

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, December/January 2023/2024

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 Aline Silva
- PCIG Matters – member input, Annual Meeting 2023 abstracts, Newcomers Guide
- HTAi Matters –Seville 2024, other HTAi news
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Welcome to our E-Bulletin

Welcome to the PCIG E-Bulletin, and Happy 2024! As we all start a new year full of hope and plans, it is important to look at 2023 to celebrate our collective achievements and reflect on the lessons learned.

Last year, the PCIG Steering Committee welcomed two new members, Cat Koola (Institute for Clinical and Economic Review, USA) and Lucas Okumura (Astellas, Brazil); our new co-chairs, Aline Silva (Patient Voices Network, Canada) and Fiona Pierce (Agency for Care Effectiveness, Singapore), and our vice-chair, Zal Press (CADTH Patient and Community Advisory Committee, Canada). Our outgoing chair, Ann Single, has moved to a new role as the HTAi Vice-President. We also got a new Technical Officer, Hadewych Honné, who is now stepping aside to focus on her Ph.D.

As usual, the year's major milestone was the Annual Meeting, held in Adelaide, Australia, with over 70 patient representatives participating. We are very thankful to our members and sponsors who provided support to make this happen and to all those who participated in many sessions, panels, symposiums, poster presentations, workshops and plenaries.

Besides that, four important projects* carried out by PCIG members were officially finalized with valuable and meaningful deliverables, such as webinars, reports and published papers that have been shared with our community here on our monthly E-bulletins and through our social media. Many thanks to the project teams, leaders and our project coordinator, Anke Holtorf, for all your efforts. Stay tuned for more coming out in the next months! In the following content, you will delve into key information and initiatives that strengthen our network.

This last year has been a testament to our members' dedication and commitment to making a positive impact on Patient and Citizen Involvement in HTA. As we welcome 2024, please feel free to reach out to get more involved with our group and to let us know how we can do better this year.

Thank you for being an integral part of the PCIG community!

Aline Silva
Co-Chair, HTAi PCIG

*001_PCPOL: Patient & Citizen Participation at the Organisational Level; 002_Impact: Stakeholders' Perspectives of Impact of Patient Involvement in HTA; 009_PIRP: Patient Insights Research Platform; 012_PPI-HTAi: Patient & public involvement at HTAi Annual Meeting

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 [X \(@pcisg\)](#)

PCIG Matters

Most patient and public involvement practices fall somewhere on the IAP2 Spectrum of Engagement

Building on that platform is:

The Spectrum of Community Engagement to Ownership which "charts a pathway to strengthen and transform our local democracies. Thriving, diverse, equitable communities are possible through deep participation, particularly by communities commonly excluded from a democratic voice and power. The stronger our local democracies, the more capacity we can unleash to address our toughest challenges, and the more capable we are of surviving and thriving through economic, ecological, and social crises. It is going to take all of us to adequately address the complex challenges our cities and regions are facing. It is time for a new wave of community-driven civic leadership."

Is this a new way to understand the involvement of patients, patient associations and communities in the lifecycle of drugs? This new framework can be downloaded here :

<https://movementstrategy.org/resources/the-spectrum-of-community-engagement-to-ownership/>

Contributed by Zal Press

The International Journal of Technology Assessment in Health Care (IJTAHC)

IJTAHC has released Volume 39, Issue S1: Abstracts from the HTAi 2023 Annual Meeting in Adelaide, Australia!

Read through the abstracts doi: 10.1017/S0266462323002660 Published Online on 14 December 2023

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/issue/27E56FEB84AC12779B557151063ACD7F>

We are delighted to announce that, from January 2024, [International Journal of Technology Assessment in Health Care](#) will become a fully open access journal. All articles accepted for publication in the journal from 30th November 2023 will be published open access with a Creative Commons licence.

For the IJTAHC community, open access means that the innovative research published in the journal is freely and permanently available to all, supporting opportunities for research discoveries. For our authors, open access provides more exposure, wider reach and greater downloads, with 75% of articles published in Cambridge University Press journals receiving 30-50% more citations than their non OA equivalents.

We have [various routes available](#) for authors looking to fund open access publication, ensuring every author can publish and enjoy the benefits of OA.

A Newcomers Guide to HTA: new collections available!

