

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

Enhanced quality and relevance of HTA through patient and citizen involvement

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

- Welcome – from our Co-Chair Alina Silva
- PCIG Matters – member input
- HTAi Matters – Seville 2024, Board of Directors election, other HTAi news
- What's Happening – in and for patient and public involvement
- Publications

Welcome to our E-Bulletin

Dear HTAi Members

Thanks to all who participated in our recent E-Bulletin evaluation survey. Your feedback will help us continue improving this valuable communication tool. We're delighted to share that 100% of respondents found the content of our PCIG E-Bulletin to be either helpful or very helpful. Your suggestions will guide us as we strive to enhance this essential communication tool throughout the year.

As we move forward, it's time for our HTAi members to participate in shaping the future leadership of our Society. The 2024 Board of Directors Election is underway, featuring an outstanding list of candidates for Treasurer and Secretary. Notably, two distinguished PCIG members, Anke-Peggy Holtorf and Farzana Malik, stand as candidates for Secretary. Please watch your email inbox or visit the HTAi website for voting links and exercise your right to influence the direction of our organization.

In other exciting news, we're thrilled to announce that all patient recipients of the HTAi Participation Grant and PCIG PASS have been duly informed and are starting to organize their attendance, either virtual or in-person, at the HTAi 2024 Annual Meeting. This wouldn't have been possible without the dedicated efforts of our PCIG PASS team, HTAi Secretary, our esteemed sponsors—Sanofi, EFPIA, Fenin, and Intuitive—and, notably, our evaluation team and technical officer Pierre Net. Together, we're ensuring meaningful patient participation at the upcoming HTAi meeting.

Lastly, please make travel arrangements to join our workshop, "Patient And Citizen Involvement In Health Technology Assessment: Networks For Sustainability And Innovation" on Sunday afternoon, June 16, 2024. For more conference details and other important info, keep reading this E-Bulletin.

Thank you for your continued engagement and support,

Aline Silva
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)

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.

Not much is known about the use of patient preference data in #HTA.

The Patient Preference Project Subcommittee of the [HTAi Patient & Citizen Involvement in HTA Interest Group](#) conducted a study to better understand whether and how patient preference data are being used in HTA. Learn about our findings just published in the International Journal of Technology Assessment in Health Care: <https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/hta-community-perspectives-on-the-use-of-patient-preference-information-lessons-learned-from-a-survey-with-members-of-hta-bodies/2DE5A5C1A8DE4CD6FD3630F600DDEDB9>

Contributed by Barry Liden

Hilgsmann M, Liden B, Beaudart C, et al. HTA community perspectives on the use of patient preference information: lessons learned from a survey with members of HTA bodies. International Journal of Technology Assessment in Health Care. 2024;40(1):e17. doi:10.1017/S0266462324000138

Lymphoma Coalition - 2024 Global Patient Survey on Lymphomas & CLL

Lymphoma Coalition, a worldwide network of lymphoma patient organisations, has launched its 2024 Global Patient Survey on Lymphomas & Chronic lymphocytic leukemia (CLL). The global survey is conducted every two years and aims to deeply understand the adult patient and caregiver experience, as well as uncover trends, themes, and geographic variation. The patient survey takes approximately 30 minutes to complete and the caregiver survey can be completed in 20 minutes. The survey is available in 20 languages and can be found at this link: <https://bit.ly/LCGPS2024>

We ask for your support in promoting the survey and have created a series of materials to make it quick and easy to share among your community, simply visit: [2024 Global Patient Survey – Lymphoma Coalition](#).

When people share their experiences, we can make an impact across the healthcare spectrum and bring the voices and values of patients to lymphoma care, research, and health policy. When more people participate, we learn more about the patient and caregiver experience. This information is used to help inform activities and programs and support advocacy efforts. Thank you.

