

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, February 2019

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 the February E-Bulletin

We noted 'Rare Disease Day on Thursday 28 February. This takes place on the last day of February each year. The main objective of the day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Looking forward, March 8 is International Women's Day, highlighting the social, economic, cultural and political achievements of women. The day also marks a call to action for building a gender-balanced world, which is also the focus of goal #5 in the Sustainable Development Goals.

<https://www.internationalwomensday.com/IWD2019>

HTAi Matters



HTAi Meeting to be held in Cologne, Germany from Saturday June 15 to Wednesday 19 June, 2019

Supported by the Institute of Quality and Efficiency in Health Care (IQWiG) and the German Institute of Medical Documentation and Information (DIMDI) as host organisations. Visit the [HTAi 2019 website](http://htai2019.org) for currently available information. <http://htai2019.org>

Engage with an extensive network of leaders, experts and key policymakers in lively discussions around the theme of the meeting: HTA Beyond 2020: Ready For The New Decade?'

HTAi welcomes those invested in the production and implementation of HTA from around the world.

Early Bird Registration ends on March 22, 2019. <https://www.htai2019.org/register/>

Any questions regarding Registration please contact registration@htai.org

Early Bird: March 22, 2019

Regular: March 23 – June 9, 2019

Onsite: June 15 – 19, 2019

Nominations to the Board of Directors

HTAi is seeking active members of the Society for nomination to the Board of Directors. We are looking for up to 4 engaged, motivated and enthusiastic Board Directors for a three-year term between 2019 and 2022.

Nominees should be prepared to:

- Chair at least one of the advisory board committees,
- Sit as a member on at least two committees or working groups,
- Travel and spend time attending two face-to-face Board meetings, and

- Carry out other duties as requested.

The Vice-President position is also open. This is a 2 year term, 2019 – 2021. Typically, the Vice-President will then assume the position of President for two years, 2021 – 2023, and then Past President, 2023 - 2025.

The nominations form can be found at

<https://www.xcdsystem.com/htai/files/2019%20HTAi%20Board%20Nomination%20Form.pdf>.

We request that applicants provide their Biography, Vision Statements and a Photograph along with supporting signatories. Any questions and nominations should be submitted by email to info@htai.org. The deadline for receiving nominations is Sunday, March 17, 2019, 23:59 MST (GMT +7).

All HTAi members in good standing are eligible to vote and Electoral Reform Services will contact each HTAi member via email with further instructions on how to vote.

What's Happening

Top Ten insights into citizen engagement: a Canadian perspective. McMaster Health Forum, Canada 26 March 2019, 12:00 – 1:00 p.m. ET

https://mcmaster.webex.com/mw3300/mywebex/default.do?nomenu=true&siteurl=mcmaster&service=6&rnd=0.2619786440727374&main_url=https%3A%2F%2Fmcmaster.webex.com%2Fec3300%2Feventcenter%2Fevent%2FeventAction.do%3FtheAction%3Ddetail%26%26%26EMK%3D4832534b00000004e43884bc16e5464b62631d6482f4ad69f86356adfddea802a6f903919abebobfo%26siteurl%3Dmcmaster%26confViewID%3D118575130846723270%26encryptTicket%3DSDJTSwAAAAQpYvXTgUQfqL4xIWD8bJP7OVsnMbTCxX6D2cBSUNUKLQ2%26

Citizen values, insights and preferences are being increasingly solicited to inform the policymaking process. Carolyn Canfield, an active citizen-patient, will share a Canadian perspective on what has been done to engage citizens in health systems policymaking, key lessons learned, and insights on other emerging approaches. François-Pierre Gauvin (Senior Scientific Lead, Citizen Engagement and Evidence Curation of the McMaster Health Forum) will also share insights from the Forum's experience in engaging citizens to better inform the policymaking process.

