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

Enhanced quality and relevance of HTA through patient and citizen involvement

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

Welcome to our February E-Bulletin

From our Chair:

This month, I'm pleased to share that PCIG has appointed a new Technical Officer, Hadewych Honné. In her PhD research at the University of Edinburgh and KU Leuven she is interested in the role of rare disease patient organizations in the appraisal of orphan medicines, especially how they navigate their position at the intersection of different interests and in relation to other stakeholders. Welcome Hadewych. The PCIG Technical Officer email is: to.patient-citizen@htai.org.
In February, we held a PCIG Exchange on patient involvement in reassessment or post-market review. It's the first time we've focused on this later lifecycle assessment (and our first insight into the Swiss HTA system) and I'm very grateful to our speakers:
Stephanie Vollenweider, Head HTA, Section Health Technology Assessment, Federal Office of Public Health (FOPH)
Sarah Berglas, Manager, Patient, Clinician, and Industry Engagement, Canada's Drug and Health Technology Agency (CADTH)
Susanne Teupen, Head of Patient Participation Staff Unit at the Federal Joint Commission (G-BA)
Thank you also to our former Technical Officer, Veronica Lopez Gousset, for organising the Exchange. Our next PCIG Exchange will be in July. It will provide a chance for those who attend HTAi 2023 Adelaide to reflect on what they heard, and those who miss out on Adelaide to gain an update and join the conversation.
In this issue, you'll find lots of information about HTAi 2023 Adelaide. Check it out.

Stay safe,
Ann Single, Chair – HTAi Patient and Citizen Involvement Interest Group
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)

PCIG Matters

List serv change

HTAi is now allowing PCIG to manage its membership list, which includes distribution of emails to the interest group membership such as this e-bulletin. We will continue to publish this e-bulletin on the HTAi website and promote it via our social media accounts on LinkedIn and twitter (@pcisg) as well as circulate directly to the email accounts of HTAi PCIG members. If you are not receiving the direct email, please check that you are (1) up to date with your membership and (2) have ticked the box for PCIG membership. Please note that patient-citizen@mailer.htai.org no longer works and any items for group dissemination should be sent to the Chair until our new Technical Officer is in position.

Registering for Annual Meeting (June 24-28, Adelaide, Australia)
Early bird registration for HTAi 2023 Adelaide is open until March 30. Don't forget to register for the PCIG workshop on Saturday 24 June. We also have our lovely contact in Adelaide finding us a spot for PCIG's informal dinner on Monday 26 June. PCIG PASS details well be available 3 March.

Early Snapshot of Patient and Citizen Involvement in HTA at HTAi 2023 Adelaide
Here's a taste (sample only) of workshops, panels and orals that PCIG members are leading or taking part in. Don't forget to let us know about your panels and orals. We love to promote them in the e-bulletin on LinkedIn and Twitter.

Sat 24 Jun	Workshops Patient and Citizen Involvement in HTA full day workshop Patient-Reported Outcomes for Health Technology Assessment HTAi Interest Group on Rare Diseases – Developing a Workplan
Sun 25 Jun	Workshop Indigenous populations and HTA full day workshop - Welcome reception
Mon 26 Jun	***Opening ceremony*** Panels: From Global to Local: what value from policy fora in HTA for patients, industries and assessors? Rare disorders: Is the lack of effect in a PRO reflecting no benefit HTA driving use of registries to optimize treatment for paediatric SMA Patients as active contributors to Horizon Scanning Digital Divide or Inclusion? Effective Deliberation Experiences: lessons beyond global health emergencies Balancing speed and rigour in patient preference studies Outcomes and lessons from implementing the International - Summary of Information for Patient Groups in Different HTA Systems Moving towards harmonizing patient involvement in HTA through stakeholder recommended and valued processes ***PCIG informal dinner***
Tue 27 Jun	Panel Equity in HTA: Approaches to incorporate equity concerns into healthcare decision making ***Conference dinner***
Wed 28 Jun	Panels

	Evaluating new genetic and genomic tests in HTA What managerial skills for patient associations active in HTA? Exploring the implications of accelerated access pathways for promising new medicines on HTA and patient access Can the US adopt a more comprehensive, coordinated approach to HTA
Orals **(Date & Time TBC)**	Did It Matter? Developing a Common Framework for Characterizing Impact of Patient Involvement in Health Technology Assessment Efficiently Transitioning into Health Technology Assessment Committees: Trialling a Mentoring Program for New Consumer Members in Australia 'Conversations for Change' – Identifying Meaningful Ways to Improve Consumer Participation in Health Technology Assessment Processes

