HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG)
E-Bulletin, February 2024

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 E-Bulletin

Welcome to the first edition of the PCIG E-Bulletin for 2024. I hope you all have had a wonderful start to the new year. I begin this month's issue by acknowledging and thanking Sarah Berglas who has recently stepped down from the PCIG Steering Committee. Her valuable and insightful contributions have been greatly appreciated and we wish her well for her future endeavours.

The year has started with a flurry of activity preparing for the HTAi Annual Meeting which is being held in hybrid format from 15-19 June 2024 in Seville, Spain. I had the privilege of reviewing some of the abstracts that have been submitted for different sessions and I was so impressed by the quality and breadth of topics covered. Like previous years, the 2024 meeting is going to be an important opportunity to hear about the latest innovations, exchange ideas, share experiences and connect with different people. Early bird registration closes on **28 March 2024**, so be sure to register soon to secure your place.

If you are attending the meeting and require financial assistance, the PCIG PASS program is also now open for applications until **15 March 2024**. This program provides financial assistance to encourage patients, caregivers, or patient representatives to participate in the annual meeting. More information about the PASS program, including the eligibility criteria, is available at https://htai.eventsair.com/htai-2024-annual-meeting/pcig-pass-program.
I hope you enjoy reading this month's issue and hearing about all of the wonderful activities and projects that our members have been involved with.

Best wishes,

Fiona Pearce
Co-Chair, HTAi PCIG

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

Welcome to our technical officer Pierre Net
(Pronouns: He/Him)
Technical officers provide critical support to Interest Group activities, fulfilling responsibilities such as defining agendas, setting calls and taking minutes, writing reports, supporting project work and scientific papers, drafting press releases and more.

Zal Press participates in the February Global Policy Forum, San Diego, USA

The Global Policy Forum was the first professional event I've attended where each invited patient representative was called on to speak or comment first in every discussion, whether breakout or plenary, regardless of how many in the room, thereby setting the tone for the conversation.
This is an authentic commitment to patient involvement and a practice all other healthcare related events should adopt. It ensures active participation of the patient voice - no tokenism here. Kudos to Dan Ollendorf for his foresight and inclusive shepherding.
As you can see, everyone's welcome, including old hippies. It was enlightening to witness the impact, intelligence and bold leadership of Sneha Dave of Generation Patient in action. She generates great optimism in the dynamic potential of the younger cohort of patient leaders.

Contributed by Zal Press

Save the date – PCIG workshop Seville
Patient and Citizen Involvement in Health Technology Assessment: Networks For Sustainability And Innovation 13:30 - 17:00 CEST, Sunday June 16, 2024
Barcelo Recinamiento, Seville, Spain
Don't forget to plan your trip to Annual Meeting so that you can attend PCIG's pre-meeting workshop. You need to register separately for it.
This workshop, led PCIG begins with an introduction to key concepts, methods and approaches to patient involvement, including examples of tools adapted internationally for efficient and good practice. This is followed by a choice of deep-dive dialogues including reporting and evaluating; and sustainable practice.

Progressing faster access to life-saving treatments
To explore and determine the principles that might be considered when establishing processes to provide faster access to life-saving treatments, Bellberry invited representatives of regulators, HTA agencies, pharmaceutical companies and, most importantly, patient groups from around the globe to Adelaide, Australia for an International Scientific Congress in June 2023.
You can read the final report here (including the Meeting Statement in Appendix B) and listen to a podcast featuring experts attending the event here.

Contributed by Ann Single

Assessment of quality of data submitted for NICE technology appraisals over two decades
Osipenko L, Ul-Hasan SA, Winberg D, et al BMJ Open 2024;14:e074341. doi: 10.1136/bmjopen-2023-074341
https://bmjopen.bmj.com/content/14/2/e074341.full
The quality of clinical data (comparator, quality of life (QoL), randomised controlled trials (RCTs) and overall quality of evidence) submitted by the manufacturers to NICE was investigated for technical appraisals (TAs) published between 2000 and 2019. This included multiple technology appraisals (MTA)=104, and single technology appraisal (STA)=305. In two-thirds of TAs, the overall quality of evidence was either poor (n=224, 55%) or unacceptable (n=41, 10%). In 39% (n=119) of the STAs, the quality of comparative evidence was considered poor, and in 17% (n=51) unacceptable. In 44% (n=135) of STAs, the quality of QoL data was considered poor, 15% (n=47) unacceptable, 33% (n=102) acceptable and 7% (n=21) as good. Over 20 years of longitudinal analysis did not show improvements in the quality of evidence submitted to NICE. In conclusion, we found that the primary components of clinical evidence influencing NICE's decision-making framework were of poor quality. It is essential to continue to generate robust clinical data for premarket and postmarket introduction of medicines into clinical practice to ensure they deliver benefits to patients

