HTAi Conference, Cologne, June 2019
HTA Beyond 2020: Ready for the New Decade?

Panel Session Report

What's needed to develop better multi-stakeholder collaboration in Health Technology Assessment (HTA) beyond 2020?

Key points

- As science and technology evolve, the imperative for multi-stakeholder collaboration in HTA becomes stronger.
- As WHO seeks to improve the lives of 3 billion people by 2023, differentiated collaborative approaches, including HTA, are needed that take account of the capacity and vulnerability of health systems.
- HTA needs to be an effective ecosystem involving all stakeholders in scientific and policy dialogues across the life cycle of a technology to ensure efficient use of resources for each stakeholder.
- Structured stakeholder involvement in HTA is essential to inform value judgements, understand the broader concepts of value, weigh uncertainties vs timeliness and deliver meaningful information to decision-makers.
- Learnings from the development of patient involvement in HTA could inform other multi-stakeholder collaborations – ensuring earlier collaboration to focus creation of clinical and patient-based evidence.

- HTA plays a key role in the healthcare ecosystem and so must be driven by the needs of its decision-makers.

- As HTA evolves, so must the stakeholders it involves and its approaches to collaboration.

- The burden and impact of collaboration should be evaluated and used to hone processes to collaborative activities that add real value.

- Platforms to support multi-stakeholder collaboration, sharing of tools and evidence are needed in HTA.

Contents

Glossary

FDA	Food and Drug Administration
HIQA	Health Information and Quality Authority
HTA	Health Technology Assessment
LMIC	Low- and Middle-Income Countries
MCDA	Multi-Criteria Decision Analysis
MDG	Millennium Development Goals
NCD	Non-Communicable Disease
NICE	National Institute for Health and Care Excellence
PCIG	HTAi Patient and Citizen Involvement Interest Group
SDG	Sustainable Development Goal
SHTG	Scottish Health Technologies Group
UC	Ulcerative Colitis
UHC	Universal Health Coverage
WHO	World Health Organization

About HTAi

Health Technology Assessment international (HTAi) is the global scientific and professional society for all those who produce, use, or encounter HTA. HTAi has members from over 65 countries and embraces all stakeholders, including researchers, agencies, policy makers, industry, academia, health service providers, and patients/consumers. HTAi is the neutral forum for collaboration and the sharing of leading information and expertise. This panel was judged by three reviewers and selected for presentation at the 2019 annual meeting by the International Scientific Program Committee.

Status of this report

This report has been prepared by an independent consultant, Karen Facey and approved by all presenters to become a public record of the HTAi panel session.

It should be cited as:
Facey KM, Garner S, Granados A, Bertelsen N, Clifton E. *What's needed to develop better multi-stakeholder collaboration in HTA beyond 2020?* Report of HTAi 2019 Panel Session. Health Technology Assessment International – Canada. 2019.

Funding

Karen Facey received a fee from Sanofi to write this report.

What's needed to develop better multi-stakeholder collaboration in HTA beyond 2020?

1. Introduction

Dr Karen Facey, Evidence Based Health Policy Consultant, Scotland

Dr Facey gave an introduction to the panel discussion by presenting the draft definition of HTA that clearly points to the need for collaboration among different stakeholders to deliver high quality HTA.

> HTA is a ***multidisciplinary*** process that uses explicit and scientifically robust methods to assess the *value* of using a health technology at different points in its lifecycle. The process is comparative, systematic, transparent and ***involves multiple stakeholders***. The purpose is to inform health policy and decision-making to promote an efficient, sustainable, equitable and high-quality health system.
>
> Definition under international consultation – spring/summer 2019.

The HTA community has been discussing the value of multi-stakeholder collaboration in order to share good practices, avoid duplication and develop HTA to better inform health policy for the past decade. However, there is a new impetus in these discussions as recent scientific advancements have a major impact on HTA. Potentially transformative and personalised health technologies require assessment with limited evidence bases, whilst new analytical techniques enable access to health data that could strengthen the evidence base for HTA and support sustainability of health systems. As Crisp (2017)[1] indicated "making health and care systems fit for the future requires a strategy *involving all sectors of society* that maximises the contribution the system makes to the economy".

With this background, a panel of experts from across the HTA community who have held a range of roles in the health system, were tasked to consider what's needed to improve multi-stakeholder collaborative approaches in HTA in 2020 and the next decade.

2. Multi-stakeholder collaboration in HTA - 2020 and beyond: the task ahead of us….

Dr Sarah Garner, Essential Medicines and Health Products Coordinator, World Health Organisation (WHO).

Dr Garner gave a perspective from the WHO, particularly considering the needs of Low- and Middle-Income Countries (LMIC) in the next decade.

