

# **Patient and Social Engagement in HTA**

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Background

Patients and their carers are present throughout the continuum of an individual’s health care. They see the full process of care, and through a different lens than healthcare providers. This means that the absence of engagement with patients and carers, as well as with those who provide healthcare access, can deprive health care of a rich source of information on the experience of living with a disease or health condition, its management, and treatment. Because patients, carers and families, and the public are generally not as well organized and resourced as other stakeholder groups, their interests and needs have not always been captured or integrated into policy development, healthcare services and health care, and research activities.

In this chapter we define social engagement as the participation of consumers, patients and their families, carers, legal representatives, patient advocates, citizens, and the broader public in healthcare policy and HTA.

Table 1 summarizes the reasoning behind why social engagement is important in health policy decision-making related to the technologies available within our healthcare systems (Wale et al 2017).

**Table 1. Why incorporating health system user healthcare experiences into HTAs is important**

1. Patient’s Rights Perspective
• WHO’s Alma-Ata Declaration (1978) – “...people have the right and duty to participate individually and collectively in the planning and delivery of their health care”
• WHO resolution on health intervention and HTA in support of universal health coverage
2. Need for Value Determination
• Value determinations and value judgements needed beyond cost effectiveness, such as patient and social value
3. Evidentiary Contributions
• Citizens, consumers, patients and their families, carers, legal representatives as well as advocates provide the ‘lived experience’ that reflects benefits (and harms) that may be broader than the outcomes reflected in trials or traditional quality of life data
4. Methodological Perspective
• New approaches for obtaining timely evidence, such as managed entry schemes
• Social input on design of and relevant endpoints for clinical studies including patient relevant outcomes

Adapted from Wale J, Scott A, Hofmann B, Garner S, Low E, Sansom L (2017).

An example of why social engagement should be a part of HTAs is provided by the Ontario Health Technology Advisory Committee from Ontario, Canada (OHTAC 2015). The health technology advisory committee strengthened social engagement in its evidence review process to foster transparency, awareness, legitimacy, acceptability and trust in the final recommendations from their HTA process.

Different levels of social engagement

At the lowest level of social engagement, the public may simply be informed about HTA recommendations, if they know where to access this information. The next level is consultation, to be invited to comment on recommendations of an HTA committee. Greater levels of engagement are by participating in the processes for decision making, providing input, and having a greater say in the decisions through collaboration. Empowerment would be where all social actors who have an interest in specific health technologies make the final decisions together (IAP2). See Table 2.

Table 2. Levels of engagement, as adapted from the IAP2 public participation spectrum

	INFORM	CONSULT	PARTICIPATE	COLLABORATE	EMPOWER
SOCIAL PARTICIPATION GOAL	To provide society with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain social feedback on analysis, alternatives and/or decisions.	To work directly with society throughout the process to ensure that social concerns and aspirations are consistently understood and considered.	To partner with society in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of society.
PROMISE TO SOCIETY	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how social input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how social input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

### **HTA to inform universal health coverage**

As countries strive to deliver universal health coverage (UHC), the process of deciding which health technologies and healthcare interventions to invest in has become increasingly important, and HTA is proposed by the World Health Organization (WHO) (WHO 2014-media release). WHO has developed a handbook to support social participation for UHC (WHO Handbook).

Countries face complex choices in deciding how to direct their finite health budgets to meeting the priority health needs of their populations, and in selecting from the vast array of technologies and interventions that are available. HTA is a multidisciplinary process to evaluate the social, economic, organizational and ethical aspects of any health intervention or technology and is directed at reaching a fair and efficient outcome. The HTA approach uses a systematic process to evaluate the properties, effects, and impacts of health technologies or interventions. It can be applied to medical devices, medicines, vaccines, procedures, health services, and public health interventions. The International Network of Agencies for Health Technology Assessment (INAHTA) recognizes patient involvement in the process of HTA as important and valuable (INAHTA Statement).

