

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, July 2017

Enhanced quality and relevance of HTA through patient and citizen involvement

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

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Welcome to this month's E-Bulletin

"Really thanks so much everyone - the collective efforts and knowledge of this group are always astounding."

In July we saw a lively discussion on our listserv, started by Tarang Sharma, about involving the public and citizens in the work of the Evidence Informed Policy team at the WHO Regional office for Europe in Copenhagen. They are looking to involve the public and relevant stakeholders in the development of their recent strategy. What they needed was a review or case studies on the benefits. While they intended to do a formal literature search, the expertise within this PCIG was readily at hand and willing to give input. This particularly drew the attention of the Citizens and Community Working Group. Some of the discussion is touched on in this E-Bulletin.

You still time to have your presentations for the HTAi Annual Meeting in Rome placed on our webpage <http://www.htai.org/interest-groups/patient-and-citizen-involvement/pcig-home/htai-2017.html>

Some of our members have told us they are finding them useful, so we would like to hear from you.

Citizens and Community Working Group

The PCIG has a number of working groups. One of these working groups is focused on citizens and community in HTA. To date the group has been quite small but it would seem that there is growing interest and experience in this area amongst those working in HTA (and beyond). It would be great to expand our membership and to understand what would be helpful to support those embarking upon citizen and community work in HTA. If you are interested in joining the working group or have any thoughts as to what you would like to see the group focusing on please fill out the following **short**

survey <https://goo.gl/forms/Xj1ookiHv26CUCci1>.

We will then report back in the next E-Bulletin and start to explore issues individuals are interested in around this topic.

Being part of a PCIG Working Group has added value for one of its members

A relatively new member of the Patient Involvement and Education Working Group has been struck by the helpfulness of fellow members of that group: ".. a big thank you to you and everyone else who has offered

help, signposted resources and written paragraphs explaining how their particular flavour of HTA works – it is an invaluable and often forgotten side effect of having so many wonderful people in one group...the collective knowledge you can call upon as a group is probably second to none”.

So think about how you can be actively involved in the work of the PCIG!

An update on what the Patient Involvement and Education Working Group are doing

This Working Group, known as PIE, is in the final stages of preparing a survey of HTAi members and more broadly to identify online resources and create a directory of patient involvement in HTA resources.

These are publicly available materials that have been specifically designed for patients and citizens to help them participate in HTA processes. We will create a shared database for everyone’s use: organisations who are interested in involving patient groups, patients and/or citizens in their HTAs; as well as patients/citizens themselves who wish to become involved and learn about their role, and HTAi members.

By sharing these materials we will increase mutual understanding of the roles that patients/citizens can have in HTA and we will support others who are new to HTA.

Let us know if you have a particular interest in this ‘mapping’ exercise and would like to contribute in some way. Our intent is that this note means those of you working in relevant organisations will be ready to receive and complete the questionnaire with web links.

htai.pie@gmail.com

News from the Scottish Medicines Consortium

From August, Scottish Medicines Consortium (SMC) is inviting all submitting Patient Group Partners to participate during HTA committee meetings. In a commitment to inclusivity, a representative from each submitting patient group will be invited to take a seat at the table for the full discussion about the medicine they submitted for, to provide points of clarity and answer questions from committee members. This coincides with implementation of a revised role for SMC Public Partners, following an internal review driven by the SMC Public Involvement Network (PIN) Advisory Group. The role of the SMC Public Partners now focuses entirely on being a representative member of the public and voting member of the committee. The SMC Public Involvement Team will take over responsibility for presenting Patient Group Submissions (formerly undertaken by Public Partners). “The changes to SMC process will further strengthen the role of patient and carer representatives in the SMC HTA process and our commitment to partnership in working with patient and carer groups. The new Public Partner role provides clarity for how we involve members of the public in making decisions about the routine availability of new medicines in NHS Scotland. Both changes will ensure openness and transparency in our decision making.”

Further information about patient group participation can be found on the SMC website:

http://www.scottishmedicines.org.uk/Public_Involvement/Participating_in_an_SMC_meeting

Jennifer Dickson

Public Involvement Coordinator | Scottish Medicines Consortium

What’s happening

HTA and stakeholder engagement in Japan

I was invited to speak at a special session on HTA on the occasion of the Annual Meeting of the Japanese Society of Medical Oncology, in Kobe, together with the head of Strategy at the National Cancer Centre, and two health economists leading the introduction of Cost-Effectiveness in Japan.

