HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG)
E-Bulletin, December 2022 / January 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 New Year E-Bulletin

From our Chair:
Welcome to this new edition of our e-bulletin. I'm very appreciative of our former chair, Janney Wale, ensuring we continue to share updates each month, even over the summer holiday period in Australia.

In this edition, may I draw your attention to information about the:
Discount flight program to HTAi 2023 Adelaide
Change to distribution of e-bulletin
Call for a new PCIG Technical Officer
Call for Expressions of Interest for a new PCIG Steering Committee (Industry-Pharma).

The new Steering Committee member is sought to fill a vacancy which arose when Todd Stephenson left Janssen in December 2022. Todd has been a valuable and committed industry representative on Steering Committee and I'm delighted that he has agreed to continue his work as our Finance Secretary.

If this has been a time of celebration or holiday for you, I hope it was restorative. Thank you for your ongoing work to improve HTA with patient and citizen involvement, and my very best wishes for a healthy and happy 2023.

Ann

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/

PCIG Matters

Call for Technical Officer
PCIG is seeking a new Technical Officer. Applications are **due Friday 20 January 2023**.
The Technical Officer position is to be filled by individuals who are:
-currently members of HTAi;
-completing studies in the field of HTA;
-a member of the Early Career Network or are members of other interest groups; and

-interested in developing their skills in specific areas of HTA.

The Technical Officer works closely with the Chair and Steering Committee. Tasks include:
-Environmental scans for articles, conferences, events, trainings of interest, etc.
-Maintaining Interest Group member contact lists.
-Scheduling meetings, issuing link to meeting and taking action point minutes
-Data collection from members.
-Drafting communications and HTAi newsletter and e-bulletin materials, maintaining website.
-Provides administrative support and facilitation, including:
-Preparing agendas in collaboration with Chair
-Collecting pre-reads and distributing them in advance Steering Committee meetings
--Other tasks as directed by Interest Group Chair(s), Executive Team or Steering Committee.
Forwarding Project Sub-Committee reports to the HTAi Secretariat for publication on the web.
-PCIG Exchange administration.

It is expected that the work will occur through email and online throughout the year, with face-to-face working opportunities available at the HTAi Annual Meetings, held in June each year.
Term and renumeration
The TO position requires commitment for a two-year term, with the possibility of extension for an additional year. Each term typically starts on January 1 and commences on December 31. It is anticipated that the TOs will work between 50-100 hours in a year (with an average of one to two hours per week). Each TO receives a stipend of $2,000 Canadian during each year they serve in capacity of TO. This stipend will be adjusted accordingly under circumstances in which a TO serves a term that is less than one year. If a TO cannot complete the agreed upon term, they will be expected to return a portion of the stipend dependent on the amount of time served. Each TO will also receive complimentary registration to the HTAi Annual Meeting, but travel and accommodation is not included.
If this is something of interest to you, please download, complete, and submit the HTAi Technical Officer Application Form along with your CV to interestgroups@htai.org by **Friday, January 20th, 2023.** Your application will be reviewed by the Interest Groups and candidates will be notified in February. Please note that you must be an HTAi member in good standing to apply for this position. If you have not renewed your membership, you can do so here.

You can contact our Chair, Ann Single (singlehaworth@gmail.com) to discuss this role. Please share with any members you think might be interested.

Expressions of Interest – PCIG Steering Committee
PCIG seeks Expressions of Interest for an industry representative (pharma company preferred) to fill a vacancy on its Steering Committee.
Please submit an Expression of Interest (no more than 200 words) to the PCIG Chair, Ann Single (singlehaworth@gmail.com) addressing the criteria below by **Wednesday 15 February 2023**. Full details of the role can be found in PCIG's Terms of Reference.
Criteria
Able to demonstrate active participation in the field of patient or citizen involvement in health technology assessment
Able to meet the expectations of Steering Committee membership as set out in the Terms of References, e.g. commit to take an active role in driving the work of the Interest Group and providing practical assistance to activities undertaken by the group as appropriate and complete a three-year term
Able to participate in additional HTAi committees
Preference will be given to those members who have actively participated in the Interest Group.

