

## **HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, May 2023**

*Enhanced quality and relevance of HTA through patient and citizen involvement*

<http://www.htai.org/interest-groups/patient-and-citizen-involvement.html>

- Welcome – from our Chair
- PCIG Matters – Call for steering committee and co-chairs, IGs, Impact, Annual Meeting planning, other matters
- HTAi Matters – HTAi2023 Adelaide
- What's Happening – in and for patient and public involvement
- Publications

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### Welcome to our May E-Bulletin

#### *From our Chair*

I confess I've become addicted to our social media. This week, our LinkedIn page has been slowly edging towards 2000 followers. As I write this, we're a painful 16 followers short. I know it's not an important number and nothing will change when we hit 2000, but still I find myself excited that nearly 2000 people are interested. Perhaps it is because I know that following grew not from any click bait or sponsored content, but from sharing the output of this group. The content is webinars, workshops, manuscripts, new tools and guidance, and opportunities. Just like the PCIG membership, our followers come from all over the world, and from different stakeholder groups and disciplines.

By the end of this month, four of our 8 current PCIG Project Sub-Committees will complete with follow up actions for Steering Committee and another project will become an ongoing activity. Two further projects will complete in the second half of this year. I'm incredibly grateful to the project sub-committee leads and members who've managed to progress our understanding of patient and citizen involvement, and adoption of good practice as we travel with COVID and the depleted resources and reserves that accompany it. While it's tempting to embark on a number of new 'must do' projects, the Steering Committee believes that there is merit in pausing to reflect and secure our foundations. With this mind, the first new project will be a review of PCIG resources to ensure they reflect the knowledge and experience gained in recent years and are much easier to access and use. If you're attending HTAi 2023 Adelaide, please come to our Annual Business Meeting (details below) to discuss this more. If you can't attend, all PCIG members will receive the slide deck and papers.

This will be my final time welcoming you to the PCIG e-bulletin. Expressions of Interest for our Co-Chairs and Vice-Chair are due Friday 9 June and an announcement will be made at our Annual Business Meeting and circulated afterwards to all by email. Chairing this group has been an absolute privilege and mostly a joy. I have as much enthusiasm for the work of PCIG as I did when I began and primarily step down to give PCIG the benefit of fresh minds in the role. With HTAi's commitment to better integrating the Interest Groups, it's an especially exciting time for ensuring patient and citizen involvement in HTA is never again an afterthought or marginal concern. Thank you for your support and dedication.

Ann Single, Chair – HTAi Patient and Citizen Involvement Interest Group  
[singlehaworth@gmail.com](mailto:singlehaworth@gmail.com)

NOTE: Present and past issues of the E-Bulletin can also be accessed on the website  
<https://htai.org/patient-and-citizen-involvement/>

Social media accounts on [LinkedIn](#) and [twitter](#) (@pcisg)

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## PCIG Matters

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### Expressions of Interests

These are being sought for Steering Committee members and PCIG Steering Committee Vice Chair and Co-Chairs (under the new Terms of Reference - see attached - the role of Chair has been changed to two co-chair positions).

- For non-officer positions (a Steering Committee member) an Expression of Interest should be no longer than 200 words.

- To apply for co-chair or vice-chair, please send your CV (no more than 2 pages) and a letter addressing the criteria to [patient-citizen@htai.org](mailto:patient-citizen@htai.org) no later than 9 June.

*The Steering Committee is currently:*

Ann Single, Chair (Patient Voice Initiative, Australia)

Neil Bertelsen, Outgoing Chair (nb consulting, Germany)

Anke-Peggy Holtorf, Project Co-ordinator (Health Outcomes Strategies, Switzerland)

Todd Stephenson, Financial Secretary (Janssen, Australia)

Sarah Berglas (CADTH, Canada)

Ana Toledo Chavarri (Canary Islands Health Service, Spain)

John Gillespie (Abbott, Asia-Pacific)

Barry Liden (USC Schaeffer & Patient Voice Advisors, USA)

Heidi Livingstone (NICE, UK)

Kate Morgan (Myeloma Patients Europe, UK)

Aline Silva (Patient Voices Network, Canada)

Valentina Strammiello (European Patients Forum, Belgium)

### The HTAi Public Health Interest Group (PHIG) is searching for its next co-Chairs

Do you have a passion for HTA in Public Health? This is your opportunity to shape the direction of the PHIG!