Contributed by Eric Lowe

Webinar: The Characteristics of Rare Diseases That Complicate the Assessment of Technology Value
Held February 27, 2024
Evaluating the value of rare disease technologies poses challenges due to factors like poor natural history, small populations, limited data, complexity, and high unmet needs. Challenges vary across the spectrum of ultra-rare to more prevalent diseases, with added complexities in different populations, such as pediatrics. This webinar highlights these characteristics, elucidates their role in hindering evidence generation and value assessment, and discusses the resulting difficulties in obtaining approvals. The session outlines the impact of these challenges and details the strategies planned by the Rare Disease Interest group to address and overcome them.
Panelists
Elena Nicod – Director, Dolon | Italy
Fleur Chandler – Head of Market Access UK and Ireland, Sanofi | United Kingdom
Dan Ollendorf – Chief Scientific Officer and Director of Health Technology Assessment Methods and Engagement, ICER | United States of America
Karen Facey – Independent | United Kingdom
Sheela Upadhyaya – Life Sciences Consultant, Independent | United Kingdom

Europe 360 Project Article from PCIG
A blog written by PCIG Members Dr Anke-Peggy Holtorf and Neil Bertelsen will be published by EFPIA later this month. The piece is based on the Europe 360 HTA Patient Involvement report already available under Projects on the PCIG page with more information coming soon.
https://past.htai.org/wp-content/uploads/2022/02/360-HTA-Patient-Involvement-Project-Dashboard-02.03.22.pdf?_gl=1*11s6vnc*_ga*MTQ0NDg3NjcxMi4xNDAyNTA2MDI4*_ga_79CPBECN0V*MTcwODQyNTQ5NC41LjEuMTcwODQyNjQ5MS4wLjAuMA..

Patient Engagement and Patient Experience Data in Regulatory Review and Health Technology Assessment: A Global Landscape Review
Bertelsen, N., Dewulf, L., Ferrè, S. et al. Ther Innov Regul Sci 58, 63–78 (2024).
https://doi.org/10.1007/s43441-023-00573-7

Health Technology Assessment: Similarities and Differences in Mechanisms, Systems and Processes across 27 Countries

In December 2023, Lymphoma Coalition produced a report titled, Health Technology Assessment: Similarities and Differences in Mechanisms, Systems and Processes across 27 Countries. The report is available on our website (in letter size and A4 format) here HTA – Lymphoma Coalition
Lymphoma Coalition (LC) is a worldwide network of patient groups with a full or partial focus on providing support to patients with lymphoma. As many LC Members are actively engaged in HTA processes and others are interested in helping to improve patient involvement, HTA is a key strategic priority area/project of our organisation. We value the opportunity to share the report with the HTAi PCIG membership.

In addition to mapping HTA mechanisms, systems and processes, LC explored patient involvement in HTA to understand some of the perceived opportunities, challenges, and barriers from the perspective of LC Members by hosting a HTA Workshop in Madrid, Spain on 19 October 2023. It was attended by Members who have a keen interest and/or firsthand knowledge of HTA within their respective countries.
The workshop was moderated by an external facilitator and 10 participants attended in person from China, Colombia, France, Hong Kong, Ireland, Japan, The Netherlands, and Sweden. Additionally, an LC Member from Australia joined virtually for a portion of the workshop.
Participants explored the role of PICO (Patients, Intervention, Comparator, Outcomes) as an important component to defining a HTA research question; and the use of a submission template.