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 ebulletin 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 a new Technical Officer is appointed.

Save the date - PCIG workshop
This year's PCIG's pre Annual Meeting workshop will be held in Adelaide on Saturday 24 June, 8.30 am-4.30 pm.
This 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.
Early bird registration for HTAi 2023 Adelaide opens later this month (when we'll also provide information on the PCIG PASS). Don't forget to register for the workshop separately to registering for the Annual Meeting.

Discount flight programs
HTAi is pleased to announce a new partnership with the Lufthansa Group and their global network of flight partners. The partnership provides Delegates to the 2023 Annual Meeting with a global and efficient travel experience at a discounted rate (up to 15%).
Visit the HTAi Annual Meeting website for more information.

Collated by Ann Single

Now available from The International Journal of Technology Assessment in Health Care Volume 38, December 2022: Abstracts from the HTAi 2022 Annual Meeting in Utrecht, Netherlands
https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/latest-issue

Join the European Health Technology Assessment Stakeholder Network
The European Commission is launching a call for applications to select members of the Health Technology Assessment (HTA) Stakeholder Network, supporting the work of the Member State Coordination Group. This HTA Stakeholder Network is a requirement of the Regulation (EU) 2021/2282 on health technology assessment (HTAR) which aim is to make it easier for Member States to assess the effects of new health technologies and their pricing on health policies. From primary research on patient involvement in HTA to advocacy around the EU HTA Regulation, EPF has been heavily involved in this area. Mandatory and meaningful involvement of the patient community in the HTA process, including the selection of technologies to be assessed, is necessary to ensure that HTAs are conducted in the interest of patients.
It is therefore of utmost importance that patient organisations are part of the HTA Stakeholder Network. The Network will be involved in the activities of the HTA Coordination Group, which will coordinate joint work on HTA and adopt methodological and procedural guidance documents for joint work. For example, the Network will contribute to the annual work programme of the Coordination Group.
Patient organisations can apply, as well as consumer organisations, health non-governmental organisations, health technology developers and health professionals. They must meet the six following criteria: established as a non-profit legal entity in the EU/EEA; registered in the EU transparency register; currently or in the future engaged in HTA development; have expertise relevant to EU HTA cooperation; geographically cover several EU/EEA Member States; have communication and dissemination capabilities.

If you are interested in joining the HTA Stakeholder Network, please find all the information on how to apply here. The deadline for applications is 17 February, 17:00 CET.

From European Patients Forum December Newsletter

NICE has communicated its sadness to hear of the passing of Sir Mike Rawlins. As founding chairman of NICE, Sir Mike led NICE from 1999 to 2013. He was also a "Former President of the Royal Society of Medicine, a medical hero, amazing academic and fantastic character."

HTAi Matters

HTAi 2023 Annual Meeting, June 24 to 28, Adelaide: The Road to Policy and Clinical Integration
Australia has some exciting updates, and plenary themes:
- 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

International Flight Discount Program for 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 provided on the Annual Meeting website.
Discounts are up to 15% and reduced fares will be automatically displayed. HTAi cannot guarantee that the fares offered through the Lufthansa Group flight program are the cheapest available in the market for any particular route, so check. HTAi does not benefit from any of its delegates booking with the Lufthansa Group, discounts are directly applied to the booking party only.
From the December HTAi Review https://htai.org/htai-review-december-23-2022/

Call for Applications: Technical Officer positions available for two HTAi Interest Groups
The Ethics Interest Group and the Patient & Citizen Involvement Interest Group (PCIG) are seeking dedicated and enthusiastic individuals who are willing to provide one to two days per month to support the group Chairs and Steering Committee as a Technical Officer (TO), from January to December 2023. Examples of responsibilities include defining agendas, setting calls and taking minutes, writing reports, supporting project work and scientific papers, drafting press releases and other similar activities. Learn more about the opportunity.