<https://htai.org/newcomers-guide/>

HTAi is pleased to announce the release of five new collections of A Newcomers Guide to HTA. Aimed at supporting those new to HTA, the resources have been developed to offer guidance in navigating the expansive HTA universe, ranging from a general introduction to the intricacies of methods and processes. The newest collections feature content tailored for the following topics: Ethical Evaluation; HTA in

Hospitals; Patient and Social Engagement; HTA Publication, dissemination, and implementation; Health professionals' involvement.

These topics join the collections previously made available: HTA 101; Research Protocol Writing.

A large global editorial team of HTAi members supports this Guide. Special acknowledgements go to Prof. David Hailey for his wonderful reviews and comments on the overall project and to Alric R  ther, Laura Sampietro-Colom, Inaki Guti  rrez-Ibarluzea, Wija Oortwijn, Yingyao Chen, the Editors of International Journal of Technology Assessment in Health Care (IJTAHC), the primary leaders of West China Hospital, Sichuan University, and the HTAi Secretariat for their kind suggestions and support.

FDA Draft guidance on diversity

<https://www.fda.gov/media/157635/download>

Diversity Plans to Improve Enrollment of Participants from Underrepresented Racial and Ethnic Populations in Clinical Trials Guidance for Industry DRAFT GUIDANCE

The purpose of this guidance is to provide recommendations to sponsors developing medical products on the approach for developing a Race and Ethnicity Diversity Plan to enrol representative numbers of participants from underrepresented racial and ethnic populations in the United States.

Contributed by Dominique Hamerlijnck



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](#)

Registration for the HTAi 2024 Annual Meeting will open in January 2024. 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 accommodations, is available online at <https://htai.eventsair.com/htai-2024-annual-meeting/>

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](#)

HTAi Ethics Interest Group webinar January 17, 2024, at 16:00-17:00 CET (UTC+1) | 08:00 – 9:00 MST (UTC-7).

[Learn more](#)

The webinar will discuss the challenges and opportunities for being involved in conducting ethical analyses at HTA agencies. Bart Bloemen, co-chair of the Ethics IG will present the work that the interest group is currently conducting on a paper that address this topic. Two speakers will then present 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 assigned as ethics advisor for Swedish health care authorities and director at the National Centre for Priorities in Health. Both will present examples of their work, and reflect upon the lessons they have learned with respect to being involved in ethical analyses in this context. These presentations will be the basis and an invitation to the audience for exchanging ideas about how to advance this interesting area of HTA.

Speakers:

Bart Bloemen, PhD candidate and associate lecturer | Radboud University Medical Centre

Renata Axler, Ethics Lead | CADTH

Lars Sandman, Director and Professor of healthcare ethics | National Centre for Priorities in Health at Linköping University

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-december-15-2023/> 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:

[X:](#) @HTAiOrg

[Facebook:](#) @HTAiOrg

[LinkedIn](#)

What's Happening

CADTH Lecture on Common Sense Oncology: Outcomes That Matter

Thursday, January 18, 2024, from 1:00 p.m. to 2:00 p.m. ET

Free online event <https://www.cadth.ca/events/cadth-lecture-common-sense-oncology-outcomes-matter>

In the past decade, there have been major advances in cancer care; however, there is growing recognition that many new treatments offer limited benefits for patients. In response, the Common Sense Oncology initiative was launched in 2023 to recalibrate cancer care back toward outcomes that matter. Join Dr Christopher Booth, Canada Research Chair in Population Cancer Care at Queen's University, as he shares how Common Sense Oncology is tackling challenges to facilitate a future in which patients — regardless of where they live — have access to the cancer treatments that make a meaningful difference in their lives.

Helping make Canada's drug system more sustainable and better prepared for the future

December 18, 2023 | Ottawa, Ontario | Health Canada

The Government of Canada has announced the creation of the Canadian Drug Agency (CDA). The CDA will be built from the existing CADTH and in partnership with Canada's provinces and territories.

<https://www.canada.ca/en/health-canada/news/2023/12/the-government-of-canada-announces-the-creation-of-the-canadian-drug-agency---helping-make-canadas-drug-system-more-sustainable-and-better-prepared.html>