In 2015, the WHO conducted a survey of member countries on their HTA capabilities (whether formally recognised as HTA or not) and the aspects of HTA that the countries assessed. Ministries of health or national health insurance bodies were the main initiators of HTAs. This survey has been used to inform the work of the WHO in promoting universal health coverage (WHO 2015 Survey). From the survey of 111 countries, WHO developed country profiles (WHO country profiles) where 'social participation' in HTA activities was one of the fields collected. A lack of qualified human resources appeared to be the main barrier to producing and using HTAs. HTAs looked principally at safety and clinical effectiveness (benefit/risk) for all types of health technologies, followed by economic and budgetary considerations. Acceptability to healthcare providers and society, ethics, equity or feasibility were less often considered. About half of the countries did not provide the opportunity for society to comment on the recommendations of HTA reports. Yet not accommodating social acceptance of technologies can lead to greater non-adherence to technologies. Among the countries that completed the WHO survey, those that included social participation were Australia, Canada, England and Scotland, Germany, Brazil, Colombia, India, Kazakhstan, Poland, Portugal, Romania, Thailand, Turkey. Others such as Ghana, Kenya, Vietnam did not have a national authority for HTA in 2015.

Social engagement can be seen as an added cost, and processes and timelines may have to change to accommodate such engagement. Similarly, objective 'hard' outcomes such as deaths, number of cardiovascular events are much easier for HTA reviewers to work with than are the more subjective, less well-defined patient relevant outcomes such as quality of life (QoL) measures. Patient-reported outcomes are not easy to measure or compare across diseases, and are much more context specific. That is, the place or setting of health care and circumstances may influence the findings, meaning that data from one country or region may not be transferable to another target country or region. How direct patient input into HTAs is incorporated into HTA decision making is more difficult again (Wale and Sullivan 2019). Potential barriers for patient involvement have been identified through review of the literature. From the HTA body or payer perspective these include limited willingness to involve patients, need for confidentiality and possible conflicts of interest of patient organisations, finding the 'right' patient representative, lack of resources to support patient involvement, and needing guidance on how to involve patients. From the patient perspective barriers include the lack of understanding of the processes, the data and evidence required to inform input, resources to be effectively involved, and guidance on how to represent a patient community (Dimitrova 2022).

### **Seeking patient input, an example**

The European Network for Health Technology Assessment (EUnetHTA) addressed patient input and its quality in the work of the network by requesting "...facts, information and summaries of experiences that give a concise, accurate and balanced overview of a range of patients' and care-givers/carers' perspectives/views" (EUnetHTA website; Elvsaa et al 2021). Different stages of disease and disease severity were specified, with a particular focus on symptoms. The stated source of information (such as web survey, helpline analysis, social networking, focus group, patients' records, interviews, one-to-one conversations with those who have experience of an intervention, patient stories, research studies, etc.) is important; as are including groups that should have special considerations, including with disease sub-types and people with other disabilities and special needs.

### **Patient evidence and the patient voice**

Patient evidence has been defined (Staniszewska and Werkö 2021) as coming from formal research methods, rather than social engagement.

Methods for gathering patient evidence include patient-relevant outcome measures (Haywood et al 2017, Ch9), Discrete Choice experiments (Tockhorn-Heidenreich et al 2017, Ch10), ethnographic fieldwork (Tjørnhøj-Thomsen and Ploug Hansen 2017, Ch12), and qualitative research (Booth 2017, Ch15). For example, a literature review can be followed by qualitative studies to inform quantitative patient preference research, where specific methods are very dependent on the diseases being investigated and patients' awareness of the disease processes (Cook et al 2019). Patient evidence can be seen as important in HTA to inform needs and value for patients and their carers. Yet efforts are being made to not just seek input from patients into HTA processes, for example using templated questionnaires (HTAi PCIG resources), but to structure the patient voice so that it can be systematically incorporated as part of the evidence. Such structure is provided with patient preference studies and patient-reported outcome measures (Wale et al 2021).

### About HTA

HTA is a field of scientific research used to inform policy and clinical decision-making on the introduction and use of health technologies. Health technologies include pharmaceuticals, devices, diagnostics, procedures and services, and other clinical, public health and organizational interventions including telehealth. HTA is often defined as a multidisciplinary field that addresses the clinical, economic, organizational, social, legal and ethical impacts of a health technology, considering its specific healthcare context as well as available alternatives. The scope and methods of HTA may be adapted to the needs of a particular health system, but HTA processes and methods should be transparent, systematic and rigorous (EUPATI).

