, including improved practice, transparency, legitimacy and comprehensiveness through the incorporation of valuable information about the ‘lived experience’ of patients and carers (12). However, concern remains that a focus on patient interests may increase pressure to publicly fund particular services, drugs and devices outside the usual funding criteria. Consideration of public interests – namely appropriate use of limited resources and preservation of a well functioning health service – can act to mitigate these concerns.

Currently, most HTA decision making processes are based on systematic reviews of safety and effectiveness and an economic evaluation that generates a cost per quality adjusted life years (QALY) and an incremental cost effectiveness ratio (ICER). If the process reflects the values held by society, the use of QALYs assumes that the public and patients highly value population

health maximisation. In most countries, however, there has been little empirical work on what the public values in terms of health technologies or what constitutes the public interest. Where this research has occurred, the public prioritised funding of technologies based on other criteria, namely, equitable distribution of resources, life-saving treatments, prevention and interventions for children (14, 15).

In Australia, the Consumer Consultative Council is designed to reflect consumer rather than public interests. The Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) processes allow and invite public input but the process primarily attracts submissions from patients, carers and patient advocacy groups (16). In 2006 the Canadian Drug Expert Committee added two public members and the Ontario Committee to Evaluate Drugs added two patient representatives but the role of both is to collect, interpret and present information from patient groups (6).

In the UK, through input from the Citizens Council, NICE has included a public perspective on broad moral and ethical issues in public health care policy sometimes at odds with economic imperatives (17). Recommendations from the Citizens Council are not directly incorporated into NICE guidance but are included in Social Value Judgement documents with which decisions are expected to align. The Citizens Council has examined trade-offs between equity and efficiency (14), and departures from the recommended ICER threshold (15). Whilst this has provided important community input into specific moral and ethical issues surrounding health funding decisions, it does not provide public input in the same way that clinician, health economist, and consumer advocate input is currently provided. In addition, it is unclear whether the general value statements are interpreted such that the final decisions would align with technology-specific recommendations if they were made directly by a public panel.

Despite involvement of patients and the public in HTA processes for more than a decade, standardized methods are underdeveloped. This has resulted in the use of the terms ‘patient’ and ‘public’ interchangeably in many HTA organisations. (5, 6). The lack of guidance around the use of terms is at odds with the traditionally rigorous standards employed in HTA to assess the safety, effectiveness and cost-effectiveness of health technologies (18, 19). It also contributes to the potential for “mismatched expectations” (5, p.96) in decision making, leaving PPI in the HTA process open to criticism. In addition, where this conflation occurs, public interests may not be explicitly included in HTA decision-making but rather they are considered in an *ad hoc* manner dependent on the inclination of those involved.

This paper clarifies the goals, terminology, interests and roles for public involvement in HTA processes and provides a rationale for why the role of the public should be distinguished from that of patients, their families and caregivers.

Methods

The term, health technology assessment was used as defined in HTAGlossary.net (accessed November 2019) an official collaboration between the peak HTA bodies including HTA international and International Network of Agencies for HTA. This definition excludes ‘decision-making’ from HTA. The decision-making step is an important point for incorporation of public values in funding decisions and therefore we included consideration of HTA-informed decision-making in this work. To conceptualize an operational definition for the ‘public’ in the context of HTA and possible goals for their involvement, we drew from i) literature reviews we had previously conducted on the use deliberative methods in HTA (See.23 & 24 in Table 2), ii) our own primary research on the inclusion of patient and public

voices in HTA (See 16-19, 21, 22,26 & 28 in Table 2), and iii) additional relevant key scholarly papers identified primarily through a literature review conducted for the doctoral thesis of author EL and with a small number of papers offered by participants in the consultation process described below (See 1-15, 20, 25 & 27 in Table 2).

We applied an iterative process with stakeholders over several years. Draft definitions were refined in consultation with academic researchers and practitioners of PPI processes in HTA, including members of the Health Technology Assessment International (HTAi) Patient and Citizen Involvement Group (PCIG) (<http://www.htai.org/interest-groups/patient-and-citizen-involvement.html>). We note that initially the distinction between patient and public was highly contentious as some argued that all stakeholders, including patients and craft groups, were members of the public. A version of the document was released for consultation to the PCIG/HTAi working groups during the period from July to September 2016. The feedback received was then used to refine the list of goals for involvement and develop a nomenclature for different types of public in the HTA process. Subsequently, the definition and goals were refined at a workshop involving individuals from different stakeholder groups at the 2017 Canadian Agency for Drugs and Technologies in Health (CADTH) Conference in Ottawa (7). A revised document was released to the PCIG, the workshop participants and the Australian public and patient engagement advocacy group, Health Technology Assessment – Australia (HTA-Aus), for a second round of consultation early in 2018. The final description was presented at the 2018 HTAi conference.

