



HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, November 2016

Enhanced quality and relevance of HTA through patient and citizen involvement

Welcome to this month's E-Bulletin

HTAi Annual Meeting 2017: Explore how the global HTA community is evolving towards an integrated ecosystem

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



Deadlines

Abstract Submissions

Workshops & Panels, December 2, 2016

Posters & Oral Presentations, January 16, 2017

Travel Grants: Application, January 16, 2017

Registration: Early Bird, March 3, 2017

International Scientific Programme Committee Co-chairs Assoc Prof Rabia Kahveci, Turkey and Prof Americo Cicchetti, Italy look forward to seeing you in Rome. "We will host discussions around what we can achieve beyond borders and how we may impact health care decision-making through HTA at the global level. Our intention is to discover a deeper understanding of the benefits and challenges of different approaches and to foster collaboration in HTA. We will describe the interactions between HTA in macro, meso and micro decision-making levels. We will not only tackle integration between HTA and regulatory systems, but also challenge such macro interactions and their impact on meso and micro levels, such as hospitals and health care professionals. Further conversations will focus around a value-based paradigm in health care systems where we will define the role of HTA, discuss ways to engage professionals and how to garner the potential contributions of big data analysis. The role of multi-stakeholder involvement in facing the ethical dilemmas related to these interactions will also be explored."

Correction: Please note the Patient Panel member from Taiwan is Kevin Yeh – I gave him a new surname in the October E-Bulletin.

Learn about the HTAi Interest Groups; also the Interest Groups Steering Committee, its role in interest group governance and funding. This committee is an advisory committee to the HTAi Board.

<http://www.htai.org/interest-groups/interest-groups.html>

<http://www.htai.org/htai/advisory-committees/interest-groups-steering-committee.html>

Activities at HAS

The French National Authority for Health (HAS = Haute Autorité de Santé, which is the public body for HTA in France) launched a new system of submissions for Patient Organizations (POs) in November 2016. The objective is to increase patient involvement in the rapid HTA process, by adding some submissions from POs to the citizen input in the committees. It concerns drugs and devices assessments.

- The procedure: information on line about coming assessments; clear deadlines for POs to contribute, compatible with HAS staff and committee processes.

- A template for "patient perspective". We translated and adapted into French the Health Technology Assessment international (HTAi) "Patient Group Submission templates". Methods used by NICE, CADTH and SMC were also studied.
- Inclusion of a support for POs in the process_(e.g. how to fill the template, to give feedback after the committee...).

After a 6 months trial period, in June 2017, we will assess the first period with the intent to improve processes.

http://www.has-sante.fr/portail/jcms/c_2666630/fr/contribution-des-associations-de-patients-et-d-usagers-aux-evaluations-de-medicaments-et-dispositifs-medicaux

Hervé Nabarette, Conseiller technique Direction évaluation économique, médicale et de santé publique at Haute Autorité de Santé in France

Colloque HAS, Patient dynamics: innovating and measuring - Paris - 16 November 2016

HAS organized its annual symposium dedicated to the contribution that patient and user perceptions can make to improving the quality of care and the health technology assessment (HTA). This scientific symposium aimed to provide a collective platform for consideration of this issue, making the best possible use of French and international experience and research, from both the hospital and ambulatory sectors according 3 parts:

- Session 1 - The contribution of users in healthcare quality and safety improvement initiatives
- Session 2 - From patient experience collecting to shared decision making
- Session 3 - The patient perspective in health technology assessment

Speakers of the session 3:

- Patient contributions: Karen Facey, International Health Policy Consultant
- Example of an agency seeking to incorporate various forms of patient perspective: Laura Weeks, Scientific Advisor, Canadian Agency for Drugs & Technologies in Health, Canada (video)
- Pilot projects for the measurement of preferences: Irina Cleemput, Senior Health Economist, Belgian Health Care Knowledge Centre, KCE, Belgium
- Pilot projects for the measurement of preferences: Marion Danner, Research Associate, Institute for Health Economics and Clinical Epidemiology, University Hospital of Cologne, Germany

The slideshows of the speakers, the participant file with the presentations of the sessions and the speakers, the videos and the scientific program are available.

The event was hosted by the leaders of HAS, showing their commitment to patient involvement across the organisation. It coincided with the launch of their patient group submission process in HTA and the discussions during the day demonstrated the keenness of patient groups to engage with (and challenge) HAS to improve the quality of healthcare and inform HTA decisions.

