



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

*Our vision: Patient and citizen perspectives improve HTA*

Welcome to the start of a new year!

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**Travel Grants to attend the HTAi 2015 Conference in Oslo**

<http://www.htai2015.org/events/2015-htai-annual-conference/custom-116-24fdbeb646af4856894b56e17ef6bd6e.aspx>



HTAi funds two travel grants to support attendance and participation at its annual meetings:  
**Travel grants for individuals from low and middle income countries** (as defined by the **World Bank**) to attend the HTAi Annual Meeting and present their work.

**Travel grants for representatives from not-for-profit patient organizations** anywhere in the world to attend Annual HTAi meetings.

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**HTAi 2015, Global Efforts in Knowledge Transfer: HTA to Health Policy and Practice**

The theme of this year’s annual meeting is focused on the latest and best thinking regarding the dissemination of HTA reports, uptake of HTA findings and implementation of decisions informed by HTA. The meeting is 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?

**In planning your travel:**

- The PCISG has one half-day preconference workshop accepted.
- We are also planning a half-day meeting of PCISG members and interested people to discuss measuring the process for and impact of patient and citizen involvement in HTA processes

### **Registration**

Open: February 2, 2015

Early Bird Deadline: April 1, 2015

### **Conference**

HTAi AGM: June 13, 2015

Pre-Conference Workshops: June 13-14, 2015

Conference: June 14-17, 2015

Welcome Reception: June 15, 2015

Conference Dinner: June 16, 2015

Notification of Abstract Acceptance: Feb. 23/15

<http://www.htai2015.org/events/2015-htai-annual-conference/event-summary-24fdbeb646af4856894b56e17ef6bd6e.aspx>

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#### **Patient group submission template for diagnostics**

HTAi Patient Involvement Methods and Impact Working Group is pleased to share that the development phase of the patient group submission template for diagnostics has begun.

We have a working group comprised by Lizzie Thomas (NICE), Laura Weeks (CADTH), Iris Pasternack (Summaryx, health technology assessment) and Victoria Wurcel (EDMA).

If you would like to join please contact Victoria at [V.Wurcel@edma-ivd.eu](mailto:V.Wurcel@edma-ivd.eu)

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#### **Update from PCISG Methods and Impact Working Group**

- coordinated a review of the GIN Public Toolkit chapter on qualitative research and is considering whether they can write a chapter about HTA tools for patient involvement to feature in the updated toolkit
- submitted an online and detailed response to EUnetHTA consultation on HTA Core Model® providing substantive comments about the social issues domain and suggesting that it needs a major rethink to take account of recent advances in eliciting patients' perspectives in HTA
- is developing new work in relation to Patient Reported Outcomes and impact

If you want to join any of this work, please contact the Coordinator, Karen Facey E-mail

[k.facey@btinternet.com](mailto:k.facey@btinternet.com)

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#### **Update from PCISG Patient Involvement and Education Working Group**

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

We are just about to begin working collaboratively with some patient organisations on developing a Charter for patients on the Values and Standards. If you are interested, please let us know [my email is at the end of this E-Bulletin].

Guidance for Patient Organisations on Completing the Medicines Template (draft for comment on Resources page at [www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html](http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html))

Have you looked at it yet; and do you have any feedback to send us?

We are now beginning an 'in brief' version.

Ethical Issues Checklist and Guidance for patient organisation guidance on gathering patient experiences to complete the templates and retain the soul of the information obtained. This work is continuing in collaboration with the Ethics Interest Sub-Group. We hope to have a draft to share with members of both ISGs early in 2015.

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**HTAi Policy Forum February 2015**

We are delighted that Eric Low from Myeloma UK has been invited to give a keynote presentation at the HTAi Policy Forum in early February. The meeting will discuss ways to improve the efficiency of evidence collection and we look forward to hearing Eric's insights into this meeting.