Patient Voice Initiative Webinar Recordings
Two Patient Voice Initiative webinars recordings are now available. Last week's 'Capturing the value of rare and paediatric treatments' was rich with insights and information from:
Karen Facey, Evidence Based Health Policy Consultant, Lead Editor 'Patient Involvement in Health Technology Assessment' (Scotland, UK)
Fleur Chandler, parent of teenager with Duchenne Muscular Dystrophy; Project Hercules Lead; Sanofi - Head of Market Access UK and Ireland (England UK)
Nicole Millis, Rare Voices Australia, CEO & Life Saving Drugs Program Expert Panel Consumer Nominee
As well as 'Beginnings - what happens at the start of HTA' and what patient communities know that is key to where we start. Valuable knowledge and experience from Australia's Medical Services Advisory Committee (MSAC) processes was shared by:
Jana Arvanitakis, Director of Australia's MSAC PICO Advisory Sub-Committee
Sally Wortley, Lead, Consumer Evidence and Engagement Unit, Office of HTA, Dept of Health and Aged Care (Australia)
Clare Stuart, Policy & Advocacy Manager, Mito Foundation (Australia)

All contributed by Ann Single

Where is patient and/or citizen involvement in HTA going?
Ann Single's 5 minute reflection given to PCIG Steering Committee to provoke reflection, discussion, better and clearer answers
Comment by David Chandler, Chief Executive Psoriasis and Psoriatic Arthritis Alliance (PAPAA) UK,
I think it's a very interesting take and reflection. I can only speak on a UK perspective, but having been involved in some conversations with people from other jurisdictions, I can recognise the issues. "It depends" I think sums is it up. Not just where you live in the world, but also the condition you have. Politics and money drive most things, but equality and equity must be our driver. One would hope that we all believe that everybody should be treated equally and access what they need, when they need it, regardless of where and how they live. Sadly, even in well-developed nations this is not the case. Value judgements in HTA, although they aim to be fair and equitable weighting considerations based on varying issues in order to be fair to all, perhaps is a difficult concept to grasp. Or perhaps they weighted inappropriately, based on who makes the decision, innovator, payer, provider, beneficiary or society.
Is it fair to favour one person over another, based on severity, length of life or rarity? How do we decide on an individual's fate - that is fair? Does the loudest voice make a difference? Are we stronger collectively or are many different voices from different directions independently saying the same thing more powerful? The role of lived-experience and patient-derived evidence needs to be weighted and used not as a 'bench mark' to support an RCT and dismissed if it contradicts, but as part of the evidence base at the earliest possible point in the HTA process. We need to publish all data, hiding failure potentially means we continue

to repeat mistakes. If something doesn't work or doesn't meet the expected outcomes, say so. Then others can look elsewhere. Sending someone down a rabbit hole in the full knowledge that it's empty is a most disingenuous scientific practice. Over promising results and benefits is just as disingenuous.
A healthy population is of course key, but we also need to be mindful that the population has a responsibility to try and remain healthy. State intervention in a country like the UK is often seen as interfering, or 'a nanny state', but equally it is expected to 'be there' and provide care on demand, regardless of the cause of the event.
Abdicating any personal responsibility for our own health should not mean we are left high and dry when something goes wrong, and blame should be removed too. But that works in both directions. We need to accept the limitations of HTA and work to improve it. It's easy to spot what is wrong in society but much harder to find solutions. Improving what we've got surely is better than throwing it away. I don't think there is a collective solution that works in all scenarios, but a general principle of 'nothing about us without us' should drive the goal to ensure HTA benefits those it serves. Who those people are is perhaps a more complicated debate.

Iona Heath, Victor Montori. Responding to the crisis of care (February 2023)
https://www.bmj.com/content/380/bmj.p464
BMJ 2023;380:p464 doi: https://doi.org/10.1136/bmj.p464
Healthcare is in crisis across most of the globe, and perhaps particularly in the United States and the United Kingdom, both of which appear more disunited than ever by the greed and carelessness that drive socioeconomic and political polarisation, and the systematic degradation of our planet. The first possible crisis response assumes that this is simply a crisis of organisation, efficiency, information, technology, and scale, seeing people as insufficiently studied biological machines. The second response assumes this is a crisis of care in and of itself, in the space between people.