English version

http://www.has-sante.fr/portail/jcms/c_2672110/en/colloque-has-patient-dynamics-innovating-and-measuring-paris-16-november-2016

French version

http://www.has-sante.fr/portail/jcms/c_2672110/fr/colloque-has-la-dynamique-patient-innover-et-mesurer-paris-16-novembre-2016

Hervé Nabarette, Conseiller technique Direction évaluation économique, médicale et de santé publique at Haute Autorité de Santé in France

Workshop for Patient Groups: Role of HTA in Cancer Drug Funding Decisions

On October 25, The Canadian Cancer Action Network (CCAN), in collaboration with the Canadian Agency for Drugs and Technologies in Health (CADTH), held a free, interactive workshop for patient groups to learn how cancer drugs are reviewed through the pan-Canadian Oncology Drug Review (pCODR) process.

<http://www.canceraction.ca/workshop-for-patient-groups/>

Patients had the opportunity to:

- Meet with the Health Technology Assessment (HTA) Patient Engagement Navigator, and become familiar with the resources and tools available to support a patient submission to pCODR
- Get best practices, tips, and advice on how to plan and make a patient submission to pCODR
- Understand how cancer drugs are approved in Canada, with a focus on the pCODR process
- Learn how costs and benefits are considered in the HTA process, with a focus on cancer drugs
- Obtain insight directly from the patient members of the pCODR Expert Review Committee (pERC) on how patient evidence and information make a difference to the Committee's recommendations.

Participants also had an opportunity to take part in a case study to understand the HTA recommendation process for a cancer drug.

The feedback from participants about this event has been overwhelmingly positive. Participants especially appreciated how the case study allowed them to learn about the pERC deliberative framework and to gain insight into how HTA committees make a funding recommendation for cancer drugs. Based on the success of this first workshop, CCAN and CADTH are considering holding future similar workshops.

Ken Bond, Director, Patient Engagement and International Affairs [CADTH](#)

CADTH symposium April 2017

If you are a Canadian patient group person and would like to go to the CADTH symposium in April 2017, don't forget to apply for a travel grant by 9 December.

<https://www.cadth.ca/2017-cadth-symposium/travel-awards>

Karen Facey, Evidence Based Health Policy Consultant

Announcing the Patient & Care-Partner Connection Program

The U.S. Food and Drug Administration's Center for Devices and Radiological Health (CDRH) is looking for public comment on the scope and nature of a new Patient & Care-Partner Connection program, intended to build upon our efforts at conducting meaningful patient engagement. We've designed the program to provide CDRH staff with a formal process they can use to engage with patients and care-partners regarding their experiences with medical devices and their treatment. The program will not be used to solicit external policy advice or opinion.

The program is directly tied to one of CDRH's strategic priorities to "[Partner with Patients](#)," aimed at fostering continuous engagement with patients, care-partners, and patient advocates during the development and evaluation of medical devices.

We welcome your comments regarding the scope and nature of the Patient & Care-Partner Connection program and how the FDA can effectively partner with patient organizations. The comment period will be open for 60 days in the Federal Register under docket number: [FDA-2016-N-3462](#).

For more information about CDRH's commitment to patient engagement, visit [CDRH's Patient Engagement webpage](#).

Patient and Public Involvement in the Development of Healthcare Guidance: An Overview of Current Methods and Future Challenges

Rashid, A., Thomas, V., Shaw, T. et al. Patient (2016). First online: 09 November 2016

Interesting new article from NICE following their major review of patient and public involvement in all their guidance work:

Clinical guidelines and health technology assessments are valuable instruments to improve the quality of healthcare delivery and aim to integrate the best available evidence with real-world, expert context. The role of patient and public involvement in their development has grown in recent decades, and this article considers the international literature exploring aspects of this participation, including the integration of experiential and scientific knowledge, recruitment strategies, models of involvement, stages of involvement, and methods of evaluation. These developments have been underpinned by the parallel rise of public involvement and evidence-based medicine as important concepts in health policy. Improving the recruitment of guideline

group chairs, widening evidence reviews to include patient preference studies, adapting guidance presentation to highlight patient preference points and providing clearer instructions on how patient organisations can submit their intelligence are emerging proposals that may further enhance patient and public involvement in their processes.

