



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

*Enhanced quality and relevance of HTA through patient and citizen involvement*

Welcome to this month's E-Bulletin.

### **Explore how the global HTA community is evolving towards an integrated ecosystem**

Join us for HTAi's 14<sup>th</sup> Annual Meeting on June 17-21, 2017 at the Ergife Palace Hotel in Rome, Italy. HTAi welcomes those invested in the production and implementation of HTA from Italy, neighbouring countries and around the world.

### **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

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### **CADTH is changing their patient evidence submission template and is asking for feedback**

#### **[Feedback on Proposed Revisions to Patient Input Template for CDR and pCODR](#)**

CADTH is inviting stakeholder comments on proposed changes to the patient input template for the CADTH Common Drug Review (CDR) and the pan-Canadian Oncology Drug Review (pCODR). Patient input is used by CADTH review teams and by the expert committees of the CDR and pCODR programs: the CADTH Canadian Drug Expert Committee (CDEC) or the pCODR Expert Review Committee (pERC).

We're aware of how much time and effort patient groups invest in collecting data and preparing patient input submissions. After looking carefully at how patient input is used by CADTH and reflecting on comments received from patient groups, CADTH staff, and committee members over time, we're proposing revisions to our patient input templates for both programs. The objective is to help improve the quality of Canadian health technology assessment drug processes.

#### **You'll notice:**

- In response to your comments, we have provided a brief explanation, for each section, on how CADTH will use your insights and experiences
- Greater focus on treatment rather than disease, which reflects the scope of our drug assessments and the mandate of the expert committees
- Caregiver views are included for each question, reflecting how patients and caregivers both share their thoughts and experiences to you.
- Updated conflict of interest declaration form, which will be identical across both processes. For both processes, dollar amounts will be redacted from the conflict of interest declaration form when the document is publicly posted on CADTH's website.

#### **Why patient input is important:**

Insights, perspectives, and experiences from patient group submissions are used to:

- Identify the outcomes upfront that are most important to patients when establishing the plan (protocol) for conducting the review
- Understand insights and information unavailable through other sources, such as patient-reported outcomes and quality-of-life data

- Help CADTH reviewers interpret and apply data emerging from clinical trials, including relevance in a Canadian health care setting
- Offer specific ways that current therapies may fall short, to better understand the potential value of new therapies
- Offer new and different scenarios about the drug under review

**Your thoughts:**

CADTH welcomes your feedback on our proposed revisions to the patient input templates. From September 12 to October 25, 2016, patient groups are invited to comment on our proposed templates. Please use the [feedback form](#) and email to [feedback@cadth.ca](mailto:feedback@cadth.ca). All feedback submitted by the deadline will be carefully considered and used to inform the final templates, targeted for use in December 2016.

For more information about the proposed changes, please see the [CDR and pCODR Patient Input Template](#)

**About CADTH**

CADTH is an independent, not-for-profit organization responsible for providing Canada’s health care decision-makers with objective evidence to help make informed decisions about the optimal use of drugs and medical devices in our health care system. CADTH receives funding from Canada’s federal, provincial, and territorial governments, with the exception of Quebec.

Learn more at: [www.cadth.ca](http://www.cadth.ca).

**Deb Maskens**

Movement is also afoot at the Scottish Medicines Consortium, where the Patient and Public Involvement team are offering a service to comment on proposed patient organisation submissions before they are submitted. We look forward to hearing more.

Heard from Jen Dicksen

**New pilot training on "HTA and Patient Engagement" in Basel, Switzerland. November 25, 08.30 to 17.00**

Healthcare markets in Europe and elsewhere are increasingly restricting patient access by health technology assessment (HTA) policies with growing focus on patient relevant outcomes and cost-effectiveness.

“Our new 1-day course has been designed for Researchers, Clinical Developers, Marketeters, or Business Developers in the pharmaceutical, diagnostic or medical device industry. The objective is to increase the understanding for the purpose and mechanisms of health technology assessment and how to address the increasing focus on patient relevant information.

A flyer about this training or the website [www.health-os.com/training](http://www.health-os.com/training) contains more detailed information. The training is designed for about 15 participants including people from industry and patients; it will take place in Basel/Switzerland. Based on the experience from this first pilot course, we hope to further develop the concept and offer more of these in 2017. It could also be tailored to company specific needs and indications or applications.

