



## **HTAi Patient and Citizen Involvement in HTA Interest Sub-Group (PCISG) E-Bulletin, April 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 all!

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### **The 10<sup>th</sup> Anniversary of the PCISG**

#### ***Dinner Sunday evening, 14 June 2015 in Oslo***

The PCISG celebrates its 10<sup>th</sup> anniversary in Oslo – we would like to celebrate by having dinner together on the evening of the 14<sup>th</sup>.

Please let us know your attention to come, by 15 May at the latest (using the contact at the end of this E-Bulletin), so that we can find a suitable place and make a booking. It will be 'pay for yourself'.

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### **A Call for Expressions of Interest for the PCISG Steering Committee; and a new Vice Chair**

If you like what we are doing, or have an alternative positively constructed viewpoint, this is the time for you to working more closely with us 'in your spare time'.

We are looking for people who are active in the area of patient and citizen involvement in HTA and keen to see continuing developments.

Expressions of interest are to be sent to Tara Blasco Raj (E-mail: [tblascoraj@htai.org](mailto:tblascoraj@htai.org)) and will be followed up with a formal process.

Due date: Friday 15 May 2015

The objectives of the PCISG are available at:

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

The Steering Committee is also looking to appoint a new Vice-Chair: expressions of interest to Tara. My term of office as Chair ends in June 2016.

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**Oslo 2015 - Discussion Forum: Sunday 14 June (2 to 4.30pm): 'What would make a difference for HTA organisations and governments to involve patients in their HTA processes'**

Working to our strategic planning, the PCISG is organising the following Discussion Forum. This is a free event and we have booked a room with a maximum capacity of 40 people so please let me know of your intention to join us (using the contact at the end of this E-Bulletin).

Many HTA organisations want to involve patients for the first time or improve the way in which they already involve patients, but the mechanisms for doing this are unclear. This discussion group will explore the facilitators and barriers to patient involvement in the HTA process by different organisations. The meeting will be structured around a discussion forum and panel, facilitated by Sue Hill (present PBAC Chair in Australia and newly appointed WHO lead for HTA), with plenty of time for open discussion.

The focus of the meeting will be to identify how the HTAi PCISG can assist in the development of patient involvement in HTA through understanding: Enablers and barriers to involving patients/patient groups; What are considered to be successful models; What would assist organisations/governments in initiating and promoting this process?

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### **Scottish Medicines Consortium Public Involvement - Working in Partnership to Capture the Patient and Carer Voice**

Just less than 60 patient groups from all around Scotland came together in Glasgow last month for a national SMC Public Involvement event. The main focus of the day was to launch a new SMC Submission System for patient groups. The SMC Public Involvement team worked closely with patient and carer groups to develop the new system, which includes a written Guide for Patient Group Partners, along with new improved Registration and Submission Forms. Some of the information in the new booklet is adapted from the guidance produced by HTAi Patient and Citizen Involvement in HTA Interest Group. You can access the new forms and guidance booklet on the SMC website:

[https://www.scottishmedicines.org.uk/Public\\_Involvement/Submission\\_form\\_and\\_guidance](https://www.scottishmedicines.org.uk/Public_Involvement/Submission_form_and_guidance)

Jennifer Dickson, SMC Public Involvement Coordinator

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### **Canadian patient and public members**

A group of Canadian patient and public members on a number of national, pan-Canadian and provincial committees that evaluate drugs or other technologies in health held an organizational meeting in Saskatoon on April 14<sup>th</sup>, 2015 in conjunction with the Canadian Agency for Drugs and Technologies in Health (CADTH)'s annual conference. Issues discussed included what patient and public members need to be effective participants, sharing of common experiences, the differences between patient representatives and representatives appointed as representing the general public, different ways that patient and public input is received, etc. A need for greater training of public and patient representatives was expressed. Mechanisms for feedback on public and patient participation were also discussed.

The group agreed to continue their discussions in electronic format with the hope of meeting again person in 2016 at the annual CADTH conference, to be held in Ottawa. Other patient and public representatives will be invited to join the group.

