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

Enhanced quality and relevance of HTA through patient and citizen involvement

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

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Welcome to our June E-Bulletin

Dear PCIG Members

I am delighted to be writing to you after the HTAi 2024 Annual Meeting which was held in Seville, Spain from 15-19 June. Like previous years, the meeting was expertly run, and the scientific programme covered a broad range of HTA topics while also featuring many interesting patient-centric panels and presentations. We were so grateful to have many patients attending the meeting this year either in-person or virtually, through HTAi grants and the generous contributions of our sponsors for the PCIG PASS. Their participation provided unique perspectives that enriched the scientific discussions. I was inspired, as I'm sure you were, by all of the patient involvement initiatives taking place around the world, and I look forward to putting some of what I learnt into practice in my work this year.

My deepest appreciation goes to Aline, our PCIG Co-Chair, who attended the meeting in-person and coordinated all of the PCIG activities including running the PCIG booth, hosting the PCIG dinner, and chairing the PCIG annual business meeting, while also being a panellist during the meeting. It was an incredible amount of work for her and our other PCIG members who supported her, and I am truly grateful for their contributions.

Thank you also to all of the members who attended the PCIG Annual Business Meeting. We had a packed agenda, but it was testament to all the work this interest group has been undertaking over the last twelve months. The minutes and slides from the meeting will be shared with members soon. You will note in the minutes that we currently have three vacancies on the PCIG Steering Committee as well as a vacancy for our E-bulletin Coordinator, that we are hoping to fill in coming months. Please take a look at the call for expressions of interest below for more information.

Lastly, we were excited to hear that the next HTAi Annual Meeting will be held from 14-18 June 2025 in Buenos Aires, Argentina. Next year will mark PCIG's 20th anniversary and we hope to have lots of exciting activities planned. If you are interested in helping PCIG organise events for the next annual meeting, we are setting up a work group and would very much welcome any volunteers. Please contact the PCIG technical officer at to.patient-citizen@htai.org if you would like to be involved or have any questions.

Many thanks for your continued support.

Kind regards,

Fiona Pearce
Co-Chair, HTAi PCIG

Expressions of Interest – PCIG Steering Committee
PCIG seeks Expressions of Interest for the following positions to fill vacancies on its Steering Committee:
Finance Secretary (manages sponsorships, strong industry connections required)
HTA agency representative
Industry representative (preferably from a medical devices/diagnostics company)
Please send a CV and cover letter (no more than 200 words) addressing the criteria below to the PCIG Technical Officer, Pierre Net, via email to to.patient-citizen@htai.org by 31 July 2024.
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 Reference (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);
Represents a stakeholder group and perspective that ensures a balanced Steering Committee composition; and
Able to participate in additional HTAi committees, where appropriate.
Preference will be given to members who have been active participants in PCIG.
Please note the positions are for a three-year term. 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.

Expressions of Interest – PCIG E-Bulletin Coordinator
PCIG is also seeking Expressions of Interest for a Coordinator, to assist with the preparation of our monthly E-Bulletin. Please send a CV and cover letter (no more than 200 words) which describes your interest and experience in preparing newsletters to the PCIG Technical Officer, Pierre Net, via email: to.patient-citizen@htai.org by 31 July 2024. All applicants must be a member of HTAi and PCIG.

The Co-Chairs, Fiona Pearce and Aline Silva, are happy to discuss any of the vacancies with interested members.

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

Thinking about ideas for the E-Bulletin

My suggestion for the E-Bulletin is to discuss the relevance of the qualitative evidence in HTA processes. This would add the opinions, perceptions and experiences of patients. A mixed method approach is an alternative. Especially so for rare and very rare diseases.
Who to start?

Contributed by Marilia Mastrocolla de Almeida Cardoso

New Project Co-Lead Supporting the Use of Plain Language Summaries in HTA

Antonella Cardone, CEO of Cancer Patients Europe is the new co-lead for the HTAi PCIG project on the implementation of the International Summary Information for Patients (SIP) template. She takes over from Kate Morgan, CEO of Myeloma Patients Europe, who recently went on maternity leave. The project aims to support and encourage the use of the SIP, which is a plain language summary of an HTA submission that can be used by patients and patient organisations to inform their contribution to the HTA process.
The availability of plain language summaries in HTA was originally developed by the Scottish Medicines Consortium (SMC) and the approach has now been adopted by the National Institute for Health and Care Excellence (NICE) in England, as well as being piloted in Australia. The project group are seeing other countries consider similar pilots to make plain language information available. They are also keen to see plain language summaries provided as part of the Joint Clinical Assessments under the EU HTA Regulations.
To be involved in the HTA process, patient experts need clear and accessible information on the treatment they are being asked to comment on. However, there are sometimes barriers, or perceived barriers, such as the perception of bias if industry is providing information, or concerns about the capacity and resources of HTA bodies to review plain language summaries. These are issues that have been addressed in countries that have implemented the approach, so the project group is looking to disseminate best practice and work to support the availability of plain language summary information.