Deborah Maskens of Canada - From the US, a plan to eliminate QALYS with some interesting quotes
https://energycommerce.house.gov/posts/chairs-rodgers-smith-and-reps-burgess-wenstrup-introduce-legislation-to-ban-qal-ys
Washington, DC - House Energy and Commerce Committee Chair Cathy McMorris Rodgers (R-WA), House Ways and Means Committee Chair Jason Smith (R-MO), and GOP Doctors Caucus Co-Chairs Rep Brad Wenstrup, DPM (R-OH), and Rep Michael Burgess, MD (R-TX), announced introduction of H.R. 485, the Protecting Health Care for All Patients Act.

From Sharmila Sousa - Resource material (report/webinar video) and potential collaboration or partnership efforts to anyone developing non-high tech (or rather high-touch) approaches to social listening
I talked last Friday with Isadora Starling and Alejandro Posada about their Internews project. The project is much more about 'reality-checking' than a 'fact-checking' initiative because they are interested in learning what people want to tell us through rumours. This is to understand the why behind the rumours; besides geolocalised monitoring of information that circulates inside communities.
Internews - Rooted in Trust Events - Turning Social Listening Data into Action: Barriers and Recommendations observed through a COVID-19 Rumor Response. Report Presentation and Roundtable Resources.
Resources from the event:
Webinar recording
Research report
Rooted in Trust website https://rootedintrust.org/

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

- Registration for the HTAi 2023 Annual Meeting is NOW OPEN https://htai.eventsair.com/htai-23-adelaide-am/annual-meeting-registration
- While completing registration for the 2023 Annual Meeting, attendees can also pick up social event tickets and register for Workshops all at the same time!
    - View the Schedule-at-a-Glance
    - View the Workshop program

PCIG's Annual Meeting workshop, Saturday 24 June, 8.30 am - 4.30 pm. The workshop will begin with an introduction to key concepts, methods and approaches to patient involvement followed by a deeper exploration of key areas for harmonisation activities such as: training and capacity building; integrating patient preferences in HTA; valuing patient and public produced evidence, defining patient-centric HTA and measuring impact.

- Travel to the Annual Meeting: Learn about the host city, view the hotel and flight deals, and check out the entry requirements. https://htai.org/traveling-to-the-2023-annual-meeting/ HTAi has initiated a partnership with the Lufthansa Group and their global network of flight partners to provide delegates to the 2023 Annual Meeting with a global and efficient travel experience at a discounted rate. The Lufthansa Group network consists of Austrian Airlines, Brussels Airlines, Eurowings, Lufthansa and SWISS. To book your flight, utilizing the Annual Meeting 2023 discount, please follow the instructions on the Annual Meeting website.

Global Policy Forum
The topic for the 2023 Global Policy Forum, taking place over 3 days from 26 March in The Hague, the Netherlands is: 'The Value and Impact Of Health Technology Assessment'. You can access the document here: https://online.pubhtml5.com/xcuo/urog/
The paper from the 2022 HTAi Global Policy Forum is now published: Trowman R, Migliore A, Ollendorf D (2023). Health technology assessment 2025 and beyond: Lifecycle approaches to promote engagement and efficiency in health technology assessment. International Journal of Technology Assessment in Health Care, 39(1), E15. doi:10.1017/S0266462323000090

The Real World Evidence & Artificial Intelligence (RWE-AI) Interest Group
The group is looking for a dedicated and enthusiastic individual who is willing to provide one to two days a month to support their Chair(s) and Steering Committee as a Technical Officer (TO), from now to December 2023. The Interest Group was established in 2020 to gather members interested in the generation and use of RWE and/or AI for HTA. It provides an environment for education and training, communication and knowledge sharing, capacity building and collaboration.

https://htai.org/real-world-evidence-and-artificial-intelligence/
To apply, please complete and submit the HTAi Technical Officer application form and your CV to interestgroups@htai.org by Friday, March 10th, 2023. For questions, contact interestgroups@htai.org.

The HTAi Board of Directors announces that the Executive Director, Rob Abbott, to resign
Rob has been part of HTAi's achievements over the past 2.5 years, and we thank him for his dedication and commitment to HTAi. We wish Rob all the best in his new position.
Transition presents renewed opportunities for growth and innovation. HTAi has experienced considerable success and impact since the Society's inception in 2003. From this favourable position, the Board and Secretariat will continue supporting HTAi's strategic vision to ensure further impact in the global HTA community. We have initiated all necessary steps to secure a smooth transition and are in the process to search for a new Executive Director. We will keep you informed of any updates.
Wija Oortwijn, HTAi President

The HTAi Review, your biweekly news source for all things HTAi. Click here to catch up on HTA news and updates from around the world.