Contributed by Marjorie Morrison, with a reminder from Anke-Peggy Holtorf

US-based PALADIN

Established in early 2023 by the Tufts Center for the Study of Drug Development (CSDD), PALADIN is a US-focused, disease-agnostic consortium of nearly two dozen patient advocacy groups (PAGs) and biopharmaceutical companies working together to improve collaboration effectiveness and efficiency. Given the large and rising number of PAG-industry partnerships established each year to support clinical research activity, PALADIN seeks to transform the pace of new medicine development.

<https://sites.tufts.edu/paladinconsortium/vision-goals-2/>

On March 1, 2024, the PALADIN Consortium announced the release of a Playbook and a Repository of Resources for patient advocacy groups (PAG) and biopharmaceutical companies to use in optimizing their collaborations. The Playbook provides process maps and forms to initiate and guide collaborations as well

as template service and confidentiality agreements to expedite PAG-industry engagements. The Resource Repository contains over 100 identified and assessed best-in-class operational resources with links to the organizations that developed them. Both the Playbook and the Resource Repository are accessible on [paladinconsortium.org](https://sites.tufts.edu/paladinconsortium/2024/02/28/paladin-consortium-unveils-playbook-resource-repository-to-enhance-collaborations-between-patient-advocacy-groups-biopharmaceutical-companies/) and they are available free of charge.

<https://sites.tufts.edu/paladinconsortium/2024/02/28/paladin-consortium-unveils-playbook-resource-repository-to-enhance-collaborations-between-patient-advocacy-groups-biopharmaceutical-companies/>

Contributed by Zal Press

The Early Career Network and Information Retrieval Interest Groups are excited to announce the launch of the Spring/Summer 2024 HTAi Mentoring Programme

The HTAi Mentoring Programme revolves around mutual sharing and support and is designed to provide mentorship and guidance to members who are looking to grow and advance in their careers. We believe this program will be an excellent opportunity for participants to connect, learn, and grow together as mentoring provides a unique setting for self-reflection, personal and professional development.

Our program will pair experienced professionals with mentees who are looking for career and professional skills-based guidance and support. Participants will be equal partners in these mutually beneficial relationships. All discussions will remain confidential, creating a safe space for mentors and mentees to address a wide range of topics.

Key details of the HTAi Mentoring Program include:

Monthly commitment of 1 hour from June 24th, 2024 to May 25th, 2025, to participate in one-on-one mentor-mentee meetings (participants will select a suitable time and format for these meetings).

Kick-off workshop on June 16th, 2024, preceding the HTAi Annual Meeting in Seville.

2 Masterclasses scheduled during the year, providing mentees and mentors will additional opportunities to learn from colleagues and expand professional networks.

If you want to become a mentor, kindly complete the survey [HERE](#).

For those envisioning themselves as mentees, please fill out the survey [HERE](#).

You are also welcome to apply for both roles by completing both surveys.

Application deadline: 19th April 2024, 23.59 CET.

Don't miss this incredible opportunity to be part of the HTAi Mentoring Program! Join us on this enriching journey of growth and development at HTAi.

Carla Fernández-Barceló
ECN IG Technical Officer
(Pronouns: *She/Her*)



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/>

View the schedule and Workshop program (<https://htai.eventsair.com/htai-2024-annual-meeting/workshop-program>)

[View the Workshops](#)

Meet Our HTAi Annual Meeting Speakers

Get ready for an incredible lineup at the HTAi Annual Meeting Keynote and Plenary sessions! We've got top-notch leaders and experts in HTA who guarantee an amazing program. Check out our fantastic speakers below (<https://htai.eventsair.com/htai-2024-annual-meeting/speakers>)

[View the Lineup](#)

Standard registration deadline: Thursday, June 6, 2024 at Midnight MDT (UTC-6)

Last-minute registration: Friday, June 7 to Wednesday, June 19, 2024

2024 Board of Directors Election

The Board of Directors and its Nominating and Election Committee are pleased to present the candidates for the 2024 Board of Directors Election. To view the nomination criteria and each candidate's nomination package, including their application, bio, and qualifications, [click here](#).

