

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, April 2017

Enhanced quality and relevance of HTA through patient and citizen involvement

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HTAi Annual Meeting 2017: Explore how the global HTA community is evolving towards an integrated ecosystem – from local needs to global opportunities

Join us for HTAi's 14th Annual Meeting June 17-21, 2017 at the Ergife Palace Hotel in Rome, Italy.

Call For Expressions of Interest to host upcoming HTAi Annual Meeting 2020

2020 Annual Meeting – Expressions of Interest: Deadline June 9, 2017

2020 Annual Meeting – Detailed Proposal: Deadline October 1, 2017

Health Technology Assessment international is seeking Expressions of Interest from non-profit organisations wishing to host the HTAi Annual Meeting in 2020. Submissions from the Asia-Pacific region are preferred for hosting the 2020 meeting.

Detailed instructions on the Expression of Interest 2020 covering letter and proposal to be submitted can be found on the [HTAi website](#)

2017 CADTH symposium: Patient Engagement Highlights

The 2017 CADTH Symposium took place April 23-25 in Ottawa and had just over 850 participants. The theme of the Symposium was "Measuring Value in Theory and the Real World." For the second year, the Symposium was sufficiently inclusive and supportive of patients to receive the "Patients Included" designation. The Symposium included workshops, plenaries, concurrent sessions, and posters with a specific focus on patients. A patient and caregiver were also a part of the Symposium planning committee and provided substantive input into the program. This is also the third year of our Patient Group Travel Award program and CADTH was able to support the attendance of more than 40 patient group members.

The Symposium began with a Patient "Meet and Greet", which took place just before the welcome reception. CADTH also supported a meeting of patient and public members from recommendation committees from across Canada to discuss the role of social values in decision making.

The Symposium's opening plenary explored how different stakeholders define and measure value and featured Dr Bettina Ryll, founder of Melanoma Patient Network Europe.

The second plenary addressed the topic "Meaningful Stakeholder Engagement and how effective engagement can help achieve high value for the health care system". MJ DeCoteau, Founder and Executive Director, Rethink Breast Cancer represented the patient group perspective.

The plenary sessions were livestreamed for free at <http://max.canwebcast.net/2017CADTHSymp>
The concurrent sessions that focused on patient engagement included a session on Patient and Public Engagement, which included results of recent qualitative research on the involvement of patients and use of patient input; a session on providing patient input to pharmaceutical reviews, which included the FDA's Patient Focused Drug Development Initiative; and a session on creating opportunities for meaningful stakeholder engagement.

CADTH also produced a list of common HTA acronyms and technical terms to make it easier for people to understand HTA presentations, reports, and recommendations. This list was sent to patients who had registered and was also distributed during symposium.

Tweets from the Symposium can be found using #CADTHSymp. Photos from the Symposium can be found on Flickr at <https://www.flickr.com/photos/124034028@No6/>

Provided by Ken Bond

Publications

Hoeck B, Ledderer L, Hansen HP (2017). Dealing with cancer: a meta-synthesis of patients' and relatives' experiences of participating in psychosocial interventions.

European Journal of Cancer Care 2017;e12652. DOI:10.1111/ecc.12652

Submitted by Helle Ploug Hansen

Maguire K, Britten N. "How can anybody be representative for those kind of people?" Forms of patient representation in health research, and why it is always contestable.

Social Science & Medicine 2017;183:62-9.

Elsevier has allowed free access until June 18th, at <https://authors.elsevier.com/a/1Uy-p-CmUdvKA>

Submitted by Nicky Britten

Karen Palmer and Joshua Tepper. Patient engagement a new frontier for drug makers

Date: April 27, 2017

An excerpt on 'building trust': Pharmaceutical companies know they need to build that trust, Choudhri (senior vice president and head, medical and scientific affairs at Bayer) says, starting with providing better information to patients and clinicians.

"There's a lot cynicism out there and we want to do it the right way so that we're being fair to the patients and it's not being seen as something where we're trying to influence the patient rather than get patient input," he says. Some of that cynicism is bred by [media reports](#) showing patients can become powerful lobbyists pressing for provincial formularies to cover the cost of pricey new drugs.