Learn more about the roles and how to apply: <https://t.co/7WvcTqPGTd>

### Are you interested in learning about Early HTA?

<https://t.co/8UzKnCty1L> <https://t.co/ozj21ska1u>

A group of HTAi members is issuing a call for all parties who may be interested in participating in an Early HTA working group and the definition of Early HTA! They have a panel presentation during the Annual Meeting in Adelaide entitled "What Is Early HTA And How Can It Facilitate Timely Patient Access To Valuable Innovations" on Monday, June 26, 13:20-14:45.

The group will also meet, on Tuesday, June 27 | 16:15 – 17:15 at the Home Ground Bistro (attached to the Conference Centre). To join the meeting, please contact Janet Bouttell [janet.bouttell@glasgow.ac.uk](mailto:janet.bouttell@glasgow.ac.uk)

### Impact of patient involvement

#### Recording available: PCIG Webinar on Impact of Patient Involvement in HTA

Did you miss PCIG's webinar 'A Framework for Characterizing Impact of Patient Involvement in HTA'?

The team has been evaluating multi-stakeholder perspectives about the perceived difference patient involvement makes in specific HTAs or HTA processes. During the recent webinar, the team presented the results of this work, including three key domains in which patient involvement is seen to have an impact. The presentation ended with an interesting discussion about potential next steps and ways to use these domains to facilitate reporting of impact across HTA contexts.

You can watch the recording [here](#).

To learn more, please contact the project co-leads: Aline Silva ([alinefarunb@gmail.com](mailto:alinefarunb@gmail.com)) or Veronica Lopez Gousset ([veronica@globalhelpgranted.com](mailto:veronica@globalhelpgranted.com)).

Contributed by Veronica Lopez Gousset

### **There has also been a recent publication on the types of impacts:**

Gunn C, Regeer B, Zuiderent-Jerak T (2023). A HTA of what? Reframing through including patient perspectives in health technology assessment processes. *Int J Technol Assess Health Care* 39(1), E27. [doi:10.1017/S0266462323000132](https://doi.org/10.1017/S0266462323000132)

Three vignettes showcase how different parameters of assessment become reframed upon the positioning of patient knowledge alongside other forms of evidence and expertise. First, cost-effectiveness considerations were reframed during an appraisal of a rare disease medicine based on patient and clinician input regarding its treatment pathway; in the second vignette reframing amounted to what counts as a meaningful outcome measure for a glucose monitoring device; in the third, evaluating pediatric transplantation services involved reframing an option's appropriateness from a question of moral to one of legal acceptability.

Conceptualizing patients' involvement helps us to consider the inclusion of patient knowledge not as complementary to, but as something that can transform the assessment process.

Contributed by Ann Single

### **And a good pragmatic discussion on challenges to capturing impact:**

**NIHR Involvement: How do you capture impact from public involvement without reducing it to a numbers exercise?** [https://www.youtube.com/watch?v=D-14\\_yQrL5k](https://www.youtube.com/watch?v=D-14_yQrL5k)

At a recent webinar event Kristin Liabo of the Peninsula ARC, unpacked common assumptions and presented work on how impact was studied in-depth.

The work follows an earlier publication:

Epistemic justice in public involvement and engagement: Creating conditions for impact  
Kristin Liabo, Emma J. Cockcroft, Kate Boddy, Leon Farmer, Silvia Bortoli, Nicky Britten  
*Health Expectations* (2022) 25(4):1967-1978. <https://doi.org/10.1111/hex.13553>

This article presents an analysis of 3 meetings and 11 interviews with public collaborators and researchers in three UK-based health research studies. Data comprised transcripts of audio-recorded research meetings and interviews with public collaborators and researchers. At meetings, public collaborators shared their experiential knowledge as stories, comments, questions, answers and when referring to their own roles. Although researchers and public collaborators made efforts to create an inclusive climate, obstacles to impact were identified.