The Sustainable Development Goals (SDG), which have been agreed by all agencies in the United Nations, address the needs of LMIC. In health, SDG 3.8 underpins the goals, with the aim to achieve universal health coverage (UHC), including financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

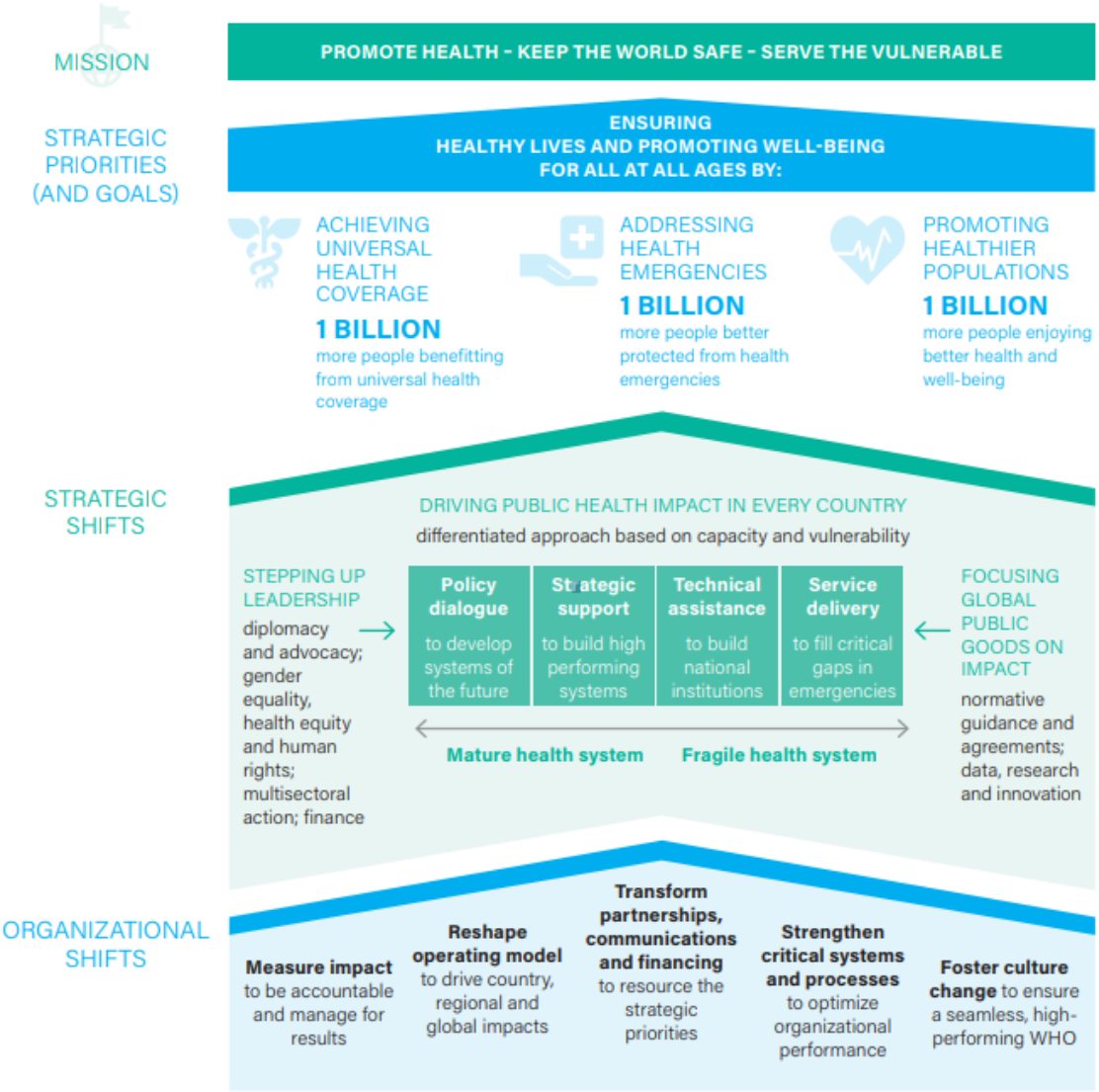
[1] Crisp N. What would a sustainable health and care system look like? *BMJ* 2017; 358 doi: https://doi.org/10.1136/bmj.j3895

This is a massive challenge, which cannot be tackled by the public sector alone. Collaboration is needed with:

- government funding (with careful consideration of sustainability of initiatives when funding is stopped)
- existence of safe health services
- a trained workforce
- health governance systems
- health statistics and information systems to understand performance.

This is seen in the new goals of WHO to improve the lives of 3 billion people by 2023 by achieving UHC, addressing health emergencies and promoting healthier populations. As outlined in Figure 1 this requires organisational and strategic shifts to transform WHO partnerships to be differentiated, depending on the capacity and vulnerability of the health system. This will lead to policy dialogues and strategic support for more mature health systems, whilst more fragile health systems will receive technical assistance and support to fill critical gaps in service delivery in times of emergency. This requires a culture change, facilitated by new leadership approaches alongside research and innovation to enable partnerships.

Figure 1. Overview of WHO's 13th general programme of work 2019-2013: strategic priorities and shifts



For medicines, a number of elements need to come together drawing on expertise from a wide range of partners:

1. efficient regulation and rational selection, including:
    - efficient regulation of quality and safety
    - reimbursement lists created from transparent and accountable procedures
    - up-to-date treatment guidelines elaborated using the best evidence
2. reliable health and supply systems, including:
    - development of pharmaceutical national policies (e.g. for purchasing)
    - quality assurance reinforcement
3. quality assured medical products at affordable prices, including:
    - price negotiation
    - sound generic policies
4. sustainable financing, including:
    - increase and prioritization of public funding for medicines
    - identification of efficiency gains.

The HTA community has contributed to processes for rational selection of medicines, but it could contribute to other areas.