Contributed by Marjorie Morrison
Director, Policy & Advocacy
Marjorie@lymphomacoalition.org
www.lymphomacoalition.org

HTA news from around the world
From Canada: The Centre for Advancing Health Outcomes published a piece on Managing Uncertainty: How early HTA improves return on research investment. Read more

WHO: The World Health Organization introduces the Health Technology Access Pool (HTAP) as the successor to the COVID-19 Technology Access Pool (C-TAP). Read more

From EMA: the Heads of Human Medicines (HMA) and EMA have launched two public electronic catalogues of real-world data (RWD) sources and studies to enhance data discoverability. Read more

HTAi Matters

HTAi 2024 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 main theme and plenary themes
The meeting will be a hybrid format, with a unique fusion of engagement and interaction for virtual and in-person attendees. Presentations will take place in-person and simultaneously stream online, ensuring that all participants can actively participate in scientific discussions, network with peers, and take part in this

celebrated hybrid event. For all attendees, select presentations will be available on-demand throughout the conference and for several weeks after.
More information on the Annual Meeting, including themes, speakers, venue, and accommodation is available online at https://htai.eventsair.com/htai-2024-annual-meeting/

Early-bird registration deadline: Thursday, March 28, 2024 at Midnight MDT (UTC-6)
Standard registration deadline: Thursday, June 6, 2024 at Midnight MDT (UTC-6)
Last-minute registration: Friday, June 7 to Wednesday, June 19, 2024

PCIG PASS Program - deadline 15 March 2024
https://htai.eventsair.com/htai-2024-annual-meeting/pcig-pass-program
HTAi's Patient and Citizen Involvement in HTA Interest Group (PCIG) offers the PCIG PASS to support patients, carers and patient representatives attend HTAi Annual Meeting and pre-meeting workshops who would be otherwise unable to take part.
You can apply if you:
have lived experience as a patient or carer, or
represent patients (such as in a patient or community organisation, including online groups), or
represent patients in an HTA committee (such as a consumer/patient/public/lay member), or
have an HTAi Participation Grant or are a plenary speaker, and fall into one of the above 3 categories and need a 'partial' PCIG PASS to cover a gap between the Grant and the PASS.

The In-Person PCIG PASS gives you:
Economy (coach) class travel to/from Seville, Spain and accommodation (lodging) for up to 6 nights booked by HTAi so you are not out of pocket
Complimentary early bird registration for HTAi Annual Meeting
Complimentary pass to HTAi Patient and Citizen Involvement in HTA Interest Group's pre-conference workshop, Sunday 16 June
Ability to claim incidentals up to USD 300 (for example: ground travel, meals not including alcohol, visa costs, accessibility support, additional workshop attendance, formal/informal dinners, mobile data expenses); Pre-HTAi Annual Meeting briefing (virtual); Option of having an Annual Meeting buddy; Patient slack chat; Daily roundup email; Invitation to PCIG informal dinner (self-funded)

The Virtual PCIG PASS gives you:
Complimentary early bird registration for HTAi Annual Meeting. Also Pre-HTAi Annual Meeting briefing (virtual); Option of having an Annual Meeting buddy; Patient slack chat; Daily roundup email

How to apply
Make sure you have a letter of support if you have not applied for a PCIG PASS in the past 5 years.
Complete the online form.
Letter of support
Please provide a short letter from someone from your organization (other than yourself) or an organisation familiar with your work which demonstrates their support for you attending HTAi 2024 Annual Meeting. If you have provided this letter for the PCIG PASS before, you do not need to do this again.
Any questions: htaipcigpass@gmail.com

Our sponsors
PCIG is grateful to our sponsors: Sanofi, EFPIA, Intuitive and Fenin Tecnología Sanitária for their sponsorship of these grants and commitment to patient participation in HTAi's Annual Meeting.

Dr Rabia Sucu, HTAi President announces Dr Hameed Khan as HTAi's new Executive Director

We are pleased to announce the appointment of the new Executive Director for HTAi: Hameed brings with him over 15 years of invaluable experience in the health research and innovation space, spanning various sectors including not-for-profit, government, industry, and healthcare delivery. Prior to joining HTAi, Hameed has successfully demonstrated his ability to work in a complex multi-stakeholder environment to develop and advance organizational objectives and achieve goals. This includes the development of strategic plans, forming strategic partnerships, developing multi-million-dollar funding programs, and work with an interdisciplinary team within the healthcare system to manage introduction of new technologies. Hameed holds a master's in business administration, as well as a BSc, MA, and a PhD in biochemical sciences.