This was an opportunity to convey information on recent hot topics of HTA in Europe and the USA (as I attended both ISPOR and HTAi annual meetings) and to draw attention to a number of developments which will impact the treatment of cancer also in Japan, e.g. pricing by indication (not by pill or vial), pan-tumor approvals based on genetic sequencing, new statistical methods to modelise cure rates over time [reference paper from Scott Ramsey].

My emphasis was on stakeholder engagement, especially patients – with my personal hard copy of ‘the BOOK’ in hand, which arrived a few days before the congress, but also with two preference studies on prostate cancer conducted in Japan and published recently (one last year and a second this year).

Two recent preference studies in Prostate Cancer, with interesting insights and conclusions

One funded by Bayer: Uemura et al. BMC Urology (2016) 16:63. DOI 10.1186/s12894-016-0182-2

Another funded by Janssen: <http://ascopubs.org/doi/pdfdirect/10.1200/JGO.2016.008045>

Contributed by Bruno Rossi

Patient involvement in HTA is available in hardcopy or ebook from Springer:

<http://www.springer.com/gb/book/9789811040672> and Amazon: https://www.amazon.com/Patient-Involvement-Health-Technology-Assessment/dp/9811040672/ref=sr_1_fkmr1_1?s=books&ie=UTF8&qid=1495583998&sr=1-1-fkmr1&keywords=patient+involvement+in+HTA

EVIPNet, and what Tarang was working on

The European programme of WHO supports all countries in the Region in developing and sustaining their own health policies, systems and programmes; preventing and overcoming threats to health; preparing for future health challenges; and advocating and implementing public health activities.

The Organization’s principal objective – the attainment by all people of the highest possible level of health.

The document being prepared was: Conceptual background and case studies. Introduction to EVIPNet Europe. This is about knowledge translation, and the Evidence-informed Policy Network, to support the use of the best available scientific evidence in policymaking, maximize intended health outcomes and strengthen health systems in the Region.

The document presents the concept of knowledge translation and lessons learned and experiences gained from the many groups around the world undertaking activities to support the use of research evidence in the policy process; and ways to establish knowledge translation platforms. The case studies are from Brazil, Peru, Uganda and Zambia.

Joining the Evidence-informed Policy Network (EVIPNet) Europe. Information for the WHO heads of country offices. Copenhagen: WHO Regional Office for Europe

http://www.euro.who.int/_data/assets/pdf_file/0012/307200/Joining-EVIPNet-Europe-HCO.pdf

Interesting threads of information from the HTAi PCIG listserv discussion

Sinikka Sihvo let us know that she is also interested in the impact of involvement as Finland is preparing for reforms. In Finland, by law, citizens should be involved in the planning of health and social services, where strategy building is one example

Christina, Taiwan Alliance of Patients' Organizations, informed us that they are participating in Taiwan Center for Drug Evaluation (CDE) research on 'public' participation in new drug reimbursement. Their issue is should it be public participation or patient participation first, in new drug reimbursement, especially when many of these new drugs have a strong budget impact.

Richard Norris (Scottish Health Council) shared some of his work. From Canada, Jo Nanson told us that a group at the University of British Columbia and the BC Cancer Agency are doing work on public participation in health care decision making, and gave a contact. Barry Stein highlighted that Canadian Partnership Against Cancer (CPAC) has completed a citizen engagement project in partnership with the Canadian Association of Cancer Agencies (CAPCA), which he is happy to follow up on. He also alerted us to the Canadian Institutes of Health Research (CIHR) Framework for Citizen Engagement http://www.cihr-irsc.gc.ca/e/documents/ce_framework_e.pdf. Cees Smit from the Netherlands also had a link.

Kristina Staley, England, knew of a reference by Fredriksson & Tritter (2017) on 'Disentangling patient and public involvement in healthcare decisions: Why the difference matters'; in *Sociology of Health and Illness* Jan;39(1):95-111. Other references were contributed by Sally Wortley (Degeling, Chris, Stacy M. Carter, and Lucie Rychetnik. 'Which public and why deliberate?—A scoping review of public deliberation in public health and health policy research.' *Social Science & Medicine* 131 (2015): 114-121.