There is a need to think about the broader definition of HTA, going beyond supporting technical assessments, to enabling delivery of policy in health systems. It is imperative to think about how support and training can be mobilised for decision-making to fill the policy related vacuum in some systems. WHO members make a wide range requests for technical assistance that relate to the wider context of HTA including issues such as:

- investment case for HTA
- political economy, advocacy, governance
- how to set up HTA “institution”
- identifying and co-ordination of stakeholders
- horizon Scanning
- national Essential Lists
- defining “benefit package” linking health products and money
- global vs. local evidence (decisions, lists)
- affordability and budget impact
- disinvestment
- pricing and procurement technical assistance
- norms and standards on procurement
- market shaping.

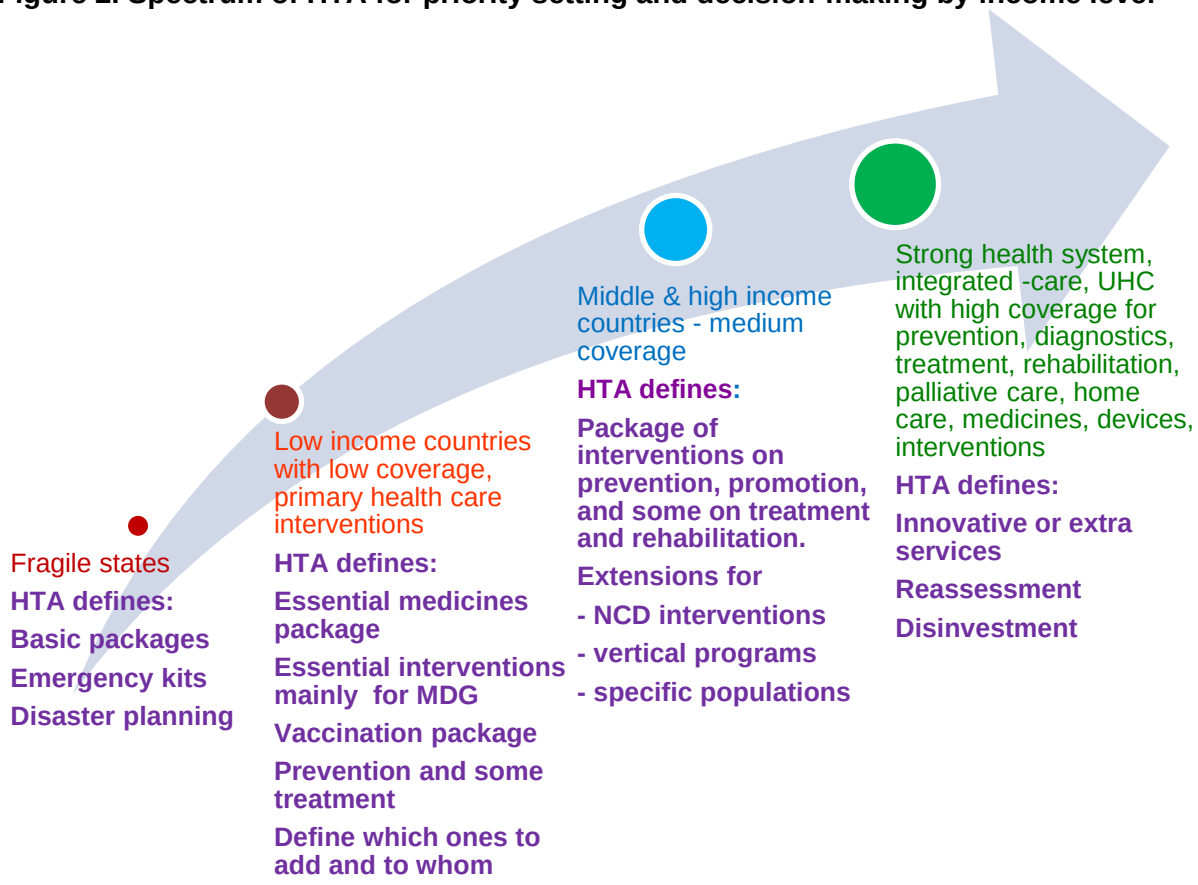
WHO has been doing work related to HTA for many years, but it may not have been labelled as HTA (e.g. its “total system effectiveness” work in vaccines). In the past two years it has sought to bring together its HTA work to review methodologies and address challenges (e.g. in malaria to develop new HTA processes that compare different forms of technologies such as bed nets vs medicines). In WHO, current HTA activities include:

- strategy development
- resource mobilisation within HTA
- transformation of norms and standards, developing quality assured processes that create consistent ways of working across WHO for public consultation, nomination of experts, patient involvement etc.
- providing guidance on ‘institutionalising’ a process for evidence-informed decision making, including ways to disinvestment decisions (how to setup an HTA body, get political support etc)
- developing HTA methods in lower income or data-poor settings, including how to develop health benefits package (including provision of guidance on decision-rules and role of thresholds for adding health technologies into an existing health benefits

package, but that other elements are more important for development of a basic benefits package)
- ASEA network proposal to harmonize HTA (clinical evidence) reporting requirements
- horizon scanning, collaborating with EuroScan
- promoting the work of disinvestment – e.g. the Essential Diagnostics List.

As shown in Figure 2, there is a greater need to perform HTA where resources are limited, but need is high. For example, in fragile states there is a need to define basic benefit packages and in low income countries to define essential interventions.