Canadians should be able to appropriately access and afford the prescription drugs they need. However, many Canadians are left vulnerable due to high drug costs, inaccessible health data, and the lack of consistent standards for prescribing practices. To better understand these challenges, the [Canadian Drug Agency Transition Office](#) (CDATO) consulted extensively with provinces, territories (PTs) and key stakeholders to identify core gaps in the pharmaceutical system. The CDA will provide the dedicated leadership and coordination needed to make Canada's drug system more sustainable and better prepared for the future, helping Canadians achieve better health outcomes. The CDA will be built from the existing Canadian Agency for Drugs and Technologies in Health (CADTH) and in partnership with provinces and territories (PTs). The CDA will build on CADTH's existing mandate and functions (health technology assessment, post-market safety and effectiveness) and expand them to include new work streams including: Improving the appropriate prescribing and use of medications, for better patient health and to support system sustainability; Increasing pan-Canadian data collection and expanding access to drug and treatment data, including real-world evidence data, to better support patients, inform health decisions and enable robust system data analytics; and Reducing drug system duplication and lack of coordination that causes expensive inefficiencies and pressures. The creation of the CDA further builds on other recent progress made by the federal government towards a national pharmacare program. In addition, the Government of Canada [announced](#) in March 2023 measures in support of the first-ever National Strategy for Drugs for Rare Diseases, with an investment of up to \$1.5 billion over three years.

The 2023 ISPOR Patient Representatives Roundtable - Europe met on 12 November in Copenhagen, Denmark as part of the ISPOR Europe Conference. Chaired by IPPOSI CEO Derick Mitchell, the discussion centred around EU Joint Clinical Assessments and how they may improve the patient experience of involvement in Health Technology Assessments. To view the slides from the roundtable, click [here](#) or the link below. Photos from the event can be found on the IPPOSI Flickr account [here](#).

<https://www.slideshare.net/ipposi/2023-isor-patient-representatives-roundtable-europe>

Including Patients as Partners in Clinical and Outcomes Research

By John Watkins

https://www.ispor.org/publications/journals/value-outcomes-spotlight/vos-archives/issue/view/patient-centricity-in-heor/including-patients-as-partners-in-clinical-and-outcomes-research?utm_medium=email&utm_source=database&utm_campaign=value+and+outcomes+spotlight&utm_content=including+patients+as+partners+in+clinical+and+outcomes+research&utm_term=featured&zs=3hXOX&zl=SuOr3

Leveraging ePRO Paradata for Patient-Centered Trial Designs

Andrzej Nowojewski, Erik Bark, Vivian H Shih, Sean O'Quinn, Richard Dearden

https://www.ispor.org/publications/journals/value-outcomes-spotlight/vos-archives/issue/view/patient-centricity-in-heor/leveraging-e-pro-paradata-for-patient-centered-trial-designs?utm_medium=email&utm_source=database&utm_campaign=value+and+outcomes+spotlight&utm_content=leveraging+e-pro+paradata+for+patient+centered+trial+designs&utm_term=heor+articles&zs=3hXOX&zl=XuOr3

Patient-reported outcome (PRO) instruments play a vital role in the drug development process by gathering valuable data directly from patients, capturing their perspectives on symptoms, functioning, and overall health-related quality of life. Typically, these data are collected through validated self-reported questionnaires. Nowadays, electronic PROs (ePROs) have become a standard, utilizing devices like tablets or smartphones.

ISPOR 2024 will be held May 5–8, 2024 in Atlanta, GA, USA

Visit <https://www.ispor.org/conferences-education/conferences/upcoming-conferences/isor-2024>

Submit your research abstracts by January 11, 2024 at 11:59 PM PST and learn more at

<https://www.ispor.org/conferences-education/conferences/upcoming-conferences/isor-2024/abstract-information>

Upcoming ISPOR Courses and Webinars

[Introduction to Health Economics and Outcomes Research](#) [Short course]

February 12-15 (Virtual)

[Introduction to Patient-Reported Outcomes Assessment: Instrument Development & Evaluation](#) [Short course]

February 28-29 (Virtual)

ICER Report: Price Hikes for Eight Drugs Lead to \$1.3 Billion Increase in U.S. Healthcare Costs

12 December 2023.

<https://www.biopharmadive.com/news/icer-unsupported-price-increase-humira-darzalex-ibrance/702143/>

The Institute for Clinical and Economic Review (ICER) reported that price increases for eight drugs led to a surge in US healthcare spending without new evidence of added health benefits. AbbVie's Humira, a rheumatoid arthritis medication, was the main contributor. Other significant contributors to the increase were Johnson & Johnson's Darzalex, Pfizer's Ibrance, and Amgen's Prolia.

ICER, funded by non-profit foundations and an insurer, identified these drugs based on the most significant US sales. Eight of the ten drugs on the final list needed more clinical evidence to justify their price hikes.