Jo Nanson, Patient Representative, Pan Canadian Oncology Drug Review Expert Review Committee

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### **IPPOSI – has hosted an annual Health Technology Assessment training day**

This was with the National Centre for Pharmacoeconomics (NCPE) in Ireland. The HTA process was explained followed by an interesting discussion about HTA and our own health preferences. One of the four Irish EUPATI Trainees contributed to the day, and EUPATI sponsored the event. IPPOSI has the presentations on its website:

<http://www.ipposi.ie/index.php/news-a-events-mainmenu-28/382-hta-training-presentations-available-here>

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### **INTEGRATE-HTA**

The INTEGRATE-HTA project is in its final year and we would like to inform you that the results of the project will be presented and discussed at the final conference on 12-13 November 2015 in Amsterdam, the Netherlands. Please save the date, and note that registration will be open from 1st June 2015.

Currently we are finalising stakeholder meetings with professionals in which patient and public representatives are invited to participate to provide their perspectives on issues relating to effectiveness, cost-effectiveness, socio-cultural, patient preferences and moderators of treatment effect. In May a meeting is foreseen in which we will mimic a decision making committee for end of life services and we will include two lay representatives.

More information on the progress of the project can be found in our newsletter; the fourth edition has just been published. You can download the newsletter via our project website: [www.integrate-hta.eu](http://www.integrate-hta.eu). Currently the draft methodological guidance is being tested by applying them in our case study on palliative care – a 'Demonstration Integrated HTA' comparing models of home based palliative care and models of home based palliative care that include a formal element of care giver support (reinforced home based palliative care). The Demonstration Integrated HTA incorporates and demonstrates the added value of the additional methodological tools developed throughout the project.

If you wish to receive more information please contact us at [info@integrate-hta.eu](mailto:info@integrate-hta.eu).

Contributed by Louise Brereton and Wija Oortwijn on behalf of the INTEGRATE-HTA project team

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### **Free online materials offered by the US Cochrane Center**

[CUE - Consumers United for Evidence-based Healthcare](http://www.uscochrane.org) is being asked to refer educated consumer advocates to serve on clinical practice guideline panels. As a result it has developed a series of videos to help people. Take a look:

<http://us.cochrane.org/serving-advisory-panel>

They also have a basic video on 'Understanding evidence-based healthcare'

<http://us.cochrane.org/online-learning>

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### **The World Health Organisation (WHO) takes a position on clinical trial results reporting**

The WHO now says that researchers have a clear ethical duty to publicly report the results of all clinical trials. Significantly, the WHO has stressed the need to make results from previously hidden trials available. You can read more about the WHO's statement and responses to it on [the AllTrials website](http://www.alltrials.org), in [Science](http://www.sciencemag.org) and [The Verge](http://www.theverge.com) and from [Reuters](http://www.reuters.com).

The WHO has called on organisations and governments to now ensure that all trials get reported. Ben Goldacre has [set out some practical suggestions](http://www.theguardian.com) on how to make this happen.

Ian Bushfield, Campaigns Support Officer **Sense About Science**  
*Science and evidence in the hands of the public*

And from PLOS Medicine:

[Rationale for WHO's New Position Calling for Prompt Reporting and Public Disclosure of Interventional Clinical Trial Results](#)

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**A series of three articles exploring future expectations for new drugs of evidence of relative effectiveness in Europe and comparative effectiveness in the USA in 2020**

The Office of Home Economics US publications are available from the link: <https://www.ohe.org/news/ohe-publishes-journal-comparative-effectiveness-research-future-expectations-evidence-relative>

The articles are co-authored by OHE's Adrian Towse and Martina Garau, by Donna Messner of the Centre for Medical Technology Policy (CMTTP) and Penny Mohr of the Patient-Centered Outcomes Research Institute (PCORI).

In the [first paper](#), focusing on the EU, the key factors influencing the future environment for generating and using relative effectiveness evidence

In the [second paper](#), focusing on the USA, the key factors influencing the future environment for generating and using comparative effectiveness evidence

In the [third paper](#), comparing EU and the USA, the authors conclude that drug companies will conduct studies for relative/comparative effectiveness in both the USA and the EU.