Figure 2. Spectrum of HTA for priority setting and decision-making by income level



As WHO has limited resources, it reaches out to collaborators to help support all this work. The WHO P4H network[2] for universal health coverage and social health protection is a global, online platform to enable communications informally within and across countries and provides tools, e.g. to support UHC. However, increasing requests have been received to provide tools about health economics, value for money and priority setting. As a result, with the support of the Gates Foundation, the Decide decision hub[3] has been established as a new platform to support such discussions and build capacity. Country areas within the hub will be monitored by Member States and tools will be included. This will support future collaborations and provides a great opportunity for developing the partnership with HTAi and its members.

[2] https://p4h.world/en
[3] https://decidehealth.world/

3. Developing better multi-stakeholder collaboration in HTA beyond 2020 - Industry Perspective

Dr Alicia Granados, Head Global Health Technology Assessment, Sanofi

Dr Granados reflected on her experiences as a clinician, scientist, researcher and policy maker.

The first thing to understand is why we need to collaborate. All stakeholders are part of the health ecosystem and each one is under pressure. Producers of health technologies have increased scientific scrutiny on innovations, pressures on pricing, entry of generic and biosimilar replacements and unsustainable models of research and development. Purchasers of health technologies have to face pressures of financial sustainability, transparency and demands for the latest technologies in a context of globalization of information and awareness of the need for evidence-based decision making. Given the pressures faced by all stakeholders, there needs to be a new way of working in the HTA ecosystem.

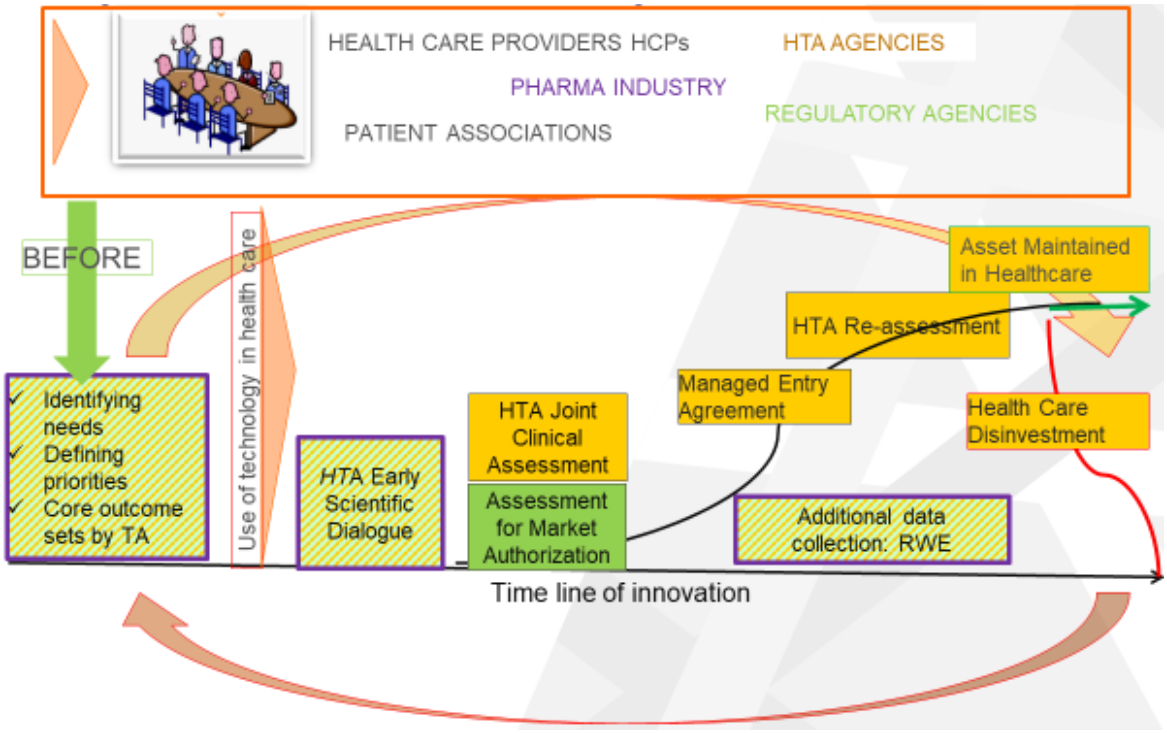
Medicine has moved from education about the functioning of individual organs to an understanding of the importance of the network of organs and within that the role of cellular networks, molecular networks and genes. Systems biology has enabled an understanding of the body as a complex system of cells that is part of a network of networks, which is essential to maintain a healthy living organism and is more than the sum of its parts. These concepts from biology can be applied to global health care networks[4] and could inspire a holistic model for the HTA ecosystem to improve multi-stakeholder collaborations.

The living organism of health care is collaborative, integrating many scientific disciplines – biology, computer science, engineering, bioinformatics, physics and others – we need to predict how these systems change over time, under varying conditions and develop solutions to the world's most pressing health and environmental issues.