<http://www.sciencedirect.com/science/article/pii/S0277953615001458>

and François-Pierre Gauvin provided his list of systematic reviews.

This was a stimulating journey, thank you all.

Surgical mesh in the news, again

The Therapeutic Goods Administration (TGA) in Australia is seeking comments from interested parties on proposed changes to up-classify regulation of surgical mesh from Class IIb to higher risk Class III; and to require provision of patient medical device ID cards (patient implant cards) to patients. These changes align the regulation of surgical mesh with the European medical device regulatory framework. The consultation closes on 25 August 2017.

Consultation: Up-classification of surgical mesh & Patient implant cards

<https://www.tga.gov.au/consultation/consultation-alignment-european-medical-device-regulatory-framework>

I am happy to co-ordinate and submit the comments to the TGA as feedback from the HTAi Patient Group - all feedback from the HTAi Patient Group to be emailed to me (via e-mail address at the end of E-Bulletin) before 15 August.

Alessandra Doolan

Australia's new National Patient & Carer Organisation Standing Committee

The Centre for Community-Driven Research (CCDR) convened the Patient and Carer Organisation Standing Committee out of a need for leadership and to demonstrate best-practice in community engagement. The purpose of the Standing Committee is to consider and make recommendations on matters of strategic importance, relevant to the Australian health system, that relate to patient engagement in health policy, with a specific focus on Health Technology Assessment (HTA).

As a group that advocates on behalf of patients and their families, this also means helping decision-makers find solutions to issues affecting stakeholders. To this end, the Standing Committee will be a valuable resource to effectively engage with patient organisations working directly with grassroots communities, to understand their most urgent needs and what they would recommend for future patients.

Identifying education and support needs of patient organisations is part of its remit

Simone Leyden, Patient Panel member

<http://www.unicornfoundation.org.au/news/152/australias-national-patient-carer-organisation-standing-committee>

The Case for National Coalitions of Patient Organisations: Louder and Stronger Together

European Patients Forum (EPF) has recently developed and published a toolkit with the purpose of supporting the constitution of national coalitions. The toolkit is available for download at http://www.eu-patient.eu/globalassets/library/toolkits/epf-toolkit_nationalcoalitions.pdf

A national coalition of patient organisations is an umbrella organisation grouping national or regional patient organisations representing individual chronic conditions (Alzheimer's diabetes, multiple sclerosis etc) or groupings of conditions (rare diseases, cancers, mental health conditions, etc). By coming together, these organisations create an umbrella that represents the collective interests of all patients in one country. <http://www.eu-patient.eu/News/News/the-case-for-national-coalitions-of-patient-organisations-louder-and-stronger-together/>

Webinars, tools and courses

IMI GetReal

Our online course about Real-World Evidence in Medicine Development starts on October 2nd. Find out more now!

<http://www.imi-getreal.eu/Course>

EUPATI guidance document webinars

These are now all in one place

<http://r.email.eupati.eu/266t74v2gi7f.html>

Marleen Kaatee

McMaster Health Forum

This month's 'hot docs' includes:

The patient perspective on the effects of medical record accessibility: A systematic review

<https://www.healthsystemsevidence.org/articles/78916-the-patient-perspective-on-the-effects-of-medical-record-accessibility-a-systematic-review>

Hashem, F., Calnan, M.W., Brown, P. Decision making in NICE single technology appraisals: How does NICE incorporate patient perspectives? *Health Expectations*. 2017; 00: 1- 10 (<https://doi.org/10.1111/hex.12594>) or <http://onlinelibrary.wiley.com/doi/10.1111/hex.12594/epdf>

This paper 'follows on' from:

Sarah Berglas, Lauren Jutai, Gail MacKean and Laura Weeks at CADTH, Patients' perspectives can be integrated in health technology assessments: an exploratory analysis of CADTH Common Drug Review. *Research Involvement and Engagement* 2016;2:21.

Janet Wale, HTAi PCIG

E-mail: socrates111@bigpond.com