### **Frontiers in Medical Technology**

A Frontiers e-book, comprising all the articles featured in your Research Topic [Where to From Here: Advancing Patient and Public Involvement in Health Technology Assessment \(HTA\) Following the COVID-19 Pandemic](#), has been compiled and is now available online on our website, [here](#).

It can also be found on the [Research Topic homepage](#), where all articles are also individually available.

### **EUNETHA guidance for patients and healthcare professionals**

Find it on this webpage <https://www.eunetha.eu/d7-2-3/>

Contributed by Dominique Hamerlijck

### **HTAi2023 Annual Meeting:**

### **PCIG Annual Business Meeting**

In line with our Terms of Reference (see 10.1), PCIG will hold its Annual Business Meeting at the HTAi Annual Meeting. Date: Tuesday 27 June 2023. Time: 12:35 – 13:35 pm

Location: Gilbert Room, Adelaide Convention Centre (following the HTA Consumer Brunch)

Packed lunch available.

An agenda of the business to be transacted will be given to all members at least seven (7) days in advance. The notes of this meeting will be circulated to all members of the Interest Group documenting the actions planned for the forthcoming year.

### **Patient and Citizen Involvement in HTA workshop, June 24**

Don't forget to register for our pre-annual meeting workshop. In the morning, speakers from around the globe will provide an:

- Introduction to HTA and patient involvement
- Introduction to resources to support patient participation in HTA
- Introduction to different forms of patient-based evidence

In the afternoon, we have three streams to choose from:

Asia Pacific 360: What's currently happening in patient involvement in HTA in the Asia Pacific, what goals do we have, can we work together to document practice and describe good practice?

Training: What's currently being offered to patient communities, where are the synergies, where are the gaps, how should this inform PCIG's review of its tools and resources?

Patient Preferences: How are patient preference studies currently informing HTA, how can we work together to improve their integration.

### **Other matters:**

#### **How do patient communities want to interact with pharma? Webinar**

New date: Thursday 24 August 12:30 AEST

Patient communities are often asked to complete surveys to measure pharma's corporate reputation, but Patient Voice Initiative and CaPPRe wanted to know how patient communities in Australia want to work with pharma and if patient involvement is improving. So, they undertook focus groups to identify 11 domains of interaction that matter to patient communities, before collecting data using two Best Worst Scaling (BWS) tasks to understand their relative importance and satisfaction and create an engagement index score for future benchmarking.

[Register here](#) to join a discussion of the findings of this survey, as well as the implications of the results, including potential approaches to improving domains of low satisfaction and high importance. Speakers: Simon Fifer (CaPPRe), Jessica Bean (PVI), Gabrielle Bietola (AstraZeneca & MA CAWG), Janelle Bowden (AccessCR and Research Gamechangers).

### **Exploring system reform opportunities that will enhance patient centricity in Australian healthcare**

Biointelect and Bristol Myers Squibb (2023) [Bring patient centricity to life](#)

This white paper highlights the key concerns and aspirations of participating health consumer organisation for reforming Australia's HTA system to meet the needs of Australian patients. The paper presents 10 recommendations across 3 key themes to enhance consumer engagement, incorporate broader value considerations in the evaluation of new medicines and improve the speed of access to innovative medicines. The recommendations range from broad scale system reform, to smaller, practical steps towards practice and process improvements.

Contributed by Ann Single



## HTAi 2023 Annual Meeting, June 24 to 28, Adelaide: The Road to Policy and Clinical Integration

<https://htai.eventsair.com/htai-23-adelaide-am/main-theme>

Fast-Tracking Clinical Innovation: The Balance of Speed and Rigour

Making HTA More Efficient: What Can we Learn about Harmonization, Work Sharing, and Adaptation?

Feasibility of Aligning Technology Evaluation Processes and Decisions in an Era of Sustainable Development

[View the Schedule-at-a-Glance](#)

### *Important dates:*

Welcome Reception Sunday, June 25 at 19:00 —at the Adelaide Convention Centre

Patient Lounge Monday, June 26 – Wednesday, June 28 — The Patient Lounge aims to facilitate a patient-friendly environment to improve the overall experience of patient delegates. The space is for registered patients to rest and refresh, which offers a number of accommodations specific to patient needs.