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'. Member feedback due on the 2023 Global Policy Forum Background Paper

The HTAi Review is your NEW biweekly news source for all things HTAi
The world of HTA is vibrant and active, and staying up-to-date with the latest HTA news is more important than ever. To keep you informed, we have launched a new, biweekly newsletter with the most recent news from the HTAi network. Each Review will include headline news from the organization, upcoming dates and deadlines, HTA news you may have missed, and a look back at events and activities from the past two weeks. Read the HTAi Review now!

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

Interesting article on the development of an open source value project in health economic modelling
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8166701/pdf/40273_2021_Article_1036.pdf
Putting Stakeholder Engagement at the Center of Health Economic Modeling for Health Technology Assessment in the United States. Richard Z Xie, Erica deFur Malik, Mark T Linthicum, Jennifer L Bright. PharmacoEconomics (2021) 39:631–638. https://doi.org/10.1007/s40273-021-01036-3
While evidence generated from health economic (HE) models is being used more commonly in health technology assessment (HTA) in the US, it is not consistently adopted by different stakeholder groups or across therapeutic areas. We hypothesize that actively engaging with multiple stakeholder groups throughout the model development process may result in models more widely considered by decision makers. To test this hypothesis, the Innovation and Value Initiative has launched a modeling effort to build an open-source HE model focusing on the disease state 'major depressive disorder'. A 20-member advisory group has been formed with representatives from patients, employers, clinicians, innovators, payers, and researchers to guide the model development process. While this effort is still in the early stages, the ongoing stakeholder engagement effort has yielded valuable insights that inform the model design. We have also identified several challenges to implementing this new approach. Our early findings suggest that the stakeholder engagement approach to HE model development has the potential to improve HTA in the US.

And an article about a project on putting stakeholder engagement at the centre of HTA assessment: An Open-Source Value Model for major depressive disorder (MDD). This is an Innovation and Value Initiative (IVI) project. https://thevalueinitiative.org/ivi-mdd-value-model/

Contributed by Dominique Hamerlijnck

The Evolution of Patient Involvement in HTA Topic at a Recent European Roundtable
The ISPOR 2022 Patient Representatives Roundtable–Europe convened virtually on 30 November 2022 with nearly 40 representatives from patient organizations, government, health technology assessment (HTA) bodies and payers, researchers, and industry representatives from more than 15 countries. Speakers highlighted an overview of the history and future direction of the roundtable, as participants celebrated the 10-year anniversary. Attendees discussed the evolution of patient involvement in HTA and engaged in

dialogue regarding the new EU legal framework on HTA and ways to improve trust between HTA agencies and stakeholders. Access the Patient Engagement in HEOR Initiative here.

ISPOR 2023 Annual Conference, 7 to 10 May in Boston, MA, USA
ISPOR Europe 2023 Annual European Conference, 12-15 November in Copenhagen, Denmark

EMA and ECDC Collaborate on Vaccine Real-World Evidence Generation Efforts
https://www.healtheconomics.com/industry-news/ema-and-ecdc-collaborate-on-vaccine-real-world-evidence-generation-efforts?utm_source=HealthEconomics.Com&utm_campaign=6e79dd1205-EMAIL_CAMPAIGN_2022_12_20_01_37&utm_medium=email&utm_term=0_-6e79dd1205-%5BLIST_EMAIL_ID%5D
Officials from the European Centre for Disease Prevention and Control (ECDC) and European Medicines Agency have met to begin a new collaboration intended to boost real-world evidence (RWE) generation for vaccine safety and efficacy trials.