The 2024 Board of Directors Election opens on **April 2, 2024 at 08:00 UTC** and closes on **May 2, 2024 at 23:59 UTC**. The election is managed by CES, a trusted third party electoral service. CES will directly email the election ballots to all members of the Society in good standing. Votes must be submitted via the unique electronic ballot provided by CES. As per HTAi bylaws, only members with up-to-date 2024 membership fees are eligible to vote. If you have not established your 2024 membership, [renew your membership today](#) to ensure you can participate.

For questions regarding the 2024 Board of Directors Election, please contact boardelections@htai.org.

Latin America Regional Meeting in Cartagena, Colombia on August 13th and 14th, 2024

We are excited to announce that HTAi, in collaboration with IETS, will be hosting a Latin America Regional Meeting in Cartagena, Colombia. This event is open to all stakeholders interested in exploring the topic "From Policy to Practice, HTA's Role in Improving Health Systems."

Registration for this event is now open!

Please note that spaces are limited, and registration will close on July 19, 2024. We encourage all interested participants to register early to guarantee a seat at the meeting. To secure your spot, please visit the Registration Portal to complete the registration process. If you are not currently an HTAi member, you can still register for the event by selecting the "Create a New Account" tab on the first page of the registration form.

We look forward to seeing you in Cartagena and engaging in meaningful discussions on the role of HTA in improving health systems across the region! For questions and further information, please contact the HTAi Policy Forum team at policyforum@htai.org.

HTAi webinars

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-march-15-2024/> 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

CADTH Symposium: Wednesday, September 4 to 6, 2024

Join Canadian and international health care and health technology assessment (HTA) experts from Wednesday, September 4, 2024, to Friday, September 6, 2024, for the 2024 CADTH Symposium, a 3-day hybrid event offering in-person and virtual attendance options. The in-person program will take place at the Shaw Centre in Ottawa, Ontario, Canada.

The theme is 'From Disruption to Opportunity: Embracing Change in Health Care'.

The CADTH Symposium has a well-earned reputation as a must attend event for anyone with an interest in the assessment, adoption, and management of drugs and medical devices. Please watch the [CADTH Symposium website](#) for updates and [subscribe](#) to receive announcements by email.

WHO Europe Telehealth Quality of Care Tool (TQoCT)

<https://www.who.int/europe/publications/i/item/WHO-EURO-2024-9475-49247-73556>

As more health and care moves to digital-based service provision, including the use of digital tools for supporting health interventions and care services provided at a distance, the quality of the care that is provided becomes more relevant. The quality of telehealth ultimately matters for increasing the adoption of this new paradigm of care because significant patient safety or QoC issues will ultimately undermine the trust populations and professionals have on this still somehow new way of practicing medicine and supporting the provision of modern and integrated care.

DemocracyNext

End of Life Citizens' Assembly Concludes with 92% Consensus, Delivers Recommendations to Macron.

Ansel Herz, April 4, 2023

<https://www.demnext.org/news/democracy-in-france-end-of-life-citizens-assembly-concludes-with-92-consensus-delivers-recommendations-to-macron>

Great to see the Paris Citizens' Assembly in action. This working group of 30 Parisians selected by sortition (lottery) has been working since September to draft a Citizen Bill for the City Council on tackling homelessness. They will deliver it in June.

For all those despairing at the state of democracy today, let's channel that energy into the hard work of building new democratic institutions that transform who has power and how we're taking collective decisions. There's a growing number of examples around the world showing us that another democratic future is possible.

<https://www.linkedin.com/feed/update/urn:li:activity:7167107786961534976/>

From the European Patients Forum Newsletter

Patient representation in the German healthcare system with BAG SELBSTHILFE

For citizens, both with and without a migration background, it is important to understand how their rights as patients are represented. So far, there has been a lack of information about the German healthcare

system in English. BAG SELBSTHILFE aims to address this issue by providing a new video in English about the opportunities and responsibilities of participation in patient representation in the Federal Joint Committee (G-BA).