If you have any questions or desire more information, please contact [anke.holtorf@health-os.com](mailto:anke.holtorf@health-os.com). Registration for this course or information about future events can be done via our Website: [www.health-os.com/Training](http://www.health-os.com/Training)”

**Learning Goals**

- **Value:** how a product has to make a difference to patients
- **Evidence:** what is involved in showing patient value to HTA agencies
- **Engagement:** How to involve patients throughout product development and to implement patient centricity



**Australian 'Patient Voice Initiative' meetings, 2016**

Simon Fifer, Zarli French, Anna Scott, Janney Wale

The Patient Voice Initiative began in 2015 when a group of stakeholders from industry, academia and patient groups came together to discuss methodologies and approaches for eliciting the patient perspective on the value of medicines. The Patient Voice Initiative is Co Hosted by Rare Cancers Australia & Community and Patient Preference Research Pty Ltd (CaPPRe).

Two facilitated meetings for patients and patient groups were held in September, in Brisbane and Melbourne, as a follow up to a multi-stakeholder meeting held in Sydney in February 2016. Another multi-stakeholder meeting will be held in Canberra on 19th October 2016. The objective of the meeting in Canberra is to devise ways of converting ideas for improvement into action.

Some of the general themes included in discussions have been: more transparency of processes, decision making and outcome; a need for information and awareness of the system; we need to improve existing consumer PBAC submissions; there is a clear need for feedback loops; more guidelines for patient are needed; how accounts of actual patient experience can be presented in a way that is helpful to PBAC decision-making; clinical trials need to be more patient relevant; PBAC needs to be more proactive in reaching out to the public in order to get more people involved.

There was considerable overlap between breakout groups in Brisbane and Melbourne on ideas and elements for improving patient involvement in PBAC processes. Additionally when the results of the Sydney workshop were shared it was agreed that there were many similarities with the Sydney ideas. Such agreement bodes well for producing actionable outcomes at the Canberra meeting planned for October.

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### **From our Patient Panel**

#### **“Who truly represents the patient perspective?”**

Cancer World (73-74) article on patient representation, 12 September 2016.

<http://cancerworld.net/patient-voice/who-truly-represents-the-patient-perspective/>

Please feel free to add comments at the end of the article – and encourage others to do so too!

#### **Evidence for and cost-effectiveness of physiotherapy in haemophilia: a Dutch perspective.**

de Kleijn P, Mauser-Bunschoten EP, Fischer K, Smit C, Holtslag H, Veenhof C.

Haemophilia. 2016 Sep 6. doi: 10.1111/hae.13076. [Epub ahead of print]

Following on from:

Personal Reflections of a Patient Representative in an Appraisal Committee. Cees Smit. Patient. 2015

Feb;8(1):5-10. doi: 10.1007/s40271-014-0086-8.

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### **Call for Expressions Of Interest from Not-for-profit Organisations To Join The HTAi Policy Forum**

A vacancy is available for one not-for-profit organisation to join the HTAi Policy Forum.

Expressions of Interest (EOIs) are invited from not-for-profit organisational members of HTAi with formal responsibilities within a health care system to make HTA-based decisions or provide HTA-based advice on coverage or pricing of health care technologies.

The expression should comprise a short document (no more than four pages A4, minimum font pt10) that includes:

- a. Confirmation that the organisation is an organisational member of HTAi;
- b. An overview of the organisation, indicating its role and activities associated with HTA;
- c. Reasons for seeking to join the Policy Forum and the contribution the organisation expects to make to the Forum;
- d. A short biography of the people in the organisation who will participate in the Policy Forum and the particular expertise and experience they bring; and,
- e. A statement of intent to join the Policy Forum for a minimum of three years and make the annual financial contribution required of members.

Not-for-profit member organisations are expected to contribute \$2,500 USD per annum in addition to their annual HTAi organisational subscription.

The deadline for receipt of EOIs is November 18, 2016 at 23:59 (GMT). EOIs must be emailed to [HTAiPF@southampton.ac.uk](mailto:HTAiPF@southampton.ac.uk)

Final decisions on the EOIs received will be taken by the HTAi Executive Committee (on the basis of advice from the Policy Forum Committee) and will be communicated to organisations by the end of November 2016, with the expectation that those selected to join the Forum will attend the Business and Topic Scoping Meeting to be held in Rome on Sunday, June 18, 2017, immediately prior to the HTAi Annual Meeting.

**More information**

Full details of the EOI submission and review process and criteria are available in the [Member Selection Process Guideline](#).

[Frequently Asked Questions](#)

Contact the [HTAi Policy Forum Secretariat](#)

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**CADTH Symposium Travel Award Program for students and patient group representatives**

CADTH is pleased to announce the 2017 CADTH Symposium Travel Award Program for students and patient group representatives.

Since 2007, CADTH has provided financial support toward conference-related costs for more than 190 student and patient group representatives as part of our commitment to making this important event accessible to all health care stakeholders.

