



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

Our vision: Patient and citizen perspectives improve HTA

Welcome to this month's E-Bulletin

XXXXXXXXXXXXXXXXXX

HTAi Annual Conference 2016 , "Value-based Evidence and Decisions in Healthcare - Embarking on a New Era"

Tokyo, 10 to 14 May (preceded by preconference workshops)

Workshops and Panel Sessions – call for abstracts, due 16 October 2015

If you plan to be in Tokyo and can provide your country's perspective on the role of the end user (patients, patient groups and clinicians) in decision making processes on which drugs or technologies should be funded

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

The PCIG is working with a number of people in the region to develop sessions (preconference workshop and a panel session) following the theme 'East Meets West'. We will encourage real interaction between first patient advocates (workshop) and then HTA agencies/governments (panel session) to discuss the role of patient involvement and the use of our tools. We would like to hear from you if you are interested in having an active part in these sessions and plan to be in Tokyo

XXXXXXXXXXXXXXXXXX

HTAi's new Managing Director, Lucy Turner

Lucy brings with her extensive research experience and familiarity with HTAs and systemic review methods, work which has involved managing research programs, projects and initiatives of international collaborative teams. This frequent participant at HTAi Annual Meetings also sat on the Cochrane Collaboration's Methods Board for over five years and is an active member of the research community taking on editorial appointments with academic journals such as Systematic Reviews Journal and conducting peer reviews for journals including BMJ, BMJ Open, JCE and Medical Research Methodology amongst others.

Lucy comes to us from the Ottawa Hospital Research Institute (OHRI) in Canada where she most recently took on the role as program facilitator for the provincial methods center for the National Strategy for Patient-Oriented Research. OHRI is a collaborator in methods development, consultation and training for the Strategy which is co-funded by the provincial Ministry of Health and the Canadian Institutes of Health Research.

The position of HTAi Managing Director is responsible for ensuring that the society's secretariat delivers support to our board and our members and oversees all general operations of the organization. Please join us in welcoming Lucy to the HTAi team and wish her every success in her new role. Lucy can be contacted directly at lturner@htai.org

From the HTAi E-Bulletin

XXXXXXXXXXXXXXXXXX

EUPATI Webinar - Strengthening patient involvement in HTA - 28 September 2015

The EUPATI Patient Expert course entails 6 modules on clinical trials; the last module is on HTA. In the second week of September the 46 EUPATI students met in Barcelona for their second face-to-face meeting. After a full day of benefit-risk evaluations and a day focused on the various aspects of pharmacovigilance, it was time on Day 3 to be submerged in HTA.

Herb Riband (Amgen) gave an introduction to HTA and Ingvil Saeterdal (Norwegian Centre for Health Services) further explained the application of the nine domains of the core HTA model. In the break-out sessions theory was put into practice, when working on different case studies.

Then Francois Maignen (NICE) gave us insights on 'Determining the value of a new therapy', which was definitely food for thought (...or rather discussion!) and 'Shaping European Early Dialogues'.

Victoria Thomas (NICE) told us 'How 'value' is determined in the context of HTA'. She also mentioned the patient involvement, answered quite a few questions on the topic and gave a nice overview of the possibilities to get tuned in with HTAi PCISG. This was a great opportunity to illustrate this with my experience during HTAi Oslo 2015, and I enthusiastically told my peers I was very welcomed by the group, learned an awful lot at the conference and got inspired about HTA. Needless to say I encouraged the other students to also become an HTAi member and get involved with PCISG!

My personal experience is that it is great, and also necessary, to dedicate at least one full day of our time to HTA. This is definitely a module where one can learn so much from the excellent speakers and have a great Q&A during the case studies. Now it's back home to dive into the HTA module. Once that is successfully completed, we can call ourselves: Eupati Patient Expert, Class of 2015.

