

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, September 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 Fiona Pearce our Co-Chair
- PCIG Matters – Steering Committee, member publications
- HTAi Matters – Abstract submissions dates for Seville 2024, other HTAi news
- What's Happening – in and for patient and public involvement
- Publications

Welcome to our September E-Bulletin

Dear HTAi PCIG Members

Welcome to the September edition of the HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin!

As a new Co-Chair of PCIG, I have spent the last few months hearing about the wonderful activities that members have been involved in, and the important ongoing projects driving patient-centred approaches in HTA and healthcare. I feel very privileged to be part of such a passionate community that is placing the patient's voice in the centre of evidence generation and policy development.

With many existing projects coming to an end, the Steering Committee will be considering which new initiatives should be prioritised over the next 12 months. Members are always welcome to share any project ideas with the Co-Chairs to ensure that the Steering Committee is representing everyone's best interests and the projects selected are relevant and produce useful outcomes. We look forward to sharing upcoming key projects with you soon.

I would like to make special mention of Anke-Peggy Holtorf, PCIG Project Coordinator, who led a very successful PCIG pre-conference workshop at the 11th HTAsiaLink Annual Conference held in Malaysia from 4-7 September. The workshop featured best practice examples and diverse experiences from different jurisdictions across Asia and explored feasible pathways to successfully integrate patient involvement in HTA processes across the Asia Pacific region.

As always, a big thank you to Janney Wale for compiling the latest updates on patient and citizen involvement from across the globe for this e-bulletin. It is encouraging to see so many activities happening each month to drive patient-centred approaches in healthcare decision-making and HTA. I hope you enjoy reading this month's issue and please be sure to check out the call for Expressions of Interest for an industry representative to join the PCIG Steering Committee.

Fiona Pearce, Co-Chair
HTAi PCIG Steering Committee

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

Expressions of Interest – PCIG Steering Committee, Industry Representative

PCIG seeks Expressions of Interest for an industry representative to fill a vacancy on its Steering Committee. Please send a CV and cover letter (no more than 200 words) addressing the criteria below to the PCIG Technical Officer, Hadewych Honné, via email: to.patient-citizen@htai.org no later than Friday, 20 October 2023.

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 (from October 2023-2026)
 - Able to participate in additional HTAi committees
 - Preference will be given to those members who have actively participated in the Interest Group.
- Please note all applicants must be a member of HTAi and PCIG.

Full details of the role of Steering Committee members can be found in PCIG's [Terms of Reference \(May 2023\)](#). The Co-Chairs, Fiona Pearce and Aline Silva are happy to discuss the role with interested members.

Contributed by
Fiona Pearce

Publications by members:

Anke-Peggy Holtorf, Andriy Danyliv, Li-Ying Huang, Yvette Venable, Alissa Hanna, Annekatrin Krause, Miranda Pierre, Donna Walsh, Aline Silveira Silva, Sou-Hyun Lee, T. Joseph Mattingly II. Using Social Media Research in Health Technology Assessment: Stakeholder Perspectives And Scoping Review.

[International Journal of Technology Assessment in Health Care](#)

doi: 10.1017/S0266462323002593. Published Online on 21 September 2023

Eunice Low, Joëlle André-Vert, Gaëlle Fanelli, Margaret Galbraith. International overview of health technology assessment training tools and materials for patients and consumers.

[International Journal of Technology Assessment in Health Care](#)

doi: 10.1017/S0266462323000533. Published Online on 21 September 2023

Disinvestment Interest Group, 2nd IG Funding Call for 2023 is now open.

For those who are interested, you may reach out and share your proposals relating to the field of Disinvestment and Early Awareness to the IG co-chairs, Rosmin Esmail and Nora Ibarгойen-Roteta and kindly cc (to.dea@htai.org and druezono@up.edu.ph).

The deadline of HTAi for submission of proposals is on October 15th, thus, we would appreciate it if you can share your proposals before this deadline to provide ample time for the IG Chairs to review the proposal.