This year, eligible students and patient group representatives can receive up to \$1,500 to offset registration, travel, food, accommodation, and other conference-related expenses.

For Students

- The CADTH Symposium offers an excellent opportunity to share your research, learn about the latest advancements in health technology assessment (HTA), and interact with peers from across the country as well as leading Canadian and international experts. If you're a full-time undergraduate or graduate student attending a degree-granting institution in Canada, and taking courses in a field relevant to CADTH's work, we invite you to apply for a travel award.

For Patient Group Representatives

- It's important that your voice is heard. If you work for a not-for-profit, patient-related organization, or a citizen's organization interested in health policy, we invite you to apply for a travel award.

How to Apply

Step 1: Review the 2017 CADTH Symposium [Travel Award Program Criteria](#)

Step 2: Complete and submit the [2017 Travel Awards Application form](#) to CADTH by **December 9, 2016**.

Travel award decisions will be made by the end of January 2017, and awards will be issued to successful applicants by the end of March 2017.

**Reminder: The Abstract Submission Deadline for the 2017 CADTH Symposium is October 28, 2016.**

If you have questions about the 2017 CADTH Symposium, or the Travel Award Program, please contact us at [symposium@cadth.ca](mailto:symposium@cadth.ca). We're looking forward to seeing you in Ottawa in 2017.

*About CADTH*

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Learn more at: [www.cadth.ca](http://www.cadth.ca)

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[A workshop bringing together health professionals and philosophers to discuss the nature and impact of 'professional vices' in modern medicine.](#)

[www.professionavices.wordpress.com](http://www.professionavices.wordpress.com)

2 February 2017, University of Warwick, Arts & Humanities Research Council

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### Some facts about the high cost of treatment for cancer patients in the US

The Centers for Disease Control (CDC), in a survey of more than 10,000 patients, found that roughly one in three families in the US reported significant financial burden as a consequence of medical care <https://costofcancercare.uchicago.edu/page/financial-toxicity-facts>  
[https://www.cancer.gov/about-cancer/managing-care/financial-toxicity-hp-pdq?cid=eb\\_govdel](https://www.cancer.gov/about-cancer/managing-care/financial-toxicity-hp-pdq?cid=eb_govdel)

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### Crowdfunding in the EU Markets Union

The European Commission identifies the crowdfunding as a useful means to support and boost the economy, especially as a possible support to SMEs and start-ups. Moreover, crowdfunding introduce a new market model based on a direct civic participation. For this reason on 3 May 2016, the Commission published a report that explains the market and regulatory landscape in this dynamic field. [http://ec.europa.eu/finance/general-policy/docs/crowdfunding/160428-crowdfunding-study\\_en.pdf](http://ec.europa.eu/finance/general-policy/docs/crowdfunding/160428-crowdfunding-study_en.pdf)

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### My Cancer Genome: Evaluating an Educational Model to Introduce Patients and Caregivers to Precision

Medicine Information. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5001739/>

Sheila V. Kusnoor, et al. AMIA Jt Summits Transl Sci Proc. 2016; 2016: 112–121.

Published online 2016 Jul 20.

After obtaining informed consent, participants were randomized equally to one of three groups (Figure 1): Group A (control) received information on targeted therapies and immunotherapy in cancer taken directly from My Cancer Genome (<http://www.mc.vanderbilt.edu/km/gl/pm/pmc-mcg.html>); Group B received the same information from MCG embedded with hyperlinks to the knowledge pearl videos (<http://www.mc.vanderbilt.edu/km/gl/pm/pmc-mcg-p.html>); Group C received a consumer-level version of the information from MCG, including hyperlinks to the knowledge pearls (<http://www.mc.vanderbilt.edu/km/gl/pm/pmc-c.html>).

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### AllTrials

Here's some big news from AllTrials: the United Nations yesterday called on governments worldwide to pass legislation requiring clinical trials to be registered, and their methods and results to be fully reported. Read what the UN said at <http://www.alltrials.net/news/un-calls-for-global-action-on-clinical-trial-transparency/>

Síle Lane, Director of campaigns and policy  
Sense about Science

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### Many Cancer Patients May Have Unrealistic Hopes When They Decide To Participate In Early Stage Clinical Trials

Dolly, S. O., Kalaitzaki, E., Puglisi, M., Stimpson, S., Hanwell, J., Fandos, S. S., Stapleton, S., Ansari, T., Peckitt, C., Kaye, S., Lopez, J., Yap, T. A., van der Graaf, W., de Bono, J. and Banerji, U. (2016), A study of motivations and expectations of patients seen in phase 1 oncology clinics. Cancer. doi:10.1002/cncr.30235  
To better inform clinical practice, this study was aimed at capturing patients' motivations for enrolling in phase 1 trials and at quantifying their expectations of the benefits, risks, and commitment associated with clinical trials and the impact of the initial consultation on their expectations.