"I think pharma has a genuine desire to reach real patients, they just haven't fully figured out how to integrate that into everything that they do," [Deb] Maskens says. "Right now, they struggle with how to operationalize 'patient-centricity' and what that really means. It means they're going to have to do business differently."

<http://healthydebate.ca/2017/04/topic/pharma-patient-engagement>

Submitted by Elaine MacPhail

ISPOR's Value in Health recently published a special themed issue that examines the development and dissemination of high-quality, unbiased value assessment frameworks

<http://press.ispor.org/index.php/isor-initiative-advances-high-quality-value-assessment-frameworks-for-health-care-interventions/>

Aggarwal A, Fojo T, Chamberlain C, Davis C, Sullivan R. Do patient access schemes for high-cost cancer drugs deliver value to society?—lessons from the NHS Cancer Drugs Fund

Ann Oncol mdx110.

<https://doi.org/10.1093/annonc/mdx110>

Hawkins M, Gill SG, Batterham R, Elsworth GR, Osborne RH. The Health Literacy Questionnaire (HLQ) at the patient-clinician interface: a qualitative study of what patients and clinicians mean by their HLO scores
BMC Health Services Research 2017;17:309

Regulations on Medical Devices and In Vitro Diagnostic Medical Devices were adopted by the European Parliament ,on 5 April

Both legislations pave avenues towards safer and more traceable devices.

From the EPF Newsletter

EUPATI webinar: EUPATI Guidance on Engagement of Patients in Pharmaceutical Industry-led Medicines Research and Development

4 May 2017 - 17:00 to 18:30 CET

This is the first webinar of a series of four.

A very important result of the EUPATI project was the development of guidances on the best approach to interaction of patients with pharmaceutical industry-led medicines R&D, regulatory authorities, ethics committees and HTA agencies.

The Guidance document is at <https://www.eupati.eu/patient-involvement/guidance-for-patient-involvement-in-industry-led-medicines-rd/>

11th European Patients' Rights Day - 'The European & National Medicines Regulatory Systems: the challenges for an equitable, timely and suitable access to innovation'

The XI European Patients Rights Day conference (10 May 2017 10:00 -14:00 EESC Brussels) will be focused on:

a) The actual regulatory system model in Europe, how to assure an equitable, timely and suitable access to innovation?

b) National experiences of management of innovation

- from Marketing Authorization to concrete access for patients: successes and failures of access of medicinal products in different EU countries (e.g. Hepatitis C, cancer etc)

c) The involvement of patient organisations in the regulatory process

- sharing good examples of involvement of patient organizations in the European Medicines Agency and the different patients' engagement modalities in the national medicines agencies processes.

Registration by 2 May

<http://www.activecitizenship.net/patients-rights/projects/155-european-patients-rights-days-what-has-been-done.html>

From the Active Citizenship Network <http://www.activecitizenship.net/>

IMI GetReal reports and tool

We're live: launch of the RWE Navigator! Explore the RWE Navigator at <https://rwe-navigator.eu/>

Policy recommendations report on Real-World Evidence from the WP1 Policy Expert Group <https://www.imi-getreal.eu/News/ID/80/Policy-recommendations-from-WP1-Policy-Expert-Group-online>

WP4 delivers report on best practices & recommendations on evidence synthesis <https://www.imi-getreal.eu/News/ID/81/WP4-report-best-practices-and-recommendations-on-evidence-synthesis>

Survey – to inform an international network on patient and public involvement (PPI) in health and social care research

We are seeking your views on our intention to form an international network on patient and public involvement in health and social care research, the priorities for the network, and for your expressions of interest to be part of this enterprise.

We have an opportunity to change the face of research across the world for good, so that its focus and methods better reflect the needs and priorities of patients, carers and the public. There are institutions, associations and individuals, whose purpose is to advance and promote PPI in research. We believe the time has come to join together and enhance the opportunities such a network would bring, enabling the sharing of expertise and evidence-based good practice. For organisations starting to develop public involvement in their own country, it would offer a powerful network of support to enable faster progress. Moreover, through collaboration, our movement would be empowered to influence international and regional health and research organisations.