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**IPPOSI** <http://www.ipposi.ie/>

IPPOSI is having a roundtable meeting in Dublin on the 24<sup>th</sup> Feb on access to orphan drugs in Ireland and the need for a separate system for assessing orphan medicinal products. Karen/Ken will forward our note on the event, might be of interest to some of your readers.

Eibhlin Mulroe, CEO

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**INTEGRATE-HTA**

The INTEGRATE-HTA project team will be seeking stakeholder input between February and May 2015 as we begin applying the methodological guidances for the assessment of complex technologies in a palliative care case study in England. Patient and public representatives (i.e. patients, carers ex-carers and members of the public with an interest in palliative care) will be invited to participate in meetings with professionals (Commissioners, practitioners, including with experience of home care services, academics with an interest in palliative care) to provide their perspectives on issues relating to effectiveness, cost-effectiveness, socio-cultural, patient preferences and moderators of treatment effect and a final workshop mimicking a decision making committee on commissioning health technology. The final case study report will be submitted in June 2015.

For more information, please visit [www.integrate-hta.eu](http://www.integrate-hta.eu). If you are interested in receiving our semi-annual newsletter by e-mail, or if you wish to receive more information please contact us at [info@integrate-hta.eu](mailto:info@integrate-hta.eu) or visit our website.

Contributed by Louise Brereton, on behalf of the INTEGRATE-HTA project team

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**Patient Solidarity Day in Uganda, 5<sup>th</sup> December, 2014: theme "*Universal Health Coverage*"**

I would like to share with you an update about our event (Patient Solidarity Day), an annual event commemorated by patient organizations in Africa and other countries. It was initiated by Alice Mwangera of Moses Morris Foundation. In Uganda it was commemorated at Kojja Health Centre, Ntenjeru Sub County Mukono District.

The day brought together over 1200 people including local and international NGOs, private sector, representative from WHO, Joint Medical Stores, Uganda Cares, Medical Access, PACE, The AIDS Support Organisation (TASO), Pharmaceutical industry, religious, political, local leaders, media and the general public. The Key Note address emphasized the need for local leaders, the private sector, advocacy organizations, government and patients as the pillars of good health to be at the forefront of advocating for Universal health coverage.

The key outcomes of the day included; networking and identification of opportunities for collaboration with key healthcare stakeholders to promote Universal Health Coverage and patient

centered health care; HIV counseling and testing (241 people tested for HIV, 15 HIV+ and referred for treatment); breast and cervical Cancer screening (91 tested, 3 suspected and referred for further investigation); hepatitis B screening (96 screened, 1 tested positive and referred for treatment), general conditions (532 accessed information and treatment for general conditions), 100 mama kits were distributed to pregnant mothers, testimonies by patients on prevention and management of disease, awareness raising through music, dance and drama, provision of health information on different diseases through exhibitions and interaction with healthcare professionals.

Patient organizations noted with concern that quality, equitable and affordable health care is more than a dream for most people in Uganda. They emphasized the fact that Universal health coverage was a human right and made a call to the key stakeholders to ensure that health care is a reality and that all people can have fair and impartial access to quality health care coverage. They called upon government to speed up the National Insurance health policy in order for all Ugandans to access health care. They further noted that Uganda suffers the double burden of communicable and non-communicable diseases coupled with a number of health care challenges like inadequate funding, human resource for health crises, low health literacy, inadequate access to medical facilities, treatment and mismanagement of funds allocated for health service delivery which impacts universal health coverage.

WHO committed to continue working with the Ministry of Health to ensure health centers have the capacity to offer treatment to patients and also ensure that people get affordable treatment with the National Health Insurance. The event was supported by WHO Country office, NGOs and patient organizations, private sector, local pharmaceutical industries donated medicines which were used to treat people on that day. Please find below a newslink about the day and some pictures in the dropbox.