The study reports that more than 80% of patients enroll in early-phase clinical oncology trials motivated by the potential of a clinical benefit, with approximately half expecting tumor shrinkage and approximately a tenth anticipating a cure. The typical phase 1 response rate is 4% to 20%, and this discrepancy exemplifies the challenges faced by patients and healthcare professionals during their interactions for phase 1 studies.

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### Bulletin du Labo du partenariat / Partnership Lab Bulletin

Septembre/September 2016

Le [Labo du partenariat](#) (dirigé par Dr. Antoine Boivin) 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](#) (lead by Dr. Antoine Boivin) 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

[“Exploring knowledge-user experiences in integrated knowledge translation: A biomedical investigation of the causes and consequences of food allergy”](#) (Libre accès/Open access)

Dixon et al. (2016) *Research Involvement and Engagement*

[Keeping it credible in cohort multiple randomised controlled trials: The Community Ageing Research 75+ \(CARE 75+\) study model of patient and public involvement and engagement](#) (Libre accès/Open access)

Heaven et al. (2016) *Research Involvement and Engagement*

[Input analysis for two public consultations on the EU clinical trials regulation](#) (Libre accès/Open access)

Langhof et al. (2016) *Health Research Policy and Systems*

[Patient engagement at a tipping point — The need for cultural change across patient, sponsor, and regulator stakeholders - Insights from the DIA Conference, “Patient Engagement in Benefit Risk Assessment Throughout the Life Cycle of Medical Products”](#) (Libre accès/Open access)

Smith et al. (2016) *Therapeutic Innovation & Regulatory Science*

[A role for children in health research](#)

Dellert (2016) *Insight*

[Community-based participatory research for co-creating interventions with Native communities: A partnership between the University of New Mexico and the Pueblo of Jemez](#)

Belone et al. (2016) *APA PsychNet*

[The path to collaboration: An exploration of the partnership development phase of community based participatory research](#)

Chilton (2016) *Alliant International University*

[Stakeholder engagement in trial design: Survey of visitors to critically ill patients regarding preferences for outcomes and treatment options during weaning from mechanical ventilation](#)

Burns et al. (2016) *Annals ATF*

[Engaging Maori in biobanking and genomic research: A model for biobanks to guide culturally informed governance, operational, and community engagement activities](#)

Beaton et al. (2016) *Genetics in Medicine*

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

[Bite size guides to participation](#) (Libre accès/Open access)

NHS England (2016)

[Patient engagement survey: Far to go to meaningful participation](#) (Libre accès/Open access)

Volpp & Motha (2016) *NEJM Catalyst*

[Do consumer voices in health-care citizens' juries matter?](#) (Libre accès/Open access)

Krinks et al. (2016) *Health Expectations*

[Expanding patient engagement in quality improvement and health system redesign: Three Canadian case studies](#)

Baker et al. (2016) *Healthcare Management Forum*

[On the road to value co-creation in health care: the role of consumers in defining the destination, planning the journey and sharing the drive](#) (Libre accès/Open access)

Janamian et al. (2016) *Medical Journal of Australia*

[Les associations de défense des intérêts de malades et des usagers au miroir de la santé publique](#)

Remondière (2016) *La revue Kinésithérapie*

[From rhetoric to reality: Consumer engagement in 16 multi-stakeholder alliances](#)

Greene et al. (2016) *AJMC*

Engagement en santé des communauté / Engagement in community health

[Multi-sectoral partnerships and patient-engagement strategies in accountable care organizations](#) (Libre accès/Open access)

Knox et al. (2016) *Frontiers in Public Health Services and Systems Research*

Engagement en enseignement / Engagement in teaching

[“Nothing about us without us” — Patient partnership in medical conferences](#) (Libre accès/Open access)

Chu et al. (2016) *BMJ*

[Patient and public involvement in medical education: Is a new pedagogy necessary?](#) (Libre accès/Open access)

Anderson (2016) *Medical Education*

[Some activity but still not much action on patient and public engagement](#) (Libre accès/Open access)

Spencer (2016) *Medical Education*

[Partnering with patients in interprofessional education in Canada and in the USA: Challenges and strategies](#)

Brault et al. (2016) *Leading Research and Evaluation in Interprofessional Education and Collaborative Practice*

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