Consumer Consultative Brunch Tuesday, June 27 at 11:10 — Consumer focused presentation and a panel discussion, followed by a brunch & mingle. This session is primarily targeted at consumers; however, it is open to all meeting attendees.

PCIG Annual Business Meeting Tuesday 27 June 2023. Time: 12:35 – 13:35 pm. Packed lunch available.

Conference Dinner Tuesday, June 27 at 19:30 — at the Adelaide Oval.

Registration at <https://htai.eventsair.com/htai-23-adelaide-am/annual-meeting-registration>

Standard Registration Deadline: Thursday, June 15, 2023 (Midnight MST)

Last-minute registration: Friday, June 16 to Wednesday, June 28, 2023

[View the Workshop program](#) : June 24–25, 2023

The HTAi 2023 Annual Meeting Workshops will take place at the University of Adelaide Health and Medical Sciences Building. A map indicating the venue location, as well as the event floorplan, is [available here](#)

A selection of Sunday workshops:

WS14 – Engaging Stakeholders to Strengthen Health systems in Low- and Middle-Income Countries (LMICs) moving towards Universal Health Coverage

Date & Time: Sunday, June 25 | 8:30AM to 12:00PM

Presenters: Jani Mueller, Anke Peggy Holtorf, Lauren Pretorius, Marilia Mastrocolla de Almeida Cardoso

Summary: This co-creation workshop addresses current hurdles in LMICs with the aim to strengthen evidence-informed decision-making for achieving more sustainability and inclusiveness in health systems on the path to universal health coverage. The multi-stakeholder participants will spend exciting 3 hours designing together possible pathways to implement HTA processes that fit the context of LMICs.

[Register Now](#)

WS15 – Values In Doing Assessments Of Healthcare Technologies (VALIDATE)

Date & Time: Sunday, June 25 | 8:30AM to 12:00PM

Presenters: Bart Bloemen, Carla Fernández Barceló, Pietro Refolo, Iñaki Gutiérrez Ibarluzea, Wija Oortwijn

Summary: HTA is widely seen as a specific type of policy-research. However, in its course of development it has failed to take account of crucially important insights from policy sciences. The VALIDATE (VALues In Doing Assessments of healthcare Technologies) approach aims to redress this and offers a framework for integrating stakeholder perspectives and ethical analysis

[Register Now](#)

WS20 – All things publishing: submitting to HTAi’s journal (IJTAHC) – what’s your article type and hot topics in publishing

Date & Time: Sunday, June 25 | 13:00PM – 16:30PM

Presenters: Wendy Babidge, Wim Goettsch, Sophie Werkö, Tara Schuller

Summary: Join Editors of HTAi’s journal (IJTAHC) to update on key areas in publishing and submission of articles. This session will comprise several short presentations, firstly highlighting the importance of IJTAHC to HTAi, describing article types for IJTAHC and other similar journals that will be followed by an interactive session where anonymized abstracts of articles will be reviewed by participants.

[Register Now](#)

WS22 – The Design Of Health Technology Assessment Processes Using Evidence-informed Deliberative Processes In Low and Middle Income Countries

Date & Time: Sunday, June 25 | 13:00PM – 16:30PM

Presenters: Wija Oortwijn, Maarten Jansen, Maryam Huda, Lyazzat Kosherbayeva

Summary: On their path towards universal health coverage, governments need to make choices in the design of HTA processes which may be challenging in countries that have limited experience with HTA. This workshop provides practical guidance on how to make these choices, informed by the theory of evidence-informed deliberative processes, international best practices and practical examples from several middle-income countries.

[Register Now](#)

**The HTAi Review** your biweekly news source for all things HTAi at <https://htai.org/htai-review-may-26-2023/>

to catch up on HTA news and updates from around the world.