Findings

Participants in the consulted groups agreed that clearer definitions of PPI were needed. The rationale for patient involvement was seen as relatively well defined, (12) namely to reflect the patient experience of diseases and technologies used in their treatment, to ensure that patient priorities were considered and to support the inclusion of the views of those stakeholders who would be most impacted by the decisions. Clearly patients are consumers (or users) of technology but consumers may also be healthy individuals who undergo screening or use vaccines or other preventive technologies. The role of consumers in HTA is very similar to those of patients, namely to reflect the consumer experience with these technologies and to support the inclusion of consumer views in decision-making. Goals for public involvement, who constitutes the public, the nature of public interests and the lines of separation between public and patient and consumer interests were seen as much less well defined. Participants described six possible goals for public involvement in HTA.

The goals and rationale for 'public' involvement

The goals for including the public are shown in Table 3.

The rationale for these goals is as follows:

1. To improve the comprehensiveness of evidence underpinning the decision-making for individual health technologies

The public may offer important insights into the value proposition of specific public health related technologies, such as vaccines or health promotion and screening programmes. They may also help to ensure that technologies which elicit strongly held social and cultural values,

such as contraceptives or assisted reproductive technologies (20) or those being considered for disinvestment (21) are assessed as holistically as possible.

2. To increase the legitimacy of the process for the assessment of preventive technologies, thereby ensuring public uptake of the findings

The public utilise preventive technologies; vaccines are an important aspect of public health, which is threatened by concerns about their safety. Similarly, doubts about the effectiveness of some screening programs impact their uptake (22). Greater public involvement in HTA processes, with associated improved public understanding, may increase legitimacy, allay community fears and improve uptake.

3. To increase the capacity of the public to engage in their own health care

Health literacy and public understanding of the assessment of new technologies may be improved by making the process of HTA more accessible to the public and more transparent. A more 'health literate' public is a public more likely to become informed about their own health care: this is an essential plank for improving population health and building support for public health measures.

4. To improve involvement of members of the public in the democratic process

Over the past 20-30 years, there has been demand for a more devolved participatory democracy in developed nations. The drivers for this demand include increased availability of evidence to all (23), the rise of social media with national and global public discussion of policies (24),

falling trust in governments (25) and the recognised ‘weaknesses in traditional representative structures’ (26, p.22). Loss of trust in governments and representative democracy is particularly evident in younger voters. (27) Public participation in policy development and decision-making processes have high levels of support amongst younger voters and could be seen as a mechanism for overcoming some of the weaknesses in representative democracy, where voting is usually around a “limited set of choices with little depth of involvement” (26, p.22). Some governments are now including deliberative informed public involvement processes in specific cases where decision making is contentious (for example, 28).

5. To ensure that the HTA process aligns with public values and that the interests of the public are included in the HTA process

Values are intangible standards or principles which guide our choices and behavioural responses and provide meaning to our lives. These might include personal Kantian virtues such as good will and moral duty. At the societal level such virtues underpin public values of fairness, accountability and integrity. Public values are typically elicited through empirical research (e.g., citizens’ juries).

Interests embody the trade-offs we are willing to make in the execution of those values. For example, many people believe autonomy and respect for personal privacy should be underpinning values guiding government processes and decision-making. The public interest therefore lies in ensuring that the HTA processes and the subsequent decision-making reflect respect for persons. This invariably requires trade-offs with other values. For example, the high public value placed on health and wellbeing and effective health services may require some loss of a privacy and autonomy due to sharing of health data. How trade-offs should play out

in HTA processes is difficult to decide if we do not understand the range of values held by the public and the weightings the public would make in trading one against the other.

In deliberations determining public values and interests or in representation of those interests, individuals should come to the deliberation as free as possible from other interests. Although others involved in the HTA process are also members of the public, they represent specific interests, including those of patients, healthcare providers, health administrators, industry and public services. They are often appointed to committees because of their affiliation with those groups through their work, professional role and qualifications. The inclusion of members of the public, without particular financial, work or personal interests in the outcome, in these committees ensures broader representation in decision making and explicit consideration of public interests. In some cases, active inclusion of the public interest may act as a bulwark against powerful vested interests wishing to undermine the rigour, impartiality and independence of the HTA process.

6. To assist in explaining to the public the rationale for difficult decisions which deny funding for potentially life-saving or life-altering health technologies

Funding for contentious health technologies which loom large in the public imagination but fail to measure up in the assessment processes are an ongoing issue for governments (for example, see 29). In acting as independent advocates for the public interest, public panels or public members present the public interest argument for denying or approving public funding for technologies which are considered overly expensive relative to public benefit or for which evidence of benefit is equivocal. This is an extension of goals 5 and 6 in that, under these

circumstances, PPI acts as a conduit for public education and informed debate but also as a process for formal input on public interests and values.