2019 CADTH Symposium, 14 – 16 April, Edmonton: Supporting Health System Transformation

<https://symposium.cadth.ca/>

This event is Patients Included

NICE 2019. 9 May, Manchester: Transforming Care

<http://www.niceconference.org.uk/agenda>

NICE makes Canadian partnership to offer scientific advice, 7th February 2019

The National Institute for Health and Care Excellence (NICE) is working with the Canadian Agency for Drugs and Technology in Health (CADTH) to offer parallel scientific advice to the life sciences industry. The collaboration aims is to help companies prepare for future HTAs by answering their questions and providing key insight on their clinical and health economic development plans.

The parallel advice service will feature a joint summary, highlighting areas of synergy from the two agencies, and two separate advice reports from NICE and CADTH. The scientific advice will also assist companies in developing evidence that demonstrates the value of a technology by providing detailed feedback on their clinical and economic evidence generation plans, using expert opinion from a range of contributors including clinicians, health economists and patient representatives.

For more information about the CADTH Scientific Advice program, please visit: www.cadth.ca/scientific-advice. For more information about the NICE Scientific Advice program, please visit:

www.nice.org.uk/about/what-we-do/scientific-advice.

NICE provides first scientific advice on patient preference study design, 14th February 2019

https://www.nice.org.uk/news/article/nice-provides-first-scientific-advice-on-patient-preference-study-design?utm_medium=social&utm_source=twitter&utm_campaign=nsanovartispatientstudy

The NICE Scientific Advice team, working with the Science Policy and Research team at NICE, has provided its first piece of advice on the design of a patient preference study, with the aim to encourage more companies to seek its advice on the development of such studies.

The studies aim to capture patients' insights so these can be incorporated into the clinical development programs for new treatments. Working with Novartis, the pilot looked at a patient preference study for people with chronic obstructive pulmonary disease (COPD). NICE anticipates that its advice will guide early evidence generation, helping to transform study design and improve the quality of current processes, with aim to support the development of new products to treat COPD patients.

Survey for ClinicalTrials.gov

There's less than one week left to take the survey to share your thoughts and opinions about clinical trial information on the ClinicalTrials.gov website. Your feedback will be used to better understand people's needs and preferences for information about clinical trials.

To take the survey, click this link by Friday, March 8th at 11am ET:

<https://www.surveymonkey.com/r/RRY5DG2>

It will take about 15 minutes to complete

Core Outcome Sets (COS) for measuring effectiveness/benefits and harms in clinical studies

Heather Bagley from COMET has sent the link to a short video. She is keen for patients to start asking whether core outcome sets exist for their health conditions. These mean consistency of reporting and capacity to draw together results of trials, and so greater consistency in patient-relevant outcomes for HTAs. Link to the video: <http://www.comet-initiative.org/resources/PlainLanguageSummary>

Submitted by Professor Sophie Staniszewska

The Alliance for Useful Evidence

<https://www.alliance4usefulevidence.org/resources/?filter-by=publication>

The Alliance for Useful Evidence is a network, hosted by the UK's innovation charity Nesta, which champions the smarter use of evidence in social policy and practice.

We do this through advocacy, convening events, sharing ideas and resources, and supporting individuals and organisations through advice and training.

We promote our work through our open access network of more than 4300 individuals from across government, universities, charities, businesses, and local authorities in the UK and internationally. Anyone can join the Alliance network, at no cost.

From the European Patients Forum (EPF) newsletters:

EPF and EUPATI at the DIA Europe 2019 Conference – Partnership in practice

DIA held its annual European conference in Vienna, Austria. 5 – 7 February 2019

<http://www.eu-patient.eu/News/News/epf-and-eupati-at-the-dia-europe-2019-conference--partnership-in-practice/>

As one of the many members of the EUPATI consortium, DIA took the opportunity to show their support not only for patient engagement, but to EUPATI itself. This came from consistent messaging throughout the conference on patient education and the role that EUPATI plays, but also in financial terms: by donating €1 for every completed participant survey, a portion of revenue from seats at their VIP reception, and by collecting spare change from attendees at the DIA lounge. All funds raised by DIA will be used to sponsor travel for trainees for the 4th Patient Expert Training Course, due to launch in 2019.