2024 HTAi Annual Meeting in Seville. MEETING THEME: A Turning Point for HTA? Sustainability, Networks and Innovation <https://htai.eventsair.com/htai-2024-annual-meeting>

With the growing emergence of new technologies and innovations, healthcare has seen significant changes. The HTA community through collaboration provides a means to pool resources and expertise for generating

reliable evidence for decision-makers. Collaboration on a global scale is essential for data exchange, evidence generation, and building regulatory and incentive mechanisms.
See 2024 Annual Meeting [main theme](#) and [plenary themes](#)

September 28, 2023: HTAi 2024 Annual Meeting Abstract submissions for all presentation categories open! Abstract Guidelines are currently available on the [2024 Annual Meeting website](#). The 2024 submission guidelines have changed.

Workshop and Panel submissions close October 25, 2023. Oral and Poster submissions close December 7, 2023.

The HTAi Jill Sanders Memorial Scholarship

The scholarship provides funding for individuals residing in African countries to further their knowledge of HTA, and to have a positive impact on HTA capacity in African countries.

By providing financial assistance to complete education programs or training in HTA for the purpose of applying their knowledge and skills in their country of origin, HTAi advances its mission of promoting the development, communication, understanding, and use of HTA around the world. A total of \$20,000 CAD is available for the HTAi Educational Scholarship program each fiscal year. Scholarship **applications are due October 15** of each year (unless otherwise specified).

IJTAHC is seeking reviewers

For people with expertise in areas within the scope of IJTAHC relating to HTA including systematic review, health economic evaluation, patient/citizen issues and health policy. Participating as an IJTAHC Reviewer is not only beneficial for your career development, it is a great way to contribute to the global HTA community! If you are interested in becoming a reviewer for IJTAHC, please send an email to [Wendy Babidge, Editor in Chief](#), and include short CV outlining areas of expertise relative to the reviewer categories.

Global Policy Forum

Meindert Boysen, head of International Affairs at the National Institute for Health and Care Excellence (NICE), has been appointed as the HTAi Global Policy Forum Chair, 2025-2027. The Forum membership is drawn from for-profit and not-for-profit organisations broadly operating in the field of HTA. Meindert will be working closely with the current Chair, Dan Ollendorf until the end of his term in July 2024.

HTAi Interest Group webinars are available online

Visit the HTAi YouTube page to check out our [webinar playlist](#) and a new addition: HTA in Robotic Surgery: Webinar from September 20th with Richard Charter, Anastasia Chalkidou and Jamo Suominen. The world of robotic surgery and digital technologies is evolving at lightning speed. So, what does the future hold, and how can the HTA community stay prepared?

The HTAi Review is your biweekly news source for all things HTAi <https://htai.org/htai-review-september-22-2023/> 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

October 10th is World Mental Health Day

World Patient Safety Day 2023 was observed on 17 September under the theme 'Engaging patients for patient safety'. This is in recognition of the crucial role patients, families and caregivers play in the safety of health care. Evidence shows that when patients are treated as partners in their care, significant gains are made in safety, patient satisfaction and health outcomes.

<https://www.who.int/campaigns/world-patient-safety-day/2023>

International HTA collaboration expands

<https://www.nice.org.uk/news/article/international-health-technology-assessment-collaboration-expands>

The Institut national d'excellence en santé et en services sociaux (Quebec) and Pharmac (New Zealand) have joined NICE, the Canadian Agency for Drugs and Technologies in Health, Australian Government Department of Health and Aged Care, Healthcare Improvement Scotland (Scottish Medicines Consortium and Scottish Health Technologies Group), Health Technology Wales, and All Wales Therapeutics & Toxicology Centre in an international collaboration aimed at sharing work to support better health system preparedness and scientific methods development.

Institute for Clinical and Economic Review (ICER) revised value assessment framework - with more emphasis on patient engagement and health equity

https://icer.org/wp-content/uploads/2023/09/ICER_2023_VAF_For-Publication_092523.pdf

Updates include:

Improving patient engagement in clinical trials and participations in ICER reviews

Introduction of clinical trial diversity rating

Use of a priori list of subpopulations

Use of "non-zero" inputs for treatment impact on productivity in modified societal perspective

Inclusion of a dynamic pricing scenario

Improved voting methodology for 'Benefits Beyond Health' and 'Special Ethical Priorities'.