Defining terminology for 'the public' in HTA and HTA-informed decision-making

In Table 4, we define terms which have been loosely defined and often used interchangeably in the HTA community. These terms were developed from scholarly literature and in consultation with a broad group of members of the HTAi community, but we suggest that there is no right or wrong definition. The actual term used is less important than achieving consensus from the HTA community about what the terms mean. In other areas of HTA, there is a clearly understood shared language.

In the consultation process, our original definition of *public*, drawn from the literature, was expanded to describe particular exclusions such as those individuals representing commercial industries manufacturing drugs and devices, the HTA industry and individuals who work or who have previously worked in the health care industry. In addition, we excluded individuals with personal interests from this term, including patients and carers, so as to be consistent about the inclusion of the public interest. Other definitions were also refined in response to feedback. For example, our original definition described a patient as someone 'with a diagnosed disease or disorder'. As a result of the consultation the word 'diagnosed' was dropped as being too narrow and the sentence: "An individual with the lived experience of a disease or disorder who can provide information pertinent to that disease or disorder" added in order to describe the contribution such a person might bring to the HTA process. The term 'representative' was removed and the word 'represent' used carefully since the capacity or remit for a person to 'represent' patients or the public was seen as problematic. Therefore, the word was only used

to describe individuals who were consumer or patient advocates and thus specifically asked to represent the views of others. Finally, we recommend against the use of the term ‘lay’. Although considered a neutral term by some (30), in the context of HTA decision-making, where we are making the case for public and patient expertise, it is damaging: for example, current common dictionary synonyms for the term include amateur, inexpert, unqualified and dilettante.

Discussion

Fifty years after Arnstein’s ladder of citizen participation (1) and 13 years after Tritter and McCallum’s work on user involvement (2), the conceptualisation of public involvement in public decision-making has shifted. Arnstein’s ladder reflected the paternalistic and rigid processes of the sixties and the contemporary push for more participatory processes and ‘citizen power’. Tritter and McCallum’s reformulation reflected the rise of patient-centred care, the empowered patient and advocacy for patient involvement in those decisions which affected them. By 2007, it was clearly problematic to ask patients to manage their own care while denying them any input into the very decisions which affected the range of health technologies to which they had access. The latest iteration in this debate, which we describe in this paper, is a recognition that patients and the public hold very different interests and both sets of interests should be systematically incorporated into public decision-making.

It is difficult to comment on differences between the public and patient populations in terms of their held values since there is little empirical evidence drawing this comparison. There is some evidence that even where values are shared they may be differently weighted, for example, some studies suggest that patients have a higher tolerance of risk than the public (31). However, as the findings from this article and Boothe (6) suggest, the interests of patients, patient

advocates and patient members lie primarily in advocating for specific medicines or treatments which will benefit a particular patient group whereas the interests of the public will always rest not only in ensuring equitable distribution of scarce resources amongst all patient groups but also in supporting a well-functioning society which sustains the wellbeing of all. Further, the goals of PPI described in this paper go well beyond the instrumental goals which might be met through observing changed recommendations from an advisory committee or an altered final funding decision as a result of PPI (6). This narrow understanding of the potential impact of PPI neglects the benefits of a more transparent and inclusive process particularly in democratic accountability and in maintaining and rebuilding public trust in government decision-making (6). More empirical research is needed to explore whether increased public and patient involvement increases public trust in the HTA process.

The ways in which Australia, Canada and the UK conceptualise public and patient engagement in HTA processes, described in the introduction to this paper, exemplify one way of differentiating the roles of patients/consumers and the public. This was identified by Fredriksson (5) as patient and consumer views drawing on “experiential knowledge generated from being a service user” and public views, exemplified by the UK NICE Citizens Council, as “collective perspectives generated from diversity”(5, p.97). Our work points to a different interpretation: the terms describing patient and public in HTA should not describe who the people are but rather the interests and values they are tasked to present in the HTA process or at the decision-making table.

Arising from the public involvement goals described in this paper, our work suggests that there are two distinct aspects to the interests held by the public which should be explicitly included in the HTA process. The first lies in ensuring democratic accountability in the process, namely

that it includes comprehensive, high-quality evidence, good deliberation and is free from bias from special interests. In this role, public members act as independent auditors for the process, building legitimacy and public trust for the process. The second ensures the inclusion of public values. These values would need to be delineated in diverse informed deliberative fora. The role of a deliberative public council might be to develop a generic set of values similar to the operation of the NICE Citizens Council with explicit inclusion of these values in the process. For example, individuals from the council might sit on any decision making body or be embedded in the HTA process. Alternatively, contentious decisions in HTA could be directly considered by a public council. The ways in which the public values and interests are explicitly included in HTA and the HTA-decision making process will need to be developed within each jurisdiction to reflect the particular policy context. Potentially public representation could act as a broker between the broader public and the decision making committee, assisting in dissemination of the rationale for decisions and increasing public understanding of the HTA process.