<http://www.newvision.co.ug/news/662606-csos-to-government-provide-health-care-for-all.html>>\*  
<https://www.dropbox.com/sh/fhwu2oa61jbbceo/AACvdxQPuayeevG-LigbUpRHa?dl=0>

Joshua Wamboga | Executive Director

Uganda Alliance of Patients Organizations (UAPO), Email: [joshuaw@ugandapatientorganizations.org](mailto:joshuaw@ugandapatientorganizations.org)

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### **EUPATI, European patients' Academy on Therapeutic Innovation**

#### **For patient advocates in Europe: Become a Patient Expert in Medicines Research and Development**

- Interacting with clinical designers and regulatory authorities about new medicines
- Learning with 50 other top patient advocates from around Europe

Apply here for our Autumn 2015 Course before 31 March 2015:

<http://www.patientsacademy.eu/index.php/en/edu/guide>

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#### **Additional reading:**

### **Improving Quality and Efficiency in Health Care through Comparative Effectiveness Analyses: An International Perspective**

*by Gerry Fairbrother; Ellen O'Brien; Rosina Pradhananga; Kalipso Chalkidou*

The international CER/HTA report has been placed on the AcademyHealth website and is being publicized through our [blog](#) and with tweets in the coming month. Please see the link to the report:

<http://academyhealth.org/files/publications/2014CERImprovingQuality.pdf>.

Gerry Fairbrother

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**The Centre for Innovation in Regulatory Science (CIRS)** <http://www.cirsci.org>

R&D Briefing 55: *The impact of the changing regulatory environment on the approval of new medicines across six major authorities 2004-2011*, now publicly available on the CIRS website.

This briefing evaluates the trends in the approval of new active substances (NASs) between 2004 and 2013 by six regulatory authorities: Health Canada, Swissmedic, Australian TGA, EMA, the US FDA and Japanese PMDA and was prepared by Magdalena Bujar ([mbujar@cirsci.org](mailto:mbujar@cirsci.org)) and Neil McAuslane ([nmcauslane@cirsci.org](mailto:nmcauslane@cirsci.org)). We do hope that you find this briefing of interest and if you have any questions or comments please do not hesitate to contact one of the authors.

If you would like a copy of the graphs as a PowerPoint presentation, please let either Gill Hepton ([ghepton@cirsci.org](mailto:ghepton@cirsci.org)) or Neil McAuslane ([nmcauslane@cirsci.org](mailto:nmcauslane@cirsci.org)) know and we will be pleased to share them with you.

Jean Mossman

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**From the McMaster Forum Update and Health Forum Evidence Service**

Forum Update is an electronic newsletter available by subscription and on the Forum website. If you would like to subscribe, click [here](#). The World Health Organization (WHO) renewed the Forum's designation as the WHO Collaborating Centre for Evidence-Informed Policy for another four-year term.

**February 23, noon to 1:00 p.m. (EST):** Cochrane Canada webinar with Dr Francois-Pierre Gauvin discussing the key features of the Forum's citizen panels, what we've learned about them, and how you can request one. [Register now](#) and follow the discussion online via #CCCWebinar.

We encourage you to register for [Health Systems Evidence](#) to receive a monthly alert of new documents related to health systems topics, themes and domains that you select as being of interest (e.g., consumer & stakeholder involvement).

Dalton J, Chambers D, Harden M, Street A, Parker G, Eastwood A. Service user engagement and health service reconfiguration: A rapid evidence synthesis. National Institute for Health Research; 2014. [Full-text report \(free\)](#)

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**Jonathan Boote has moved!**

He is now Reader in Patient Experience and Public Involvement, Centre for Research in Primary and Community Care, University of Hertfordshire. His new email is [j.boote@herts.ac.uk](mailto:j.boote@herts.ac.uk).

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**New journal now accepting submissions: *Research Involvement and Engagement*** <http://www.researchinvolvement.com>

The journal aims to develop the evidence-base underpinning patient and public involvement and engagement in health research. The Editorial Board includes academics, patients, carers and policy-makers, working together.

*Research Involvement and Engagement* is published by [BioMed Central](#), the leading open access publisher. It is part of the Medical Evidence portfolio, and can benefit from its close relationship with journals such as [Trials](#), [Systematic Reviews](#) and [Journal of Negative Results in BioMedicine](#).