Website: https://htai.org/
HTAi Social Media
Feel free to follow us or check in on our social media channels and re-post our messaging:
Twitter: @HTAiOrg
Facebook: @HTAiOrg
LinkedIn

What's Happening

Barriers to Fair Access - ICER
In September 2020, ICER published the white paper: 'Cornerstones of 'Fair' Drug Coverage: Appropriate Cost-Sharing and Utilization Management Policies for Pharmaceuticals'. This paper analyzes the ethical and practical dimensions of insurance coverage policy, while presenting a corresponding set of criteria that will support a more transparent discussion among all health care stakeholders about whether specific policies are delivering 'fair' patient access to prescription drugs.
Building on the criteria discussed within that paper, ICER's second annual Barriers to Fair Access report examines how well major insurers' prescription drug coverage policies in 2022 aligned with a set of fair access standards developed by ICER with expert input from patient advocates, clinician specialty societies, US payers, pharmacy benefit managers, and life science companies. The webinar recording reviewing the 2022 Fair Access Report is available here.

Contributed by Ann Single

Psoriasis project benefits from patient research partners' perspective https://www.ihi.europa.eu/news-events/newsroom/psoriasis-project-benefits-patient-research-partners-perspective
IMI psoriasis project HIPPOCRATES is a great example of best practice when it comes to patient involvement in research, and it's already seeing the benefits of its approach.

The UK government will partner with German COVID-vaccine company BioNTech to fast-track - people with cancer into clinical trials for mRNA immunotherapy treatments
The National Health Service and Genomics England will run the Cancer Vaccine Launch Pad project, which will start recruiting participants in September and run until 2030. About one-third of BioNTech's mRNA vaccine candidates for cancer are already in clinical trials in the United Kingdom.

https://www.nature.com/articles/s41587-023-01693-z?utm_source=Nature+Briefing%3A+Translational+Research&utm_campaign=18471e958a-briefing-tr-20230222&utm_medium=email&utm_term=0_872afe2a9a-18471e958a-47439240

The US Food and Drug Administration (FDA) will soon require researchers and companies to include a diverse set of participants in late-stage clinical trials
Proponents of the move say that it is needed to make medicines more effective across the entire population. Before the policy can take effect, the FDA must finalize its guidance and offer the public a comment period, which could take more than two years.
https://www.nature.com/articles/d41586-023-00469-4?utm_source=Nature+Briefing%3A+Translational+Research&utm_campaign=18471e958a-briefing-tr-20230222&utm_medium=email&utm_term=0_872afe2a9a-18471e958a-47439240

Second webinar on the FDA PFDD, March 7
The ISPOR Patient Centres Special Interest Group is one of the organisers FDA Patient-Focused Drug Development (PFDD) Guidance – Part 2
Advanced Patient-Reported Outcomes [Short course] March 8-9
The FDA is developing Patient-Focused Drug Development (PFDD) guidance documents to inform the inclusion of patient experience when developing new medical therapies and products. This webinar series highlights the four methodological guidance documents, which includes two finalized guidances (1 and 2), a draft guidance (3), and guidance that is under development (4.) - for health economics and outcomes research. The 2 first guidances have been finalised:
Guidance 1, Patient-Focussed Drug Development: Collecting Comprehensive and Representative Input, how stakeholders (patients, researchers, medical product developers and others) can collect and submit patient experience https://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-focused-drug-development-collecting-comprehensive-and-representative-input
Guidance 2, Patient-Focussed Drug Development: Methods to Identify What is Important to Patients, how stakeholders (patients, researchers, medical product developers and others) can collect and submit patient experience data and other relevant information for medical product development and regulatory decision-making.
Guidance 3 (draft guidance) and 4 all still in development.
https://www.fda.gov/drugs/development-approval-process-drugs/fda-patient-focused-drug-development-guidance-series-enhancing-incorporation-patients-voice-medical
Recording of webinar part 1:
https://www.ispor.org/conferences-education/education-training/webinars/webinar/fda-patient-focused-drug-development-(pfdd)-guidance---part-1?https://www.ispor.org/conferences-education/education-training/webinars/webinar/fda-patient-focused-drug-development-(pfdd)-guidance---part-1?https://www.ispor.org/conferences-education/education-training/webinars/webinar/fda-patient-focused-drug-development-(pfdd)-guidance---part-1