Conclusion

Including the public and patients in HTA and HTA-informed policy decisions has become an imperative in many jurisdictions using HTA as the basis for government health care provision. However, their inclusion has been compromised by the lack of clarity around goals and the roles of the public and patients. This paper provides definitions of those goals and roles drawn from the literature and shaped in a consensus building process. The definitions provided here are particular to the HTA context, but may also be useful in other areas where patients and the public are included in decision making. The next step is a broader discussion across all HTA stakeholders in order to provide an industry-wide understanding of the distinct roles and interests of patient and public members in the HTA process.

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Table 1: Definitions in common usage in HTA

	Definition provided by HTAGlossary.net *	Definition provided by Glossary for Consumers and Patients, HTAi Patient and Citizen Involvement Interest Group *
public	No definition provided	No definition provided
patient	A person, presenting with clinical signs or not, who consults a physician. See consumer	See consumer
consumer	A person who uses, is affected by, is entitled to or is compelled to use a health service. Note: In the health care field, the term <i>consumer</i> is used mainly in the United States, where there is no universal health insurance system. Elsewhere ‘patient’ is often used, but since this word should be applied only to persons who consult a physician, terms such as <i>user</i> , <i>recipient</i> and <i>client</i> are used in the Canadian health system. Syn.: patient, user, recipient, client	A person who is the ultimate user of the health care resource. A consumer may or may not have a specific health issue, condition or disease. A patient is someone with a specific health condition. All patients are consumers, but not all consumers are patients
user	See consumer and patient	No definition provided
Carer / care giver	1) A duly trained and paid person who provides a person with a disease or disability with care. 2) A person (often a family member or friend), paid or unpaid, who regularly provides a person with a disease or disability with any form of care.	A person who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.
lay	No definition provided	No definition provided
stakeholder	No definition provided	No definition provided

consumer representative	A person or organisation who/that is actively involved with others and presents the perspectives and concerns of a group of patients. Syn.: patient representative.	No definition provided
consumer advocate	No definition provided	See advocate: Advocate: Someone who speaks on behalf of themselves or another person. In health, an advocate is usually a person who speaks on behalf of a health care consumer or patient, or a group of consumers or patients. An example of an advocate is a person who is closely involved with consumers or patients or a consumer support group, and is able to voice any concerns and views of a consumer or patient group
patient representative	See consumer advocate.	See consumer advocate
Public/patient/consumer member	No definition provided	No definition provided

*Accessed November 2019

Table 2: Literature used to support the development of an operational definition for the ‘public’ in the context of HTA and possible goals for their involvement,

#	Reference	Contribution to concept development
1	Abels G. Citizen involvement in public policy-making: does it improve democratic legitimacy and accountability? The case of pTA. <i>Interdisciplinary Information Sciences</i> . 2007; 13(1):103-16.	Describes the normative claims for citizen participation. Distinguishes between the scientific assessment of new technologies and the normative evaluation of their impact. Critiques and explores the functions, goals and models of participatory technology assessment.
2	Abelson J, Giacomini M, Lehoux P, Gauvin FP. Bringing 'the public' into health technology assessment and coverage policy decisions: From principles to practice. <i>Health Policy</i> . 2007; 82(1):37-50.	Explores questions of which publics to involve and the goals of public engagement in health technology assessment. In particular distinguishes between process-oriented goals and instrumental goals for this involvement.
3	Abelson J, Wagner F, DeJean D, Boesveld S, Gauvin F-P, Bean S, Axler R, Petersen S, Baidoobonso S, Pron G, Giacomini M, Lavis J. Public and patient involvement in health technology assessment: A framework for action.	Collates the international HTA practice of patient and public involvement (PPI) in HTA agencies extracting the goals and rationales for PPI. Distinguishes between patients, the public and other stakeholders, advocates the establishment of a <i>common language</i> to support PPI and suggests the different groups should be involved at different stages in the HTA process.
4	Anderson W, Florin D, Gillam S, Mountford L. <i>Every Voice Counts: Primary Care Organisations and Public Involvement</i> . London: The Kings Fund; 2002.	A case study of the development of public involvement structures in six UK primary health care organisations and in particular the meaningful inclusion of public voices in decision-making. Includes the value and goals of public involvement and the some of the issues encountered in developing participatory processes. Critiques <i>Arnstein's Ladder</i> as a framework.
5	Barham L. Public and Patient Involvement at the UK National Institute for Health and Clinical Excellence. <i>Patient</i> . 2011;4(1):1-10.	Describes and critiques the involvement of patients and public members in NICE processes.