Companies will want to meet regulator and payer concerns through pre-launch studies where possible. However, an increasingly data-rich environment in the USA could promote use of post-launch observational studies aimed at payers, although the latter retain a strong preference for randomized controlled study evidence to support key elements of value. In Europe, likewise, while there is development in non-experimental methods, multi-country registries, and increased acceptance of observational data by payers and regulators, both prefer randomized controlled studies.

The papers used semi-structured key informants interviews and three rounds of modified Delphi as their basis. The research was funded by a consortium of five pharmaceutical companies: Amgen, GSK, Lilly, Novartis, and Sanofi.

Towse, A., Garau, M., Mohr, P. and Messner, D.A., 2015. Futurescapes: expectations in Europe for relative effectiveness evidence for drugs in 2020. *Journal of Comparative Effectiveness Research*, Pages 1-18.

Download the full paper [here](#).

Messner, D. A., Mohr, P. and Towse, A., 2015. Futurescapes: evidence expectations in the USA for comparative effectiveness research for drugs in 2020. *Journal of Comparative Effectiveness Research*, Pages 1-16. Download the full paper [here](#).

Messner, D. A., Towse, A., Mohr, P. and Garau, M., 2015. The future of comparative effectiveness and relative efficacy of drugs: an international perspective. *Journal of Comparative Effectiveness Research*, Pages 1-9. Download the full paper [here](#).

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**Quality of Life Research. Volume 24 Number 5** is now available online

[Read all open access articles published in this journal.](#)

Patient Engagement Special Section

## [Editorial](#)

### [Introduction to special section on patient engagement](#)

Carolyn E. Schwartz & Dennis A. Revicki

### [Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute](#)

Lori Frank, Laura Forsythe, Lauren Ellis, Suzanne Schrandt, Sue Sheridan, Jason Gerson, Kristen Konopka & Sarah Daugherty [open access]

### [Patient and public engagement in health-related quality of life and patient-reported outcomes research: what is important and why should we care? Findings from the first ISOQOL patient engagement symposium](#)

Kirstie Haywood, Jo Brett, Sam Salek, Nancy Marlett, Colin Penman, Svetlana Shklarov, Colleen Norris, Maria Jose Santana & Sophie Staniszewska

### [Beyond lip service and box ticking: how effective patient engagement is integral to the development and delivery of patient-reported outcomes](#)

K. Absolom, P. Holch, B. Woroncow, E. P. Wright & G. Velikova

### [Gaps between patients' reported current and preferred abilities versus clinicians' emphases during an episode of care: Any agreement?](#)

Diane D. Allen, Carolina Talavera, Stephen Baxter & Kimberly Topp

And lots more

Brought to our attention by Asha Hareendran, Evidera

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## **New international journal for patient and public involvement in research**

In collaboration with Biomed Central, the open access publisher, we have established a new journal, *Research Involvement and Engagement*, an interdisciplinary, health and social care journal focussing on patient and wider involvement and engagement in research, at all stages. The journal is co-produced by all key stakeholders, including patients, academics, policy makers and service users. Sophie Staniszewska is Co-editor in Chief, with a patient Co-editor in Chief, Richard Stephens, reflecting a new model of academic publishing which recognises the value of the patient contribution in co-producing knowledge. We encourage submissions from patients and researchers and have a pool of academic and patient peer reviewers who read each paper or commentary. We are busy reviewing papers and commentaries submitted to date, with a formal launch of *Research Involvement and Engagement* in June 2015.

### **Accepting submissions**

<http://www.researchinvolvement.com/>

We are looking for patient and academic reviewers from around the world. If you are interested in getting involved with the Journal, please email [researchinvolvement@biomedcentral.com](mailto:researchinvolvement@biomedcentral.com)

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## **Breaking Boundaries Review launched**

We have been part of a strategic review of public involvement in the National Institute for Health Research (NIHR). Sophie Staniszewska was Vice Chair for the Review, working closely with Simon Denegri, the National Director for Patients and the Public in Research and Chair of INVOLVE, who led the Review. Patients, carers, researchers and international, third sector and industry representatives contributed to the review by submitting documents, audio and video evidence, completing questionnaires and online surveys, and through taking part in workshops, meetings and social media, all of which informed the final report and recommendations.