For HTA and health care, there is a need to intensive the scientific and policy dialogues across the whole life cycle of health technology, including healthcare providers, HTA bodies, pharma industry, patient groups and regulatory agencies. As outlined in Figure 3, this needs to start at a very early stage, before a technology is developed. Such very early dialogues could identify needs, define priorities and agree core outcome sets. For example, Sanofi has worked in Africa to explore the potential of digital health and in Latin America to help identify priorities and develop policies. When a health technology is being developed, Early Dialogue/Scientific Advice with HTA and regulators is important to understand if the research plan is acceptable. This may need to be iterative at important decision points as evidence accumulates and should be multi-stakeholder including, clinicians and patients. In Europe, work is underway to consider how Joint Clinical Assessment reports can be developed in an efficient manner. There is a need to consider whether post-licensing evidence generation (Managed Entry Agreements) is required and what stakeholder roles are in that process. Then there may be a need for HTA reassessment to consider whether the health technology should be maintained in the health system or be disinvested.

[4] Hoffman SJ and Cole CB Mapping of Global Health Actors & Networks. Global Health. 2018; 14: 38. https://doi.org/10.1186/s12992-018-0340-2

Figure 3. Opportunities for multi-stakeholder engagement before and over the whole medicine life cycle
Modified from European network for Health Technology Assessment (EUnetHTA) JA3 2016-2020



Reflecting on the biological system, if one part of the system is not functioning properly the ecosystem can become ill or even die, so collaboration is needed to ensure the ecosystem is healthy. In the healthcare ecosystem, all stakeholders share the goal of improving the health of patients, which can be achieved through optimization of health care systems and pharma research and development. With appropriate rules of engagement, collaboration can enable dialogues about science and policy issues that builds trust among all parties. HTAi is an ideal safe harbour for such multi-stakeholder collaborations and dialogues.

4. Developing better multi-stakeholder collaboration in HTA beyond 2020 - HTA Perspective

Dr. Ed Clifton, Unit Head, Scottish Health Technologies Group (SHTG)

Dr Clifton gave an overview of the work of SHTG and reflections on how to develop better multi-stakeholder collaboration considering two key areas:

1. involving clinicians, patients, public and industry in understanding the broader concepts of value in its appraisal work
2. aligning SHTG work to focus on informing health service decisions.

4.1 Involving stakeholders to understand the broader concepts of value

SHTG is the national HTA body in Scotland that provides independent evidence reviews and advice to inform NHSScotland decision-making about the use of new and existing non-medicine health technologies[5]. SHTG seeks to be receptive to the needs of stakeholders and, in doing so, aims to make best use of staff expertise and put collaboration at the heart of its approach. The SHTG (appraisal) Committee includes representatives from each health

[5] Including ddiagnostic test, medical device, interventional procedure, patient pathway

board in Scotland, across a number of core functions (Chief Executive, Finance Director, Medical Director, Primary Care etc.) and includes four public partners and two members from the medical device industry. Each is a full member, with equal influence and subject to the same code of conduct for management of interests.

The new international definition of HTA stresses not only the multidisciplinary and scientific aspects of the process, but also allows for the inclusion of value judgements to inform decision-makers. The importance of these broader concepts of value has been driving the evolution of the way SHTG undertakes HTA.

Figure 3. SHTG process to understand broader concepts of value

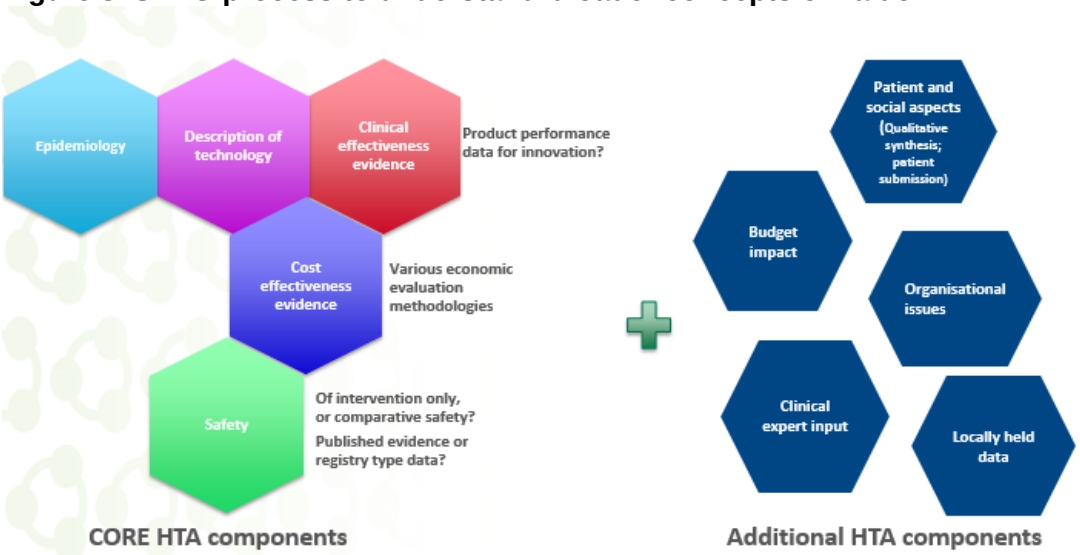


Figure 3 provides a framework for SHTG collaboration with its stakeholders; illustrating how assessments can be tailored to include 'additional HTA components' alongside 'Core HTA components'. This approach facilitates a broader understanding of value when seeking to provide timely advice to decision-makers.

As Voltaire said, "uncertainty is an uncomfortable position, but certainty is an absurd one." It is almost impossible to have full information and complete certainty. A balance must be struck between comprehensive of assessment versus timeliness to inform decisions and some gaps can be filled by improved stakeholder engagement. SHTG has developed processes to engage with topic proposers to understand the heart of their question in relation to the decision to be made in NHSScotland and this helps focus the HTA components accordingly. In addition to stakeholder collaboration, making best use of all relevant data is important. Scotland has good health data that could be used alongside published evidence to understand use of health technologies in the Scottish setting.