6	Bombard Y, Abelson J, Simeonov D, Gauvin FP. Eliciting ethical and social values in Health Technology Assessment: a participatory approach. <i>Social science & medicine</i> . 2011;73(1):135-44.	Describes a Canadian empirical deliberative process eliciting the ethical and social values which should be considered in every assessment of a technology
7	Degeling C, Carter SM, Rychetnik L. Which public and why deliberate? A scoping review of public deliberation in public health and health policy research. <i>Social science & medicine</i> . 2015;131(0):114-21.	Distinguishes between different publics, particularly citizens, consumers and advocates, their roles and the strengths that each bring to the process of public deliberation.
8	Degeling C, Rychetnik L, Street J, Thomas R, Carter S. Influencing health policy through public deliberation: Lessons learned from two decades of Citizens'/community juries. <i>Soc Sci Med</i> . 2017;179:166-71.	Discusses the ways in which the public is framed in public deliberation, critiques claims of representativeness and the value of public deliberation in policy decision making.
9	Fredriksson M, Tritter JQ. Disentangling patient and public involvement in healthcare decisions: why the difference matters. <i>Sociology of Health & Illness</i> . 2017;39(1):95-111.	Distinguishes between patients and citizens in community involvement in health care decisions and describes the slippage in the way in which the terms have been used. Highlights the interests of patients versus citizens and the different perspectives, goals and benefits each brings to decision making.
10	Gagnon MP, Desmartis M, Lepage-Savary D, Gagnon J, St-Pierre M, Rhainds M, et al. Introducing patients' and the public's perspectives to Health Technology Assessment: a systematic review of international experiences. <i>International Journal of Technology Assessment in Health Care</i> . 2011;27(1):31-42.	Systematic review of studies reporting participation of patient and public in the HTA process and the limited roles that they fulfil.
11	Gauvin F-P, Abelson J, Giacomini M, Eyles J, Lavis J. "It all depends": Conceptualising public involvement in the context of health technologies assessment agencies. <i>Social science & medicine</i> . 2010;70:1518-26.	Conceptualises public involvement in the context of HTA. Examines how <i>public involvement</i> is constructed in HTA and how the rationale for public involvement may conflict with HTA

		narrowly defined (i.e. a focus on effectiveness, safety and cost effectiveness).
12	Gauvin F, Abelson J, Lavis J. Evidence brief: strengthening public and patient engagement in health technology assessment. Ontario, Hamilton, Canada: McMaster Health Forum; 2015.	Defines patients, the public and stakeholders and describes the theorized goals of public and patient engagement in HTA
13	Guttman N. Bringing the mountain to the public: Dilemmas and contradictions in the procedures of public deliberation initiatives that aim to get "ordinary citizens"to deliberate policy issues. Communication Theory. 2007;17(4):411-38.	Discusses the theoretical and pragmatic issues in involving <i>ordinary</i> citizens in public deliberation on policy issues. Defines the goals and benefits of public deliberation and normative concerns in public participation initiatives. Explores the potential clash between normative and instrumental goals in public deliberation.
14	Jorgensen TB, Bozeman B. Public values: an inventory. Administration and Society. 2007;39;354-381	This paper attempts to elicit the boundaries and meanings of public values and the public interest from relevant literature primarily drawn from the area of public administration
15	Lehoux P, Daudelin G, Abelson J. The unbearable lightness of citizens within public deliberation processes. Soc Sci Med. 2012;74(12):1843-50.	Challenges the notion of the ‘ordinary’ citizen. Explores the complexity and richness of the contribution of four individual citizens within a public deliberation process.
16	Lopes E, Carter D, Street J. Power relations and contrasting conceptions of evidence in patient-involvement processes used to inform health funding decisions in Australia. Social Science & Medicine. 2015;135(0):84-91.	Examines beliefs about the role of patients and public in HTA and hence what Australian Advisory Committee members consider to be reliable information to inform the HTA process.
17	Lopes E, Street J, Carter D, Merlin T. Involving patients in health technology funding decisions: stakeholder perspectives on processes used in Australia. Health Expectations. 2016.;19(2):331-44.	Explores the idea of representativeness in HTA and the inadequate explication of the role (task) of patients and patient input in HTA processes in Australia at the time.