HTA follows market authorisation and is often used to inform reimbursement and the choice of funding model for introduction of new technologies into clinical practice. Different HTA decisions can be made in different countries (Mamzer et al 2018; Nicod 2017). This is because HTA is context-dependent, not least of all in terms of budgetary impact and economic analyses (HTAsiaLink 2013). Service delivery opportunities need to be in place within a country, with appropriate staff, equipment, time and resources to provide the technology. The technology can then be accepted as part of health care. Countries may also seek clinical trials within their own countries, as for example occurs in Japan.

### **Social engagement in HTA**

Countries such as England (NICE; Thomas et al 2017), Scotland (SMC), Germany (G-BA, Haefner and Danner 2017), Canada (CADTH, Weeks et al 2017) and Australia (PBAC, MSAC, Wortley and Wale 2017) have robust, clearly articulated patient and public participation strategies (Facey et al 2017). Support is often provided for social engagement through a public and patient involvement specialist team whose job it is to coordinate the engagement. These support teams can build in improvement mechanisms, for example by incorporating an advisory public, patient and carer group network (SMC, CADTH, EUnetHTA) and by offering feedback mechanisms, support and training. Meetings involving healthcare providers and patient organisation representatives together (as with PACE in Scotland, EUnetHTA) is an important development (Wale and Sullivan 2019).

The HTAi Patient and Citizen Involvement in HTA Interest Group (HTAi PCIG) used formal research methods with international participants to develop a generic template for obtaining relevant patient input on medicines to inform HTAs. Templates for medical devices and diagnostics were also developed (HTAi PCIG resources). The templates seek the unique knowledge and perspectives of patients most likely to inform HTAs and inform value assessments. The methodology involved a workshop using a nominal group technique and three stage Delphi process, with direction from an international steering committee. Guidelines were also developed for patient groups, adapted from a Canadian pan-Canadian Oncology Drug Review document (HTAi PCIG resources). The generic templates have been used by HTA agencies to inform their templates, for example EUnetHTA (EUnetHTA website), and have been translated into other languages (e.g., Italian, Lo Scalzo 2017).

For EUnetHTA, as with the Canadian Agency for Drugs and Technologies in Health (CADTH), patient input is received before developing the plan or protocol for the assessment. EUnetHTA planned to make the patient submissions it receives publicly available on a webpage at the timing of publication of the project plan. The Joint Assessment report will document how the information from patients was considered in developing the scope of the EUnetHTA Joint Assessment. This clarification of how the information is used is an important element of providing input (Wale and Sullivan 2019). The German G-BA (Haefner and Danner 2017, Ch25) stated that more and more, the acceptance of decisions will depend on the ability and commitment of the HTA body to describe how patient perspectives have been determined, involved and considered.” (p310)




Transparency is an important element as HTA decisions can have political implications and become a political construct (Haefner and Danner 2017; Lopes et al 2020).

PCIG Values for social engagement in HTAs

HTAi PCIG has developed values and standards for patient involvement in HTA (HTAi PCIG) to be applied by HTA bodies and national authorities, see Table 3.

Table 3. HTAi Patient and Citizen Involvement in HTA Interest Groups Values for HTA bodies working with patient groups



### Why do we involve patients in HTA?

Relevance	Fairness	Equity	Legitimacy	Capacity building
Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.	Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.	Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.	Patient involvement facilitates those affected by the HTA recommendations/d ecision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process.	Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

The values are: relevance (of patients’ experiential knowledge), fairness (that patients are involved), equity (in contributing to), legitimacy (of decision making), and capacity building (the need for). A specific skill set is required by staff of HTA bodies to enable social engagement, and the purpose of the social engagement needs to be clearly defined for those who are participating (HTAi PCIG resources).

**Some key points in relation to social engagement**

In a number of countries or regions within countries it is a legislative requirement that HTA is considered when introducing new medicines: Australia, Brazil (Lopes et al 2020), Canada, Colombia, Germany, Hungary, Kazakhstan (mandated), Poland, Portugal, Romania, UK; and that social participation is part of the HTA process (WHO 2015 survey).