Authors who genuinely cannot afford to pay the article-processing charge are able to request a discretionary waiver, to allow patients, carers and those without institutional funding to submit.

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[Orphanet Journal of Rare Diseases](#) is an [open access](#), online journal that encompasses all aspects of rare diseases and orphan drugs, including rare immunological diseases. The journal publishes high-quality reviews on specific rare diseases, and also considers clinical trial outcome reports and articles on public health issues in the field. We are the official journal of [Orphanet](#) – the global portal for rare diseases and orphan drugs.

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The EMA is currently looking for cancer patients in soft tissue sarcoma, gastric cancer or non-small cell lung cancer with knowledge of HTA to participate in some meetings.  
If you can assist please let Kathi know.

Kathi Apostolidis

Breast Cancer & Patient Rights Advocate, Email [kathi.apostolidis@gmail.com](mailto:kathi.apostolidis@gmail.com)

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#### **Sense About Science: clinical trial results reporting**

The Institute of Medicine has just said that clinical trial data sharing should "[become the norm](#)." The IOM is a highly respected voice on medical issues in the US and its new report sets a high bar for the future of data sharing. It straightforwardly addresses specific challenges to data sharing with practical solutions. So now the only people and organisations still saying challenges to data sharing make it impossible are those who don't want to share their results.

Dr Jeffrey Drazen, one of the authors of the report, said: "We need to recall every day that selfless volunteers put themselves at risk to advance medical science by enabling the data to be gathered. To honour that sacrifice, we need to turn those data into applicable knowledge."

Deborah Zarin, director of the US clinical trials register, called the report "a tipping point event."

[Read more about what we have said about the report and find links to some of the coverage on AllTrials.net.](#)

If you haven't already, [please support the US Government's proposals](#) to require more trials to be registered and results reported.

Ian Bushfield, Campaigns Support Officer

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G-I-N/North America invites you to the next presentation in its webinar series, "**Developing and Disseminating Patient Versions of Clinical Practice Guidelines: Feedback from Patients and the Public.**"

Date: Thursday, February 5, 2015

Time: 12:00 pm-1:30 p.m. (Pacific), 2:00-3:30 p.m. (Central), 3:00-4:30 p.m. (Eastern)

The comprehensive information in clinical practice guidelines represents an excellent source of information which can be communicated to patients and the public. Today, many guideline organisations write and provide some type of patient version of their guidelines. One stream of the DECIDE project ([www.decide-collaboration.eu](http://www.decide-collaboration.eu)) is exploring how to disseminate guidelines to this audience. We will present the results from focus groups in patients and the public, a review of the literature about their views about guidelines, a

content analysis of patient versions currently available, and user testing. We have found that people want information from guidelines for a variety of purposes, including to manage their own care and as reassurance about the care they receive. But they have difficulty determining what guidelines and recommendations apply to their own situations. Based on some examples of patient versions which meet these needs and our user testing, we are developing guidance about how to write patient versions and are incorporating the guidance into the Guideline Development Tool/GRADEpro software ([www.gradepro.org](http://www.gradepro.org)) to facilitate the production of patient versions from guidelines.

***Please feel free to share this information with others who may be working on Clinical Practice Guidelines in North America.***

**Presenters:**

**Nancy Santesso**, Assistant Professor at the Department of Clinical Epidemiology & Biostatistics  
McMaster University, Canada

**Shaun Treweek**, Professor of Health Services Research at the Health Services Research Unit  
University of Aberdeen, UK

**Moderator:**

**Marguerite Koster, MA, MFT** Chair, G-I-N/North America Steering Group

**Learning Objectives:**

1. Understand the difference between clinical and patient/public versions of clinical practice guidelines.
2. Learn what patients want from clinical practice guidelines and how they use this information
3. See different formats of patient versions of guidelines and how they will be incorporated into the Guideline Development Tool/GRADEpro software.

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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.*

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