18	Menon D, Stafinski T. Role of patient and public participation in health technology assessment and coverage decisions. <i>Expert Rev Pharm Out.</i> 2011;11(1):75-89.	Sets out potential roles for patients and the public in HTA. Distinguishes between the roles that patients and public can fulfil and suggests that they be considered separately when they are involved in HTA
19	Merlin T, Street J, Holton C, Mundy L, Tamblyn D, Juneja V, et al. Review of MBS items for specific ophthalmology services under the MBS Quality Framework. For consideration by Medical Services Advisory Committee. Canberra, ACT: Commonwealth of Australia; 2011.	Using social media extracts public and patient views on the use of selected health technologies. This process demonstrated the different functions these two groups bring to HTA.
20	Nabatchi T. Putting the public back in public values research: Designing public participation to identify and respond to public values. The Copenhagen Public Value Consortium Biennial Workshop 2010 - Heterogeneity and convergence in public values research; Leiden, The Netherlands June 10-12 2010.	Explores the nature of public values and provides a framework of goals for public participation corresponding to a spectrum of participation.
21	Ploug-Hansen H, Street J. Reflections on terms, goals and organisation. In: Facey K, Ploug-Hansen H, Single A, editors. <i>Patient Involvement in Health Technology Assessment.</i> Berlin: Springer; 2017. p. 31-42.	Discusses the interests held by patients including patients as a group across the disease spectrum. Sets out the terms used to describe patients in HTA and how these terms define the type of participant included in the process and the goals (implicit, explicit or indefinite) which underpin their inclusion/exclusion.
22	Stafinski T, Menon D. Explicating social values for resource allocation decisions on new cancer technologies: We, the jury, find... <i>Journal of Cancer Policy.</i> 2017;14:5-10.	Uses citizens juries (Canadian) to generate social value statements demonstrating consistency in the findings across juries.
23	Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: a systematic review. <i>Social science & medicine.</i> 2014;109 C:1-9.	Examines the ways in which publics have been selected for citizens juries for health policy decision-making. Critiques the use of the term citizen in juries and how well juries support "active" citizenship.

24	Street J, Lopes E. Deliberative methods to involve patients in HTA. In: Facey K, Ploug-Hansen H, Single A, editors. Patient Involvement in Health Technology Assessment. Berlin: Springer; 2017. p. 165-74.	Examines the nature of deliberation in HTA and those factors which contribute to good deliberation. Distinguishes between patients and the public. Maps current potential stakeholders in HTA deliberations and the interest that they hold.
25	Whitty JA. An international survey of the public engagement practices of Health Technology Assessment organizations. Value in Health. 2013;16(1):155-63.	Documents international practice in public and patient engagement in HTA organisations.
26	Wortley S, Street J, Lipworth W, Howard K. What factors determine the choice of public engagement undertaken by health technology assessment decision-making organizations? J Health Organ Manag. 2016;30(6):872-90. 24.	Describes the factors - and hence the underpinning goals - which determine the choice of public engagement in HTA organisations. Distinguishes between different types of public.
27	Wortley S, Tong A, Howard K. Community views and perspectives on public engagement in health technology assessment decision making. Aust Health Rev. 2017;41(1):68-74	Provides community views on public and patient engagement in HTA in Australia. The findings indicate potential goals for the inclusion of publics including patients or consumers.
28	Young A, Menon D, Street J, Al-Hertani W, Stafinski T. Engagement of Canadian Patients with Rare Diseases and Their Families in the Lifecycle of Therapy: A Qualitative Study. The patient. 2018:1-7.	Explores the role of patients with rare diseases in the orphan drug lifecycle.

Table 3. Goals for public involvement in HTA

1. To improve the comprehensiveness of evidence underpinning the decision-making for individual health technologies
2. To increase the legitimacy of the process for the assessment of preventive technologies, thereby ensuring public uptake of the findings
3. To increase the capacity of the public to engage in their own health care
4. To improve involvement of members of the public in the democratic process
5. To ensure that the HTA process aligns with public values and that the interests of the public are included in the HTA process values
6. To assist in explaining to the public the rationale for difficult decisions which deny funding for potentially life-saving or life-altering health technologies

Table 4. Definitions of terms for use in public and patient involvement in the context of Health Technology Assessment and decision making