Contributed by Dominique Hamerlijnck

On 30 November 2022, 33 representatives from patient organisations, payers, HTA organisations, regulatory bodies, government, industry, and research/academia convened virtually for the 10th annual ISPOR Patient Representatives Roundtable (PRR) – Europe. The Roundtable focused on amplifying the patient voice in health economics and outcomes research (HEOR) and decision-making. To read the summary report of this roundtable meeting, click here https://www.ipposi.ie/wp-content/uploads/2023/02/ISPOR-PRR-Europe-2022_Summary-Report-Final.pdf

European Patients Forum (EPF) – from their February Newsletter

The master programme in International Patient Advocacy Management, developed by EPF in collaboration with ALTEMS Università Cattolica, is open for admissions. The course will provide to students the management skills required for a successful coordination and development of patients' organizations' activities in the reference healthcare scenario. The programme in 10 modules is addressed to those who already have a master's degree and aims to provide a professional training to develop management skills for patients' organisations working at local, national and international level. The courses will span from healthcare management, European legislation on health, patient involvement, fundraising, strategic communication, planning and bookkeeping, stakeholder management, and more.
See the full curriculum and the course calendar here and head to our dedicated website page for detailed information!

EPF is looking for a designer within a new call for tender to produce high-quality, engaging, and accessible communications assets, including a brand kit, as part of its work on the IMI 2 IMMUcan project. This highly technical project aims to study the tumor microenvironment. Some concepts central to the project are not easily understood by non-expert audiences. Full details here.

EHDEN (European Health Data & Evidence Network) and *H2O* (the Health Outcomes Observatory) projects launched their lay-language course collaboration on Patient Reported Outcomes. This is the 4th course in the series of introductory-level courses on the EHDEN Academy, which have been co-produced in partnership with EPF. You can access the course, plus many other free training materials at the EHDEN Academy.

The Periscope Talks are back with the second episode of Season 2! It focuses on the Massive Open Online Courses (MOOCs), developed by the PERISCOPE project partners, that are available on Coursera's e-learning platform. These courses aim to offer insights into the COVID-19 pandemic and propose new ways forward for better crisis response. The PERISCOPE MOOCs are completely free of charge, 100% online, and administered in a self-paced learning modality, with the possibility of receiving a certificate of completion after the successful conclusion of all its modules. Listen to the episode here.

Rewriting the Playbook on Health Technology Assessment: Equity and Economic Impacts on Patients and Families
The 4th Annual Innovation and Value Initiative (IVI) Methods Summit, Washington DC March 13 – 14 2023 will identify actionable changes and outline immediate actions, roles, and accountability metrics needed for substantive change to achieve health equity and true value in health technology assessment.
https://thevalueinitiative.org/2023-methods-summit/
Day 1: Public Event (In-person with Livestream) centered around Changing Accountability and Practice of HTA for Health Equity.
Day 2: Public Event (Webinar) and Invitation Only Event, Creating our Framework for Measuring Economic Impacts on Patients and Families

Precision Medicine Forum, two-day multi-track conference dedicated to advancing the diagnosis, prognosis and treatment of cancer in and across the Nordics
Nordic Precision Oncology Forum taking place from 26-27 June 2023 in Stockholm
The forum will consist of 3 focused events; Precision Oncology Forum, Immuno-Oncology Forum and Nordic Pathology Forum. Each event will provide a collaborative platform for information sharing through presentations, panel discussions, round-tables, keynote and plenary sessions. By registering, you will gain access to all three events, allowing you the opportunity to move freely between areas of interest and to network with all of those who are the driving force behind oncology across the Nordics and beyond.
This one-of-a-kind meeting will attract healthcare providers, researchers, industry executives, payers, policy makers, NGOs and patient groups and will feature dedicated session topics on: Sequencing for the Clinic, Cancer Vaccines, Digital Pathology, Multi-Omics Techniques, Cell and Organoid Therapy, AI Based Image

Analysis, Precision Oncology Initiatives, Advanced Antibody Therapies, Molecular Pathology, Lung Cancer Molecular Tumor Boards, Combination Therapies, Trends in Nordic Pathology.
In addition there will be two plenary sessions to highlight key challenges in Oncology: Early Detection and Screening, Improving Access to Precision Cancer Medicine
The preliminary agenda for all 3 meetings can be found here. To register your place, please visit the event booking page.