If you would like further information contact the project group through martin.coombes@opened-door.com
On behalf of Jose Diaz, Miryah Morris and Antonella Cardone, Co-leads HTAi PCIG Project on Implementation of the Summary Information for Patients Template

HTAi DCIG and IISA joint webinar 26th July 2024 at 3:30 pm CEST
Abhirup has been a member of PCIG since early 2023, actively contributes to the Rare Diseases and Hospital Based-HTA Interest Groups (IGs). He works as a HTA statistician and contributes to assessments throughout the lifecycle:
I along with HTAi Developing Countries (DCIG) chair Dr Jani Mueller and Dr Antonio Remiro-Azocar (Methods and Outreach from Novo Nordisk) am organizing a webinar on HTA and the role of statisticians jointly hosted by HTAi DCIG and the International Indian Statistician Association (IISA).
We plan to touch base on the role of statisticians and the need/issues to use plain language or simple summaries considering complex concepts such as estimands, ITC, and other statistical considerations in light of the EU HTA Regulation (EU HTAR) and global shifts in evidence requirements for HTA. We also plan to focus on India and LMICs. The webinar will be engaging and interactive.

Link to register -
https://internationalindianstatisticalassociation.my.webex.com/webappng/sites/internationalindianstatisticalassociation.my/meeting/register/2970906 9b95f4f859e546f33a3b1d20b?ticket=4832534b0000000074741d6e253954da0f29fee21c663780b2e4c8f81251f0b7b10cf2ffce8816603&timestamp=1719545378438&RGID=ra7d5c183659e884477b4ce91c00b1a22

Abhirup Dutta Majumdar

CALL FOR PARTICIPANTS, CAN YOU HELP - patient preferences study in Duchenne Muscular Disease to inform healthcare decision making, in particular reimbursement decisions

Researchers from the Dept of Clinical Pharmacology and Pharmacotherapy at KU Leuven (Belgium) are looking for patients with Duchenne Muscular Disease (DMD) or their caregivers to fill in a survey on their treatment preferences. This study aims to ensure that the needs of patients and caregivers are considered in healthcare decisions, such as future medicine reimbursement.

Patients 16 and older can fill in the survey themselves or with help from their relatives, and caregivers can complete the survey on behalf of patients of any age. It is available in Dutch, English, French, Italian, Spanish, Portuguese, and Ukranian. If you or someone you know suffers from DMD, please fill in the survey or share the following link: https://kuleuven.eu.qualtrics.com/jfe/form/SV_blN6hcmjKCuapxk or access via the QR code included in the flyer. For any questions, you can contact Thomas Desmet (thomas.desmet@kuleuven.be)

Tips on how we can reach more patients are also welcome!
Alessandra Blonda

Finally from the E-Bulletin editor and a previous chair of PCIG:
A sad farewell to Sarah Berglas of the previous CADTH – you did so much for and with us PCIG members and you were always ready for a good discussion.
Thank you!

HTAi Matters

THANK YOU FOR ATTENDING THE HTAI 2024 ANNUAL MEETING IN SEVILLE!
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. The HTAi 2024 Annual Meeting focused on the opportunities and challenges for growing valuable networks for HTA and how collaboration can support the evaluation of innovative healthcare solutions through sharing.

The Annual Meeting Team is currently preparing the session recordings for upload onto the Virtual AM Platform (OnAir) and getting the abstract book ready. Notifications will be sent out per email as soon as materials are ready. Once available, session recordings and online galleries will remain accessible for three months, until the end of September.