The video "Patient representation in the German healthcare system with BAG SELBSTHILFE" (with [subtitles](#) | with [audiodescription](#)) explains how the Federal Joint Committee (G-BA) is composed, which decisions regarding the German healthcare system are made there, and the role that self-help groups and patient representatives play in determining essential components of statutory health insurance. In patient representation, it is important for people with a migration background to contribute as experts in their own right, bringing the issues and experiences of this population group into the discourse to achieve an improvement in the healthcare system for all affected individuals. If people with a migration background are not represented in these important bodies, their interests cannot be adequately represented. An important task of BAG SELBSTHILFE is to inform patients about the various aspects of the healthcare system and self-help work. It is important that this information is as accessible as possible, with few barriers. In order for people who do not speak German to access this information, videos in English are increasingly being published on the BAG SELBSTHILFE [YouTube channel](#) as part of the project "[Engaging People with Migration Backgrounds in Self-Help Exchange](#)".

Join this year's edition of the Patient Engagement Open Forum (PEOF)

This year's Patient Engagement Open Forum (PEOF) will take place from 21 to 23 May 2024, in Baveno Italy. PEOF is a multi-stakeholder event organised by EPF, EUPATI, and PFMD.

This year EPF is organising several on-site and online sessions:

A dedicated session on early feasibility studies for medical devices, introducing HEU-EFS.

Another session will discuss the ongoing project IDERHA, with a focus on inclusive decision-making and patient engagement in institutional and organisational policies for data use in research.

A virtual session happening on 25 April from 14:00 to 15:30 pm will introduce **Gravitate Health**. Through an interactive booth, EPF and its Consortium partners will be presenting the MVP2 of G-Lens.

Last but not least, there will be a separate session on Health Technology Assessment (HTA).

Don't miss out: find more information [here](#)!

Information Services Cuts at the Canadian Agency for Drugs and Technology in Health

On February 15, 2024 6 librarians and 2 library technicians at the Canadian Agency for Drugs and Technology in Health (CADTH) lost their jobs as part of an ongoing erosion of CADTH's research services. These people, our colleagues, accounted for half of CADTH Research Information Services department staff.

Health librarians and knowledge synthesis researchers in Canada and around the world have looked to the Research Information Specialists at CADTH for their expertise in knowledge synthesis and expert searching for decades. If you have ever used the PRESS checklist to peer review a search strategy, the Grey Matters checklist for grey literature searching, or CADTH's search filters database, you have benefited from the work and expertise of a CADTH librarian.

The termination of CADTH's librarians and technicians is the latest move by CADTH, a taxpayer funded organization, that will negatively impact the ability of Canadian health care systems to access unbiased and objective evidence to inform health care policy and decision making. These changes at CADTH include:

- The switch to allowing industry sponsors of CADTH drug reimbursement reviews to provide the research evidence CADTH committees use to make recommendations, rather than using in-house expertise to generate unbiased clinical and economic analyses.
- Sunsetting valuable rapid response and rapid review services used by decision-makers across the country to answer time-sensitive questions impacting the health of Canadians.
- A restructuring of the liaison services in various jurisdictions across Canada resulting in a reduction in timely responses to complex health system questions and compromises CADTH's ability to respond to emerging health issues like the COVID-19 pandemic.

These changes have implications for health care budgets that are already stretched thin. While provinces

like British Columbia, Alberta, and Ontario continue to have their own health technology assessment services, we fear other provinces and territories will be left without access to critical health information services previously provided to them by CADTH. Health care and health policy decision-making in these jurisdictions will suffer as a result, furthering inequity in the provision and delivery of health care across the country.