Monitoring progress towards universal health coverage in Europe: a descriptive analysis of financial protection in 40 countries – in Europe

[https://www.thelancet.com/journals/lanepi/article/PIIS2666-7762\(23\)00245-4/fulltext](https://www.thelancet.com/journals/lanepi/article/PIIS2666-7762(23)00245-4/fulltext)

Sarah Thomson, Jonathan Cylus, Lynn Al Tayara, Marcos Gallardo, Martínez Jorge Alejandro García-Ramírez, María Serrano Gregori et al.

The Lancet Regional Health Europe. December 12, 2023 DOI: <https://doi.org/10.1016/j.lanepe.2023.100826>

Catastrophic health spending is consistently concentrated in the poorest fifth of the population and is largely driven by out-of-pocket payments for outpatient medicines, medical products, and dental care. Ensuring that access to health care is affordable for everyone—financial protection—is central to universal health coverage (UHC). Countries are more likely to move towards UHC if they reduce out-of-pocket payments in a progressive way, decreasing them for people with low incomes first.

European Patients Forum - December Newsletter

The digital transformation can bring many benefits to care, but its challenges also have to be addressed to ensure patients' trust – our October 2023 [paper](#) on Artificial Intelligence (AI) in healthcare highlights some key recommendations in this regard. We are using the paper as a key advocacy tool as we engage with EU institutions and agencies on this topic. Thanks to all who helped shape our input! On the legislative front, while 2022 marked the development of the [EPF position](#) on the European Health Data Space (EHDS), in 2023 we were able to shape this initiative to better address patients' needs. On 13 December, the European Parliament adopted its position

Throughout the spring and fall meeting, as a Youth Group we were engaged in analysing and finalising our "Patient Involvement in Patient Organisations" Project.

The Health Equity Fellowship for Trainees (HEFT)

This is a part of Health Affairs' national initiative to advance equity in health policy and health services scholarly publishing.

Applications for the 2024–2025 Health Equity Fellowship for Trainees cohort are [now open](#) to February 15, 2024

https://www.healthaffairs.org/content/forefront/sounding-alarm-anti-science?utm_campaign=forefront&utm_medium=email&_hsmi=285775313&_hsenc=p2ANqtz-tOetYe07NPYJriU2-7kEqRvTWgcOgDc3_y1-l9TBANFVjyoc9PLcEJJOzajDSFXCowWvn4ziao9cBgz5jRmS_Xd7FA&utm_source=hasu

The purpose of the Fellowship is to increase the quantity and quality of manuscripts published by early-career researchers interested in addressing health inequities among underserved racial and ethnic populations, while cultivating future health equity research leaders. In the program, fellows will receive multilayered mentorship from experienced Health Affairs authors and editorial staff for eighteen months (July 2024–December 2025).

COVID-19

Global Lessons From COVID-19

The December issue of Health Affairs features contributions from researchers worldwide, analysing the policies and programs implemented by various nations throughout the COVID-19 pandemic - highlighting their trade-offs, and offering a forward-looking approach toward preparedness for future health crises.

A review by Mark Jit and colleagues reflects on [epidemiological modeling used to inform policies](#) in Western Europe throughout the pandemic. The authors highlight the similarities and differences between models, how they were used to inform policy, and lessons for future pandemics including the need for sustainable data collections systems and greater engagement between modelers, policy makers, and the public.

From Germany, Lasse Falk and coauthors explore the complex relationship between [objective and subjective measures](#) of the stringency of COVID-19 lockdown policies in seven European countries. Their findings illustrate a diverse array of factors influencing individual perceptions and shed light on how lockdown policies may inadvertently worsen existing inequalities.

From Argentina, Adolfo Rubinstein and coauthors illustrate the trade-off between [the epidemiological and sociological impacts](#) of public health and social measures in Argentina, Brazil, Jamaica, and Mexico using an integrated epidemiological-economic model. Their findings are reinforced by a qualitative exploratory study by Cristian A Herrera and colleagues, who explore [the impact of service disruptions](#) through the perspective of health care system decision makers and managers.

A systematic review by Rory Smith et al. examines [the effectiveness of various measures](#) implemented by governments, public health authorities, and social media platforms to counter misinformation.

Ashley Fox and coauthors [consider twin barriers to vaccine access](#) in low- and middle-income countries: accessibility and vaccine hesitancy.

