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

Our vision: Patient and citizen perspectives improve HTA

Welcome to this month's E-Bulletin

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
HTAi 2017 will be in Rome.

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From Oslo

Plenary Session – Producing HTA: Knowledge in the 21st century: What, When and How? Sophie Staniszewska focused on the patient perspective.

Laura Norburn and David Grainger led the panel session – One Year On: Implementing the Values and Quality Standards for Patient Involvement in HTA

Bruno Rossi, based in Osaka, said: The highlight of our SIG meeting, Sunday afternoon, was that we have to initiate patient and citizen engagement much earlier in the development process (disease burden, endpoints, PRO tools, trial enrolment, etc.), not only at the "last step" in HTA submissions and their reviews. That also came up strongly in the plenary session on the last day.
Attending a session of the East Asian HTA agencies ("HTAsiaLink") – HTA role in Ensuring Universal Health Coverage in Asia Pacific Region, I was disappointed that the Values and Quality Standards issued at HTAi 2014 (and reviewed and reconfirmed at HTAI 2015) are not equally shared, nor even accepted by all members of HTAi itself.
At HTAi 2016 in Tokyo, it will be a particular challenge for patients and advocates to attend from Europe (distance, costs, language and other cultural barriers, etc.). This would be most unfortunate.

For Marleen Kaatee of PSC Patients Europe, and based in the Netherlands, this was her first HTAi Annual Meeting. She felt warmly welcomed by members of the PCISG and her views were listened to during the sessions. Marleen is doing the EUPATI expert training for patients and patient representatives and has shared her experience with her colleagues, through Twitter.

From our Twitter activity @PCISG
Marleen Kaatee: Let's start with values for patient involvement in HTA and take it from there

Eric Low: We need PCISG to show how to operationalize the template
Karen Facey: from Sue Hill, we need PCISG to describe HOW and WHY you need patient involvement to add to the WHAT that is in the template
The template is great starting point but needs to be part of a wider toolkit to see how it fits

Karen Facey: In every plenary and many panels HTA doers mentioned their own experience of engagement with patients and the difference that made
Impact of PCISG - 3 pre-conference meetings, plenary presentations, 3 oral sessions on patients, patient representatives in lots of panels, patients asking questions

Janet Hiller: Oslo great resource for patients, citizens and all interested in evidence informed healthcare

Russell McGowan: Marie-Pierre Gagnon explored role for patient reps in prioritising HTA topics in Canada generating 12 topics from stakeholders

Deb Maskens: Use of social media gives HTA orgs like CADTH "personality" and ability to interact; not just a push but conversation

Karen Facey: PCISG ethical checklist developed from international knowledge and experience but need to make it usable for small patient groups

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INTEGRATE-HTA
A number of stakeholders have assisted in the application of new methodological guidances for the assessment of complex technologies in a palliative care case study in England as part of the INTEGRATE-HTA project. Patient and public representatives (i.e. patients, carers ex-carers and members of the public with an interest in palliative care) have participated 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. These meetings have taken place face to face or via skype and included six carers or ex-carers, one of whom is also a patient and 13 professionals from a variety of disciplines. Two lay people were invited to take part with an end of life care commissioning group in a final mock decision making meeting on the 18th May. The project comes to a close in December 2015 and we look forward to sharing what we have learned about stakeholder involvement with the wider HTAi group. For more information, please visit 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 or visit our website.

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

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I would like to share a link to a short video which we recently produced to draw attention to a new Collaboration Platform 'Patient Research Exchange':
https://youtu.be/4SOK8CA6mQk

The video is also available in other languages (French, Spanish, Italian, German) - in youtube and on our website

under the menu item 'EduClips': http://www.health-os.com/?page_id=285

In addition, the link to the communication & collaboration platform, launched in mid-May, is:
www.patientresearchexchange.org
The platform build-up has been sponsored by Novartis, but it is owned by the steering committee and the idea is that it becomes independent of the original sponsor.

Health Outcomes Strategies GmbH
Dr. Anke-Peggy Holtorf MBA, Managing Director

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From DIA 2015 Annual meeting, Washington DC: A PatientsLikeMe-FDA research collaboration seeks to increase patient experience of drugs in post market reviews (by Stephanie Baum)

This collaboration is "to make more information available about side effects of drugs from the people taking them" and so to improve drug safety. The FDA's post-approval drug safety surveillance is currently based on voluntary reporting by individual healthcare professionals and patients, although reporting adverse events to the FDA is mandatory for drug product manufacturers. The PatientsLikeMe network includes 350,000 patients and covers 2,300 conditions.
http://medcitynews.com/2015/06/patientslikeme-fda-research-collaboration-seeks-to-increase-patient-experience-in-post-market-reviews/?roi=ech04-30385324813-63308860-e0fd924932c4bba32cae333194247ce3&utm_source=Highroad&utm_medium=email&utm_campaign=NA_15001_Thursday-Highlights-NONAttendees_2015-06-19

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Papers of interest

Acceptability and perceived benefits and risks of public and patient involvement in health care policy: A Delphi survey in Belgian stakeholders. Cleemput I, Christiaens W, Kohn L, Léonard C, Daue F, Denis A. Value in Health 2015;18(4): 477-483. http://www.valueinhealthjournal.com/article/S1098-3015(15)00007-8/abstract

Are new models needed to optimize the utilization of new medicines to sustain healthcare systems?
Brian Godman, Rickard E Malmstrom, Eduardo Diogene, et al. Expert Rev. Clin. Pharmacol. 2015;8(1), 77–94.
Proposed models centre on the three pillars of pre-, peri- and post-launch including critical drug evaluation, as well as multi-criteria models for valuing medicines for orphan diseases alongside potentially capping pharmaceutical expenditure. In conclusion, the proposed models involving all key stakeholder groups are critical for the sustainability of healthcare systems or enhancing universal access. The models should help stimulate debate as well as restore trust between key stakeholder groups.

Evaluation of patient involvement in a health technology assessment. Mylène Tantchou Dipankui, Marie-Pierre Gagnon, Marie Desmartis, France Légaré, Florence Piron, Johanne Gagnon, Marc Rhiands and Martin Coulombe. International Journal of Technology Assessment in Health Care / *FirstView* Articles
Qualitative methods were used to evaluate patient involvement (consultation and direct participation) in the assessment of alternative measures to restraint and seclusion among adults in short-term hospital wards (in psychiatry) and long-term care facilities for the elderly.
Patient consultation enriched the content of the HTA report and its recommendations. This also made it possible to suggest other alternatives that could reduce the use of restraint and seclusion and helped confirm some views and comments from healthcare professionals consulted in this HTA. The direct participation of patient representatives enabled rephrasing of some findings so as to bring the patient perspective to the HTA report.

What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials
Dudley L et al. PLoS ONE 10(6):e0128817.doi10.1371/journal.pone.0128817

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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