Some countries stipulate one, or a few patient/consumer organization(s) to provide the voice of patients and the public in government policy. For example, in Germany the Federal Ministry of Health recognizes four relevant national umbrella patient organizations (Haefner and Danner 2017), the Australian Department of Health works predominantly with the Consumers Health Forum (Wortley and Wale 2017), in France Assos Santé is authorized to represent users with respect to public health authorities, information and public consultations on health-related issues in France (Mamzer et al 2018). For Brazil and its National Committee for Health Technology Incorporation (CONITEC website), participation of civil society in the HTA process is formalized through members of the National Health Council (CNS). All CONITEC recommendations are open to public consultation for 20 days (publicized through website content, email, and social media) – with summarized versions in simplified language. Suggestions (available on spreadsheet on website) are compiled and discussed as part of the final technical report, which appears on the CONITEC website.

### **Experience of developing HTA and patient input in Taiwan, Republic of China**

Taiwan, Republic of China, has shown that patient involvement can be delivered even when resources are significantly more limited than in many Western countries. It has found that patient engagement is important for understanding the needs of the target patient population, yet challenges remain in ensuring timely patient engagement and provision of relevant resources. So further efforts are needed to implement and improve the visibility of patient input into the HTA process.

Taiwan has a mandatory single-payer Health Insurance (NHI) program that covers more than 99% of Taiwan's population. This program is known for its low premiums and co-payments. The Health Insurance Act, amended in 2013, protects patients' rights and invites them to voice their opinions. Taiwan conducts health technology assessments (HTAs) to support the Health Insurance Administration's (NHIA) reimbursement policies on new drugs. The HTAs consider the health and well-being of all citizens, medical ethics, and cost-effectiveness with regard to the financial framework of the NHI program. The HTA department operates under the supervision of the Center for Drug Evaluation (CDE). A short history of the HTA development process in Taiwan has been reported by Chiu et al (2015). Five social values must be considered for decision-making pertaining to the inclusion of new medicines within the domain of healthcare benefits. These are: the safety and efficacy of the drug; cost-effectiveness; the principle of equality and protection of the weaker sections of society; attention to the quality of life of patients; and the life-saving and urgency factor of the drug.

Patient groups are invited to participate in PBRS Committee meetings. For new drug applications, patient opinions are collected only if the product being discussed is related to treating the diseases included in the NHI's major illnesses/injuries list. A summary of the submissions is developed by the CDE/HTA division and incorporated into the HTA report for consideration by the PBRS Joint Committee. The report is published before the PBRS Joint Committee meeting, allowing stakeholders to learn about patients' experiences.

The NHIA has a webpage that enables patients, caregivers, and patient groups to submit their opinions about new drugs and also medical devices (NHIA website). The online platform is supported by a patient involvement guideline to assist people making submissions in expressing their opinions. The initial guidelines were revised by the CDE/HTA team with more practical guidelines to help patients have their voices heard and so motivate patients and patient groups to contribute their views. The CDE/HTA also initiated a series of educational programs for patients, caregivers, volunteers in hospitals, and patient organisations. These training courses were held across Taiwan.

Patients can participate in PBRS Joint Committee meetings in two ways. First, two patient representatives attend the meetings. The CDE developed a project to assist patient representatives in understanding more about the HTA process, diseases, and patient voices. The CDE/HTA team also holds a pre-meeting for patient representatives, beneficiary representatives (consumers) and case-related patient organisations, who have provided input on the platform to discuss patients' perspectives before the PBRS Joint Committee meeting. In a resubmission case, the NHIA can invite two disease-specific patient representatives to voice their opinions during the meeting (NHIA website).

In some technology assessment projects, the CDE/HTA has conducted interviews or distributed questionnaires to patients regarding their experiences with a technology or medical procedure, such as robotic surgery, artificial electronic ears or transcatheter aortic valve replacement, chemotherapy, and radiation therapy. Patient organisations assisted the CDE/HTA in finding appropriate patients to ensure that the final report included the views of those who had experience of these procedures. Other projects related to the improvement of the patient involvement mechanism have also involved a high degree of cooperation with patient organizations – including interviews with patient organisations so that the patient involvement mechanism could be made more structured and adapted to local conditions.