**Website:** <https://htai.org/>

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Feel free to follow us or check in on our social media channels and re-post our messaging:

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[Facebook:](#) @HTAiOrg

[LinkedIn](#)

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#### What’s Happening

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##### **FDA Project Orbis: A three-year review**

<https://www.fda.gov/about-fda/oncology-center-excellence/project-orbis>

The project was launched by the FDA Oncology Center of Excellence to facilitate faster patient access to innovative cancer therapies in multiple countries. Leveraging a consortium of participating regulatory agencies across countries, Project Orbis aims for concurrent submission, review, and regulatory action for high-impact clinically significant marketing applications. This highlights the benefits and challenges for stakeholders in the 3½ years since the first regulatory decision under Project Orbis took place in September 2019

##### **How ‘surrogate outcomes’ influence long-term health outcomes**

<https://www.nice.org.uk/news/blog/how-surrogate-outcomes-influence-long-term-health-outcomes>  
Building our understanding of the relationship between surrogate outcomes and how they influence longer-term health outcomes ... has led to an increase in drugs that are approved based on improving a surrogate outcome in clinical trials

Dr Jacoline Bouvy, Technical Director, UK NICE Scientific Advice

### **G7 Global Plan for UHC Action Agenda**

G7: spotlight on Health Financing for universal health care, digital rights management and global health institution architecture - synergies, sustainability, integration.

<https://www.mhlw.go.jp/content/10500000/001096405.pdf>

### **The International Society for Priorities in Health (ISPH)**

The Society exists to strengthen the theory and practice of priority setting in health care. The Society provides the leading international forum for health researchers, clinicians and managers involved in priority setting to come together to exchange ideas and experiences.

The 14th ISPH conference will be hosted by the [Health Intervention and Technology Assessment Program \(HITAP\)](#) in Bangkok.

HITAP Thailand: Priorities2024 Conference is coming to Thailand on 8-10 May 2024 under the theme 'Shaping the Future of Health Prioritization: strategies for sustainable solutions'! Get more information and subscribe for updates. <https://priorities2024.com/>

### **[FDA approves ALS drug](#)**

The US Food and Drug Administration has approved pharmaceutical company Biogen's drug for a rare form of motor neuron disease, known as amyotrophic lateral sclerosis (ALS), despite uncertainty that the treatment works. The drug tofersen, which will be sold as Qalsody, can reduce levels of a protein that has been linked to damage to nerve cells. However, clinical trial results showed that [the drug did not slow the disease's progress](#) or improve participants' ability to speak, swallow or perform other activities of daily living.

### **["I console myself with the normal excuse: If I hadn't done it, somebody else would have."](#)**

Pioneering artificial-intelligence researcher Geoffrey Hinton has quit his job at Google so he can speak freely about the dangers of the technology, and says that a part of him now regrets his life's work. Geoffrey Hinton was an artificial intelligence pioneer. In 2012, Dr. Hinton and two of his graduate students at the University of Toronto [created technology](#) that became the intellectual foundation for the A.I. systems that the tech industry's biggest companies believe is a key to their future.

"The idea that this stuff could actually get smarter than people — a few people believed that," he said. "But most people thought it was way off.

The best hope is for the world's leading scientists to collaborate on ways of controlling the technology. "I don't think they should scale this up more until they have understood whether they can control it," he said.

### **What's the greatest untapped resource in healthcare right now? Hint: you're probably holding it on your phone**

<https://datasaveslives.eu/blog/whats-the-greatest-untapped-resource-in-healthcare-right-now-hint-youre-probably-holding-it-on-your-phone52023>

May 11, 2023. Madeleine Brady, inflammatory bowel disease (IBD) patient, Engagement Consultant and formerly a comms lead for Health Outcomes Observatory (H2O), presents a personal view on the impact of H2O on patients.

If you have the usual features of a Smartphone, you probably already gather PROs. You could be doing this through even the simplest health app. These apps can be great to track your sleep, calorie intake, or how many stairs you might have climbed. Some of us even track specific conditions by filling in migraine apps, tracking menstrual cycles, or keeping an eye on our moods; all very typical examples of PROs. They are a

great way to keep an eye on our own health, get a sense of changes over time, and prompt discussions with our healthcare providers.