HTAi Interest Group webinars are available online
Visit the HTAi YouTube page to check out our webinar playlist

The HTAi Review
Your biweekly news source for all things HTAi https://htai.org/htai-review-may-24-2024/ 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

ICER in the US has developed an ICER Clinical Trial Diversity Rating tool (CDR)
The CDR Tool presents a framework for evaluating the demographic diversity of clinical trial populations in a consistent, transparent manner leading to an overall diversity rating. Evaluating the diversity in trials and the CDR tool should become part of the HTA process, regulators, policymakers and individual researchers setting up and evaluating trials and will hopefully increase diversity in trials.
The tool can be downloaded from the ICER website at
https://icer.org/our-approach/methods-process/icer-clinical-trial-diversity-rating/

The article on its development is:
Foluso A, Wright AC 2024. J Clinical Epidemiology 169, 111299. A Framework for evaluating the diversity of clinical trials, https://doi.org/10.1016/j.jclinepi.2024.111299
https://www.jclinepi.com/article/S0895-4356(24)00054-4/abstract
Try ResearchGate

Contributed by Dominique Hamerlijnck

NEED (health-needs.eu)
The project NEED (Needs Examination, Evaluation and Dissemination) was undertaken in Belgium with Irina Cleemput of KCE as Project Coordinator. It set out to develop an independent research infrastructure that collects evidence on unmet health-related needs, both from the patients' perspective and that of society, and stores it in a database that can be used by all relevant stakeholders. The availability of explorable evidence on patient and societal needs is a prerequisite for moving from a supply-driven system towards a more needs-driven system. NEED should provide the infrastructure and content to allow for such policies.
Rare diseases, Crohn's disease, malignant melanoma
- Includes methodological approach and application, assessment framework

NEED considers relevant innovations for Belgian and European policy-making and society.
Reform of the EU pharmaceutical legislation (April 2023, European Commission): although "unmet medical needs" is a central concept in the new legislation, a clear operational definition or procedure for identifying unmet medical needs is still lacking. NEED might provide input into the discussion at EU level on how to implement and use the concept of "unmet medical needs" in practice.
European Medicines Agency (EMA): several of EMA's Regulatory Science Research Needs to 2025 include research on (the identification of) unmet medical needs.
EU Health Technology Assessment (HTA) network: knowledge on the needs of patients and society is crucial for joint clinical assessments of new pharmaceutical products and medical devices.
Research activities: the European Commission's DG Research & Innovation recently commissioned a group to study "high-burden under-researched conditions" in Europe and beyond with the objective to steer future research funding.

The Canadian Drug Agency (CDA): The federal government's national pharmacare agenda gives CADTH a new name and an expanded mandate
Trevor Richter and William (Bill) Dempster
ISPOR - HTA Policy Update
Health technology assessment (HTA) is set to take on a broader role in Canada. CDA is a not-for-profit corporation with a board of directors comprising provincial and territorial public drug program leaders. Its mandate extends beyond CADTH's HTA functions to focus on appropriate use of medications, pan-Canadian data collection, and expanding access to health data, including real-world evidence. It is unclear how the increased emphasis on a federal health policy agenda might impact HTA programs that have primarily served provincial and territorial interests.
The provinces and territories recently established the pan-Canadian Pharmaceutical Alliance as an independent agency with a mandate to negotiate drug prices, questions have arisen about the appropriateness of the provinces and territories participating in the federally controlled CDA,[6] and the CDA has had to reassure stakeholders that reimbursement reviews will not be affected by its creation. Regardless of whether HTA programs that support access and reimbursement decisions for pharmaceuticals remain within the new CDA or elsewhere, it is crucial during this transition to maintain the integrity of Canada's existing HTA infrastructure.

ISPOR Good Practices Task Force Report Published in Value in Health
ISPOR Good Practices Report Offers Guidance for Using Real-World Data From EHRs in Health Technology Assessments
ISPOR Good Practices Task Force report "Assessing Real-World Data from Electronic Health Records for Health Technology Assessment: The SUITABILITY Checklist: A Good Practices Report of an ISPOR Task Force " is available in the current issue of Value in Health . The report addresses issues of limitations with the related data sources that can impact electronic health records (EHR) validity and relevance for health technology assessment; and was accompanied by an editorial, "Perspectives on Improving Value Assessment With the ISPOR SUITABILITY Checklist ," emphasizing the growing importance and challenges of value assessment and the potential for real-world EHR data to enhance this effort.

QALY: Love It or Hate It? Latest Issue of Value in Health Presents Different Perspectives
ISPOR - Volume 27, Issue 6
Still undecided about the usefulness of the quality-adjusted life year (QALY) measure? This issue of Value in Health presents 5 different perspectives arguing for and against its use in healthcare decision making. The journal's Editors-in-Chief contribute an editorial about the enduring debate over QALYs; a commentary discusses the value of the QALY; an article by Feng Xie, et al examines whether the QALY discriminates against the elderly; and a Letter to the Editor and Author Reply continue the debate about QALY alternatives like the Health Years in Total (HYT).