In Taiwan, patients participating in HTA and the reimbursement decision-making process are supported by the NHIA. In this process, the CDE/HTA team plays a crucial role in supporting not only the NHIA, but also patients and patient organizations. However, some challenges remain. The impact of allowing patients to engage with the HTA and reimbursement process on decision making therefore remains unclear. Few patients have chosen to share their experiences, especially with medical devices, via the online platform. This is likely because many patient organizations are still not aware of the online platform. The HTA agency and patient organizations both lack human resources and windows of time are short for patients to contribute (Chen 2022).

### Why experiential knowledge is important

Societal members can contribute with their unique experiential knowledge about a disease, its diagnosis, treatment, and impact on the health system. People with experience of a disease or health condition and its treatment can therefore provide valuable input into the assessment of the value of a new technology and on the clinical trials that support an HTA, as listed in Figure 1 for treatment interventions.

**Figure 1. Patient considerations when looking at a new technology and the clinical trial evidence that supports its use.**



Clinically held beliefs of what is important to patients may differ from the needs expressed by patients themselves (Gibofsky et al 2018; Morel and Cano 2017). Different populations may also show important differences in their needs and beliefs. As a result, knowledge of the benefits and side effects of technologies and of disease management on the outcomes most relevant to patients is important. If these are not addressed, the different perspectives can lead to uncertainty in an HTA appraisal (Menon et al 2015). Patients are also able to provide context to the use of health technologies, including unmet needs, disease and treatment burdens, and give personal accounts of quality of life to compare with clinical trial results (Wale and Sullivan 2019).

**Possible ways of engaging with society on HTAs**

Table 4 summarizes ways that social engagement can take place at different levels of participation. The following section details some of the concepts behind social engagement in health care; and strategies that can be utilised to capture societal viewpoints in HTAs (Scottish Health Council participation tools).

**Table 4. Approaches to social engagement in HTAs at the different IAP2 levels of participation**

	INFORM	CONSULT	PARTICIPATE	COLLABORATE	EMPOWER
METHOD OF ENGAGEMENT	Websites and fact sheets, at conferences, media releases.	Surveys, focus groups, public meetings, hearings, on-line feedback and comments, online discussion.	Forums, including multi-stakeholder, in-depth discussion, committee involvement or membership.	Partnerships and joint projects.	Integration into governance.

**Social engagement concepts and strategies**

We recognize that increasing numbers of people are living with chronic illnesses (including mental illness and cancer survivorship). These people live with the demands of managing their health care 24 hours a day, seven days a week. More and more, doctors recognize that they have to involve patients and their families and carers in the continuity of care, and extend opportunities for shared decision-making and person-centred health care.

The internet has meant that the public has greater access to information on diseases and health conditions. People are able to recognise the different stages of disease – going from diagnosis, treatment, management of symptoms and any adverse effects of both the disease and its treatments; to prognosis and how health care is accessed.

People are able to investigate options for themselves (or their family members) and link up with other people living with a disease through the internet and social media. People can read scientific information on the internet and organise clinical data in open databases that they themselves manage, either by themselves, through advocates, or patient and consumer groups. They know what treatments are available and where they are being used or trialled; although their knowledge and understanding of how the treatments work and other relevant considerations may be limited.

### **Community participation models**

Social movements are very effective in increasing social participation to include the community and patient voice in health care. Technology-based platforms are social networks formed by Facebook, Twitter, blogs and forums, patient association web-based platforms, patient online communities, and others (Ravoire et al 2017). These media have advantages in answering questions about health products, societal approaches, and the organization of care. Large numbers can quickly become involved and from varied sociodemographic groups, but with legal and methodological (such as verifying data and participants) constraints. Limitations include representativeness of participants and the influence of media reports. Potential biases include age, sociocultural and professional characteristics, living in urban or rural areas, and lifestyle. Patient opinion leaders also have potential influence, maybe in a particular condition, and they may be involved in patient-focused drug development. An example of a technology-based platform is the web-based platform PatientsLikeMe, which has developed structured methods of obtaining data from patients that is suitable for research and quality of care measures (Burstin et al 2017). Online surveys, discussion papers and questionnaires can be used by organizations including HTA bodies to target a broad population of people, if effectively disseminated.