The review of public involvement in the NIHR, commissioned by the Director General Research and Development/Chief Medical Officer in March 2014, provided an opportunity for an independent review panel to assess how far the NIHR has been successful in achieving public involvement across its activities to date and to recommend a direction for the NIHR for the future that builds on these achievements.

"Going the extra mile," is now published on the NIHR website:

<http://www.nihr.ac.uk/newsroom/get-involved-news/going-the-extra-mile-a-strategic-review-of-public-involvement-in-the-national-institute-for-health-research/2739>

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**McMaster Health Forum**

<http://www.mcmasterhealthforum.org/>

**May 21: *Wearable technologies***, a presentation by Nora Young, host of CBC Radio's *Spark* and author of *The Virtual Self*. McMaster Innovation Park (175 Longwood Rd. South, Hamilton). Join us in person or online via [live web stream](#). Follow the discussion on Twitter via #MacAging

It would be great if you could include the link to the report I sent you last week. I've pasted it below:

<http://www.hqontario.ca/Portals/o/documents/eds/special-reports/report-subcommittee-20150407-en.pdf>

For those who are interested, this work will be presented at the HTAi Annual Meeting:



**A Framework for Patient and Public Involvement in Ontario's Health Technology Assessment Process**

Presenter: Deirdre DeJean, McMaster University, Hamilton, Ontario

Brought to our attention by Julia Abelson

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**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): Discussion Forum

### **PCISG Panel session**

Wednesday 17 June 9am: One Year On: Implementing the Values and Quality Standards for Patient Involvement in HTA

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### **Our Travel Grant recipients will be busy:**

Francois Houyez from Eurordis will act as discussant in two panels:

- the HTAi Policy Forum panel on the topic of improving the effectiveness of evidence generation for HTA, which will be held on Monday at 12.00
- a panel on Early Dialogue in HTA (SEED) on Tuesday at 11.30am.

Others receiving grants have also committed to involvement in panels, the PCISG workshop and the Discussion Forum.

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### **Those who have let me know about their oral presentations in Oslo**

Stakeholder views on Australian public- and patient-involvement in HTA.

Edilene Lopes, Jackie Street, Drew Carter, Tracy Merlin

Teasing apart the patient and citizen: the perils in using the term 'public'.

Jackie Street, Edilene Lopes, Tania Stafinski

Integration of ethics principles into the processes for patient group submissions to HTA: a case of knowledge translation

PCISG and Ethics ISG members

Optimizing the Design of a Population-Based Reflex Testing Program for Lynch Syndrome in Ontario: Health Care Providers' Perspectives.

Yvonne Bombard

Public preferences on engagement in health technology assessment decision-making: a nominal group study.  
Sally Wortley

What factors determine the type of public engagement undertaken by health technology assessment decision-making organizations?

Sally Wortley

Laura Norburn from the Public Involvement Programme at NICE will be doing an oral presentation entitled "Are we eliciting knowledge effectively? Evaluating patient involvement in medical technologies guidance at NICE"

This oral presentation will look at evaluating the questionnaire used to facilitate patient and public involvement in NICE's evaluation of medical devices and diagnostics. We'll present analysis of questionnaire

responses received over a 2 year period and determine how well the questionnaire was eliciting useful responses. We'll then move on to talk about how we modified the questionnaire to incorporate elements of the HTAi non-medicines template and removed questions that were not generating useful information, and our plans for piloting the new template. PCISG members would be more than welcome at the session!

Heidi Livingstone from the Public Involvement Programme at NICE will be doing an oral presentation at Oslo titled "Patient commentary for NICE's Interventional Procedures guidance: does it meet the needs of decision makers and patients?" (Time/date tbc, as oral sessions are not yet scheduled on the programme). The oral presentation will briefly introduce interventional procedures and explain the review of the questionnaire we use to obtain input from patients to inform committee decisions to ensure it meets the needs of the decision making committee and patients. We redesigned the questionnaire, with committee input, when we use it, looked at barriers we encounter and also introduced a data recording system. The new questionnaire is easier and quicker for patients to complete whilst still capturing information that the decision making committee needs.