Furthermore, these changes do not align with CADTH's new role as the Canadian Drug Agency and compromise their ability to support emerging programs, like the new national pharmacare plan that has recently been unveiled and their involvement in the recently announced drugs for rare diseases program.

Jeff Mason, MLIS (He/Him/His)
Health Sciences Librarian: Innovation and Entrepreneurship
Health Sciences Library

Contributed by Catherine Voutier

Publications

Goulao B, Morisson S. "The power imbalance was blown out the window": developing and implementing creative workshops to enhance communication of statistics in patient and public involvement in clinical trials. *Res Involv Engagem* 10, 32 (2024). <https://doi.org/10.1186/s40900-024-00560-8>

Marsh K, Collacott H, Thomson J, Mauer J, Watt S et al 2024. [Using Patient Preferences in Health Technology Assessment: Evaluating Quality-Adjusted Survival Equivalents \(QASE\) for the Quantification of Non-health Benefits](#). Patient – Patient-Centered Outcome Research DOI

10.1007/s40271-024-00676-9

Interest in using patient preference (PP) data alongside traditional economic models in health technology assessment (HTA) is growing, including using PP data to quantify non-health benefits

<https://www.webofscience.com/wos/woscc/full-record/WOS:001172864100001?AlertId=27b1df03-831a-42c0-afa8-032bda4bf13c&SID=EUW1EDoA21hrvo2YAmnmYP7xE5ETi>

Hu W (2024). Imagining the model citizen : A comparison between public understanding of science, public engagement in science, and citizen science. *Public Understanding of Science* (Bristol, England), 9636625241227081. <https://doi.org/10.1177/09636625241227081>

Zogas A, Sitter KE, Barker AM, Fix GM, Khanna A, Herbst AN, Vimalananda VG (2024). Strategies for engaging patients in co-design of an intervention. *Patient Education and Counseling*, 123, 108191. <https://doi.org/10.1016/j.pec.2024.108191>

Chudyk AM, Stoddard R, Duhamel TA, Schultz ASH (2024). Future directions for patient engagement in research : A participatory workshop with Canadian patient partners and academic researchers. *Health Research Policy and Systems*, 22(1), 24. <https://doi.org/10.1186/s12961-024-01106-w>

Pomey MP, Wong C, Berkesse A, Jackson M, Descôteaux A, Karazivan P, Boivin A, Rouly G, Clovin T, Dumez V, L'Espérance A (2024). Le modèle de Montréal, quelle mise en oeuvre depuis 2015? *Gestions hospitalières*, 633, 78-83.

Stefanik-Guizlo K, Allen C, Brush S, Mogk J, Canada S, Peck M, Ramos K, Volpe K, Lozano P (2024). Sustaining connections : Feasibility and impact of long-term virtual patient engagement. *Research Involvement and Engagement*, 10(1), 28. <https://doi.org/10.1186/s40900-024-00558-2>

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>

Barber MJ, Gotham D, Bygrave H, Cepuch C. Estimated Sustainable Cost-Based Prices for Diabetes Medicines. *JAMA Netw Open*. 2024;7(3):e243474. doi:10.1001/jamanetworkopen.2024.3474
<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2816824>

What could prices of insulins, sodium-glucose cotransporter 2 inhibitors (SGLT2Is), and glucagonlike peptide 1 agonists (GLP1As) be if they were closer to the cost of production?

In this economic evaluation of manufacturing costs, estimated cost-based prices per month were US \$1.30 to \$3.45 for SGLT2Is (except canagliflozin), and \$0.75 to \$72.49 for GLP1As, substantially lower than current market prices in nearly all comparisons. Twice-daily mixed human insulin NPH could cost \$61 per year, while basal-bolus treatment with insulin glargine and aspart could cost \$111 per year, with reusable pen formulations having the lowest estimated prices.

This suggest that insulins, SGLT2Is, and GLP1As can likely be manufactured for prices far below current prices, enabling wider access.

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