The ultimate goal is to provide meaningful information for decision-makers and this is improved through targeted involvement of clinicians, patient groups, public partners and industry as outlined in Table 1.

Table 1. Stakeholder involvement in SHTG

Stakeholder	Role *(learnings)*
Clinicians	Topic advisor • Work with researchers to scope the appraisal • Identify clinical groups to provide and receive information
	Peer review • Of draft SHTG outputs (Evidence reviews, SHTG Advice)
	Expert group meeting (optional) • Validation/sense-check of modelling inputs prior to presentation to SHTG committee
	Clinical expert input to SHTG Committee • Specific and insightful perspectives about use of the health technology in Scotland • *Issues around relevant interests and process during meeting*
Public	SHTG Public Partners sit on Assessment and Appraisal Committees • Four public partners, supported by SHTG Public Involvement Advisor • *Good feedback on their experiences at SHTG*
	Lay summaries • Produced for all SHTG Advice since March 2018 and published on website
Patients	Mechanism for patient involvement • Agreed criteria used to determine the type of patient involvement at the outset of each HTA (also reviewed during the process)
	Patient organisation contribution to SHTG committee since June 2018 • Diabetes Scotland, Bowel Cancer UK, MS charities recent submissions • Patient group presents during SHTG Committee meeting and can contribute to initial discussion • *Positive feedback from the patient organisations and SHTG Committee*
	Supporting patient organisations • Public Involvement Advisor building relationships with individual patient organisations and umbrella patient groups • Pro-actively engaging with patient organisations at the beginning of the SHTG review process to agree the appropriate level of involvement • SHTG topic proposal form being promoted to patient organisations
	Patient Issues Search • Dedicated social and patient aspects section within each review • Peer reviewed by patient organisations
Industry	Discussion of strategic direction • Industry User Group established from outset, now 'MedTech Forum', with industry co-lead and support from Association of British HealthTech Industries • Life Sciences Scotland Industry Leadership Group • Liaise with Scottish Government
	Process developments as part of MedTech Forum • Explaining how industry can be involved in SHTG work • Industry submissions • Peer review of draft SHTG outputs • Implementation and the 'so what'…?

4.2 Aligning SHTG work to inform health service decisions

HTA bodies often undertake a range of activities including:

- *horizon scanning and trying to identify the 'right' topic*
- prioritisation of what to assess
- assessment of effects and impacts
- appraisal to determine overall value
- *implementation.*

SHTG is a small organisation that needs to focus its work. Therefore, emphasis is placed on improving its prioritisation, assessment and appraisal processes, whilst offering support towards improving horizon scanning and implementation across Scotland. For example, SHTG seeks to align with key groups in Scotland who have an awareness of priority areas and live issues to identify the right topics and with groups that have the ability to affect change. Within Scotland, examples include National Planning, National Specialist Services and Chief Executive groups.

SHTG intends to continue to evolve the way it collaborates with different stakeholders in 2020 and beyond to ensure that its HTAs consider the broader concepts of value and inform important health service decisions.

5. Patient involvement in HTA - 2020 and beyond

Neil Bertelsen, Chair HTAi Patient & Citizen Involvement Interest Group

Mr. Bertelsen reflected on the evolution of patient involvement in HTA over the past decade, considering how the challenges and lessons learned could inform multi-stakeholder collaboration.

The HTAi Patient and Citizen Involvement Interest Group (PCIG) has taken a leading role in working with all stakeholders in the HTA community to develop methods and share good practices. In 2014, HTAi published tools to support patient group submissions to HTA and through a rigorous Delphi process it developed Values and Quality Standards for Patient Involvement in HTA[6]. The Values, which should drive all patient involvement processes in HTA are relevance, fairness, equity, legitimacy and capacity building. Capacity building, for both HTA bodies and patient organisations, is particularly important to address barriers and enhance collaborative working. The question is what concepts and values would drive HTA collaboration with other stakeholder groups?

PCIG has recognised that in terms of implementing patient involvement processes in HTA there is no “gold standard”. Mechanisms for patient involvement need to take account of the remit of the HTA body, its legal basis, resources, connectedness in international networks, the structure and funding of the health system. This is further influenced by the cultural and societal context of the healthcare system and politics in which patients and patient groups interact. It is imperative to think about the best approaches to patient involvement within systems and societies. This has led to development of a wide variety of methods for patient involvement. Examples include informal discussions with patients organisations on an ad hoc basis, public consultation, written submissions from patient groups, patient and public representation at committee meetings, patient testimony. The methods used depend not only on context, but on the purpose of involvement, which will be different at different stages of HTA – from Early Dialogues to scoping, evidence submission, committee deliberation and publication of HTAs.

Case studies can demonstrate the impact of different approaches.