<http://link.springer.com/article/10.1007/s40271-016-0206-8>

Karen Facey

Call for Expressions of Interest for HTAi 2017 Asia Policy Forum Scientific Secretary

Due: 16 December, 2016

HTAi Asia Policy Forum

The HTAi Asia Policy Forum is one of three HTAi Fora and provides a unique opportunity for senior people from public and private sector organisations working regionally and using HTA to support decisions or recommendations about product development and coverage to meet one another, members of the HTAi Board, for strategic discussions about the present state of HTA, its development and implications for health care systems, industry, patients and other stakeholders. The aim of the Forum is to provide an environment where leaders can engage in strategic discussions informed by the perspectives of their different organisations without the constraints associated with discussions of specific products or organisational policies.

Discussions at Forum meetings lead to a range of outputs, typically including a short report or memo of the meeting for Forum members, and a peer reviewed journal paper.

Role of the HTAi Asia Policy Forum Scientific Secretary 2017

The HTAi Asia Policy Forum Scientific Secretary for 2017 will:

- a) Write a background paper to support general discussion at the 2017 meeting
- b) Support and coordinate the development by Forum members of presentations, background materials and case studies for the sessions led by Forum members
- c) Take notes of the discussions arising on the topic during the Policy Forum meeting (which will constitute key material for the development of the paper)
- d) Lead the preparation of a short report of the meeting for those attending, reviewing and complementing the short report with identification of key discussion points and key messages supported by the HTAi Policy Forum Manager
- e) Write a journal paper based upon the meeting, linked to any supporting papers (if produced)

The Policy Forum Scientific Secretary works closely with the Policy Forum Chair, HTAi Forum Manager and HTAi Secretariat in accordance with clearly documented and agreed scientific and administrative processes and timelines. The Policy Forum Committee and Chair steer the content of the scientific materials, but the Scientific Secretary is expected to be the lead author of the background paper, the short report and/or slide deck for members, the journal paper and the panel session commentary. The Chair is responsible for the development and final content of the Meeting Agenda, in close discussion with, the Scientific Secretary and the Committee.

The duties of the Scientific Secretary 2017 are expected to take a suitably qualified and experienced person up to a maximum of 20 days across the 12-month period from January 2017 to December 2017.

Responsibilities

1. Join teleconference meetings of the HTAi Asia Policy Forum Committee and regular project team discussions with the Chair and Secretariat as required throughout the twelve-month period.
2. Prior to the Autumn 2017 meeting:
 - a. Lead the drafting, in close consultation with the Chair, and Committee, of:
 - A background paper to support discussions at the meeting, and to be made available on the HTAi website for non-Forum members.
 - Case studies and/or such other material as may be required to support general discussion at the meeting.
 - b. Support the development by Forum members of presentations, background materials and case studies.
3. Attend in person the 2017 meeting. The Asia Policy Forum, the date is yet to be determined.
4. Following the 2017 meeting, lead the drafting, in close consultation with the Chair and Committee, of:
 - A short meeting report for Forum members
 - A journal paper based on discussions at the meeting

Person Specification

A flexible person is required with a strong track record of relevant work in HTA, excellent drafting skills and a proven willingness and ability to work collaboratively with a wide range of partners and stakeholders.

Essential Qualifications

- An internationally recognised track record in policy work relevant to HTA, as demonstrated by relevant publication record and academic and/or policy positions
- Experience in successfully supporting complex policy and/or scientific discussions
- Excellent writing skills and a proven track record as a lead author of journal papers
- An understanding of the work of HTAi
- An understanding of the perspectives of both for-profit and not-for-profit organisations in HTA and health system policy
- A proven record of willingness and experience of working flexibly and successfully with a team of colleagues from around the world in the development of scientific materials
- Strong communication and relationship building skills.

Compensation

- Modest compensation will commensurate with experience and will reflect the time required—up to 20 days across the twelve-month period.
- It is expected that the Scientific Secretary will be recognised as the lead author for those materials where he or she leads the drafting. Forum meetings and materials attract considerable interest at the highest levels in the HTA field, and our journal articles are highly accessed. It is hoped that this position might be helpful to the standing and career of the Scientific Secretary.
- Travel (economy air fares) and reasonable expenses for attendance at the meeting will be reimbursed.

How to apply

Interested applicants should:

1. Submit a short Letter of Intent (LOI) no more than two pages in length (single-spaced, 11 point font) stating qualifications and experience and expected level of remuneration, together with a Curriculum Vitae.
2. The letter and CV should be sent to the HTAi Secretariat via email to the following address: info@htai.org. Any questions or queries should also be sent to this email address.
3. All applications should be received by December 16, 2016.
4. It is anticipated that shortlisted applicants will be interviewed by telephone in early January.

European Patients Forum: News on HTA Collaboration

A new impetus from the Commission has marked encouraging improvements in patients' relations with institutions and organisations working on HTA both at European and international level. Let's take some time to reflect on those.