Call for Expressions of Interest – HTAi HTA in Developing Countries Interest Group (DCIG)
https://htai.org/call-for-expressions-of-interest-vice-chair-steering-committee/
DCIG is currently accepting expressions of interest from those wishing to join the Steering Committee, in particular, the IG has open positions for: Vice Chair; Steering Committee members.
All candidates must use this form to submit their motivation, a short bio, and suggestions for initiatives or activities for the IG that you wish to implement. Applicants should be able to commit to the role for one term (3 years, 2024-2027). Please consult the terms of reference for more information on the IG.

Renew your membership for 2024
HTAi memberships are valid from January 1 to December 31 each year. Your 2023 membership expired on December 31. Renew your membership now to continue participating in HTAi activities, including Interest Groups and Committees, award nominations, and voting in elections. For assistance, contact our membership team at info@htai.org.

HTAi Global Policy Forum
The HTAi 2024 Global Policy Forum is taking place January 27-29, 2024 in San Diego, USA. Discussions will revolve around the main topic 'Designing Collaborations Involving HTA: Finding The Rhythm For Success'. The Policy Forum Advisory Committee Chair is Iñaki Gutiérrez-Ibarluzea

The Global Policy Forum is supported by a Chair and Scientific Secretary, and their expertise and guidance helps to ensure each Forum is a success. Thank you to Meindert Boysen, Rebecca Trowman, and Dan Ollendorf, whose support helped ensure the success of #2024GPF!
Thank you to our 2024 Global Policy Forum Patient Representatives whose perspective and expertise provide critical contributions to Policy Forum discussions.

Our 2024 Patient Representatives

Sneha Dave
Executive Director
Generation Patient
United States of America

Zal Press
Vice Chair, Patient And Community Advisory Committee
CADTH
Canada

Tiffany Westrich-Robertson
CEO
International Foundation for Autoimmune & Autoinflammatory Arthritis
United States of America

HTAi Ethics Interest Group webinar January 17, 2024
The recording from HTAi's webinar on ethical analyses at HTA agencies is now online.
https://www.youtube.com/watch?v=PxaKy30sDsc
The webinar discussed the challenges and opportunities for being involved in conducting ethical analyses at HTA agencies. Bart Bloemen, co-chair of the Ethics IG presented the work that the interest group is currently conducting. Two speakers presented their experiences with working as an ethicist at HTA institutes. Renata Axler leads the development of ethics methodologies and practices at the Canadian Agency for Drugs and Technologies in Health (CADTH). Lars Sandman is professor at Linköping University, and also ethics advisor for Swedish healthcare authorities and director at the National Centre for Priorities in Health.
HTAi Ethics Interest Group webinar January 17, 2024
The recording from HTAi's webinar on ethical analyses at HTA agencies is now online.
https://www.youtube.com/watch?v=PxaKy30sDsc
The webinar discussed the challenges and opportunities for being involved in conducting ethical analyses at HTA agencies. Bart Bloemen, co-chair of the Ethics IG presented the work that the interest group is currently conducting. Two speakers presented their experiences with working as an ethicist at HTA institutes. Renata Axler leads the development of ethics methodologies and practices at the Canadian Agency for Drugs and Technologies in Health (CADTH). Lars Sandman is professor at Linköping University, and also ethics advisor for Swedish healthcare authorities and director at the National Centre for Priorities in Health.

Visit the HTAi YouTube page to check out our webinar playlist

The HTAi Review
Your biweekly news source for all things HTAi at https://htai.org/htai-review-february-16-2024/ 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

SUSTAIN HTA Feb 15, 2024
The kick-off meeting of the Support Utilisation of Sustainable and TAilored INnovative methods for HTA (SUSTAIN_HTA) project was held in Utrecht (The Netherlands).
This EU-funded project aims to upskill the HTA body workforce and harmonise HTA expertise in the EU. Led by the University of Utrecht, the project consortium includes leading universities, HTA bodies, a non-Government Organisation, and small and medium-sized enterprises (SMEs) from across Europe. Activities will be embedded in a larger network of HTA bodies and will involve other experts and a wide group of stakeholders through our Forums. Together, we aim to contribute to the use of innovative health technology assessment (HTA) methodologies across Europe and support the methodological activities as part of the Regulation (EU) 2021/2282 on health technology assessment (HTAR).
https://twitter.com/SUSTAIN_HTA/status/1758060879247991214

DIA Join DIA Europe 2024 this March, the premier hub for healthcare knowledge and networking in Europe. Over 250 speakers will deliver cutting-edge insights spanning the drug development lifecycle.