Collaboration, Alignment, and Harmonization Must Drive Healthcare Innovation (diaglobal.org)
Vedran Raguz, DIA
One of the overarching themes of *DIA Europe 2024* was the imperative of alignment and harmonization across regulatory bodies and stakeholders. Representatives from the European Medicines Agency (EMA), World Health Organization (WHO), US Food & Drug Administration (FDA), and Japan's Pharmaceuticals and Medical Devices Agency (PMDA) echoed the importance of increasing regulatory convergence, particularly in real-world evidence (RWE) guidance for drug safety assessments. Collaborative efforts at the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH) and the International Coalition of Medicines Regulatory Authorities (ICMRA) have proven instrumental in driving this agenda forward and have paved the way for more streamlined processes and enhanced regulatory coherence.

The significance of sustained dialogue and collaboration is exemplified by ongoing DARWIN EU studies. DARWIN EU is a federated network of data, expertise, and services that supports better decision-making throughout the medicine lifecycle by generating reliable evidence from real-world healthcare data.

European Patients Forum (EPF) Patients' Perspective June 2024

EPF's analysis of the European Parliament reports on the revision of the EU pharmaceutical legislation (eu-patient.eu) EPF's analysis of the European Parliament reports on the revision of the EU pharmaceutical legislation (eu-patient.eu)

On 10 April 2024, the European Parliament formalised the revision of the EU pharmaceutical legislation. The main changes proposed by the European Parliament that are relevant to the patient community:

- Inclusion of patient representatives in the ad hoc working groups set up by the Committee for Medicinal Products for Human Use.
- Inclusion of a patient organisation representative in the Coordination Group for Decentralised and Mutual Recognition Procedures.
- Reimbursement of patients' expenses incurred in performing their duties as members or alternates of EMA's scientific committees.
- Consultation of patients in drawing up the Union's list of critical shortages and critical medicines.
- Establishment of a system for patients to report shortages at national level.
- Consultation of patients if a Member State decides to implement electronic patient information leaflets only.
- Inclusion of a key information section in the package leaflet reflecting the results of consultations with patient organisations.
- Allowing patient organisations to submit data for new indications for any medicine, beyond those addressing unmet medical needs.

Read the full analysis here.

Patient Organisations Release 10 Key Recommendations for Enhancing Joint Clinical Assessments Under the EU HTA Regulation

10 Key Recommendations for Enhancing Joint Clinical Assessments Under the EU HTA Regulation (eu-patient.eu)

Leading patient organisations across Europe have come together to release a set of ten key recommendations aimed at improving patient involvement in Joint Clinical Assessments (JCAs) under the EU Health Technology Assessment (HTA) Regulation. This collaborative effort highlights the crucial role of patient experiences and insights in shaping effective healthcare assessments and ensuring that the voices of those directly affected by medical innovations are heard and valued.

The recommendations, developed with input from a wide range of patient groups and based on extensive consultation and practical experience, are designed to foster a more inclusive, transparent, and patient-centered approach to JCAs.

The full text of the recommendations is available here.

EPF's feedback on the draft Implementing Act for Assessing and Managing Conflict of Interest (eu-patient.eu)

The Implementing Act for assessing and managing conflict of interest will determine which patients and clinical experts participate in Health Technology Assessment (HTA) cooperation at the EU level.

When it comes to HTA, it is essential to maintain the high integrity of the assessment process to secure trust and acceptance from national HTA bodies and involved stakeholders. Integrity implies accountability of those taking part, and transparency and reliability of sources informing the decision-making process. In other words, it is in the interest of all parties to generate soundly based decisions.

However, elevating the risk of CoI to an exclusion criterion for patient involvement in HTA risks producing the unwanted effect of missing valuable input generated through interactions with other stakeholders.

Four recommendations to ensure optimal patient involvement in EU HTA processes:

1. Establish a scoring system to assess risk of Conflict of Interest among experts;
2. Allow the "expert witness" status for experts in HTA process;
3. Develop guidelines to mitigate CoI among patients;
4. Offer accessible and patient-friendly onboarding support for EU HTA processes

You can find out more in the full statement.