ICER Releases List of Top Drugs with Unsubstantiated Price Hikes in 2021
https://www.healtheconomics.com/industry-news/icer-releases-list-of-top-drugs-with-unsubstantiated-price-hikes-in-2021?utm_source=HealthEconomics.Com&utm_campaign=3f1a59a89d-EMAIL_CAMPAIGN_2022_12_12_08_02&utm_medium=email&utm_term=0_-3f1a59a89d-%5BLIST_EMAIL_ID%5D
A new report published by the Institute for Clinical and Economic Review (ICER) gives the top 10 therapeutics that had unsupported price rises.

When implanted neurotechnology goes bust
https://www.nature.com/immersive/d41586-022-03810-5/index.html?utm_source=Nature+Briefing&utm_campaign=d184358ab0-briefing-dy-20221206b&utm_medium=email&utm_term=0_c9dfd39373-d184358ab0-44432605
When a neurotechnology company goes under, it can leave people with non-functional implants that they can't control, can't be removed and that can be an obstacle both to medical imaging and future implants. It can also force people to face levels of pain or disability that they thought were behind them. Neurosurgeon Robert Levy says, "Making them the victims of bad business practices or a bankruptcy is horrible for patients, horrible for the field and grossly unethical."

Science Twitter – "not only lets us geek out about whatever we want, like the best parts of a conference, it also lets us invite others to join us."
https://www.americanscientist.org/blog/macroscope/what-we-lose-if-we-lose-science-twitter?utm_source=Nature%20Briefing&utm_campaign=d184358ab0-briefing-dy-20221206b&utm_medium=email&utm_term=0_c9dfd39373-d184358ab0-44432605
Marine conservation biologist explains why the downhill slide of Twitter is upsetting to so many scientists.

Big-name systems like Cleveland Clinic and North Shore charge for certain patient portal queries
https://www.fiercehealthcare.com/providers/major-providers-decision-bill-time-consuming-electronic-patient-messages-could-usher
Though the new policies drew swift pushback from consumers and transparency groups, a successful rollout could see more provider organizations follow their example. A major health system's public notice of plans to begin charging for previously free patient-provider messaging has sparked public debate over the value of a clinician's time. There's also speculation that similar policies will become the norm among providers with digital touch points. The Cleveland Clinic released a notice that, as of Nov. 17, it would begin billing up to $50 for certain messages sent by patients to their provider through its MyChart patient portal.

Cleveland Clinic now bills for messages that require medical expertise and "typically taking five or more minutes for your provider to answer," such as a potential change to the patient's medication. Quicker notes, including appointment scheduling or clarification after a recent visit, remain free.

IPPOSI Funding for Public Education in Genomics
The Health Research Board in late 2022 announced 1.2m Euro funding under its Knowledge Translation Initiatives. IPPOSI's proposal for a Public Education Programme in Genomics, has been successful and together with matched funding from a number of IPPOSI industry members, they have launched this 12-month project.

How to speed up paediatric drug trials
https://www.nature.com/articles/d41586-022-04346-4?utm_source=Nature+Briefing&utm_campaign=2bc755ed32-briefing-dy-20221219_COPY_01&utm_medium=email&utm_term=0_c9dfd39373-2bc755ed32-44432605
It takes at least seven years for adult-approved drugs to be authorized for children. Pharmaceutical companies see little reason to pursue paediatric trials: they are expensive because it's difficult to recruit participants, there are more ethical hoops to jump through and there's less money to be made. This often leaves paediatricians with little choice but to prescribe decades-old treatment or use adult medicines off-label — a risky approach, because children can react very differently from adults, says paediatric gastroenterologist David Ziring.
Nature Outlook: Children's health, an editorially independent supplement produced with the financial support of Sanofi.