In England, a costly, biologic treatment for ulcerative colitis (UC) was appraised by NICE that resulted in remission, not cure. This meant that bowel surgery may be delayed, but still have to be paid for by the health service within the lifetime of the patient and patients would likely still suffer consequences of surgery. So, there was a need to quantify what that delay in surgery was worth to patients. Patient groups made submissions to the appraisal committee,

[6] https://htai.org/interest-groups/pcig/values-and-standards/

and patients and their representatives contributed to the appraisal meeting. They clarified the burden of the condition (being housebound with frequent hospitalisations) and noted a specific population for whom delaying surgery would be particularly important – namely teenagers and young adults. They could be, for example, studying for exams, looking to find a partner or starting their career and surgery is particularly unacceptable to them as it impacts fertility, ability to socialize, is irreversible and has life-long impacts. The new treatment could potentially give complete remission and give patients their lives back. Here the patient involvement clearly articulated why surgery as a comparator was unacceptable to this particular patient population. Therefore, the committee concluded that “a drug treatment which brings disease into remission would have a major effect on quality of life and that avoiding surgery was important to people with UC”.

In Canada, a treatment for kidney cancer with a novel mechanism of action was only recommended for restricted use as another treatment, with a different mode of action, had already recently been recommended nationally by CADTH. This led to divergent decisions in the Provinces about whether the new treatment could be offered to patients. As a result, the Provinces initiated a “Request for Advice” call, but CADTH had no data comparing the two treatments, making specific advice difficult to develop. The patient groups had 10 days to submit information. They recognised that the decision-makers did not need to know about the burden of the disease on patients, instead they wanted to know if these two new treatments delivered comparable outcomes. There were no head-to-head trials to answer this question definitively. So, Kidney Cancer Canada tapped into a patient registry which they had helped establish. They worked with researchers to extract data on the effects of the two treatments and were able to show similar outcomes. CADTH used the data provided by the patient group to update its guidance and recommended use of either treatment.

A lot has been learnt through the evolution of patient involvement in HTA over the past decade and there is evidence that it actually helps decision making. However, thinking about 2020 and beyond, we need to critically reflect on our processes. For conditions where there is a lot of innovation, a large burden has been placed on patients and patient groups to be involved in HTAs. For example, in the UK a lung cancer patient group was asked to contribute to 16 HTAs in one year. Patient groups also have limited resources and they have to decide whether to be involved in an HTA and if their input will make a difference to the decision. For the lung cancer case, the patient group worked with their scientific board to identify the treatments that were most important to invest their time in.

In terms of making a difference to the HTA, patient groups are recognizing that they can put a lot of effort into a patient group submission, but when they hear the HTA deliberations, they realise that the uncertainties in the evidence are so large that their input is never going to close the gap and lead to a positive recommendation. In such circumstances they wish that they had more visibility on this before they invested the time and resources into their submission.

Another challenge is that the patient community has heeded the call from HTAs to generate good submissions, including good evidence in short timelines – which puts immense pressure on patient groups to deliver within the timeframe. However, as treatments become more targeted and personalized, patient groups often struggle to find a patient in their country who fits the criteria for the relevant patient population and has experience of the new treatment.

Solutions to these problems of patient participation at the pressurized HTA appraisal timepoint are presented in Figure 4. They begin with patient involvement much earlier in the life cycle of technology development to focus patient-focused clinical evidence fit for HTA and include development of high-quality patient-based evidence that can be shared across sectors.

Figure 4. Trends that could take the pressure off patient groups to be involved in HTA in 2020 and beyond

Patient involvement much earlier in development	• Patients' perspectives are already reflected in evidence package • Less pressure on developing quick evidence from the patient community at point of appraisal
Increased use of patient preference studies, rapid Qualitative Evidence Synthesis and tools such as MCDA	• Industry, research community and HTA bodies build patient-based evidence about preferences, perspectives, experiences and outcomes • Patient involvement still needed to contextualise evidence
Shared libraries of patient experience data (and more patient-based evidence from regulators)	• Regulators such as FDA renewing a focus on patient experience data • Chance to build an international library of evidence to be shared

6. Discussion

Dr Facey thanked the panelists for their interesting contributions and reflected on the need for "smart stakeholder collaboration", who do we need to involve, how and when, for what purpose. The audience were invited to ask questions.

****

Gesa Pellier (Novartis): How has the set of stakeholders involved in HTA changed with the evolution of science and technology?

EC – The set of stakeholders has changed and continues to change. In Scotland, it is influenced by what is happening in Scottish government. For example, there are new initiatives relating to artificial intelligence and big data that SHTG has been given extra resource to contribute to. SHTG has also been involved in processes to support innovation in Scotland, contributing to wider government initiatives to boost the economy.

AG – The HTA ecosystem is evolving, so new actors need to enter. For example, there is a need to build capacity in health data analytics.

SG – From a global health perspective, there has been a concern about talking to the private sector (industry). Now there is formal engagement through the International Federation of Pharmaceutical Manufacturers and Associations and with some individual companies on specific issues. It would be good to see more of that engagement, with companies proposing solutions for how they can support access to health technologies. In terms of patient involvement, cultural contexts of some countries can make this challenging. Currently WHO focus on civil society engagement, but we can learn from HTAi and others.

NB – Patients would like to see engagement outside the traditional areas of the submission process, and as healthcare delivery becomes more complex, new approaches to involvement will be needed that include all patients, including those who are currently considered as "hard to reach".

KF – Academics involved in patient preferences and qualitative research need to be involved to understand the rapid timelines of HTA and consider how patient-based evidence can be developed to inform HTA decision-making.