Secure your place now to engage with key stakeholders from the European Commission, EMA, global Regulatory Authorities, industry leaders, academia, HTA bodies, payers, and patient organisations - all on a neutral platform designed for open dialogue and collaboration.
This year, experience a groundbreaking addition to our program: the Collaboration Hub. Designed for collaborative and co-creative work, these sessions offer a unique opportunity to discuss specific topics with a wide range of experts and strategize next steps.
Explore the full programme.

ISPOR conducts horizon scanning and monitoring of the trends that affect healthcare decision making around the globe:
Real-World Evidence
Drug Pricing
Artificial Intelligence - Bridging Real-World Data and Regulatory Decision Making
Fostering Innovation - Elasticity of Innovation
Health Equity
Accelerated Drug Approvals
Value Measurement - Preventive Health Interventions
Patient Centricity
Challenges in Developing Patient-Centered Sensor-Based Outcomes (eg Wearables)
Precision Medicine
Public Health - Implementing Comprehensive, Integrated, Whole-Person Care Models Using Real-World Data

ISPOR's Top 10 HEOR Trends report, a biennial publication
https://www.ispor.org/heor-resources/about-heor/top-10-heor-trends

ISPOR 2024 May 5-8, 2024 | Atlanta, GA, USA
https://www.ispor.org/conferences-education/conferences/upcoming-conferences/ispor-2024?https://www.ispor.org/conferences-education/conferences/upcoming-conferences/ispor-2024&gclid=Cj0KCQiA5-uuBhDzARIsAAa21T_s01isHI7PqMG7JNWdpCPhQap4QPmC_6BSsdZMd51cjLnNsf8sOp4aAnriEALw_wcB
Register by March 28 to save up to 20% with Early Bird rates

ISPOR Patient-Centered Research Summit 2024 - Sunday, May 5, 2024 | A co-located half day event at ISPOR 2024
https://www.ispor.org/conferences-education/conferences/upcoming-conferences/ispor-patient-centered-research-summit-2024
ISPOR is pleased to provide Travel Grants to support in-person attendance at ISPOR 2024! Learn more about Travel Grants, Student Travel Grants, and Patient Representative Travel Grants'
https://www.ispor.org/about/awards-grants/ispor-conference-grants

ISPOR Education Center
https://www.ispor.org/education-training/ispor-education-center

The European Patients Forum Launches Ambitious EU Elections 2024 Campaign Advocating for Patient-Centric Healthcare Policies
The European Patients Forum (EPF) has officially launched its European Election Campaign 2024, focused on elevating the voice of patients in the EU healthcare landscape.
Key Messages of the Campaign:
Strengthening Involvement: EPF is dedicated to enhancing the role of patient organisations in shaping healthcare policies at both national and regional levels.

Ensuring Participation: The campaign highlights the importance of fostering participation grounded in solidarity, equity, mutual trust, sustainability, empowerment, and responsibility.
Meaningful Participation: EPF emphasises the need for a meaningful and viable involvement of patient organisations, identifying effective channels and mechanisms in collaboration with patients.
Broadening Horizons: Beyond healthcare, EPF calls for the involvement of patient organisations in other policy areas related to public health and quality of life.
Inclusive Policy Development: The campaign calls on policy makers to enable patient organisations to participate actively in all stages of policy development, ensuring their voices are heard and considered.
Institutionalising Participation: EPF calls for the institutionalisation of participatory processes, diversifying opportunities for patient organisations to contribute meaningfully.
Health Technology Assessment Inclusion: The campaign advocates for the inclusion of patient organisations in health technology assessment and related processes, recognising their unique perspectives.
Formalised Decision-Making: EPF seeks to formalise patients' participation in any decision-making body on health and related policies.
Stable Funding: EPF is committed to ensuring that patient organisations have access to long-term and unrestricted operational funding.
Key Partnerships: The campaign calls on policymakers to recognise patient organisations as key partners in improving patient education and building capacities and skills.
Anca Toma, EPF Executive Director, emphasises: "Let this be a commitment towards person-centric healthcare systems and democratic participation of patient organisations. Inclusiveness in healthcare decision-making is a moral obligation as much as a strategic imperative."
- read the manifesto and be among the first ones to sign our petition!