In May the first graduates of the International Patient Advocacy Master Programme had their graduation ceremony. The study programme was established by Università Cattolica del Sacro Cuore, in partnership with EPF. Registrations open for the 2024-2025 academic year.
International Patient Advocacy Management - IPAM | Alte Scuole ALTEMS (unicatt.it)

PEOF Provocative Co-creation in Baveno (Italy) 2024 in-person meeting committed to shaping a patient-driven future
PEOF Provocative Co-creation in Baveno (Italy) (synapseconnect.org)
As presented by PFMD and EPF PFMDEUPATIEUROPEAN PATIENTS' FORUM (EPF)
Session resources from PEOF 2024 in Baveno are now available online! Our session organizers have diligently compiled, reflected on, and digested your valuable input, all of which is now accessible on Patient Engagement Synapse.
PEOF 2025 in-person event will take place from June 10 - 12. I am already excited and invite you to subscribe to the PEOF mailing list

World Patients Alliance Conference October 19 – 20, 2024, Cape Town – South Africa
Conference Program - World Patients Alliance
Registration is now open for the 2nd World Patients Conference which is being held on 19 - 20 October 2024 at Cape Town, South Africa.
The theme of the two-day conference is The Role of the Patient in a Changing World. The conference will bring together global leaders of non-profit organizations, medical experts and leaders in the field of patient advocacy to network, exchange information, share experiences, learn from each other, raise their voice, and advocate for patients' cause internationally.
It will be a hybrid event. For participants attending Conference online, all sessions will be broadcasted live in the South African Standard Time. For those who cannot attend during the scheduled times, all the sessions will be recorded and made available online via the WPA website for viewing at a later time.
Virtual registration is entirely free, with no registration fee required.
Additionally, you can pay and participate as a paid In-person registrant.
If you have questions, please send us an email at conference@worldpatientsalliance.org

Uncovering the True Cost of Healthcare: Prioritizing Patient Perspectives - The Innovation and Value Initiative (IVI)
Uncovering the True Cost of Healthcare: Prioritizing Patient Perspectives – Innovation and Value Initiative (thevalueinitiative.org)
View the Webinar Recording

Singapore report 'Model AI Governance Framework for Generative AI - Fostering a Trusted Ecosystem'
Model-AI-Governance-Framework-for-Generative-AI-May-2024-1-1.pdf (aiverifyfoundation.sg)
Outlining AI policy & regulation. A trusted environment enables end-users to use Generative AI confidently and safely, while allowing space for cutting-edge innovation. Nine dimensions are given: Accountability, Data, Trusted Development and Deployment, Incident Reporting, Testing and Assurance, Security, Content, Provenance, Safety and Alignment research and development, AI for Public Good

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Publications

Faluyi D, Ovseiko PV, Dziedzic K, Scott F (2024). NIHR Race Equality Framework : Development of a tool for addressing racial equality in public involvement. Research Involvement and Engagement, 10(1), 44. https://doi.org/10.1186/s40900-024-00569-z

Phillips OR, Harries C, Leonardi-Bee J, Knight H, Sherar LB, Varela-Mato V, Morling JR (2024). What are the strengths and limitations to utilising creative methods in public and patient involvement in health and social care research? A qualitative systematic review. Research Involvement and Engagement, 10(1), 48. https://doi.org/10.1186/s40900-024-00580-4

Eberl M, Cruickshank SM (2024). A culture shift to support public involvement and engagement in research. The Journal of Experimental Medicine, 221(6). https://doi.org/10.1084/jem.20240268

Klassen T (2024). Ethical patient engagement in healthcare governance. Healthcare Management Forum, 8404704241251898. https://doi.org/10.1177/08404704241251898
Health leaders are faced with a lack of public trust in healthcare governance. This waning trust relationship was further solidified through the pandemic. Improving the relationship between health organizations and the community/citizens/patient partners is a moral imperative of which ethical governance is a significant factor. Ethical governance that recognizes the significant contributions and value of engaged patient partners can be achieved and may be one of the significant levers required to transform healthcare.