Term	Definition and rationale
Public	<p>A community member who holds the public interest and has no commercial, personal or professional interest in the HTA process</p> <p>Rationale: Public is an umbrella term which, in the context of the HTA process, incorporates all non-patient, non-commercial and non-professional stakeholders within the health sector. This would exclude patients and carers and representatives from patient and consumer organisations since in the context of HTA they will invariably hold different interests to those of the society at large and it is important that these perspectives are kept separate. It will also exclude representatives from commercial vendors of drugs and devices and organisations offering paid health services; individuals engaged in the Health Technology Assessment industry; and individuals who work or who have worked in the healthcare industry. These individuals are excluded from the term because they have a potential conflict of interest and already have a defined role in the HTA process. The term ‘public’ would include individuals with professional or commercial interests outside these areas e.g. a physicist or a lawyer.</p>
Patient	<p>An individual with a disease or disorder who is using some aspect(s) of the healthcare system because of this disease or disorder.</p> <p>Rationale: Patients are individuals with the lived experience of a disease or disorder who can provide information in the HTA process pertinent to that disease or disorder.</p>

Consumer/User	<p>An individual who uses, has used or intends to use a particular health technology or service.</p> <p>Rationale: A consumer may be a patient but may also be a user of a preventive health technology e.g. screening or vaccination. The word consumer might also be seen to include health workers and professional and non-professional caregivers since all of these use technologies and therefore are consumers with the capacity to inform the HTA process. However, in the context of the HTA process we would exclude professional consumers from this category since they are represented in the process in their capacity as clinical stakeholders. We note that there is often conflation between the term consumer and patient in healthcare settings in that a healthy person using a vaccine, for example, will be termed a ‘patient’. In HTA we recommend that these terms be differentiated.</p>
Carer/Caregiver	<p>An individual who is the unpaid informal primary or secondary caregiver for a patient.</p> <p>Rationale: A carer or caregiver is usually recognised as holding the interests of the patient(s) in their care but may have additional needs and interests. In context of the HTA process, unless otherwise specified, the carer is assumed to be non-professional.</p>
Lay	<p>An individual who has no professional healthcare qualifications or expert healthcare knowledge.</p> <p>Rationale: Since all individuals have expert knowledge of their own lived experience, we suggest that this term should not be used to describe the patient or the public in the HTA process. In addition, we recognise that many individuals who act as patient or public members have professional qualifications in other fields.</p>
Stakeholder	<p>An individual with an interest in the outcome of the HTA process final decision.</p> <p>Rationale: A stakeholder is someone who will be impacted i) through a change in health or lifestyle, ii) financially or iii) in some other way, by the decision to exclude or include a technology from public support Potential stakeholders in Health Technology Assessment include patients, consumers, carers, industry representatives, healthcare providers, employers, health insurers and other payers who are impacted by decisions made in response to the assessment. Members of the public and taxpayers may also be considered to be distal stakeholders in the HTA process because of their interest in a viable effective health system and the judicious use of public funds.</p>

Patient Advocate	<p>An individual who represents and advocates for the interests of a particular group of patients on a committee e.g. patients with breast cancer.</p> <p>Rationale: We have distinguished a patient advocate from a patient member since a patient advocate is directly charged with representing the interests of a particular patient organisation or group.</p>
Public Member	<p>An individual who has been selected to support the inclusion of the interests of the society at large on a decision-making committee in HTA.</p> <p>Rationale: We recognise that society has an interest in maintaining an efficient, effective and equitable health service which, as far as possible, meets the needs of all individuals in society including balancing the range of needs of patients using the system. The use of the word ‘partner’, for example, a public partner, suggests the member holds more power than is usually the case. We suggest the term ‘public partner’ should be avoided. The public member may sit on a cross-disciplinary panel of HTA stakeholders (e.g. industry sponsors and clinical stakeholders) or may be one of several sitting on a public or community panel.</p>
Patient Member	<p>An individual who has been selected to support the inclusion of the interests of patients in Health Technology Assessment processes on a committee.</p> <p>Rationale: We recognise that patients have unique information relevant to inform the HTA process. Representation of this information on decision making committees is important. This individual may be a patient or an unpaid caregiver and may collate the experiences of patients relevant to particular technologies considered by the committee.</p>
Consumer Member	<p>An individual who has been selected to support the inclusion of the interests of consumers on a committee.</p> <p>Rationale: we have included this term since it is used in some HTA jurisdictions e.g. Australia and, based on the definition of consumer, we see the remit of the member as wider than the remit of a patient member</p>

Supplementary Table 1: Public and patient involvement in HTA and HTA-decision making