H2O recently held an event to celebrate the launch of the H2O observatories in the Netherlands, Austria, and Spain, with Germany and Denmark to follow. The event showcased expert views and deep-dives into a variety of topics, including: the potential H2O holds for national healthcare systems and how it can be a catalyst for sustainable and value-based healthcare systems around the world and the pressing need for linked and standardised data. You can watch the event's presentations and roundtables [here](#).

To learn more about H2O, visit [www.health-outcomes-observatory.eu](http://www.health-outcomes-observatory.eu)

Gostin LO. The World Health Organization on Its 75th Anniversary. JAMA Health Forum. 2023;4(4):e231568. doi:10.1001/jamahealthforum.2023.1568

The WHO has advocated for health governance for years, yet it has been deficient itself. The WHO's [Framework of Engagement with Non-State Actors](#) makes it nearly impossible for grassroots civil society organizations to have a voice. The Framework of Engagement with Non-State Actors treats civil society organizations the same as large philanthropies and corporations. Widening civil society participation would guide meaningful activities and help the WHO gain the trust of affected communities.

## COVID-19

**Two-year follow-up of patients with post-COVID-19 condition in Sweden:** a prospective cohort study.

Carl Wahlgren, Gustaf Forsberg, Anestis Divanoglou, Åse Östholm Balkhed, Katarina Niward, Sören Berg, Richard Levi. The Lancet Regional Health - Europe 2023;28: 100595 <https://doi.org/10.1016/j.lanepe.2023.100595>

The regional population-based Linköping COVID-19 study included all patients hospitalised due to COVID-19 during the first pandemic wave. Of 185 patients with post-COVID-19 condition (PCC) at 4 months post-discharge, 181 were alive at the 24-month assessment, 165 agreed to participate. Of those, 21% (35/165) had been readmitted to hospital for various causes in the interim period. The majority of patients (139/165, 84%) reported persisting problems affecting everyday life at 24 months. Cognitive, sensorimotor, and fatigue symptoms were the most common persisting symptoms at 24 months. Despite some improvements over time, we found a high prevalence of persisting symptoms and a need for long-term follow-up and rehabilitation post COVID-19 infection.

**Masks Work. Distorting Science to Dispute the Evidence Doesn't Masks Work. Distorting Science to Dispute the Evidence Doesn't**

<https://www.scientificamerican.com/article/masks-work-distorting-science-to-dispute-the-evidence-doesnt/>

Matthew Oliver, Mark Ungrin, Joe Vipond. New mask studies relying on a medical paradigm do not erase decades of engineering and occupational science that show they work. For masks, are randomized trials an appropriate way of evaluating a basic engineered safety system in the first place? We don't rely on such trials for seat belts, bike helmets or life jackets, and the oft-cited randomized trial [of parachutes](#) is an old running joke. When failures like a plane crash or catastrophic bridge collapse do occur, they are recognized and [systematically analyzed](#) to ensure they don't happen again. The contrast with the [lack of attention paid to public health failures](#) in this pandemic is stark.

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## Publications

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Wang T, McAuslane N, Goettsch W, Leufkens H, De Bruin M (2023). Regulatory, health technology assessment and company interactions: The current landscape and future ecosystem for drug development, review and reimbursement. Int J Technol Assess Health Care, 39(1), E20. doi:10.1017/S0266462323000144  
Multi-stakeholder interactions have evolved at product and policy levels. There is a need to assess the current and future landscape of interactions between companies, and regulatory and HTA agencies to



address challenges and identify areas for improvement. To assess the added value of interactions as well as limitations; and explore the future ecosystem for stakeholder interactions.

Three separate questionnaires were developed for companies, regulators and HTA agencies, respectively, to assess their experiences and perceptions. The responses were discussed at a multi-stakeholder workshop. All seven regulators and seven HTA agencies in the survey indicated that they had stakeholder interactions. More formal collaboration occurred with regulators compared with HTA agencies. All nine companies have taken early advice but indicated the need for future prioritization. Four principles were proposed for the future ecosystem: separate remit and functions between regulators and HTA; align processes; converge evidence requirements where possible; increase transparency.

