



HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, August 2015

Our vision: *Patient and citizen perspectives improve HTA*

Thoughts from Oslo: it felt like another step towards integration, patient and public involvement felt strong. *Sophie Staniszewska UK*

Welcome to this month's E-Bulletin!

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New Resources to Help Strengthen pCODR Patient Advocacy Group Submissions

Two new narrated slide presentations have been introduced to help patient advocacy groups with their submissions to the CADTH pan-Canadian Oncology Drug Review (pCODR). The presentations were developed as part of the ongoing Patient Engagement Collaboration Project by the Canadian Cancer Action Network (CCAN) and CADTH's pCODR program, and are available now on the [CCAN](#) and [CADTH](#) websites.

The first presentation - [Strengthening Your pCODR Submission: An Overview](#) - is narrated by Marjorie Morrison, Chief Executive Officer, CCAN. It outlines the pCODR process and provides information on the resources available to support patient evidence submissions.

The second presentation - [Strengthening Your pCODR Submission: Collecting and Presenting Information](#) - is narrated by Mona Sabharwal, Executive Director, pCODR, CADTH. It offers guidance on how best to collect and present patient evidence. The examples included in both presentations are based on observations and comments from the pCODR Expert Review Committee (pERC).

pCODR has separately issued a performance report including against key performance indicators https://www.cadth.ca/sites/default/files/pcodr/pcodr_metrics_report_17apr2015.pdf

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FINAL CONFERENCE – INTEGRATE-HTA project - 12/13 November 2015, Amsterdam, the Netherlands

Using palliative care as a case study, the INTEGRATE-HTA project aims to develop concepts and methods that enable a patient-centred, comprehensive assessment of complex health technologies. Specific elements of the INTEGRATE-HTA methodology include scoping, logic models, inquiry into the wider socio-cultural, legal and ethical implications of health technologies, and multi-criteria decision making.

During the conference, the results of the project will be presented and representatives of various European HTA agencies and other experts in the field will act as referees.

For more details on the programme and registration, please visit: www.paoheyendael.nl/integrate
The number of available places is limited and acceptance is in order of registration and payment.

For more details on the INTEGRATE-HTA project, please visit our project website: www.integrate-hta.eu

On behalf of the INTEGRATE-HTA project team,
Kim Weistra and Wija Oortwijn

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The HTAi journal, International Journal of Technology Assessment in Health Care

The new Associate Editor for the Patients and citizens issues for the International Journal of Technology Assessment in Health Care is Jackie Street. Jackie is from the School of Public Health, University of Adelaide, AUSTRALIA, and is on our Steering Committee as well as co-leading the Citizen and Community Involvement in HTA Working Group with Tania Stafinski.

The number of Associate Editors is increasing to create closer connections to the HTAi Interest Groups, and the PCIG is one of the first four. The Editor-in-Chief is Professor Marjukka Mäkelä, Research Professor, Finnish Office for HTA (FINOHTA) at the National Institute for Health and Welfare.

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Papers of interest

Bridie Evans has let us know about the following paper:

Involving older people in a multi-centre randomised trial of a complex intervention in pre-hospital emergency care: implementation of a collaborative model
Authors: Koniotou Marina, Evans Bridie, Chatters Robin, Fothergill Rachael, Garnsworthy Christopher, Gaze Sarah, Halter Mary, Mason Suzanne, Peconi Julie, Porter Alison, Siriwardena A., Toghill Alun, Snooks Helen.
Trials.2015, 16:298. DOI: 10.1186/s13063-015-0821-z
URL: <http://www.trialsjournal.com/content/16/1/298>

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Maarten de Wit also has a paper he would like us to know about as it may be of interest to you:

Patient participation as an integral part of patient-reported outcomes development ensures the representation of the patient voice: a case study from the field of rheumatology, free access paper
<http://rmdopen.bmj.com/content/1/1/e000129.full.pdf+html>

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Here's a fascinating blog post on the British Medical Journal site about the use of twitter as a form of public involvement and developing knowledge to combat disease.
<http://blogs.bmj.com/bmj/2015/08/20/amy-price-bmj-and-the-twitter-footprint/>

The diagram about patient involvement is hard to read, so go to this source site to see it full page and to see how it was generated.

<https://nodexlgraphgallery.org/Pages/Graph.aspx?graphID=50796>

Sent in by Karen Facey

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Sophie Staniszewska is the editor of an important new journal called Research Involvement and Engagement. There has already been a social media buzz about the first few articles and this recent article about measuring the impact of patient involvement in research has some important messages for us.

<http://www.researchinvolvement.com/content/pdf/s40900-015-0008-5.pdf>

Sent in by Karen Facey

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Citizen and Patient Involvement Library – HTAi vortal

Do not forget we have a list of relevant references on the HTAi vortal:

<http://vortal.htai.org/?q=cpil>

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The Informed Health Consumer – Making sense of evidence

A new course being run by Cardiff University starts on 7 September and runs for 4 weeks, notionally 3 hours per week. It may be of interest to aspiring consumer representatives and others.

<https://www.futurelearn.com/courses/informed-health-consumer>

Sent in by Russell McGowan

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McMaster Health Forum - Cochrane Canada webinar recordings released

Cochrane Canada recently published the recordings from the Cochrane Canada Live! webinar series held earlier this year. Three of these webinars featured experts from the McMaster Health Forum.

- Dr. John N. Lavis explored the key features of stakeholder dialogues, what we've learned about them and how you can request one.
- Dr. François-Pierre Gauvin highlighted the key features of citizen panels and what we've learned about them.
- Dr. Kaelan Moat provided an introduction to Health Systems Learning and outlined how you can enroll in one of the training opportunities.

[Watch](#) these Cochrane Canada webinars and others from 2014

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Uncertainties in health care

The James Lind Alliance is a not-for-profit organisation that brings patients, carers and health professionals together to identify and prioritise the top 10 uncertainties, or 'unanswered questions' in different areas of health care. The James Lind Alliance Partnerships looks for the views of patients, carers and health professionals

<http://www.lindalliance.org/top-tens.asp>

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AllTrials - Registration of clinical trials

The judgement in the judicial review brought by Richmond Pharmacology against the Health Research Authority (HRA) in the UK has been published. The judge has found that the HRA has a clear legal right to monitor researchers' compliance with legal and ethical obligations to register clinical trials. The Judge said that the HRA has a remit to impose sanctions on researchers who breach those obligations. But he also found that the HRA's website is currently too ambiguous and confusing about what those obligations are to be able to lawfully do this. The Judge asked the HRA "as a responsible public body to cast a self-critical eye over the whole of its website material in this domain."

The HRA now has a clear mandate to continue its work promoting trial registration and reporting. The judgment is a very clear and comprehensive setting out of the issues and of the legal and ethical obligations on researchers, it's a good read, [find it and key points from it here](#).

The AllTrials campaign <alltrials@senseaboutscience.org>

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HTAi 2016

Please note that HTAi 2016 will be in Japan and will be much earlier than usual, 10-14 May 2016, running from Tuesday to Saturday. The deadline for workshops and panels is October 16th.

<http://www.htai.org/meetings/htai-2016-tokyo.html>

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Janet Wale, Chair HTAi PCIG

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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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