ICER and Peterson Health Technology Institute (PHTI) release framework for digital health assessment

<https://phti.com/press-releases/peterson-health-technology-institute-releases-new-digital-health-assessment-framework/>

The Peterson Center on Healthcare launched the [Peterson Health Technology Institute](#) (PHTI), a nonprofit organization that provides independent evaluations of innovative healthcare technologies to improve health and lower costs. Launched with a commitment of \$50 million, PHTI will deliver rigorous, evidence-based assessments that will analyze the clinical benefits and economic impact of digital health solutions, as well as their effects on health equity, privacy, and security.

<https://petersonhealthcare.org/launches-new-50-million-institute-evaluate-digital-health-technologies>

EMA shares its achievements with EUnetHTA 21 consortium

<https://www.ema.europa.eu/en/news/towards-permanent-collaboration-framework-ema-health-technology-assessment-bodies>

EUnetHTA 21 ceases to operate on 16 September 2023, but preparations will continue for the implementation of the Regulation, under the direction of the [HTA Coordination Group](#).

[The Regulation on Health Technology Assessment \(EU\) 2021/228](#) which entered into force in January 2022 and applies as of January 2025, will govern the European cooperation between medicine regulators and HTA bodies. Under the new framework, EMA and HTA bodies will collaborate in the context of joint clinical assessments, joint scientific consultations, and the identification of emerging health technologies.

New WHO Civil Society Commission to strengthen civil society organizations' role in accelerating progress in Global Health

<https://www.who.int/news/item/24-08-2023-new-who-civil-society-commission-to-strengthen-civil-society-organizations--role-in-accelerating-progress-in-global-health>

According to WHO officials, the Commission provides, for the first time, the ability to channel advice and recommendations in a more structured and systematic manner from civil society to WHO on health priorities and related issues.

Dr Hans Henri P. Kluge, WHO Regional Director for Europe, provides statement at the conclusion of the WHO Traditional Medicine Global Summit in Gandhinagar, India, 18 August 2023: Shaking up the status quo that separates different approaches to medicine and health. <https://www.who.int/europe/news/item/21-08-2023-statement---shaking-up-the-status-quo-that-separates-different-approaches-to-medicine-and-health>

- By taking aim at silos, we are saying we will collaborate all the more to find optimal ways to bring traditional, complementary and integrative [TCI] medicine well under the umbrella of primary health care and universal health coverage.

New ISPOR Special Interest Group for Global Access to Medical Innovation

https://www.ispor.org/member-groups/special-interest-groups?utm_medium=email&utm_source=database&utm_campaign=strategic_initiatives&utm_content=engage_september2023_non-member-communication_sept28&_zs=3hXOX&_zl=qFXl3

A new ISPOR Special Interest Group focusing on Global Access to Medical Innovation has been established especially as it relates to the role of health economics and outcomes research.

The ISPOR Medical Devices and Diagnostics Special Interest Group recently published 6 Terms and Definitions Monographs related to diagnostics, in vitro diagnostics, medical device, molecular diagnostics, point-of-care testing, and time-and-motion studies. Each monograph contains a brief definition of the term as well as further explanation and references.

<https://www.ispor.org/member-groups/special-interest-groups/medical-devices-and-diagnostics/medical-device-diagnostics-terms-and-definitions-monographs>

Sharing trade secrets is key to the pandemic agreements - Addressing this IP issue is crucial to ensuring pharmaceutical products are available in future emergencies. Ellen 'T Hoen

<https://www.ft.com/content/c76d6f5a-0d82-493c-8d8a-5cdf8cf4a1d4?sharetype=blocked>

The current WHO discussions represent a desperately needed opportunity to better prepare for the future. They must deliver a set of international rules robustly adequate to the task.