Increasing Patient Engagement (PE) & Patient Focused Medicines Development (PFMD) footprint in terms of awareness, endorsement, and adoption levels
I am sharing the article - "Patient Engagement That Enables Regulatory Decisions." The article reflects on the progress of PE and the remaining work to do but also lists existing resources that one has an excuse not to use anymore. We have authors from different stakeholder groups, including regulators, and many of the initiatives and resources you've all contributed to are reflected in its pages. Click here to check it out. Also, you can check out below a video capturing the dynamic of the last in-person Patient Engagement Open Forum (PEOF), as well as some key thoughts from our global patient engagement (PE) community and its champions.
I'm pleased to share two new PE Guidelines (previously known as Country Cards) for the UK and Romania, available here. If you missed it, you could also check out the Spain, Belgium, and Netherlands cards available since last year. Work on Japan, Switzerland, Singapore, and France is underway. More about this work here.
And don't forget to use and spread the word about the Patient Engagement Management Suite (PEM Suite) - your global hub for practical tools to plan, assess and execute any patient engagement initiative. The PEM Suite helps curate and integrate good practices, methodologies, and tools, making your PE practices coherent and actionable. Ready for you to apply within your context.

Contributed by Nicholas Brooke

https://www.thisinstitute.cam.ac.uk/about/
Welcome to The Healthcare Improvement Studies Institute
Our manifesto: Everyone wants safe and high-quality healthcare, and health systems worldwide undertake improvement initiatives to achieve these priorities. Yet improvement projects are too often supported by weak evidence.
To date, efforts to develop the evidence base needed to support healthcare improvement have been hindered by challenges including a lack of scientific credibility, an overemphasis on small-scale quality improvement work and a limited infrastructure for participatory research.
Our goal is to create a world-leading scientific asset for the NHS about how to improve quality and safety in healthcare. We are guided by a highly participatory, collaborative ethos that combines academic rigour with the real concerns of the people who use and work in the NHS.
Our approach: Our work is underpinned by the principle that efforts to improve care should always be based on the highest quality evidence. So we're boosting research activity to provide more clarity on what works, what doesn't, and why.
We work directly with NHS patients and staff, as well as academics and the public, to produce evidence about improvement that is both highly relevant and scientifically excellent. We use innovative methods of research such as citizen science to deliver large-scale research projects.
Our projects study interventions and techniques aimed at improving quality and safety in healthcare, and are mindful of challenges to standardisation, harmonisation, replication and scaling.

Contributed by Dominique Hamerlijnck

A February ISPOR HEOR Theater presentation focused on the findings of an October 2022 Health Technology Assessment (HTA) Roundtable for the Middle East and Africa (MEA) region at which the World

Health Organization (WHO) Health Technology Assessment and Health Benefit Package Survey 2020/2021 was presented, as well as their document Institutionalizing Health Technology Assessment Mechanisms: a How to Guide. Participants from 3 countries in the MEA region reflected on the document and the status of HTA in their country.
https://www.ispor.org/conferences-education/event/2023/02/23/default-calendar/heor-theater---hta-implementation-in-the-mea-region-an-overview-from-who-and-country-updates

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Publications

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von Huben A, Howell M, Norris S, Wong KC, Tang J, Kazi S, Laranjo L, Chow CK, Howard K. Stakeholder preferences for attributes of digital health technologies to consider in health service funding. Int J Technol Assess Health Care. 2023 Feb 14;39(1):e12. doi: 10.1017/S0266462323000089. Best-worst study of 1,251 stakeholders from Australia, Canada, UK, New Zealand. A total of 1,251 participants completed the survey (576 general community members, 543 patients/carers, and 132 health professionals). Twelve attributes achieved a preference score above 50 percent in the stakeholder group model, predominantly related to safety but also covering technical features, effectiveness, ethics, and economics. Results from the latent class model supported this prioritization. Overall, connectedness with the patient's healthcare team seemed the most important

Debjani Mueller, Leila Alouane, Mouna Jameleddine, Irene Lenoir-Wijnkoop. Scaling up health technology assessment capacities in selected African countries – A conceivable route ahead. International Journal of Technology Assessment in Health Care Jan 2023 doi: 10.1017/S0266462323000016 Problems related to nutritional care represent one of the major priorities in the surveyed countries. A future multi-country study will provide valuable insight into the potential of low-cost primary prevention orientations.