The unmistakable impact of real-world evidence (RWE) on regulatory approvals in the US, Volume 2
https://info.panalgo.com/rweusecase-booklet2-healtheconomics?utm_source=HealthEconomics.Com&utm_campaign=bff1268b32-EMAIL_CAMPAIGN_2022_11_17_02_32&utm_medium=email&utm_term=0_-bff1268b32-%5BLIST_EMAIL_ID%5D
RWE has steadily grown to supplement Randomized Clinical Trial (RCT) data for regulatory approvals. The FDA, signalling its embrace of RWE as a way to determine drug efficacy and safety, responded by drafting guidelines in 2021 on the usage of real-world data (RWD) and RWE. Now, life sciences companies are heavily investing in analysts and technologies to generate RWE to increase the speed to market for their products. Case studies have been collected. Volume one, now Volume two of examples of RWE either moving or significantly influencing regulatory approval of a new drug or label expansion on a currently approved drug

African Development Bank unveils the African Pharmaceutical Technology Foundation at the 2nd International Conference on Public Health in Africa
https://www.afdb.org/en/news-and-events/press-releases/african-development-bank-unveils-african-pharmaceutical-technology-foundation-2nd-international-conference-public-health-africa-57650
The African Development Bank Group has formally introduced its new initiative that will join hands with the African Union to boost Africa's capacity to produce drugs, vaccines, diagnostics, and therapeutics all along the value chain, to help build its pharmaceutical sector.
The African Pharmaceutical Technology Foundation (APTF) was the focus of a forum hosted by the African Development Bank under the theme: "Technology Access for Pharmaceutical Manufacturing: The African Pharmaceutical Technology Foundation." The event was part of the 2nd International Conference on Public Health in Africa in Kigali, Rwanda, on 14 December. The African Development Bank estimates that the continent imports more than 70% of the medicines it needs at the cost of $14 billion annually.
The Foundation, hosted by the Government of Rwanda in Kigali, is expected to commence operations in early 2023. The Foundation was designed to help African countries bridge the technology gaps in sustainable domestic manufacturing. The Foundation, approved by the African Development Bank's Board

of Directors in June 2022, is expected to boost Africa's access to technology for manufacturing the full range of pharmaceutical products, focusing on building supply chains and expanding access to building block technologies of various kinds.
The WHO, the Coalition on Epidemic Preparedness, the South Centre, Geneva, and the Federal Ministry for Economic Cooperation and Development of Germany have expressed keen interest in working with the Foundation in the coming year.

COVID-19
Biointelect Pty Ltd and the Victoria University Centre of Policy Studies, with the support of Pfizer Australia, recently launched -
The Value of Vaccines: A Tale of Two Parts in the peer-reviewed journal Vaccines
https://www.mdpi.com/2076-393X/10/12/2057?linkId=194166649
The publication examines the impact of the COVID-19 pandemic and subsequent lockdowns on the Australian economy and demonstrates the positive economic and societal effects of the timely population-wide COVID-19 vaccines rollout. The publication's key finding reveals the timely rollout of COVID-19 vaccinations is estimated to have reduced the impact of the pandemic on the economy to $214 billion, resulting in a positive incremental benefit of $181 billion.
Fox N, Adams P, Grainger D, Herz J, Austin C. The Value of Vaccines: A Tale of Two Parts. Vaccines (Basel). 2022 Nov 30;10(12):2057. doi: 10.3390/vaccines10122057.

Transforming global health education during the COVID-19 era: perspectives from a transnational collective of global health students and recent graduates. DW Krugman, M Manoj, G Nassereddine, G Cipriano, F Battelli, K Pillay, R Othman, K Kim, S Srivastava, VA Lopez-Carmen, A Jensen, M Schor. BMJ Global Health 2022; 7(12) https://gh.bmj.com/content/7/12/e010698.full
Inspired by the 2021 BMJ Global Health Editorial by Atkins *et al* on global health (GH) teaching during the COVID-19 pandemic. A group of GH students and recent graduates from around the world convened to reflect on the impact the COVID-19 pandemic and broader systemic inequities and injustices in GH education and practice have had on us over the past 2 years. In light of the mounting health crises that loom over our generation, emerging GH professionals have a unique role in critiquing, deconstructing and reconstructing GH education to better address the needs of our time. We identify autonomous collectives as a potential viable alternative to encourage pluriversality of knowledge and action systems and to move beyond Western universalism that frames most of traditional academia.