Zimmermann G, Michelmore S, Hiligsmann M (2023). Stakeholder perspectives on cooperation in the clinical and nonclinical health technology assessment domains. *Int J Technol Assess Health Care*, 39(1), E29. doi:10.1017/S0266462323000077

Eighteen semi-structured interviews were conducted with experts from European HTA bodies (HTAbs), former board members of the European Network for Health Technology Assessment (EUnetHTA), and representatives from the pharmaceutical industry, a regulatory agency, academia, and patient organizations. The stakeholders were asked about their support of the EUnetHTA's intent, about the general strengths and challenges of the EUnetHTA and its Joint Action 3 (JA 3), the strengths and challenges of the clinically oriented HTA collaboration in oncology during JA 3 across the technology life cycle, about future challenges to HTA in oncology with consequences for collaboration, and about collaboration in the economic domains of HTA. The experts described challenges in early dialogues (EDs) and rapid relative effectiveness assessments (REAs) meant to analyze clinical effectiveness in oncology. The majority attached increasing importance to collaboration in the future to cope with the uncertainty of HTA. Several stakeholders also proposed the incorporation of joint postlaunch evidence generation (PLEG) activities.

Breslau R, Cohen J, Diaz J, Malcolm B, Neumann P (2023). A review of HTA guidelines on societal and novel value elements. *International Journal of Technology Assessment in Health Care*, 39(1), E31. doi:10.1017/S026646232300017X

After categorizing 'societal' and 'novel' elements of value, we reviewed fifty-three HTA guidelines. The HTA guidelines mention on average 5.9 of the twenty-one societal and novel value elements we identified (range 0–16), including 2.3 of the ten societal elements and 3.3 of the eleven novel value elements. Only four value elements (productivity, family spillover, equity, and transportation) appear in over half of the HTA guidelines, whereas thirteen value elements are mentioned in fewer than one-sixth of the guidelines, and two elements receive no mention.

Irina Kinchin, Valerie Walshe, Charles Normand, Joanna Coast, Rachel Elliott, Thilo Kroll, Philip Kinghorn, Alexander Thompson, Rosalie Viney, David Currow, James F O'Mahony. Expanding health technology assessment towards broader value: Ireland as a case study. *Int J Technol Assess Health Care* doi: 10.1017/S0266462323000235, 2 May 2023

Healthcare innovations often represent important improvements in population welfare, but at what cost, and to whom? Incorporating "broader value" in HTA as derived from social values and patient experience could provide a rich evaluative space for informing resource allocation decisions. Ireland serves as an example of a healthcare system that both has an explicit role for HTA and is evolving under a current program of reform to offer universal, single-tier access to public services. There are various ways in which HTA processes could move beyond health, including considering the processes of care delivery and/or expanding the evaluative space to some broader concept of well-being.

2023 ASCO Meeting <https://meetings.asco.org/abstracts-presentations/218125>

Cristiane Decat Bergerot, Benjamin D Mercier, Daniela V Castro, et al. Health-related quality of life (HR-QOL) measures in renal cell carcinoma (RCC): Patient-reported relevance of items of the FKSI-19, EORTC QLQ-C30, and EQ-5D. *J Clin Oncol* 41, 2023 (suppl 16; abstr 4540). DOI [10.1200/JCO.2023.41.16\\_suppl.4540](https://doi.org/10.1200/JCO.2023.41.16_suppl.4540)  
Given the need to balance both quantity and quality of life among patients with advanced cancer, developing a robust, relevant, and consensus-driven patient-focused measurement strategy is a necessity. Few items across surveys were identified as meaningful including 8/19 FKSI-19 questions (lack of energy, fatigue, appetite, sleeping, worry, able to work, enjoyment and quality of life), 3/30 EORTC QLQ-C30 questions (tired, overall health and quality of life), and 0/5 EQ-5D questions. Patients suggested items pertaining to treatment side effects, emotional symptoms, physical function, social/family support, and financial distress should be included. Notably, 58% of patients were open to using wearable devices to assess HRQOL.

Trisha Greenhalgh, Eivind Engebretson, Roland Bal, Sofia Kjellstrom. Toward a Values-Informed Approach to Complexity in Health Care: Hermeneutic Review. *Milbank Quarterly* 2023.