This is your opportunity to help shape the network. We need your input. To this end, you are warmly invited to complete the survey which is found at <https://www.surveymonkey.co.uk/r/MYWRFDY>. The survey will take up to 15 minutes to complete depending on how much you want to tell us. The closing date for this survey will be **31st May 2017**. If you are aware of other national or international PPI in research organisations that might be interested in being part of this network, please send them the link to this survey. Note: we only need one response per organisation.

We plan to announce the results at the forthcoming Global Evidence Summit in Cape Town (<http://www.globalevidencesummit.org>) and launch the new network at the INVOLVE conference in the UK in November 2017 (www.invo.org.uk).

If you have any questions relating to the survey or the international network, please contact Richard Morley by emailing rmorley@cochrane.org. Richard will respond on behalf of the team. Our details can be found below.

From Simon Denegri, National Institute for Health Research (NIHR) National Director for Public Participation and Engagement in Research

Bulletin du Labo du partenariat / Partnership Lab Bulletin

Avril/April 2017

Engagement en recherche / Engagement in research

[Patient- and community-oriented research: How is authentic engagement identified in grant applications?](#)

(Accès libre/Open access)

Ramsden et al. (2017) *Canadian Family Physician*

[Strategies to improve engagement of 'hard to reach' older people in research on health promotion: A systematic review](#) (Accès libre/Open access)

Liljas et al. (2017) *BMC Public Health*

[Stakeholder involvement in systematic reviews: A protocol for a systematic review of methods, outcomes and effects](#) (Accès libre/Open access)

Pollock et al. (2017) *Research Involvement and Engagement*

[A framework for public involvement at the design stage of NHS health and social care research: Time to develop ethically conscious standards](#) (Accès libre/Open access)

Pandya-Wood et al. (2017) *Research Involvement and Engagement*

["Hitting the spot": Developing individuals with lived-experience of health and social care as facilitators to deliver a course to enhance public involvement in research – A Welsh perspective](#) (Accès libre/Open access)

Meudell et al. (2017) *Research Involvement and Engagement*

[The ECOUTER methodology for stakeholder engagement in translational research](#) (Accès libre/Open access)

Murtagh et al. (2017) *BMC Medical Ethics*

[Partnering with patients in translational oncology research: Ethical approach](#) (Accès libre/Open access)

Mamzer et al. (2017) *Journal of Translational Medicine*

[Partnering with patients: How did you involve patients in your research?](#) (Accès libre/Open access)

Goldbeck-Wood & Belfield (2017) *Journal of Family Planning & Reproductive Health Care*

[Book chapter >> Une vision transdisciplinaire du partenariat patient en santé: Une bioéthique en évolution](#)

Guérin & Fernandez (2017) *La transdisciplinarité et l'opérationnalisation des connaissances scientifiques*

[Amplifying each patient's voice: A systematic review of multi-criteria decision analyses involving patients](#)

Marsh et al. (2017) *Applied Health Economics and Public Policy*

Prioritizing research topics: A comparison of crowdsourcing and patient registry

Truitt et al. (2017) *Quality of Life Research*

Engagement dans la transformation des systèmes de santé / Engagement in health-system transformation

Public and patient involvement and the right to health: Reflections from England (Accès libre/Open access)

Stuttaford et al. (2017) *Frontiers in Sociology*

Co-producing interprofessional round work: Designing spaces for patient partnership (Accès libre/Open access)

Thörne et al. (2017) *Quality Management in Health Care*

Service user and caregiver involvement in mental health system strengthening in Nepal: A qualitative study on barriers and facilitating factors (Accès libre/Open access)

Gurung et al. (2017) *Journal of Mental Health Systems*

Families as partners in hospital error and adverse event surveillance

Khan et al. (2017) *JAMA Pediatrics*

Numéro spécial >> Le patient dans le système de santé, *Revue française des affaires sociales* (2017)

Engagement en santé des communauté / Engagement in community health

Community engagement: What the NICE guidance means for community practitioners (Accès libre/Open access)

Bagnall et al. (2017) *Primary Health Care*

Engagement en enseignement / Engagement in teaching

Co-producing public involvement training with members of the public and research organisations in the East Midlands: Creating, delivering and evaluating the lay assessor training programme (Accès libre/Open access)

Horobin et al. (2017) *Research Involvement and Engagement*

François-Pierre Gauvin

Janet Wale, HTAi PCIG

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