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**Eucomed Symposium: How can HTA evaluate and facilitate better and faster patient access to technologies that improve or change health care systems**

Join the Eucomed panel discussion during the HTAi Annual Conference in Oslo. The session will take place on 16 June from 7:30 to 9:00. We would like to foster the debate within the HTA community about necessary initiatives and future focus to improve the conduct and the relevance of HTAs performed on technologies that improve or change healthcare delivery to patients.

These technologies have the potential to limit the clinical and economic burden of chronic diseases in an ageing population while offering tailored treatment to patients. Despite considerable achievements in recent years, contemporary HTA may not be fully equipped for the assessment of these technologies and of a health system's performance. The patients' and the caregivers' perspectives are still not systematically incorporated. In addition, organisational, economic, social, legal and ethical components of healthcare innovation are not always exhaustively or correctly assessed.

Sophie Cros and Zuzana Pisano

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**Feedback with regard to medical conferences and patient advocates**

Thanks for putting together a very interesting March Newsletter.  
.... the article that got my attention is the articles from BMJ on patient participation in medical conferences. This is a topic of great interest to me since the mid- 90s when I had to argue to get a free registration to an oncology conference in Athens till now that a group of patient advocates from many countries decided to support the PatientsIncluded movement launched by Lucien Engelen, that somehow acted like a catalyst uniting many voices in various countries. In Greece we have already a [PatientsIncluded conf.](#) the Patients in Power Annual Conference, which is a conference fully organized by a Steering Committee of Patients, with patients on the floor and in the audience.

Now PatientsIncluded has grown and have already some 10 international conferences that bear the logo! A recent development is that in March some twitter connected people decided to have a google hangout to talk about patient participation in medical conferences in view of drafting a charter. Andrew Spong undertook to put nicely [in a post on his blog](#) these discussions and draft the wording of the charter....

In the meantime, in London Tessa Richards at The BMJ has also undertaken a mighty effort to make the patient voice heard... Will all these still small movements converge into something bigger, more vocal? It remains to be seen...

Kathi Apostolidis

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Janet Wale, Chair HTAi PCISG  
E-mail: [socrates111@bigpond.com](mailto:socrates111@bigpond.com)

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



## **VALUES AND QUALITY STANDARDS FOR PATIENT INVOLVEMENT IN HTA**

The HTAi Interest Sub-Group for Patient/Citizen Involvement in Health Technology Assessment (HTA) has developed Values and Quality Standards for patient involvement in HTA via an 18-month research process<sup>[1]</sup>. This included an evidence review, nominal group technique with an expert work shop and three-round Delphi process to develop international consensus. The consensus process received input from 150 respondents in 39 countries.

### **Values for Patient Involvement in HTA**

#### **Relevance**

Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.

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<sup>[1]</sup> This research was led by Karen Facey PhD who was partially funded by an unrestricted research grant from Eli Lilly and Company in collaboration with a Research Steering Committee from the HTAi Interest Sub-Group including Professor Helle Ploug Hansen, Moira Howie, David Grainger, Elaine Macphail, Ann Single,

Sophie Staniszewska PhD, Sophie Werko PhD, Janet Wale PhD.

**Fairness**

Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.

**Equity**

Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.

**Legitimacy**

Patient involvement facilitates those affected by the HTA recommendations/decision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process.

**Capacity building**

Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

**Quality Standards for Patient Involvement in HTA****General HTA process**

1. HTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients.
2. HTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA.
3. HTA participants (including researchers, staff, HTA reviewers and committee members) receive training about appropriate involvement of patients and consideration of patients' perspectives throughout the HTA process.
4. Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA.
5. Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them.

**For individual HTAs**

6. Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.

7. Clear timelines are established for each HTA with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained.
8. For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA.
9. In each HTA, patients' perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported.
10. Feedback is given to patient organizations who have contributed to an HTA, to share what contributions were most helpful and provide suggestions to assist their future involvement.

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Values and Standards for patient involvement in HTA (<http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html>)

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