<https://doi.org/10.1111/1468-0009.12656>

<https://onlinelibrary.wiley.com/doi/10.1111/1468-0009.12656>

The concept of value complexity (complexity arising from differences in people's worldviews, interests, and values, leading to mistrust, misunderstanding, and conflict among stakeholders) is introduced and explained. Relevant literature from multiple disciplines is reviewed.

Key theoretical themes, including power, conflict, language and framing, meaning-making, and collective deliberation, are identified. Simple rules derived from these theoretical themes are proposed.

Gao Y, Laka M, Merlin T (2023). Is the quality of evidence in health technology assessment deteriorating over time? A case study on cancer drugs in Australia. *Int J Technol Assess Health Care*, 39(1), E28.

doi:10.1017/S0266462323000259

We reviewed public summary documents (PSDs) reporting on subsidy decisions made by the Pharmaceutical Benefits Advisory Committee (PBAC) from July 2005 to July 2020. Overall, 214 PSDs were included in the analysis: 37% lacked direct comparative evidence; 13% presented observational or single-arm studies as the basis for decisions. Among PSDs presenting indirect comparisons, 78% reported transitivity issues. 41% of PSDs reporting on medicines supported by head-to-head studies noted there was a moderate/high/unclear risk of bias (RoB). PSDs reporting concerns with RoB increased by a third over the past 7 years, even after adjusting for disease rarity and trial data maturity. No time trends were observed regarding the directness of clinical evidence, study design, transitivity issues, or sample size. The evidence supplied to the PBAC is often the same as that supplied to other global decision-making bodies.

Cadeddu C, Regazzi L, Di Brino E, et al W. (2023). The added value of applying a disinvestment approach to the process of health technology assessment in Italy. *Int J Technol Assess Health Care*, 39(1), E17.

doi:10.1017/S0266462323000107

Cost-Effectiveness Analysis and Disability Discrimination. Greg Bogнар. For Adam Cureton and David Wasserman (eds.) *The Oxford Handbook of Philosophy and Disability*.

<https://gregbogнар.net/files/Bogнар-CEA-Disability-Discrimination.pdf>

Cost-effectiveness analysis (CEA) is an analytical tool in health economics. One of the most important objections to it is that its use can lead to unjust discrimination against people with disabilities. This chapter evaluates this objection.

Clare Robertson, Shafaque Shaikh, Jemma Hudson, et al 2023. The RoboCOS Study: Development of an international core outcome set for the comprehensive evaluation of patient, surgeon, organisational and population level impacts of robotic assisted surgery. *PLOS One*.

<https://doi.org/10.1371/journal.pone.0283000>

The RoboCOS core outcome set, derived from an international Delphi prioritisation survey, includes the outcomes of importance to all stakeholders, is recommended for use in all future evaluations of robot-assisted surgery to ensure relevant and comparable reporting of outcomes.

O'Donohoe P, Reasner DS, Kovacs SM, Byrom B, Eremenco S, Barsdorf AI, Arnera V, Coons SJ. Updated Recommendations on Evidence Needed to Support Measurement Comparability Among Modes of Data Collection for Patient-Reported Outcome Measures: A Good Practices Report of an ISPOR Task Force. *Value Health*. 2023 May;26(5):623-633. doi: 10.1016/j.jval.2023.01.001. Guidelines and best practices for assessing the need to demonstrate measurement comparability of patient-reported outcome measure data collection modes in clinical research

Ayers JW, Poliak A, Dredze M, et al. Comparing Physician and Artificial Intelligence Chatbot Responses to Patient Questions Posted to a Public Social Media Forum. *JAMA Intern Med*. Published online April 28, 2023. doi:10.1001/jamainternmed.2023.1838

[https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2804309?blm\\_aid=17773](https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2804309?blm_aid=17773)

In this cross-sectional study of 195 randomly drawn patient questions from a social media forum, a team of licensed health care professionals compared physician's and chatbot's responses to patient's questions asked publicly on a public social media forum. The chatbot responses were preferred over physician responses and rated significantly higher for both quality and empathy.

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