Facilitated discussions with a knowledgeable person as facilitator can be an effective way of seeking people's views and encouraging them to participate in discussions. These can be face-to-face, through telecommunications or online, including through online bulletin boards (Cook et al 2019). A proposal can be formed and developed by the group with clarification of opinions to come to a consensus view, if needed. Participants can be trained or coached in the processes before participating, and the approach can be multidisciplinary. Patient interactions on social media platforms are relatively quick to analyse to help identify what is important to patients, carers and families (Cook et al 2019).

The online discussions can provide insightful patient and disease relevant information (Street and Farrell 2017, Ch14). Such 'listening' to self-initiated online discussions does not impose a burden on patients.

Community-based participatory research is where community members and researchers work together as equal partners – to increase skills, share relevant and effective ideas, and create connections and opportunities for learning and growth. Partners have diverse knowledge, skills, expertise and experiences to address complex problems. Benefits include increasing community trust in research; increasing likelihood that research results will lead to effective programs and products that communities want and can use; increasing validity of research results; creating connections between community organizations, healthcare organizations and researchers that support partnerships and share effective and relevant programs and products; increasing skills, connections and opportunities for growth for all partners (for example, SoLaHmo Partnership). Such participatory research is a type of “citizen science and/or citizen research” methodology.

### **The evolution of citizen science and/or citizen research**

Citizen science and/or citizen research is an umbrella term that applies to a wide range of activities to engage society with science, acknowledging the need for scientists and members of society to work together to tackle complex challenges such as sustainable development. The term developed out of the work of UK-based Alan Irwin and US-based Rick Bonney in the mid-1990s (Riesch and Potter 2013). Within health care, patients and citizens establish social networks to share their experiences, symptoms and cures. They organize their own clinical trials (Wicks et al 2014) and join professional researchers for the advancement of large-scale research projects such as genomics, disease research, and microbiomes (for example, micro-organisms in the gut). Questions that professional researchers have been struggling with for years, or even decades, can be solved by people playing computer games (for example, designed to enable the public to help determine the folding structure of protein in Khatib et al 2011). The notion of 'crowdsourcing' has been applied by many authors to discuss novel forms of collective knowledge production and collective intelligence (Prainsack 2014; Woolley et al 2016; McGowan et al 2017). In this sense, the emergence of citizen science and/or citizen research has produced a paradigm shift on the pace and impact of collective knowledge production and innovation. This process is catalyzed by internet platforms (such as PatientsLikeMe, Citizen Science Alliance) and social media.

Citizen science and/or citizen research initiatives involve the participation of non-professional scientists at any and every stage of scientific knowledge production, from data collection or generation, data analysis and interpretation through to product application, dissemination, and evaluation. Differing visions for the role of scientific research in society call attention to the complex relationships between science, public goods, societal good, and public participation (Woolley et al 2016). Prainsack (2014) argues that “the increasing prominence of citizen science and/or citizen research challenges and reconfigures the ways in which knowledge production in the health domain takes place. At the same time, it raises ethical and regulatory questions pertaining, for example, to how contributions from citizens should be attributed in scientific publications; what research ethics procedures should apply to studies that are self-organized by patients; and how new modes of citizen participation in medical and bio-scientific knowledge production and decision-making can or should be integrated into existing institutional structures (e.g., into existing systems of healthcare delivery)”.

Across the spectrum, almost all citizen science and/or citizen research initiatives share three features that make its rhetoric particularly appealing to apply to large population-based biomedical research projects: (1) connections to the spreading popularity of personal information communication technologies (ICTs); (2) ‘crowdsourced’ problem-solving; and (3) the ‘grass-roots’ fundraising strategies that they facilitate. The recent explosion of citizen science and/or citizen research initiatives can largely be attributed to the integration of ICT into everyday life through computers, smartphones, the internet, and social media. As such, citizen science is touted as a way to tackle otherwise intractable, laborious, and potentially costly research problems. Being capable of coordinating the efforts of millions of lay people around the globe, it is said to allow researchers to think about data collection on a population-wide scale.