Publications

Textbook: Making Health Systems Work in Low and Middle Income Countries by Sameen Siddiqi, Awad Mataria, Katherine D. Rouleau and Meesha Iqbal
https://www.cambridgeblog.org/2022/12/why-a-textbook-on-health-systems/?utm_source=Twitter&utm_medium=hootsuite&utm_term=&utm_content=&utm_campaign=GND_913_Siddiqi_Blog_Dec22_IOC

Potential Barriers of Patient Involvement in Health Technology Assessment in Central and Eastern European Countries Dimitrova, Maria; Jakab, Ivett; Mitkova, Zornitsa; Kamusheva, Maria; Tachkov, Konstantin; et al. Frontiers in Public Health

Differences in Evidentiary Requirements Between European Medicines Agency and European Health Technology Assessment of Oncology Drugs—Can Alignment Be Enhanced?
Sharon Wolters, Frank GA Jansman, and Maarten J Postma
Recommendations on potentially increased alignment to minimize and optimally manage these differences are suggested.

A Comparison of Seven Oncology External Control Arm Case Studies: Critiques From Regulatory and Health Technology Assessment Agencies
A Jaksa, A Louder, C Maksymiuk, GT Vondeling, L Martin, N Gatto, E Richards, A Yver, M Rosenlund.
A comparison of regulatory and health technology assessment agencies' use and critiques of external control arms submitted for oncology product approval and reimbursement.

Patient and Caregiver Views on Measures of the Value of Health Interventions. Dominic Voehler, Peter J Neumann, Daniel A Ollendorf. Patient Preference and Adherence 2022:16 3383–3392.
A modified Delphi approach using a web-based survey of around 60 adult patients managing a chronic condition or caregivers of a patient with chronic illness in the US. Respondents ranked most highly domains considered traditional domains of value (for example, survival, costs). Patient activists were about six times more likely to rate each domain as important or very important compared to general disease advocates. Significant factors associated with a higher odds of rating a domain as important or very important were age 35–54 and 55–64 compared to 18–34, while factors associated with a decreased odds were males and patients compared to caregivers.

Letter: Patient Perspectives: An Integral Part of Health Technology Assessment Methodology. Spangler J, Huth T, Xie R. (2022). International Journal of Technology Assessment in Health Care, 38(1), E85. doi:10.1017/S0266462322003270
The article Patient-centered health technology assessment: a perspective on engagement in health technology assessment by three patient organizations and a health technology assessment body (20 October 2022) brings forth important considerations of vital patient engagement during health technology assessment (HTA), and specifically, with the value assessment review by the Institute for Clinical and Economic Review (ICER) of two lupus therapies.
The Innovation and Value Initiative (IVI) states that ICER's commitment needs to go beyond eliciting patient-important factors merely as inputs for "contextual considerations."
As one example, the authors noted the importance of factors such as "patients' and caregivers' career goals," but our field does not currently have good approaches for measuring and incorporating these impacts into economic models.
Reference: Linthicum M, Jalowsky M, Valentine A, Ahmed R, Bright J, Chapman R. Finding Equity in Value - Racial and Health Equity Implications of US HTA Processes. IVI Sick Cells Whitepaper. Published online 2022. Accessed December 12, 2022. https://www.thevalueinitiative.org/wp-content/uploads/2022/10/IVI_Sick-Cells_Equity-in-Value_2022.pdf

Book (2023). Sweden's Pandemic Experiment. Edited by Sigurd Bergmann, Martin Lindström
https://www.routledge.com/Swedens-Pandemic-Experiment/Bergmann-Lindstrom/p/book/9781032266718#sup

Is the assumption of waning of treatment effect applied consistently across NICE technology appraisals? A case-study focusing on disease-modifying therapies for treatment of multiple sclerosis
Xavier Armoiry, Xia Wang-Steverding, Martin Connock, Amy Grove, Aileen Clarke, Tarunya Arun, Carl Counsell, Peter Auguste
International Journal of Technology Assessment in Health Care