Publications

Characterising meaningful patient and public involvement in the pharmaceutical industry research setting: A retrospective quality assessment. Dews S-A, Bassi A, Buckland S, et al. (2023). *BMJ Open*, 13(8), e071339. <https://doi.org/10.1136/bmjopen-2022-071339>

"I think there has to be a mutual respect for there to be value": Evaluating patient engagement in a national clinical trial on de-implementation of low value care. Etchegary H, Linklater S, Duquette D 'Arcy, et al. (2023). *Research Involvement and Engagement*, 9(1), 70. <https://doi.org/10.1186/s40900-023-00483-w>

Patient and public involvement is suboptimal in randomized controlled trials addressing a chronic condition. Husson M, Dechartres A, Ramdjee B, et al. (2023). *Journal of Clinical Epidemiology*, 160, 71-82. <https://doi.org/10.1016/j.jclinepi.2023.06.012>

Closing the loop between horizon scanning and health technology assessment – An overview of topics submitted for appraisal in England. Khan S, Gonzalez-Moral S, Lanyi K, Ogunbayo D, Craig D (2023). *International Journal of Technology Assessment in Health Care*, 1-20. doi:10.1017/S0266462323000491

Hospital-based health technology assessment of innovative medical devices: insights from a nationwide survey in France. Tess Martin, Alessandra Guercio, H  l  ne Besseau, Laure Huot, Pascale Guerre, Jamal Atfeh, Laurent Piazza, Judith Pineau, Brigitte Sabatier, Isabelle Borget, Nicolas Martelli (2023) International Journal of Technology Assessment in Health Care. doi: 10.1017/S0266462323000521.

Economic evaluation of remote patient monitoring and organizational analysis according to patient involvement: a scoping review. Myriam Le Goff-Pronost, Isabelle Bongiovanni-Delarozi  re (2023) International Journal of Technology Assessment in Health Care doi: 10.1017/S0266462323002581.

The disease burden and economic burden of cancer in 9 countries in the Middle East and Africa. Hofmarcher T et al (2023). Value in Health Regional Issues 37:81-87

Data Privacy and Health: How Do We Achieve the Right Balance? C Daniel Mullins and Michael F Drummond (2023) Value in Health 26(9):1283-1285. DOI:<https://doi.org/10.1016/j.jval.2023.06.013>
Today nearly 30% of the world's data are generated by the healthcare industry.¹ These data are typically collected for administrative purposes and are often proprietary. Data on factors that influence health (such as social determinants) increasingly are captured outside of the healthcare system. Although big healthcare data have the potential to improve patient outcomes and ultimately reduce healthcare costs, much of these data are siloed in disparate systems and platforms, making it difficult to access by researchers. In addition, in many jurisdictions, access to personal data is regulated by data privacy legislation. There is a direct trade-off between assuring data privacy and allowing access to de-identified data to support health research aimed to improve population health.

To leverage health data for research purposes, interoperability—that is, the ability to access, integrate, and cooperatively use data in a coordinated way both within and across different information systems, devices, and countries—is essential. Nevertheless, regulating the acceptable and appropriate uses of data while protecting patient privacy is a huge challenge.

A Rapid Review on the Value of Biobanks Containing Genetic Information. Rodriguez Llorian E, Kopac N, Waliji LA, et al (2023). Value Health 26(9). <https://doi.org/10.1016/j.jval.2023.02.017>. Biobanks containing genetic information have succeeded in expanding the scientific knowledge base and affecting clinical practice, but improved data collection and reporting are needed

Reimagining Patient Data Access for Researchers. Parente ST, Phelps CE (2023). Value Health 26(9). <https://doi.org/10.1016/j.jval.2023.06.012>.

Maximizing researchers' access to patient data requires important policy changes regarding patients' data access, data privacy, and new organizations to aggregate patient data.

Does EQ-5D Tell the Whole Story? Statistical Methods for Comparing the Thematic Coverage of Clinical and Generic Outcome Measures, With Application to Breast Cancer. M  nica Hern  ndez Alava, Stephen E Pudney, and Allan J Wailoo (2023) Value in Health 26(9),1398-1404.

<https://doi.org/10.1016/j.jval.2023.05.016>

Incomplete coverage of health benefits by generic instruments is assessed for breast cancer patients, suggesting missing domains in EQ-5D, but potential biases might be modest.

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