HEALTH AFFAIRS FOREFRONT

Why Dropping Most COVID-19 Vaccine Mandates Is Now Ethical. Nir Eyal, Matthew K Wynia, Thomas D Harter, Debra DeBruin, Jason T Eberl (2023). Health Affairs Forefront [10.1377/forefront.20231206.51079](#)

https://www.healthaffairs.org/content/forefront/why-dropping-most-covid-19-vaccine-mandates-now-ethical?utm_campaign=forefront&utm_medium=email&_hsmi=285775313&_hsenc=p2ANqtz-8kE8WiPmVBqK_2fyQkqrMbTJnR5TYJMHdz23zhU1wco8MN-QYoJs1-ZCirGzFkSVR64uSWkwbkRf_xMfZ9APWVn6RLWug&utm_source=hasu

Illness from COVID-19 is still [common](#), and vaccinations [remain effective](#) at diminishing the possibility of serious illness and death. But recent variants have had [milder clinical outcomes](#) across the population, due to a combination of widespread vaccination, infection-related immunity, better treatments, and changes in the biology of the virus. Hospitalization rates for COVID-19 have [declined dramatically](#) since fall 2021, and US health systems are no longer at imminent risk of collapse from being swamped with severely ill, unvaccinated COVID-19 patients. Meanwhile, the benefits of vaccination for reducing transmission to contacts [have also been dropping](#). For instance, recent data suggest that vaccination against Omicron might reduce secondary transmission by [only 31 percent](#) (compared to 96 percent against Alpha and 87 percent against Delta strains) and that prior infection [provides comparable levels of protection](#) against forward transmission. Since nearly everyone now has been infected, vaccinated, or both, the marginal

benefit of vaccination in terms of preventing onward transmission to the community is much lower today than it was in 2021.

Publications

Shelagh M Szabo, Neil S Hawkins, Evi Germeni 2023. The extent and quality of qualitative evidence included in health technology assessments: A review of submissions to NICE and CADTH.

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

doi: 10.1017/S0266462323002829, 24 pages. Published Online on 21 December 2023

Rebecca Trowman, Antonio Migliore, Daniel A Ollendorf 2023. The value and impact of health technology assessment: discussions and recommendations from the 2023 Health Technology Assessment International Global Policy Forum.

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

doi: 10.1017/S0266462323002763, 6 pages. Published Online on 22 December 2023

Susana Afonso, Ana CL Vieira, Carla Pereira, Mónica D Oliveira 2023. Advancing hospital-based health technology assessment: evaluating genomic panel contracting strategies for blood tumors through a multimethodology.

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

doi: 10.1017/S0266462323002751, 8 pages. Published Online on 22 December 2023

Kidholm K, Jensen LK, Johansson M, Montori VM. Telemedicine and the assessment of clinician time. A scoping review. *Int J Technol Assess Health Care*. 2023 Dec 15:1-22. doi: 10.1017/S0266462323002830. Epub ahead of print. PMID: 38099431.

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

doi: 10.1017/S0266462323002830, 22 pages. Published Online on 15 December 2023

Milou Amber Hogervorst, Rick Vreman, Inkatuuli Heikkinen, Wija Oortwijn 2023. [RESPONSE TO UNCERTAINTY MANAGEMENT IN REGULATORY AND HEALTH TECHNOLOGY ASSESSMENT DECISION-MAKING ON DRUGS: GUIDANCE OF THE HTAi-DIA WORKING GROUP – AUTHOR’S REPLY.](#)

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

doi: 10.1017/S0266462323002817, 7 pages. Published Online on 18 December 2023

Sebastián García Martí, Andrés Pichón-Riviere, Federico Augustovski, Manuel Espinoza 2023. [Real-world evidence: experiences and challenges for decision making in Latin America](#)

[International Journal of Technology Assessment in Health Care](#) doi: 10.1017/S0266462323002647, 6 pages.

Published Online on 18 December 2023

Introducing NEJM AI, a New Journal

[VOL. 1 NO. 1](#)

Clinicians are already using artificial intelligence to analyse radiological images, determine diagnoses, identify possible treatments, communicate with patients, and much more. How will AI impact your practice? That’s the focus of [NEJM AI](#), a new journal from NEJM Group coming in 2024.

Data sets and benchmarks drive progress by Eric J Rubin, Editor-in-Chief

“The rigor that the New England Journal of Medicine has brought to clinical trials for procedures, treatments, and medications, we want to bring to the new diagnostic and therapeutic intervention of artificial intelligence.”