****

Patient group representative for a global group in a rare cancer: The burden on patient groups is clear and actually worse for rare diseases. Thinking about collaboration beyond 2020, what's the potential for working across HTAs to create better, more efficient ways of patient involvement? Could a group of HTA bodies create a database of patient experience that would be useful at the front end of HTA?

NB – This issue has been raised frequently, particularly within disease areas as shown in the lung cancer case. There is also often a flow of product launches around the world. A patient group in the first launch country may start gathering evidence, but then there is a question about how that can be shared to support later HTAs in other parts of the world. Some of this is happening already and it will be accelerated, for example by the FDA initiative that is requesting patient experience evidence as part of the regulatory submission. However, there is more to be done, not just within a single disease area, but also across the patient advocacy community to create a knowledge-base for patient-based evidence. The challenge is to find a place to hold such information. We aren't there yet, but it's really needed.

SG – There are some platforms to capture patient experience, such as the Centre for Community Driven Research[7] in Australia, Patients Like Me[8] and healthtalk.org (previously called Dipex). We need to review these to understand their remits and map out the gaps.

AG – There is investment in some of these platforms, particularly for rare diseases. One of the challenges is that industry, patient organisations and others are doing different things. The question is how can we work together.

KF – PCIG had hoped that HTAi would be the home for such repositories/databases but it has not yet been possible to create the technical infrastructure and it requires funding.

SG – All these initiatives struggle to get funding as they are not on the radar of funders. We need to bridge that so that it is not imperative to take industry funding to exist. We also need to be more understanding about why it is necessary to do so, focusing on how to manage perceived or real conflicts of interest. So perhaps a philanthropic funder is needed.

****

Conor Teljeur – Chief Scientist HTA, HIQA, Ireland: How can the whole process of developing and adopting a new technology be made more coherent so that there is consistent use of collaboration, expertise and knowledge carried through? This considers the steps before and after the HTA from when the first evidence of effectiveness of a technology is published through regulatory approval, HTA, policy decision and implementation. At present the process is disjointed with different people inputting at different stages, with much wheel reinventing. I suspect that collaboration is undermined when people get the feeling that their input does not directly feed into a roll-out decision.

EC – The work SHTG has done to focus its assessments on health service needs and provide more directive advice is aiming to smooth that pathway to adoption. SHTG is also being more transparent about reassessment of some technologies to share understanding of the use of a technology in the health service among all stakeholders.

[7] www.cc-dr.org
[8] www.patientslikeme.com

After the meeting CT submitted the following additional considerations and questions that have been responded to by the authors.

CT - Should we view the media as a stakeholder that we should be collaborating with? They act as a conduit for information that goes to the public and they can [un]intentionally distort a message with grave consequences. We have had major issues in Ireland with HPV vaccination and more recently our Cervical Screening programme. Our general route is to provide media with a press release at the time of publication but maybe we need to get them on board more and educate them so that they may educate the public.

KF - The media is an important stakeholder. Some other professional societies provide specific training for journalists and give awards for good journalism in the field (e.g. the Royal Statistical Society in the UK).

CT - How do we represent patients who will not benefit from the intervention, but actually stand potentially to lose due to the redistribution of resources? Do we need citizen/patient forums and can they feed into the HTA process from start to finish?

KF – In some HTA processes the “public partners” or lay members have a role to be the “citizens” voice and some have explicit citizen engagement processes through citizen juries. Public consultation is also an opportunity for citizen engagement.

CT - How do we manage ongoing and meaningful collaboration in small countries where there is a serious risk of stakeholder fatigue (the same people repeatedly giving up their own time and energy)? Can we pool expertise across agencies in such small countries?

SG – We need to think about how to capacity develop and engage stakeholders in the discussion. Learning from good examples and enable communication.

KF – Collaboration is often easiest across countries that have similar cultures and systems, so the Celtic collaboration between Ireland, Scotland and Wales is interesting. It shows that evidence, analyses and processes can be shared to reduce duplication but input to decisions that are bespoke. Also, HTA bodies could use information from past assessments to inform their work and check it with stakeholders to find out new information.

CT - Is there any evidence about what works best in collaboration – does absolute clarity of purpose, terms of reference, and expected outcomes of the process help? What agencies collect feedback from collaborators and what do they find? For such an evidence-based discipline, I’m not sure we take a very evidence-based approach to collaboration.

KF – Some HTA bodies have evaluated different elements of collaboration. There are various publications about evaluation of patient involvement in HTA processes. Some HTA bodies take feedback on their appraisal meetings from the stakeholders involved and use this in organisational development. Some HTA bodies undertake regular developmental workshops with particular stakeholder groups.

****

Dr Facey asked the panelists to give their final reflections on what was needed to improve multi-stakeholder collaboration in HTA up to 2030.

NB – Taking what we've learnt already from involvement of specific stakeholder groups and applying that to multi-stakeholder collaborations. Identifying what has worked well and why, considering what that means for multi-stakeholder collaborations in 2020-2030 to make them grow and work well.

EC – We need meaningful multi-stakeholder collaboration in the future. The answer to the "so what" question.

SG – There is a need to highlight best practice and make the case for why multi-stakeholder collaboration is important and how it helps.

AG – Need to have platforms for collaboration – such as the Innovative Medicines' Initiative public-private partnership. It would be interesting to consider if such partnerships can go beyond scientific issues to consider policy questions that relate to all stakeholders, for example improving the efficiency of health care systems and of research and development.

****