EFPIA held a 'Patients' Think Tank' in February

27 February 2019, Brussels

An example of how pharmaceutical companies are communicating with patients and caregivers:

'Novartis Commitment to Patients and Caregivers – Celebrating a year of progress'

Today we are celebrating the first anniversary of the [Novartis Commitment to Patients and Caregivers](#). One of the key messages was to continue the dialogue and share progress on how our Commitment directs and shapes the way we work.

We have much more work to do, however, I am pleased to share the progress we have made. When we launched the Commitment to Patients and Caregivers, we committed to focus on three critical areas: to increase the number of patient-friendly summaries for our phase 1-3 clinical studies, the number of clinical development plans for new compounds with a patient engagement component, and the number of patients reached through managed access programs.

Have a look at our [factsheet](#) which illustrates what we have achieved so far. We are working tirelessly to bring the four pillars of our Commitment to life every day. We continue to engage with patients and their representatives and appreciate the open dialogue that nurtures our learning and deep understanding of the expectations from the patient community. I recently had the opportunity to have a [conversation with National Health Council CEO Marc Boutin](#). Amongst other things, he pointed out the importance of early dialogue with patients starting in research.

IPPOSI 'A Charter for Patient Involvement in Medicines Assessment & Reimbursement' (24 page document) - to improve the transparency, accountability and communication on how medicines are assessed & reimbursed

http://www.ipposi.ie/wp-content/uploads/2019/02/IPPOSI_Patient-Charter_A4_LO_FINAL.pdf

Strategic Commitment: Patients call for a strategic commitment to advance their involvement

Education & Training: Patients need education, training and support to facilitate their involvement

Transparency & Communication: Patients demand access to information and regular communication

Patient & Clinical Evidence: Patients ask that patient + clinician evidence & input is systematically considered

Early Engagement: Patients want early and sustained engagement across the process

Right to Appeal: Patients request the right to appeal

The Charter was co-ordinated by the Irish Platform for Patient Organisations, Science & Industry (IPPOSI), with the support of the Medical Research Charities Group (MRCG) and Rare Disease Ireland (RDI) and sets out 29 actions. It is a call to action from Irish patient organisations to the Irish Department of Health, the Health Service Executive (HSE) and the National Centre for Pharmacoeconomics (NCPE) to explore how patient involvement can be improved.

The proposal to develop a Charter was initiated by IPPOSI. In proposing a Charter, IPPOSI sought to collate many of the proposals put forward over the last ten years by patient organisations into one comprehensive, coherent and compelling document.

In 2017 and 2018, IPPOSI – in partnership with the MRCG – invited its members to attend three workshops on the topic of access to medicines. [Two 'Drug Iceberg' reports](#) detailed conclusions from the workshop discussions, and several of the report's recommendations have informed various provisions contained within the Charter. A Third report is due in Spring 2019. In 2018, IPPOSI members agreed on an Annual Theme of 'Access to Medicines'. An 11-member IPPOSI Board Sub-Group from patient, science and industry members and a network of Research & Advocacy Officers from eight Irish patient organisations were established to feed into the Charter development process. In May 2018, IPPOSI consulted the patient representatives of the [EUPATI National Platform in Ireland](#), and later in the same month, IPPOSI invited three health technology assessment agencies (Canada, Scotland, and Sweden) – identified as leading on the topic of patient involvement – to share their experience with members via [a webinar](#).

In July 2018, IPPOSI invited its patient members to provide their comment and feedback on a first public draft of the Charter and to express their interest in becoming signatories.

In September 2018, two IPPOSI representatives traveled with the NCPE to meet the Scottish Medicines Consortium (SMC) Patient Involvement Team and to observe the consideration of evidence at the SMC Patient and Clinician Engagement (PACE) meeting.

In October and November IPPOSI engaged (separately) members of the HSE Corporate Pharmaceutical Unit (CPU) team and the NCPE on the draft text.

The IPPOSI Board approved the final version of the Charter in December 2018 for publication and dissemination.