The core features of citizen science and/or citizen research, leveraging of widely distributed ICT, harnessing the ‘collective wisdom’ of the populace, and cultivating enthusiasm and support for science, make it very attractive to governments interested in propelling labour and data-intensive research in a cost efficient manner (Woolley et al 2016).



### **How is citizen science and/or citizen research relevant to HTA?**

The key here is to consider the concept of technology. Researchers in the translational fields of political economy, science and technology studies and public health have outlined, in the 1980s that there are two types of technology: 'hard' or high-density technologies (that is, the conventional conceptualization of what technology means, such as diagnostic tests, vaccines, health programs etc.) and 'soft' or social technologies (that is processes, as a set of techniques, transformative methodologies, developed or applied in the interaction with and appropriated by the population, and which represent solutions for social inclusion and improvement of living conditions). Thus, outlining the relevance of constructing appropriate techniques also for the realm of human relations, so we can think of scientific ways to deal with social structures, human interaction processes, and motivational techniques. In this sense, social technologies can be used for the exercise of self-government and intercessor processes (Ferreira et al 2009; Campos 2011; Jin 2011; Dagnino 2014). If social participation models and methods are processes, that is 'soft' or social technologies, then patient and social engagement with both development and implementation of such technologies means that citizen science and/or citizen research is another type of technology within the scope of HTA. Citizen science and/or citizen research's goal in HTA is to avoid tokenistic social participation approaches (that is, to involve society without effective participation) and to promote skills in members of society to contribute competently to the establishment of quality and effective deliberation processes. Furthermore, citizen science and/or citizen research approaches cover the need for early social engagement throughout the HTA processes, including at early stages (such as policy formulation and development) as well as at later stages (such as implementation and monitoring of (new) technologies in health systems).

In this sense, citizen science and/or citizen research initiatives should be both promoted and supported across the technology cycle (Shah et al 2009) by not only professionally-trained researchers but also HTA implementers, decision-makers and other social actors. Citizen scientists, better known as 'patient research partners', have been described in the Netherlands (Abma et al 2009) to meet HTA's purposes in a more sustainable, responsible and equitable manner. As such, citizen science and/or citizen research comprises the 'collaboration' model referred to in Tables 8-2 and 8-4. Tools such as STARDIT that aim to standardise the way that information about such initiatives are reported, including information about which tasks were done by different people are key. Reports can be updated at all stages, from planning to evaluation, and can report impacts in many languages, using Wikidata.

STARDIT is free to use, and data can be submitted by anyone. Report authors can be verified to improve trust and transparency, and data checked for quality (Nunn et al 2021).

### **Patient groups and participation in HTAs**

The traditional role of patient groups has been to provide support to patients, families and carers. In the late 1980s, the AIDS movement in the US led the way to patient involvement in changing health policy and access to new treatments, in a life and death situation. Breast cancer patients soon followed the lead. Patient groups have now moved beyond providing support in everyday care of patients to gaining experience and knowledge in scientific and clinical research to make demands for new treatments and early access to those treatments (Bedlington et al 2017). Patient advocates have been given 'a seat at the table' in research, health policy, service delivery and quality of healthcare committees, and HTA (Scott and Wale 2017). National, regional and international umbrella patient groups access greater expertise and provide stronger, more unified patient voices (Wagstaff 2018); and can more effectively apply citizen science and/or citizen research roles and provide value (Levitan et al 2018).

Social engagement in HTA decisions requires skills, resources and support, from both the HTA bodies and patient groups. For HTA bodies this work best when well resourced (Mamzer et al 2018). Addressing knowledge and skills requirements of patient groups to participate in HTAs and evidence-based healthcare decision-making and to manage patient expectations is another important element. Social participation opens the way for broader consideration of patient-relevant clinical trial outcomes and broader experience in and acceptance of qualitative and other forms of evidence. It is important that patients and the public can speak for themselves rather than through clinicians or researchers alone. Online resources and digital platforms are important enablers, in keeping with a person-centred approach to healthcare (Roy et al 2018). Attention must be given to how patient groups can interact effectively with HTA and policy processes.