Deliberative processes in decision making informed by health technology assessment in Latin America
Andrea Alcaraz, Andrés Pichon-Riviere, Sebastián García-Martí, Verónica Alfie, Federico Augustovski, Héctor Castro
International Journal of Technology Assessment in Health Care (2022). doi: 10.1017/S0266462322003294

Incorporating environmental and sustainability considerations into health technology assessment and clinical and public health guidelines: a scoping review Ana-Catarina Pinho-Gomes, Seo-Hyun Yoo,

Alexander Allen, Hannah Maiden, Koonal Shah, Michael Toolan
International Journal of Technology Assessment in Health Care (2022). doi: 10.1017/S0266462322003282

Paying for Kidneys: Reflections on Welfare Economics, Political Economy, and Market Design
Louis P Garrison, Jr. The author reflects on the economic implications of allowing some financial compensation to living donors of kidneys to patients with kidney failure.

Analyzing the Pain/Discomfort and Anxiety/Depression Composite Domains and the Meaning of Discomfort in the EQ-5D: A Mixed-Methods Study. Fanni Rencz and Mathieu F. Janssen
Value in Health, Volume 25, Issue 12, 2003 - 2016
This study provides a comprehensive analysis of the use of EQ-5D composite domains and the meaning of discomfort.
Both qualitative and quantitative data were collected in an online cross-sectional survey involving a nationally representative general population sample in Hungary (n = 1700). Respondents completed the 5-level version of EQ-5D, followed by the composites split into individual subdomains. Open-ended questions were asked to explore respondents' interpretations and experiences of discomfort.
We found empirical evidence of measurement error in the composite responses on the EQ-5D, including under- and inconsistent reporting, ordering effects, potential differential item functioning, and interdomain dependency. Our findings contribute new knowledge to the development of new and refinement of existing self-reported health status instruments beyond the EQ-5D.

A Qualitative Investigation of Older Adults' Conceptualization of Quality of Life and a Think-Aloud Content Validation of the EQ-5D-5L, SF-12v2, Warwick Edinburgh Mental Wellbeing Scale, and Office of National Statistics. Hannah Penton, Christopher Dayson, Claire Hulme, and Tracey Young
The validity of scores obtained from patient-reported outcome measures depends on respondents' understanding of questions and the comprehensiveness and relevance of items.

Deciding Between SF-6Dv2 Health States: A Think-Aloud Study of Decision-Making Strategies Used in Discrete Choice Experiments. Lynne Broderick, Jakob B Bjorner, Miranda Lauher-Charest, Michelle K. White, Mark Kosinski, Brendan Mulhern, and John Brazier
Understanding how individuals make decisions during discrete choice experiments is key to ensuring they are completed and interpreted accurately. The findings from this study add to the understanding of the generation of SF-6Dv2 health utility weights and the validity of these weights (e.g., reinterpreting health states could undermine the validity of DCEs and utility weights), and the overall usefulness of the SF-6Dv2.
A qualitative, cross-sectional, noninterventional study asking participants to use a think-aloud approach to compare SF-6Dv2 health states in DCEs. Participants (N = 40) used 3 main strategies when completing DCEs: (1) trading, (2) reinterpretation, and (3) relying on previous experience. Trading involved prioritizing key attributes, such as preferring a health state with significant depression but no bodily pain. Reinterpretation involved reconstructing health states by changing underlying assumptions (eg, rationalizing selecting a health state with significant pain because they could take pain medications). Some relied on previous experience, in dealing with pain, for instance, prioritized health states with the least impact in this dimension.

Preference Variation: Where Does Health Risk Attitude Come Into the Equation? Samare PI Huls, Jorien Veldwijk, Joffre D Swait, Jennifer Viberg Johansson, Mirko Ancillotti, and Esther W de Bekker-Grob
This study aims to determine whether and how health risk attitude and heterogeneity of health preferences in discrete choice experiments are related.

