

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

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

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

- Welcome from the Chair
- HTAi2018 call for oral presentation, vignette and poster abstracts
- PCIG Working Groups meeting and updates
- Materials for the PCIG Repository of Online Resources for patients and public
- What's happening – publications

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### Welcome to this month's E-Bulletin

Dear members,

I hope that you all managed to submit some panel abstracts for the HTAi congress in Vancouver next year. Remember that there is also still time to submit oral abstracts. In Rome this year, we were really impressed with the quality and number of oral sessions devoted to patient and citizen involvement and we do hope that this success will be repeated next year. The deadline for Oral, Vignette and Poster submissions is November 24th, and the submission portal can be found at: <http://htai2018.org/abstracts/> Last week many of those working in the PCIG working groups met in Paris. We were very kindly hosted by our colleagues at Haute Autorité de Santé and our sincere thanks goes to them for being such welcoming hosts. During the three days that we were together, the interest group focused on the projects and work streams that are currently underway as well as developing concepts and ideas to take forward into next year. We are just assembling the notes from these sessions and will post them shortly. Those in the Patient Involvement & Education working group (PIE) advanced their work building a resource catalogue for patient involvement and well as defining a potential schedule of webcasts for our members. In the Methods & Impact (M&I) working group, the group discussed the myths surrounding qualitative evidence and had a focused discussion on the role of PROs in HTA deliberations. This group also saw value in developing a series of webinars for our members. We will continue to develop these concepts and work on a schedule of potential webinars for you all to take part in.

Neil Bertelsen




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**Welcome to the 2018 Annual Meeting Website, Vancouver, Canada, June, 2018**  
<http://www.htai2018.org/call-for-abstracts-now-open/>

Abstract submissions play a vital part of the scientific success of our upcoming HTAi 2018 Annual Meeting. Submission deadlines are different based on submission type. Please note below important dates regarding abstract submissions. No extensions to these deadlines will be made.

Deadline for Oral, Vignette & Poster Presentation submissions: **November 24, 2017**

Please review the Abstract Submission Guidelines before submitting an abstract.

[Submit Abstract](#) [HTAi Submission Guidelines](#)

Receipt of abstract submission will be acknowledged via e-mail prior to submission close

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**About the 2018 HTAi Annual Meeting**

HTAi celebrates its 15th Annual Meeting in Vancouver from June 1-5, 2018, providing an unparalleled opportunity to consider, debate and clarify the role of health technology assessment (HTA) in the health care ecosystem.

The Annual Meeting's central theme is "[Strengthening the Evidence-to-Action Connection](#)", HTAi 2018 welcomes all stakeholders – patients/consumers, health care providers, academic researchers, HTA agencies, payers, policy makers, industry – bringing together more than 1000 delegates from around the globe to discuss the latest advances in this constantly evolving field.

The three plenary sessions that all support this theme are: how HTA needs to change its approach to generating, synthesizing and presenting evidence in order to remain relevant in a rapidly changing world; what is required to enable the implementation of evidence into evidence-informed policies and practices, and what can be done to strengthen and accelerate the evidence-to-action connection.

[HTAi2018.org](http://HTAi2018.org) #HTAiVancouver2018

Promotional information prepared for your use. [HTAi2018.org/Media](http://HTAi2018.org/Media)

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### **PCIG Working Group face-to-face meeting**

Active members of the Methods and Impact (M&I) and Patient Involvement and Education (PIE) Working Groups met in Paris from 24 to 27 October to discuss their work plans. Our gracious host was the Haute Autorité de Santé (HAS), who gave us presentations on their work and provided those present to give comment and information from their HTA agency perspectives. Impact of patient involvement and the ability to measure it was a topic of discussion throughout the meeting, with some HTA agencies taking steps to address this issue. The time was spent very productively with each of the Working Groups working separately to take note of where they are up to and planning their work for the year ahead. Patient representatives were present and we thank Valentina Strammiello (European Patients Forum), Marleen Kaatee (Netherlands), and Helen Burchmore (England) who is a member of PIE for taking the time to be with us. Thank you particularly to Hervé Nabarette, Marc Guerrier and Chantal Belorgey for their support for the duration of the meeting.

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### **A brief update on the work plans**

#### ***M&I Working Group***

The Working Group has consolidated and continues to progress its work on patient preferences studies and use of patient reported outcomes. An important stream of the work is on qualitative synthesis, with Canadian Agency for Drugs and Technologies in Health (CADTH) sharing its recent experience in this area

#### ***PIE Working Group***

The Working Group brainstormed ideas around its main work streams. We discussed how sections of the HTA book can be developed as webinars to particularly assist countries just starting the journey of patient involvement in HTA. We went on to discuss our work on identifying best practice from NICE, SMC and CADTH patient group submissions. The final area of discussion was the PCIG Repository of Online Resources for Patient and Public Involvement. We have sufficient responses to our questionnaire identifying resources to move forward in the design of the Repository.

It is our intent to have these work plans made available on our webpages.

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### **Thanks to those of you who completed the PCIG questionnaire – we are still happy for more organizations to inform us about their resources for patients and public....**

Does your organisation have or access resources for patients and citizens to be able to contribute to HTA processes?

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

Please complete our questionnaire to provide us with your web links – so that we can collate a useful, widely accessible resource. Send your completed questionnaire (along with any extra resources in the email)

to: [htai.pie@gmail.com](mailto:htai.pie@gmail.com)

## What's Happening



Deep Dive: Market Access October 2017

<http://deep-dive.pharmaphorum.com/deep-dive-market-access-october-2017>

As part of PCIG's Stakeholder Engagement and Communications plan, and in support of the promotion of Springer Nature's Patient Involvement in HTA, I am delighted to share a feature we secured in one of the leading pharmaceutical company trade publications. Authored by myself and Ann

Single, this provides an overview of patient involvement in HTA for the pharma industry, with guidance on their role in this.

Two key takeaway messages for the industry are:

- Work with third party organisations (such as us of course) and support them in their activities
- Patient involvement is no substitute for good data and appropriate pricing
- Pharma's priority should be on generating appropriate evidence supported by patient involvement in all stages of medicines involvement

These articles are non-promotional. However, HTAi PCIG is referenced within the copy, within the author details (drop down at end) where there is a link to purchase the book, and there is a drop down at the end that provides a short overview of HTAi and PCIG.

Finally, in terms of the book, there has been 4,930 downloads to date. This compares to 5,400 for Hospital-based HTA launched in 2016.

Neil McGregor-Paterson

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## **Multi-morbidity: A patient perspective on navigating the health care system and everyday life.**

Lisbeth Ørtenblad, Lucette Meillier and Alexandra R Jønsson. *Chronic Illness* 0(0) 1–12, 2017

### Abstract

**Objective:** The importance of everyday life when managing the burden of treatment is rarely studied. This article explores the burden of treatment among people with multi-morbidity by investigating the tension between everyday life and the health care system.

**Method:** This was an ethnographic study using individual interviews and participant-observations. An inductive analytical approach was applied, moving from observations and results to broader generalisations.

**Results:** People with multi-morbidity experience dilemmas related to their individual priorities in everyday life and the management of their treatment burdens. Dilemmas were identified within three domains: family and social life; work life; agendas and set goals in appointments with health professionals. Individual resources and priorities in everyday life play a dominant role in resolving dilemmas and navigating the tension between everyday life and the health care system.

**Discussion:** People with multi-morbidity are seldom supported by health professionals in resolving the dilemmas they must face. This study suggests an increased focus on patient-centredness and argues in favour of planning health care through cooperation between health professionals and people with multi-morbidity in a way that integrates both health and everyday life priorities.

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