<http://www.eu-patient.eu/News/News/new-european-commissions-initiatives-on-hta-for-2017/>

On September 27, a delegation of patient organisations met with the European Commission HTA team led by Flora Giorgio and EUnetHTA Joint Action 3 Coordinator, Wim Goettsch. The purpose was to gather patient representatives' views and to present an upcoming initiative promoted by the European Commission in the framework of HTA, aimed to foster cooperation at EU level beyond 2020.

The initiative foresees the publication of an [inception impact assessment](#) describing the current state of play and putting forward several options for the continuation of the EU cooperation on HTA beyond 2020. In the same framework the European Commission has also recently launched a [public stakeholder consultation](#) on strengthening EU cooperation on HTA, to collect views on outcomes and benefits of the current cooperation on HTA and provide input on the future. All interested parties including patient organisations are invited to submit their responses by 13 January 2017.

The European Commission and Health Commissioner Vytenis Andriukaitis, following a Council and European Parliament's request, are showing great interest in moving forward towards deeper cooperation on HTA at European level: the Commissioner announced that in 2017 a set of legal instruments will be proposed to allow standardisation of HTA throughout the Union.

New legal instruments towards HTA EU-standards

This news is very **promising** for the patient community that will take the whole EC initiative on HTA as an opportunity to have a stronger impact on policies and procedures on HTA.

Alongside the work developed at European level, EPF is also strengthening collaboration with HTA International (HTAi), "*the global scientific and professional society for all those who produce, use, or encounter HTA*".

EPF is part of the Steering Committee of the Patient and Citizens Interest Group (PCIG) and is currently involved in the Patient Involvement and Education Working Group, aimed to promote knowledge, skills and opportunities for effective patient involvement in HTA activities across countries in all regions of the world.

Valentina Strammiello, Programme Officer

Assessing claims about treatment effects

Testing Treatments interactive is a website that helps you to understand the key concepts about the effects of treatments. Read more here:

<http://www.testingtreatments.org/key-concepts-for-assessing-claims-about-treatment-effects/>

and while you are at it, download the FREE copy of "Testing Treatments" by Imogen Evans, Hazel Thornton, Iain Chalmers and Paul Glasziou

http://www.testingtreatments.org/wp-content/uploads/2012/09/TT_2ndEd_English_17oct2011.pdf

Relevant literature

The prioritization preferences of pan-Canadian Oncology Drug Review members and the Canadian public: a stated-preferences comparison | Skedgel C | *Current Oncology* 2016 23(5)

<http://www.current-oncology.com/index.php/oncology/article/view/3033/2265>

Shared by Deb Maskens, HTAi PCIG Patient Panel

How to identify existing literature on patients' knowledge, views, and values: the development of a validated search filter

By Monique Wessels, Lian Hielkema, Trudy van der Weijden. *J Med Libr Assoc.* 2016 Oct; 104(4): 320–324.

Shared by Catherine Voutier

CJCheck Stage 1: development and testing of a checklist for reporting community juries - Delphi process and analysis of studies published in 1996-2015

Thomas R, Sims R, Degeling C, Street JM, Carter SM, Rychetnik L, Whitty JA, Wilson A, Ward P, Glasziou P. *Health Expect.* 2016 Oct 5. doi: 10.1111/hex.12493. [Epub ahead of print]

Bulletin du Labo du partenariat / Partnership Lab Bulletin

Novembre/November 2016

Le [Labo du partenariat](#) du [Centre d'excellence sur le partenariat avec les patients et le public](#) (CEPPP) produit une veille électronique mensuelle qui vise à faciliter l'accès aux nouvelles publications sur l'engagement des patients et du public. Si vous ne souhaitez pas recevoir le bulletin, n'hésitez pas à nous écrire.

The [Partnership Lab](#) of the [Centre of Excellence on Partnership with Patients and the Public](#) (CEPPP) is producing a monthly electronic newsletter that seeks to facilitate access to new publications on public and patient engagement. If you do not wish to receive the newsletter, please send us an email.