Barbora Decker, Tomas Mlcoch, Anastasie Pustovalova, Tomas Dolezal. Novel approach to decision making for orphan drugs. International Journal of Technology Assessment in Health Care Feb 2023 doi: 10.1017/S0266462323000053 a special pathway for the reimbursement of orphan medicinal products - a rigorous pricing and reimbursement procedure with strict timelines and elaborated methodology has been recently adopted in Czechia.

Lavinia Ferrante di Ruffano, Isobel M. Harris, Zhivko Zhelev, Clare Davenport, Sue Mallett, Jamie Peters, Yemisi Takwoingi, Jon Deeks, Chris Hyde. Health technology assessment of diagnostic tests: a state of the art review of methods guidance from international organizations. International Journal of Technology Assessment in Health Care Feb 2023 doi: 10.1017/S0266462323000065

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Norman, R., Mulhern, B., Lancsar, E. *et al.* The Use of a Discrete Choice Experiment Including Both Duration and Dead for the Development of an EQ-5D-5L Value Set for Australia. *PharmacoEconomics* (2023). https://doi.org/10.1007/s40273-023-01243-0

In total, 4477 people completed at least one choice set and were included in the analysis. The results reflected the monotonic structure of the EQ-5D-5L, in that moving from no problems to extreme problems led to worsening utility in each dimension. Inclusion of interaction terms demonstrates that the disutility of the first dimension moving to a poor level (defined as either level 5, or level 4 or 5) had a large impact, but subsequent dimensions moving to a poor level had a relatively smaller disutility.

Cost-utility analysis (CUA) is the most prevalent form of economic evaluation and is recommended as the preferred method for the economic evaluation of new pharmaceuticals and health technologies in Australia and internationally. CUA employs the quality-adjusted life year (QALY), which combines length and quality of life, as the main measure of outcome. Preference-based measures (PBMs) of health-related quality of life (HRQoL) provide the quality-of-life input to the QALY. PBMs include a descriptive system that describes health states and a value set that provides a value for every health state described. The most widely used PBM internationally is the EQ-5D, and value sets are available for many countries.

We have developed a value set for use in Australian health care decision-making. We believe that the findings in this paper suggest that including interaction effects means that the values used in decision-making more accurately reflect the preferences of the Australian population, rather than reliance on findings from different countries, or from our older pilot data, which were based on a smaller sample size.

Slejko JF, dosReis S. Navigating Patient-Preference Studies for Cross-Stakeholder Decision Making: A Roadmap Guides the Way. Value Health. 2023 Feb;26(2):151-152. doi: 10.1016/j.jval.2022.12.013

The authors advocate that the time is right for the ISPOR Roadmap for Patient Preferences in Decision Making and believe that its impact will be assessed over time as it is implemented by the research community.

Bridges JFP, de Bekker-Grob EW, Hauber B, Heidenreich S, Janssen E, Bast A, Hanmer J, Danyliv A, Low E, Bouvy JC, Marshall DA. A Roadmap for Increasing the Usefulness and Impact of Patient-Preference Studies in Decision Making in Health: A Good Practices Report of an ISPOR Task Force. Value Health. 2023 Feb;26(2):153-162. doi: 10.1016/j.jval.2022.12.004

The authors highlight good practices to assist researchers and others in designing, conducting, and disseminating patient-preference studies that are useful for and impactful in decision making.

Crown W, Dahabreh IJ, Li X, Toh S, Bierer B. Can Observational Analyses of Routinely Collected Data Emulate Randomized Trials? Design and Feasibility of the Observational Patient Evidence for Regulatory Approval Science and Understanding Disease Project. Value Health. 2023 Feb;26(2):176-184. doi: 10.1016/j.jval.2022.07.003 Variation in decision making by real-world data research teams can result in differences in study cohorts, statistical design and methods and, potentially, differences in study conclusions.

Pangestu S et al. Comprehensive Score for Financial Toxicity and Health-Related Quality of Life in Patients with Cancer and Survivors: A Systematic Review and Meta-Analysis
Value in Health, Volume 26, Issue 2, 300 – 316.
This is the first systematic review and meta-analysis to summarize the literature on the association of financial toxicity and HRQOL in patients with cancer and survivors. Our findings substantiate financial toxicity as a relevant outcome of cancer care that is associated with a decline of HRQOL.

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