Publications

A co-produced method to involve service users in research: the SUCCESS model. Evans BA, Porter A, Snooks H, Burholt V. BMC Med Res Methodol. 2019 Feb 15;19(1):34. doi: 10.1186/s12874-019-0671-6. Open access <https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0671-6>

Public and patient involvement is a routine element of health services research methods to produce better designed and reported studies. Although co-production is recommended when involving people in research, methods for involving people are usually designed and managed by researchers and there is little evidence about methods to co-produce models for effective public and patient involvement. We recruited people with experience of chronic conditions, as patients and carers, and supported them to develop and implement the involvement model. We collected written records to describe the processes of coproduction. Sixteen service users were involved through a series of workshop, meeting and email discussions. They specified principles and operating characteristics of the model which concerned an inclusive culture, adequate resources, accessibility, good communication and clarity of purpose and roles. Components of the model included an on-line Panel of members (n = 20), Steering Group meetings, representation and communication system, facilitator, supportive research environment and access to research activities. Over 8 years, members were active in 218 research activities and held 22 Steering Group meetings. The model was named SUCCESS standing for Service Users with Chronic Conditions Encouraging Sensible Solutions.

Patient involvement in reflective multicriteria decision analysis to assist decision making in oncology. Badia X, Aguarón A, Fernández A, et al. 2019. International Journal of Technology Assessment in Health Care, 1 - 8. <https://doi.org/10.1017/S0266462318003641>

Value in Health publications:

A Review of Patient Reported Outcomes Labeling for Oncology Drugs Approved by the FDA and the EMA (2012-2016)

[https://www.ispor.org/publications/journals/value-in-health/abstract/Volume-22--Issue-2/A-Review-of-Patient-Reported-Outcomes-Labeling-for-Oncology-Drugs-Approved-by-the-FDA-and-the-EMA-\(2012-2016\)](https://www.ispor.org/publications/journals/value-in-health/abstract/Volume-22--Issue-2/A-Review-of-Patient-Reported-Outcomes-Labeling-for-Oncology-Drugs-Approved-by-the-FDA-and-the-EMA-(2012-2016))

Perceptions of Response Burden Associated with Completion of Patient Reported Outcome Assessments in Oncology

<https://www.ispor.org/publications/journals/value-in-health/abstract/Volume-22--Issue-2/Perceptions-of-Response-Burden-Associated-with-Completion-of-Patient-Reported-Outcome-Assessments-in-Oncology>

Association between Disability-Cognition-Fatigue-EQ-5D-3L Domains – and Utilities Estimated with Different Western European Value Sets in Patients with Multiple Sclerosis

<https://www.ispor.org/publications/journals/value-in-health/abstract/Volume-22--Issue-2/Association-between-Disability--Cognition--Fatigue--EQ-5D-3L-Domains--and-Utilities-Estimated-with-Different-Western-European-Value-Sets-in-Patients-with-Multiple-Sclerosis>

Other papers in this issue:

The Internal Validity of Discrete Choice Experiment Data: A Testing Tool for Quantitative Assessments
F Reed Johnson, Jui-Chen Yang, Shelby D Reed.

Was it worth introducing health economic evaluation of innovative drugs in the French regulatory setting?
The case of new hepatitis C drugs. Valérie Clément, Véronique Raimond.

Comparison of Recommendations and Use of Cardiovascular Risk Equations by Health Technology
Assessment Agencies and Clinical Guidelines. Marissa Blieden Betts, Sandra Milev, Meredith Hoog, et al.
Open Access

Submitted by Sam Thomas

Patients' perspectives on COPD: findings from a social media listening study
Nigel S. Cook, Konstantinos Kostikas, Jean-Bernard Gruenberger, et al. ERJ Open Research 2019 5: 00128-
2018; DOI: 10.1183/23120541.00128-2018
<https://openres.ersjournals.com/content/5/1/00128-2018>

Purposive sampling in a qualitative evidence synthesis: a worked example from a synthesis on parental
perceptions of vaccination communication. Heather Ames, Claire Glenton, Simon Lewin. BMC Medical
Research Methodology 2019 19:26.
<https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0665-4>

Participatory methods to engage health service users in the development of electronic health resources:
systematic review. Moore G, Wilding H, Gray K, Castle D. Journal of Participatory Medicine
2019;11(1):e11474. <https://jopm.jmir.org/2019/1/e11474>

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