New England Journal of Medicine Free virtual event - Regulating Medical AI – Staying Safe in the Fast Lane
April 10, 2024 / 12:00 - 2:00 PM ET
In a world where technological advances outpace the speed of policy and regulation, how do we ensure cutting-edge AI technologies are safe, and that regulatory requirements enable, rather than inhibit, the potential benefits of AI?
Save the date for our free virtual event on April 10th, and join a lively discussion on the regulation of AI — where current regulation works and where it falls short of ensuring novel AI technologies are safe for medical use. NEJM AI editors will speak with regulatory experts, scientists, and policymakers about what challenges lie ahead for new AI technologies as well as how scientific evidence, ethical principles, regulation, and regulatory science can enable, and even accelerate, the positive of AI impact on patients
Register now for this event.

The World Health Organization has introduced the Health Technology Access Pool (HTAP)
This is the successor to the COVID-19 Technology Access Pool (C-TAP). HTAP will promote access to health products that respond to public health priorities including pandemic preparedness and with relevance during and outside health emergencies. Read more
The World Health Organization is releasing new guidance on the ethics and governance of large multimodal models, with more than 40 recommendations for consideration by governments, technology companies, and healthcare providers to ensure the appropriate use of this generative artificial intelligence technology to promote and protect the health of populations. Read more

FDA Mandates Black Box Warning for All Commercial CAR-T Therapies Due to Secondary T-Cell Cancer Risk
https://healtheconomics.com/fda-mandates-black-box-warning-for-all-commercial-car-t-therapies-due-to-secondary-t-cell-cancer-risk/

The FDA is set to add a black box warning, the most severe safety alert, for all six commercial CAR-T therapies due to the risk of secondary T-cell cancers.
Read more

Valuing Rare Disease Treatments in Healthcare: Real Experience, Real Impact
https://thevalueinitiative.org/wp-content/uploads/2024/02/2024-Rare-Disease-Project-Report-Final.pdf
There are an estimated 10,000 rare diseases and disorders that are often irreversibly progressive, physically disabling, negatively impact life expectancy, and effect an estimated 300 million people worldwide. The Innovation and Value Initiative (IVI) and the EveryLife Foundation for Rare Diseases partnered to explore common patient-centered outcomes across rare diseases, identified evidence gaps, and built consensus on addressing unique research challenges as part of IVI's Rare Disease Project.

European Patients Forum February newsletter

In the European Union, more than 900,000 individuals die prematurely each year due to preventable disease risk factors. Transitioning from conventional disease treatment methods to a 'person-centred' emphasis on prevention and early diagnosis could curb this trend. Although prevention is nowadays a high priority at EU level, personalised preventive strategies are not as widely used as other personalised medicine approaches. To address this gap, we invite you to participate in a survey designed by PROPHET on the perceived barriers, challenges, and enablers for the adoption of personalised prevention strategies in the EU and beyond.
Funded by the European Commission under the Horizon EUROPE Programme, PROPHET aims to support the definition and implementation of innovative, sustainable and high-quality personalised strategies that effectively tackle chronic diseases. Take the survey here.
The results will contribute to the development of a Strategic Research and Innovation Agenda (SRIA) for personalised prevention. Read more here!

Take a look at EUCAPA Fast-Track and Extended Training
EUCAPA is an educational platform specifically designed to equip patients and their representatives with the necessary skills in HTA.
Being at the intersection of complex and different disciplines, Health Technology Assessment (HTA) can feel inaccessible at times. EUCAPA's mission is to reduce this knowledge gap and centre the evaluation of Health Technology around the ultimate recipient of healthcare: Patients.
Check out the courses:
In this comprehensive 8-hour online training program, patients and patient representatives are equipped with the skills, tools, insights, and expertise they need to engage in joint clinical assessments and scientific consultations within the EU HTA regulation.
A 3-Day in-person training program in HTA for patients and patient representatives at UMIT TIROL - University for Health Science and Technology, in Austria. An in-depth training program designed to deepen your knowledge of the principles and methods of HTA, health decision sciences, and patient involvement. You will learn about communication and personal skills, such as presenting and discussing patient-relevant topics.