Injecting Artificial Intelligence into Medicine by Isaac S Kohane (2023)

NEJM AI 2023;1(1) DOI: 10.1056/Ale2300197

This editorial reflects on AI’s historical milestones and current capabilities, particularly large language models, and the imperative for their rigorous clinical evaluation. NEJM AI commits to fostering a

multidisciplinary discourse and the development of a transparent, patient-centered approach to AI in health care, with an emphasis on the critical importance of diverse and accessible datasets.

In our eyes, the most impactful articles will blossom from the fertile ground of multidisciplinary teams, reflecting the vibrance at the intersection of computer science, clinician–patient dynamics, and biomedical research. Our editorial board, a meld of pioneers from the realms of AI, life sciences, ethics, and policy, is genuinely thrilled to engage with our community to find how best to navigate these complex, uncharted waters with precision, curiosity, and integrity.

Hannah van Kolfschooten, Carmel Shachar 2023. The Council of Europe's AI Convention (2023–2024): Promises and pitfalls for health protection. *Health Policy* 138, 104935
<https://doi.org/10.1016/j.healthpol.2023.104935>.

(<https://www.sciencedirect.com/science/article/pii/S0168851023002208>)

The Council of Europe, Europe's most important human rights organization, is developing a legally binding instrument for the development, design, and application of AI systems. This "Convention on Artificial Intelligence, Human Rights, Democracy and the Rule of Law" (AI Convention) aims to protect human rights against the harms of AI. The AI Convention may become the first legally-binding international treaty on AI. In this article, we highlight the implications of the proposed AI Convention for the health and human rights protection of patients. We praise the following characteristics [1]. Global regulation for technology that easily crosses jurisdictions [2]. The human rights-based approach with human rights assessment [3]. The actor-neutral, full-lifecycle approach [4]. The creation of enforceable rights through the European Human Rights Court. We signal the following challenges [1]. The sector-neutral approach [2]. The lack of reflection on new human rights [3]. Definitional issues, and [4] The process of global negotiations. We conclude that it is important for the Council of Europe not to compromise on the wide scope of application and the rights-based character of the proposed AI Convention.

Lichtenberg Frank R. The Relationship Between Pharmaceutical Innovation and Cancer Mortality in Spain, From 1999 to 2016. *Value in Health* 26(12), 1711 - 1720

Scholte, Mirre et al. Care Pathway Analysis to Inform the Earliest Stages of Technology Development: Scoping Oncological Indications in Need of Innovation. *Value in Health* 26(12), 1744 - 1753

Care pathway analysis is a mapping process, which produces graphical maps of clinical pathways using important outcomes and subsequent consequences. We performed care pathway analyses for glioblastoma, breast, bladder, prostate, renal, pancreatic, and oral cavity cancer. Differences between a "perfect" care pathway and the current care pathway in terms of percentage of inadequate margins, associated recurrences, quality of life, and 5-year overall survival were calculated to determine unmet needs. Impact on survival was largest for bladder and oral cavity cancer with positive margins.

Pellegrini M, Chakravorty S, Del Mar Manu Pereira M et al (2023). Sickle cell disease: Embedding patient participation into an international conference can transform the role of lived experience. *Orphanet Journal of Rare Diseases*, 18(1), 341. <https://doi.org/10.1186/s13023-023-02951-8>

Worboys HM, Broomfield J, Smith A et al (2023). Incorporation of patient and public involvement in statistical methodology research : Development of an animation. *Research Involvement and Engagement*, 9(1), 102. <https://doi.org/10.1186/s40900-023-00513-7>

Geissler J, Makaroff LE, Söhlke B, Bokemeyer C (2023). Precision oncology medicines and the need for real world evidence acceptance in health technology assessment: Importance of patient involvement in sustainable healthcare. *European Journal of Cancer* 193, 113323 <https://doi.org/10.1016/j.ejca.2023.113323>

Hosie A, Firdaus M, Clarkson J, et al (2023). Citizen science to improve patient and public involvement in GUIDeline Implementation in oral health and DENTistry (the GUIDE platform). *Health Expectations* <https://doi.org/10.1111/hex.13921>

Monfort E, Latour P (2023). Fostering patient engagement through the co-design of seizure detection and monitoring technologies: A roadmap for collaboration between research and development. *Revue Neurologique*, 50035-3787(23)01115-3. <https://doi.org/10.1016/j.neurol.2023.10.005>

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>

Janet Wale, HTAi PCIG

E-mail: pcig.htai@gmail.com