Marleen M Kaatee, President PSC Patients Europe

XXXXXXXXXX

If you are not yet a EUPATI Network Member and wish to attend a webinar, you need to register by clicking on the following link: [EUPATI Network registration](#), it is free and takes only a few minutes

E-mail: eupati@efgcp.eu

EUPATI Website: <http://www.patientsacademy.eu>

XXXXXXXXXXXXXXXXXX

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

Two public involvement representatives from England, Mrs Jacqui Gath and Mr George Wood, will co-present at the conference in a session that considers how stakeholders were involved from the start of the project. Jacqui and George have had long standing involvement in the project and will share their experiences of advising on the project in individual and group meetings that have been conducted

either face to face or via Skype. Their experience in meetings encompasses working in groups with other lay advisors and working in a mixed group of stakeholders (i.e. a meeting where both lay and professional stakeholders were present).

The conference offers the audience to engage in a discussion with Jacqui and George about their involvement as they will be present during both days of the conference.

For more details on the programme and registration, please visit: www.paoheyendael.nl/integrate
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,
Louise Brereton

Submitted by Wija Oortwijn

XXXXXXXXXXXXXXXXXX

Health Sector CSOs call on government and all partners to put HIV positive women at the centre of Uganda's Mother-to-Child Transmission (eMTCT) response

Political leaders: stop using language that stigmatizes and blames women living with HIV

Health sector organizations recognize the leadership and effort of all partners in implementing Uganda's eMTCT program. However, today's eMTCT launch in Masaka is an important moment to draw attention to recent eMTCT launches that have used discriminatory and stigmatizing language. For example, the previous eMTCT launch in Soroti isolated and stigmatized a group of HIV positive children, while characterizing the mothers of a group of HIV negative children as 'heroes.'

Some HIV positive mothers despite having embraced the eMTCT programme as recommended nevertheless have delivered HIV positive children. These mothers should be applauded as much as those whose children are HIV negative. All women need to be supported to care for the children so that they lead a normal and meaningful life. eMTCT launches should portray this fact and not be perceived to put down some mothers.

Moreover, the First Lady concluded that if any child is born with HIV in Uganda currently, it is the fault of that child's mother. These are extremely harmful comments and no matter what the intention of the organizers, they should not be repeated in Masaka. No woman wants her baby to be HIV positive – and no HIV positive child should be told that his or her mother is not a hero. Furthermore, quality pediatric HIV treatment means HIV positive children can live with HIV.

The language used during eMTCT launches – including speeches, entertainment, and media communications – must be stigma free. Blaming HIV positive women is unacceptable; it could also drive women further from ante natal care services because they will fear judgment and discrimination from the health sector. .

HIV treatment and quality ANC services must be made more accessible to HIV positive pregnant women in Uganda. We call for the following immediate interventions to ensure the success of the national eMTCT program:

- Increase uptake of eMTCT services by ensuring the health sector delivers respectful, quality services to HIV positive women and their families
- Require all eMTCT service delivery sites to use family support groups, and trained and compensated mentor mothers

- Increase retention in care by providing high impact loss to follow up prevention services, such as home based follow up following missed clinic visits

Joshua Wamboga | Executive Director | UNASO

XXXXXXXXXXXXXXXXXX
ISPOR Training

The ISPOR Health Technology Assessment (HTA) Training was developed by the ISPOR HTA Council which consists of the Chairs of the ISPOR HTA Roundtable in Europe and North America, of HTAnetAsia, and the Chair of HTAnetLatAm. The ISPOR HTA Training Program became a priority for the Council based on input from ISPOR members and regional groups for support in knowledge building. The Training Program is a 1–3½ day modular program intended for 'users and doers' in government, such as Ministries of Health and health insurance funds, evolving and established HTA agencies or other government departments responsible for health care decision making. It is also designed for public and private payers, industry, health plans, academia, and patient group representatives, interested in learning how to conduct various aspects of HTA with an emphasis on clinical and economic evaluation. The program is also intended to aid decision makers in understanding how to interpret data presented to them, as well as what a good HTA process requires and how this can be tailored to different settings.