Country	Organization	Specifications of the decision problem	Information inputs into the decision-making process	The decision-making process	Public accountability and decision implementation considerations
Australia	Pharmaceutical Benefits Advisory Committee	<ul style="list-style-type: none"> Refer technology for consideration: anyone 	<ul style="list-style-type: none"> Part of sub-committee who provides advice during evaluation: patients 	<ul style="list-style-type: none"> Membership on advisory committee: patient representative 	No role identified
Australia	Medical Services Advisory Committee	<ul style="list-style-type: none"> Refer technology for consideration: anyone 	<ul style="list-style-type: none"> Part of advisory panel who defines scope of appraisal: patients 	<ul style="list-style-type: none"> Membership on advisory committee: patient representative 	No role identified
Belgium	Drug Reimbursement Committee	No role identified	No role identified	No role identified	No role identified
Canada	Canadian Agency for Drugs and Technologies in Health	No role identified	<ul style="list-style-type: none"> Submit information to group preparing evaluation report: patients and patient organizations 	<ul style="list-style-type: none"> Membership on advisory committee: 2 patient representatives (pan-Canadian Oncology Review); public representative: 2 “public” representative Canadian Drug Expert Committee): 	No role identified

Supplementary Table 1: Public and patient involvement in HTA and HTA-decision making

Country	Organization	Specifications of the decision problem	Information inputs into the decision-making process	The decision-making process	Public accountability and decision implementation considerations
Denmark	Danish Medicines Agency	No role identified	No role identified	No role identified	No role identified
France	French National Authority for Health	<ul style="list-style-type: none"> Refer technology for consideration: patients and patient organizations 	<ul style="list-style-type: none"> Participate in defining scope of the appraisal: patients Participate in consultations during evaluation: patients 	<ul style="list-style-type: none"> Membership on advisory committee: patient representative (HAS Interdisciplinary Economic Evaluation and Public Health Committee (CEESP)) 	No role identified
Germany	Federal Joint Committee (G-BA)	No role identified	<ul style="list-style-type: none"> Participate in defining scope of the appraisal: patients Comment on draft protocol for evaluation: anyone Submit information to group preparing evaluation report: anyone 	<ul style="list-style-type: none"> Membership on advisory committee: patient representative 	No role identified

Supplementary Table 1: Public and patient involvement in HTA and HTA-decision making

Country	Organization	Specifications of the decision problem	Information inputs into the decision-making process	The decision-making process	Public accountability and decision implementation considerations
Italy	Italian Medicines Agency	No role identified	No role identified	No role identified	No role identified
Japan	Drug Pricing Organization	No role identified	No role identified	No role identified	No role identified
New Zealand	Pharmaceutical Management Agency of New Zealand (PHARMAC)	<ul style="list-style-type: none"> Refer technology for consideration: patients and patient organizations 	<ul style="list-style-type: none"> Submit information to group preparing evaluation report: anyone 	No role identified	No role identified
Norway	Norwegian Medicines Agency	No role identified	No role identified	No role identified	No role identified
Scotland	Scottish Medicines Consortium	No role identified	No role identified	<ul style="list-style-type: none"> Membership on advisory committee: patient representative Submit written testimonials: patient organizations 	No role identified
Singapore	Singapore Ministry of Health Drug Advisory Committee	No role identified	No role identified	No role identified	No role identified

Supplementary Table 1: Public and patient involvement in HTA and HTA-decision making

Country	Organization	Specifications of the decision problem	Information inputs into the decision-making process	The decision-making process	Public accountability and decision implementation considerations
Spain	Ministry of Health (Directorate General of Pharmacy and Health Products)	No role identified	No role identified	No role identified	No role identified
Spain	National Health System Inter-territorial Council	No role identified	No role identified	No role identified	No role identified
Sweden	Dental and Pharmaceutical Benefits Board (TLV)	No role identified	No role identified	<ul style="list-style-type: none"> Membership on advisory committee: 2 patient representative 	No role identified
The Netherlands	Dutch Health Care Insurance Board (CVZ)	<ul style="list-style-type: none"> Refer technology for consideration: patients 	No role identified	No role identified	No role identified
United Kingdom	National Institute for Health and Clinical Excellence (NICE)	<ul style="list-style-type: none"> Refer technology for consideration: patients and the general public 	<ul style="list-style-type: none"> Participate in defining scope of the appraisal: patient organizations Submit information to group preparing evaluation report: 	<ul style="list-style-type: none"> Membership on advisory committee: 2 patient representative Submit written testimonials: 	Appeal recommendations: patient organizations

Supplementary Table 1: Public and patient involvement in HTA and HTA-decision making

Country	Organization	Specifications of the decision problem	Information inputs into the decision-making process	The decision-making process	Public accountability and decision implementation considerations
			patient organizations	patient organizations • Comment on draft recommendations: public and patients	
United States	Centres for Medicare and Medicaid Services (CMS)	• Refer technology for consideration: patients	• Submit information to group preparing evaluation report: anyone	• Membership on advisory committee: patient representative • Submit additional information: anyone • Present to advisory committee: anyone	Appeal recommendations: anyone
Wales	All Wales Medicines Strategy Group	No information found	No information found	• Membership on advisory committee: patient representative • Attend committee meeting: public and patients	