### **Evaluation of social engagement**

Effective evaluation of social engagement in HTA and health policy is limited. Where it has been done, it is largely to improve processes for obtaining patient input (Weeks et al 2017). Any impact of patient input on individual HTAs is often opportunistic and cannot be systematically assessed as dependent on quality of patient input (Facey et al 2018). Indeed, patient involvement can act covertly, and rarely has a single impact.

This raises the question whether effective input is pragmatic, or if it can be driven by philosophical and cultural changes in processes and attitudes (Roy et al 2018; Wale and Sullivan 2019). Haefner and Danner (2017) identified that respectful, purposeful, inclusive, timely, transparent processes are important enablers for evaluation and impact.

Gagnon et al in their chapter on evaluation of patient involvement in HTA (Gagnon et al 2017) argued that rather than 'impacts' we would be better to talk about short and medium-term outcomes of patient involvement. Relevant dimensions (Esmail et al 2015) are the context of patient involvement, processes used, and impact. That is, the goals of patient involvement, roles played, expectations and process are important (Dipankui et al 2015). It is difficult to evaluate the input of patients and carers under these circumstances. A preferable way may be to accept that social engagement in HTA is important and to apply quality improvement methodologies to continuously improve how it is approached. This could be in the form of repeated plan-do-study-act (PDSA) cycles (Cleghorn and Headrick 1996). Each cycle begins with a plan and ends with an action. Including the right people on a process improvement team is critical to a successful improvement effort.

The impact of social engagement can ultimately be determined in terms of person-centred health care and partnerships in healthcare decision making, policy and practice (Table 5).

### **Concluding Remarks**

To deliver affordable and equitable universal health coverage diverse HTAs are required, including for service delivery models, vaccines, drugs, and medical devices. This challenges a purely biomedical model to be broadly applied to HTA assessments. Social engagement has an important role in working together with researchers and clinicians to identify and prioritize technologies that best meet population needs and the needs of the health system.

The acceptance of decisions by HTA bodies has political aspects and depends on an HTA body's ability and commitment to describing how patient and social perspectives have been determined and considered in decision making processes. The set goals of social engagement, roles played, expectations, and processes used are important and challenge evaluation. Respectful, purposeful, inclusive, timely, transparent processes are important enablers for social engagement to have an impact, and for it to be evaluated.

International HTA bodies and a supportive national policy context can have critical roles in driving patient involvement in HTA. Activities that address concerns about patient involvement among HTA professionals, for example any hidden interests (or industry connections) and challenging advocacy standpoints (lobbying positions), are important to address. Changing culture with respect to social engagement in HTA and introducing a person-centred input to policy making decisions in health care as well as in service delivery and quality of care are key.

**Table 5. A conceptual model for goals of social engagement in research, clinical guidelines and HTA**

Research – PCORI <sup>1</sup>	Clinical Guidelines <sup>2</sup>	HTA <sup>3,4</sup>
Culture of patient-centredness	Setting patient-centred scope	Clear processes and roles in HTA
	Shaping discussions and how conducted	
	Describing personal impact of disease and its treatment options, comorbidities, unmet needs	
	Impacting how professional team members view patient involvement	
Meaningful and effective partnerships	With improved communication - providing upskilling, support	
Relevant to patients/stakeholders	Identifying themes, subpopulations, carer role that may be overlooked or given different priority by researchers and medical professionals	
	Helping select patient-relevant topics and outcomes	Patient-important outcomes, key questions
	Influencing guideline structure, development	Patient preferences provide context for cost effectiveness analysis and recommendations
Use of results in health decisions	Facilitating guideline dissemination, implementation	Noticeable effect on decisions - in appraisal committee recommendations, advice
		Guidance for end-user uptake, actively disseminating to patient groups

1. Frank et al 2015; 2. Armstrong et al 2018; 3. Rosenberg and Bayoumi 2017; 4. HTAi PCIG 2018

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