Engagement en recherche / Engagement in research

[Assessment of a multimedia-based prospective method to support public deliberations on health technology design: participant survey findings and qualitative insights](#) (Accès libre/Open access)

Lehoux et al. (2016) *BMC Health Services Research*

[A devolved model for public involvement in the field of mental health research: case study learning](#) (Accès libre/Open access)

Moule & Davies (2016) *Health Expectations*

[Public involvement in research within care homes: benefits and challenges in the APPROACH study](#) (Accès libre/Open access)

Froggatt et al. (2016) *Health Expectations*

[Defining priorities for future research: Results of the UK Kidney Transplant Priority Setting Partnership](#) (Accès libre/Open access)

Knight et al. (2016) *PloS One*

[The impact of advertising patient and public involvement on trial recruitment: embedded cluster randomised recruitment trial](#) (Accès libre/Open access)

Hughes-Morley et al. (2016) *Trials*

[Initiative to support patient involvement in research \(INSPIRE\)](#) (Accès libre/Open access)

Lavallee et al. (2016)

[Synthetic biology in the Science Café: what have we learned about public engagement?](#) (Accès libre/Open access)

Einsiedel & Navid (2016) *Journal of Science Communication*

[Combining citizen science and public engagement: the Open AirLaboratories Programme](#) (Accès libre/Open access)

Davies et al. (2016) *Journal of Science Communication*

[A national patient and public colorectal research agenda: Integration of consumer perspectives in bowel disease through early consultation](#)

McNair et al. (2016) *Colorectal Disease*

[Patient engagement: What partnering with patient in research is all about](#)

Duffett (2016) *Thrombosis Research*

[PPI in the PLEASANT trial: involving children with asthma and their parents in designing an intervention for a randomised controlled trial based within primary care](#)

Boote et al. (2016) *Primary Health Care Research and Development*

[Patient engagement in research and innovation: A new framework](#)

Ruco & Nichol (2016) *Journal of Medical Imaging and Radiation Sciences*

[Maximizing value and minimizing barriers: patient-centered community consultation for research in emergency settings](#)

Fordyce et al. (2016) *Clinical Trials*

[The expert patient](#)

O'Neill et al. (2016) *Evidence Based Nursing*

[Patient and public involvement in the development of healthcare guidance: An overview of current methods and future challenges](#)

Rashid et al. (2016) *The Patient-Patient-Centered Outcomes Research*

[Tailoring methods of stakeholder involvement-does one size fit all?](#)

Goyder et al. (2016) *European Journal of Public Health*

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

[Patient advisors: How to implement a process for involvement at all levels of governance in a healthcare organization](#) (Accès libre/Open access)

Pomey et al. (2016) *Patient Experience Journal*

[Public and patient involvement in health policy: A continuously growing field](#) (Accès libre/Open access)

Souliotis (2016) *Health Expectations*

[Patient and family involvement in adult critical and intensive care settings: a scoping review](#) (Accès libre/Open access)
Olding et al. (2016) *Health Expectations*

[Citizens' preferences on healthcare expenditure allocation: evidence from Greece](#) (Accès libre/Open access)
Xesfingi et al. (2016) *Health Expectations*

["How can we talk about patient-centered care without patients at the table?" Lessons learned from Patient Advisory Councils](#) (Accès libre/Open access)
Sharma et al. (2016) *The Journal of the American Board of Family Medicine*

[Patient participation groups in general practice: building better partnerships](#)
Wilkie (2016) *British Journal of General Practice*

[Disentangling patient and public involvement in healthcare decisions: Why the difference matters](#)
Fredriksson & Tritter (2016) *Sociology of Health and Illness*

[Experience-based co-design in an adult psychological therapies service](#)
Cooper et al. (2016) *Journal of Mental Health*

[Démarche réflexive d'analyse en partenariat sur l'élaboration de stratégies pour améliorer l'offre de services en santé mentale des personnes ayant subi un traumatisme craniocérébral modéré ou grave](#)
de Guise et al. (2016) *Revue canadienne de santé mentale communautaire*

[An evaluation of in-person and online engagement in Central Newfoundland](#)
Wilson et al. (2016) *Healthcare Policy*

[Public participation in the definition of health policies in Bahia state, Brazil](#)
Júnior & Pinheiro (2016) *European Journal of Public Health*

Engagement en santé des communautés / Engagement in community health
[Social learning through stakeholder engagement: New pathways from participation to health equity in US West Coast HIA](#) (Accès libre/Open access)
McGrath (2016) *Chronicles of Health Impact Assessment*

[Design and implementation of community engagement interventions towards healthcare quality improvement in Ghana: a methodological approach](#) (Accès libre/Open access)
Alhassan et al. (2016) *Health Economics Review*

François-Pierre Gauvin, PhD
Associé de recherche
Labo du partenariat
Centre d'excellence sur le partenariat avec les patients et le public

Janet Wale, HTAi PCIG
E-mail: socrates111@bigpond.com