Wende ME, Wilcox S, Rhodes Z et al. Developing criteria for research translation decision-making in community settings: a systematic review and thematic analysis informed by the Knowledge to Action Framework and community input. Implement Sci Commun 3, 76 (2022). https://doi.org/10.1186/s43058-

022-00316-z Overall, the criteria identified through our review highlighted the importance of an intervention's public health, cultural, and community relevance. Not only are intervention characteristics (e.g., evidence base, comparative effectiveness, acceptability, adaptability, sustainability, cost) necessary to consider when contemplating introducing an intervention to the 'real world', it is also important to consider characteristics of the target setting and/or population (e.g., presence of supporting structure, support or buy-in, changing sociopolitical landscape).

Tenni B, Moir HVJ, Townsend B et al. What is the impact of intellectual property rules on access to medicines? A systematic review. Global Health 18, 40 (2022). https://doi.org/10.1186/s12992-022-00826-4

Guidelines should consider clinicians' time needed to treat. Minna Johansson, Gordon Guyatt, Victor Montori. BMJ 2023; 380:e072953. doi: https://doi.org/10.1136/bmj-2022-072953
Assessing the implementation time of guidelines would help make best use of clinical resources - Clinical practice guidelines aim to contribute to efficient and high quality care.1 Efforts are already made to overcome barriers to implementation such as lack of credibility because of financial or intellectual conflicts of interests, and clinicians' inability to change habits or keep up to date with new recommendations. It is rarely acknowledged that implementing guidelines may require appreciable clinician time and therefore have considerable opportunity costs in the clinical encounter. Including an assessment of time needed to implement might alter the recommendations of guideline committees and help clinicians to prioritise.

Tolerating bad health research: the continuing scandal. Pirosca S, Shiely F, Clarke M et al. Trials 23, 458 (2022). https://doi.org/10.1186/s13063-022-06415-5
We focus on randomised trials and look at scale, participants and cost. We randomly selected up to two quantitative intervention reviews published by all clinical Cochrane Review Groups between May 2020 and April 2021. We identified 96 reviews authored by 546 reviewers from 49 clinical Cochrane Review Groups that included 1659 trials done in 84 countries - 1013 (62%) were high risk of bias (bad), 494 (30%) unclear and 133 (8%) low risk of bias. Bad trials were spread across all clinical areas and all countries. Well over 220,000 participants (or 56% of all participants) were in bad trials. The low estimate of the cost of bad trials was £726 million; our high estimate was over £8 billion.

From health systems to systems for health: much more than semantics By Kent Buse.
BMJ 2022; 379:03016 doi: https://doi.org/10.1136/bmj.03016
https://www.bmj.com/content/379/bmj.03016
There's something in the air. Ministries of health in the Bahamas, Barbados, and Botswana have added wellness to their titles—so too have Belize, Jamaica, and Mauritius. India recently relaunched its health centres as health and wellness centres. Meanwhile the department of health in South Australia has become that of health and wellbeing.
The Alliance report explicitly seeks to provide a unifying framework to support WHO to deliver on its triple billion targets (i.e. health security, UHC, and healthy populations). Implicitly, it might serve as a guide for ministries seeking to extend their mandates to wellness in a way that will inspire rather than alienate the UHC community. The UHC framework focused on individual access to healthcare and financial protection rather than managing the upstream structural determinants of health and wellbeing. The systems for health approach attempts to correct this shortcoming with a more holistic approach.
Although a systems approach may be more complex and challenging than the building blocks approach, it represents a much needed step change to enabling more people to live healthier and longer lives with dignity and wellbeing. If the Alliance's conceptualisation can get traction, it will go some way to fostering healthy societies by fixing systems, not people.
Shroff ZC, Marten R, Hanson K, eds. *Systems for health: everyone has a role.* Flagship report of the Alliance for Health Policy and Systems Research. WHO, 2022. Google Scholar

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