



## **HTAi Patient and Citizen Involvement in HTA Interest Sub-Group (PCISG) E-Bulletin, March 2015**

***Our vision: Patient and citizen perspectives improve HTA***

Thanks to all who have contributed to this E-Bulletin – we would like to hear from you!

### **Check out our reorganized web pages**

Our web pages have undergone changes – we have a new structure to the site!

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

We have been limited with the current technology, which doesn't allow for any staging or testing of the site, so we have to go live and then test. We would very much appreciate your feedback and ideas, sent to:

HTAi PCISG Secretariat [htaipcisg@gmail.com](mailto:htaipcisg@gmail.com)

The entire HTAi website is to be updated this year, which we have kept in mind during this restructuring. So it is the content and how it is set out that we are asking you about.

As Chair of the PCISG, I very much thank Peter Murphy for all the hard work he has put into developing these web pages, finding spare time in his daily life to voluntarily do this for us. We are lucky to have Tara Blasco Raj of the HTAi Secretariat and the web manager helping with this updating.

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New items included:

**HTAi 2015, Global Efforts in Knowledge Transfer: HTA to Health Policy and Practice** [www.htai2015.org](http://www.htai2015.org)

—organized by the Norwegian Knowledge Centre for the Health Services in collaboration with the HTA agencies from Sweden, Denmark and Finland.

### **Key Meeting Sub-themes/Plenary Topics Producing HTA**

- Knowledge in the 21st century—What, when and how?
- Using the knowledge: Needs of decision makers, clinicians and patients
- International collaboration in knowledge synthesis and transfer: Is it worth the effort?

### **PCISG Preconference events:**

- Sunday 14 June, morning: half-day workshop on 'Supporting patient groups to provide input on patient experiences to inform HTAs through the use of our resources'

- Sunday 14 June, afternoon (2 to 4.30): half-day meeting and panel discussion on 'What would make a difference for HTA organisations and governments to involve patients in their HTA processes'. Sue Hill, newly appointed to work on HTA in WHO will lead a discussion panel. All are welcome. We will finalise key participants facilitating the discussion once we have a better idea of who will be in Oslo. This is a PCISG meeting and there are no fees attached. We would like to know, however, if you are planning to take part in the discussions.

**Has your oral presentation been accepted?**

If so, please let us know so that we can put it in our E-Bulletin – also any panel sessions.

**Registration**

Early Bird Deadline: 1 April 2015

Successful travel grant applicants have now be notified

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**Update from the PCISG Working Groups**

Collecting information from patients: A checklist and guidance on ethical issues to consider  
 This work is progressing and we expect to open it up to broad consultation in the next E-Bulletin. We are working with the Ethics ISG on these materials, and an oral presentation has been accepted for Oslo.

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**CADTH Annual Meeting 13 April 2015**

We can't all attend the CADTH Annual Meeting, but we can take part in one of their plenary sessions via webinar on Patient Engagement in HTA:

13 April 3.30 to 5 pm East Coast USA. Sign up by 10 April.

<http://www.cadth.ca/en/events/2015/webinar-patient-engagement-in-health-technology-assessment>

Karen Facey says: Thanks to CADTH for this great initiative.

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**Patient partnership**

**– How can we make patients the ringmasters and no the monkeys at healthcare conferences?**

From BMJ Patient Panel members Anya de longh and Ceinwen Giles: Patients and healthcare conferences: what does true involvement look like? BMJ 2015;350:h1325 doi: 10.1136/bmj.h1325 (Published 10 March 2015)

They say: We have relatively little understanding about how to do it well. Conferences are basically collections of conversations, and while there is an increasing understanding of the need to involve patients in those conversations, how this happens is rarely debated.

The patients' perspective on the success of involvement needs to be captured. While organisers may believe that they have done an excellent job of involving patients, that belief may not be shared by the

patients. The only way this can be understood is to ask them what they think and seek to learn what could be changed.

We believe that health conferences are a useful lens through which to examine the quality of patient involvement.

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### **BMJ online blog**

An interesting new blog on the British Medical Journal website:

[The economic value of patients in the improvement of healthcare](#)

The authors strongly believe that patients need to be given a more equal and profitable role in the healthcare system – information patients and carers can potentially provide for the transformation of healthcare must be acknowledged. An economic evaluation of the input of patients – with analysis of the positive impact on other patients' lives, organisations and society is needed.

They list four business models that would economically value patients' contributions to improving healthcare, and empower them to operate as active partners:

- A realistic payment 'for services' (as with freelance healthcare professionals);
- Shared savings, which allow cost savings to be partly shared among those who have helped make the saving (as with doctors and some health insurance companies in the Netherlands).
- A model drawn from the recent intellectual property claim of [the KWF Cancer Foundation](#), where part of the revenue could be used for reimbursing patients for their active input into research topics;
- Benefit sharing, to provide a fair and equitable sharing of the benefits of an activity.

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### **Information on new drugs at market entry:**

retrospective analysis of health technology assessment reports versus regulatory reports, journal publications, and registry reports (Open access)

<http://www.bmj.com/content/350/bmj.h796.long>

A paper by Köhler M, Haag S, Biester K, Brockhaus AC, et al from <sup>1</sup>Institute for Quality and Efficiency in Health Care (IQWiG)

When a new drug becomes available, patients and doctors require information on its benefits and harms. In 2011, Germany introduced the early benefit assessment of new drugs through the act on the reform of the market for medicinal products (AMNOG). Conventional, publicly available sources provide insufficient information on new drugs, especially on patient relevant outcomes in approved subpopulations. This type of information is largely available in AMNOG documents, albeit only partly in English. The AMNOG approach could be used internationally to develop a comprehensive publication model for clinical studies and thus represents a key open access measure.

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### **EUPATI – and the training course for patient experts in drug development and HTA**

Recently published in Nature Medicine

<http://www.nature.com/nm/journal/v21/n3/full/nm0315-209.html>

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One of the top 5 papers in the Milbank Memorial's journal for 2014 was an important paper identifying factors that affect the effectiveness of public involvement:

[What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation](#)

Antoine Boivin, Pascale Lehoux, Jako Burgers and Richard Grol

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*I am happy to address any questions you may have as a result of this e-Bulletin, and to forward information.*

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