<http://www.ispor.org/Education/HTATraining/Index>

XXXXXXXXXXXXXXXXXX
From the European Patients' Forum (EPF) Newsletter

EPF Secretary General Nicola Bedlington is a speaker at:
the 'Pharmaceutical Pricing and Reimbursement Policies: Challenges Beyond the Financial Crisis' conference organised by the Pharmaceutical Pricing and Reimbursement Information (PPRI) will bring together leaders from around the globe to discuss issues in pricing and reimbursement policies of pharmaceuticals.

The WHO Collaborating Centre for Pharmaceutical Pricing and Reimbursement Policies in Vienna invites people to take part in the discussions with renowned experts and high-level representatives in the pharmaceutical field, 12 to 13 October 2015.

<http://whocc.goeg.at/Conference2015/About>

XXXXXXXXXXXXXXXXXX
PCIG/Patient Involvement and Education Working Group (PIE) meeting in Ottawa, Canada 18 to 20 October 2015

Some members of the PCIG, with an emphasis on PIE members, are meeting in Ottawa, Canada next month to further our work and participate in rich discussions. We are grateful to Ken Bond and CADTH staff (past and present) for making this possible.

We will be extending our discussions to members of the Methods and Impact Working Group via the internet; and hope to give you a report back in the next newsletter.

XXXXXXXXXXXXXXXXXX
Papers of interest

Li KK, Abelson J, Giacomini M, Contandriopoulos D. Conceptualizing the use of public involvement in health policy decision-making. *Social Science & Medicine* 2015;138:14-21.

Public involvement is a part of health system planning and policy decision making in some countries (such as UK, Australia, Canada, USA). Stated reasons are to improve the quality and legitimacy of decision making, enhance accountability, and inform (or educate) citizens. Measuring the impact of the use of public involvement is difficult, with uncertainty about how best to incorporate the patient voice alongside other forms of evidence and influences.

The authors identified that conceptual work is needed on the processes through which public involvement is used in health policy decision making. They carried out a literature survey to identify key attributes followed by semi-structured interviews to confirm and expand on the attributes. People interviewed were public involvement practitioners or administrators; researchers; key figures in think tanks and policy research agencies from Canada, UK, USA). An important part of this work was to explore the relationship between 'use' and related terms (such as accountability, consideration, power and influence, trust).

The findings were organised around how the concept of use is understood, interpreted and operationalised. Key dimensions of public involvement use were: a) listening as a precursor to use (and the willingness to listen), b) mediating use via public involvement brokers (seen as a crucial role requiring authenticity), and c) responding back to the public as a signal of use (and to demonstrate accountability and transparency). Use was seen as a process and not an outcome, which should be orientated towards solving a policy problem and filling an information gap to enable better decision making rather than for political or tactical reasons.

Rachul C, Caulfield T. The media and access issues: content analysis of Canadian newspaper coverage of health policy decisions. *Orphanet Journal of Rare Diseases* 2015;10:102.

This study involved content analysis of 530 Canadian news articles about access to health therapies and technologies, published in 15 major newspapers over a 10-year period (January 2003 to December 2012). The types of reasons or arguments used for or against a particular access issue were analysed. The news coverage was generally sympathetic toward increasing healthcare funding and access (77%). In all, 97% discussed why access to healthcare needed to increase and only 34% questioned increased access. The patient perspective was highlighted in 42% of articles. Rare diseases and orphan drugs were commonly addressed (23%).

The study demonstrated that Canadian news media favours patient access, supporting the need to increase funding and availability of medical therapies or technologies. The authors conclude that this may make it difficult to present a more evidence-based perspective to influence funding decisions. This study looked at print media only. It showed some of the challenges to communicating relevant justifications for health policy decisions – a long way from Canadians “receiving quality healthcare based on transparent policies that are rooted in good evidence and rational and appropriately informed debate”.

XXXXXXXXXXXXXXXXXX

Janet Wale, Chair HTAi PCIG

E-mail: socrates111@bigpond.com

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

To unsubscribe from this group and stop receiving emails from it, send an email to isg-patientinvolvement+unsubscribe@htai.org.