Value in Health, Volume 27, Issue 6. June 2024
Quality-Adjusted Life Years, Quality-Adjusted Life-Year-Like Measures, or Neither? The Debate Continues Devlin, Nancy J. et al. Value in Health, Volume 27, Issue 6, 689 – 691. doi: 10.1016/j.jval.2024.04.021
The quality-adjusted life year (QALY) is over 50 years old Debate about the ethical basis for the QALY and its use in cost-effectiveness analysis (CEA) and policy decision making are almost as old. At the center of the debate the fundamental question about whether the QALY itself is a valid measure persists. In the US anti-QALY lobbying by the pharmaceutical industry and opposition to the use of QALYs by patient groups has placed political pressure on legislators. Therefore, the use of QALYs, or similar measures, in decisions concerning Medicare coverage and reimbursement is legislatively forbidden. Proposed legislation would expand this to place a ban on QALYs "and other similar discriminatory measures" in all federal programs.
Articles:
The Value of the Quality-Adjusted Life Years. Willke, Richard J. et al. Value in Health, Volume 27, Issue 6, 702 - 705
Do Quality-Adjusted Life Years Discriminate Against the Elderly? An Empirical Analysis of Published Cost-Effectiveness Analyses. Xie, Feng et al. Value in Health, Volume 27, Issue 6, 706 – 712
Critical Comments by Food and Drug Administration Reviewers on Patient-Reported Outcomes in Food and Drug Administration Regulatory Submissions (2018-2021). Slota, Christina et al. Value in Health, Volume 27, Issue 6, 755 - 766
Logical Inconsistencies With Expected Utility Theory May Align Better With Patient Preferences—A Response to Paulden et al. Basu, Anirban. Value in Health, Volume 27, Issue 6, 815 - 816
Author Reply. Paulden, Mike et al. Value in Health, Volume 27, Issue 6, 817 - 819

How To Advance The Debate Over QALYs: A Response To Kaplan et al. Health Affairs Forefront, June 10, 2024. DOI: 10.1377/forefront.20240607.883603

July 2024 issue of NEJM Catalyst Innovations in Care Delivery PATIENT-CENTERED INNOVATION THEME
Current Issue | NEJM Catalyst Innovations in Care Delivery
A special theme issue centered on patient-centered innovation, includes articles, case studies, and research reports on patient-centered care, PROMs and PREMs, at-home acute care, and payment for patient safety. Compassion, empathy, and humanism have been at the center of care delivery since the advent of modern medicine. Yet experience is a relatively new term. The contemporary patient experience movement has its

origin with the introduction of formal patient satisfaction surveys nearly 30 years ago. The standardized Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys in the United States and their link to value-based purchasing served to focus provider organizations on enhancing the experience for patients.
The Insights Report in this issue, "Keys to Measuring Patient-Centered Care" highlights the perspectives NEJM Catalyst Insights Council members — who are clinicians and health care leaders from around the world — on incorporating patient feedback across the health care journey.
"Understanding What Matters to Patients" Council members from the United States and Argentina discuss how to assess patient-centered care. Nearly all survey respondents espouse the importance of patient-centered care both personally and professionally. Fully 98% say patient feedback should be incorporated into care delivery, and 96% say that patient-reported outcomes measures (PROMs) are a critical component of patient-centered care.
IN DEPTH: Mass General Brigham's Patient-Reported Outcomes Measurement System: A Decade of Learnings. Jason B Liu et al.
CASE STUDY: Emergency Department in Home (EDiH): A Novel Approach to Delivering Acute Care. Evan Berg et al.
Case Study | NEJM Catalyst: The Amsterdam PROM Implementation Strategy: Policy and Pathway
Groenewegen A et al. NEJM Catal Innov Care Deliv 2024;5(7)
Building on years of experience with patient-reported outcome measures (PROMs), leaders at Amsterdam University Medical Centers established a multidisciplinary PROM implementation team that developed and deployed a PROM Policy and a PROM Pathway. Together, these tools guide a centralized, evidence-based process to integrate PROMs into routine practice.
ARTICLE: How Payers Can Help Hospitals Become Safer Through Value-Based Programs. Eugene Hsu et al.
COMMENTARY: Outcomes or Experiences — What Do Patients Value More When Evaluating Medical Teams? Gregory Katz et al.
INSIGHTS REPORT: Keys to Measuring Patient-Centered Care. James Merlino.
INSIGHTS INTERVIEW: Understanding What Matters to Patients. Jonathan Bees.
FROM THE EDITORS: Innovation in Pursuit of Patient-Centered Care. James Merlino.

CEPPP – Centre d'excellence sur le partenariat avec les patients et le public
You will find papers published in the last month on the theme of partnership with patients and the public in care, research, education and digital health in this link Centre d'excellence sur le partenariat avec les patients et le public (list-manage.com)

Janet Wale, HTAi PCIG
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