EUCAPA's programmes are mainly designed for cancer and rare disease patients, but also other patient categories will be considered! Attending the Fast-Track training is a prerequisite for participation in the extended training.
Enrol in the Fast-Track Training: https://bit.ly/3NoehFs
Enrol in the Extended Training: https://bit.ly/3NpX8Lv

Publications

KR Harkin, J Sorensen, S Thomas. Lifecycle evaluation of medical devices: supporting or jeopardizing patient outcomes? A comparative analysis of evaluation models
International Journal of Technology Assessment in Health Care
doi: 10.1017/S026646232300274X, 12 pages. Published Online on 5 January 2024

Bin Wan, Jiaojie Shen, Jiali Chen, et al. Quantifying Stakeholders' Preference for Implantable Medical Devices in China: A Discrete Choice Experiment
International Journal of Technology Assessment in Health Care
doi: 10.1017/S0266462323002799, 23 pages. Published Online on 15 January 2024

L Levin, M Sheldon, RS McDonough, N Aronson, M Rovers, CM Gibson, SR Tunis, RE Kuntz. EARLY TECHNOLOGY REVIEW: TOWARDS AN EXPEDITED PATHWAY
International Journal of Technology Assessment in Health Care
doi: 10.1017/S0266462324000047, 37 pages. Published Online on 29 January 2024

Jayne Eunice U Yang, Faisal H Jackarain, Tisha Isabelle M de Vergara, Joshua F Santillan, Patrick Wincy C Reyes, Ma Cecilia Victoria B Arellano, Jainor Timothy Uchida Garcia, Sheena Jasley G Samonte, Anne Julienne Genuino Marfori, Anna Melissa S Guerrero. ACCEPTABILITY OF SELF-ADMINISTERED ANTIGEN TEST FOR COVID-19 IN THE PHILIPPINES
International Journal of Technology Assessment in Health Care
doi: 10.1017/S0266462324000035, 27 pages. Published Online on 17 January 2024

Roquette C, Crisóstomo S, Milagre T, Ribeiro RS, Pedro AR, Valente A (2024). Patient organisations' views, motivations and experiences on patient involvement in cancer research : A pilot study in Portugal. BMJ Open, 14(1), e077444. https://doi.org/10.1136/bmjopen-2023-077444

Scholz B, Kirk L, Warner T, O'Brien L, Kecskes Z, Mitchell I (2024). From a Single Voice to Diversity : Reframing « Representation » in Patient Engagement. Qualitative Health Research, 10497323231221674. https://doi.org/10.1177/10497323231221674

Jiang S, Wu Z, Zhang X, Ji Y, Xu J, Liu P, Liu Y, Zheng J, Zhao L, Chen J (2024). How does patient-centered communication influence patient trust? : The roles of patient participation and patient preference. Patient Education and Counseling, 122, 108161. https://doi.org/10.1016/j.pec.2024.108161

Centre d'excellence sur le partenariat avec les patients et le public (CEPPP), Centre de recherche du Centre Hospitalier de l'Université de Montréal
https://ceppp.us19.list-manage.com/subscribe?u=fe6724e4a3bbbac315fa15dd6&id=a562f9236b

Littell JH (2024). The Logic of Generalization From Systematic Reviews and Meta-Analyses of Impact Evaluations. Evaluation Review, 0(0). https://doi.org/10.1177/0193841X241227481
This article presents a pragmatic approach to generalizability assessment for use with systematic reviews and meta-analyses. This approach is applied to two systematic reviews and meta-analyses of effects of 'evidence-based' psychosocial interventions for youth and families. Evaluations included in systematic

reviews are not necessarily representative of populations and treatments of interest. Generalizability of results is limited by high risks of bias, uncertain estimates, and insufficient descriptive data from impact evaluations. Systematic reviews and meta-analyses can be used to test generalizability claims, explore heterogeneity, and identify potential moderators of effects. These reviews can also produce pooled estimates that are not representative of any larger sets of studies, programs, or people. Further work is needed to improve the conduct and reporting of impact evaluations and systematic reviews, and to develop practical approaches to generalizability assessment and guide applications of interventions in diverse policy and practice contexts.

Janet Wale, HTAi PCIG
E-mail: pcig.htai@gmail.com
