

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

Enhanced quality and relevance of HTA through patient and citizen involvement

Welcome to this month's E-Bulletin!

But first, a few questions so that we can understand our audience and what you want from the E-Bulletin. Responses, with thanks, to Janney Wale, e-mail: socrates111@bigpond.com

Please answer the following questions in terms of how you usually respond to the HTAi PCIG E-Bulletin e-mail in your Inbox.

1. Do you open the e-mail:
Soon after receiving it...
When you have more time to go through it...
If the latter, when is this most likely to be (eg Friday afternoon, over weekend, other)...
2. What would you like to see more of in the E-Bulletin....
3. What would you like to see less of....
4. What, if anything, do you always try to read...
5. How can we improve the presentation of the E-Bulletin...
6. How often do you want to receive an E-Bulletin....
7. Do you have any other comments you would like to make....



HTAi Annual Meeting 2017: Explore how the global HTA community is evolving towards an integrated ecosystem – from local needs to global opportunities

Join us for HTAi's 14th Annual Meeting June 17-21, 2017 at the Ergife Palace Hotel in Rome, Italy.

Take note, early bird registration: by March 3, 2017

Proposed changes to improve patient and public involvement at NICE

Neil would like to let the PCIG know that he has pulled the comments he received into one document and has submitted them.

Neil Bertelsen

Employment Opportunity: Executive Director, Health Technology Assessment international

Health Technology Assessment international (HTAi) is a professional global society established to support all stakeholders who use or produce HTAs for policy decision makers. HTAi was formally established in 2003, with membership collaborations dating back to the early 1980s. The Society has seen growth year on year with over sixty international organisational and thousands of individual members currently. HTAi's Strategic Plan through to 2020 is designed to support the international HTA community. As HTA increases to become a more prominent method for policy decision makers to use in the comprehensive assessment of drugs and medical devices, HTAi becomes an ever-increasing hub for international dialogue.

The HTAi Board of Directors is seeking an energetic, articulate, experienced business leader to consolidate and build on substantial recent transitions and further establish the business models of the Society to support continued growth and ensure our long-term sustainability. Ideal candidates would be looking to commit to the position as a start to their next five-year career plan.

Job Description

The Executive Director is responsible for all operations of the Society, and is to ensure as head of the Secretariat and main point of contact for the Society's contractors that the agreed-to levels of support to the Society's members as directed by our elected Board are delivered efficiently and professionally. The Executive Director is responsible for using resources available to:

- Oversee and actively contribute to all general internal operations, such as the Society's Financial Audit, the Society's annual budget, monthly monitoring and reporting on financial and workload performance, the delivery of the Annual Meetings, Policy Forums, and the enhancement of Interest Groups activities;
- Manage a team of 5-7 members of staff, their hiring, ensuring the Society's compliance with the Employment Standards of Alberta, allocating and reviewing work flow and operational and administrative systems support, performance reviews;
- Manage and provide guidance to the Chairs of all formal committees of the Society, such as the Board of Directors, the Executive Committee and the Finance and Audit Committee;
- Work with the Chair of the Business Development Advisory Committee to critically appraise and enhance all operational business models, develop short, medium and long term business plans and consider avenues for revenue generation to support staggered investment in activities of the Society's membership;
- Develop, implement with continual improvement the progress on the Society's Strategic Planning;
- Ensure all workings of the Society are compliant with the Society's by-laws and the Societies Act of Alberta;
- Take an active role in member and external organisational partner engagement, as possible, connect members and partners with common interests to support discussions within the community;
- Lead, with support by the Board, the fostering of relationships with key sponsors, and take an active role in fund raising;
- Oversee and actively contribute to capacity building, liaise with the Editor-in-Chief and Publisher of the Society's journal, the running of all associated committees, the procurement, administration, delivery and evaluation of the Society's contractors, the development and implementation of the Society's communications plan;
- Any other duties as required as directed by the Society's President, Society's Board or Senior Management of the Host Institution.

For requirements and further information, please email info@htai.org. Applications to info@htai.org by Friday, March 24, 2017.

PCIG releases draft patient group submission documents for diagnostics – for your comments

Please contact Karen Facey if you would like to comment on the documents (Karen.facey@btinternet.com).

The IMI PREFER (patient preferences project)

<http://www.imi-prefer.eu/>

Kathi Apostolidis has let us know that her organisation the European Cancer Patient Coalition (ECPC, <http://www.ecpc.org/>) has a key role in this project. Kathi is Vice-President.

Consultation on HTA in Europe

The European Commission public consultation on how to strengthen EU cooperation on Health Technology Assessment (HTA) has closed with good responses from patient organisations and a number of individuals.

http://ec.europa.eu/health/technology_assessment/consultations/cooperation_hta_en

You may find [here](http://ecpc.org/ECPC%20position.pdf) ECPC's response to the EU Consultation (<http://ecpc.org/ECPC%20position.pdf>). You can also see the questions asked as this is a template.

Highlights from the European Patients' Forum (EPF)

"How to Achieve Universal Health Coverage for All Patients by 2030"

From January 2017, EPF carries a one-year flagship campaign on Access to Healthcare. This theme is a long standing priority for EPF and its membership, and is at the heart of the vision of the organisation.

Under the tagline 'Universal Health Coverage For All', the campaign is an opportunity to raise awareness about the barriers patients face in accessing healthcare, and to build on current political momentum – including the [UN Sustainable Development Goals](#) for health – to foster more EU cooperation on access to healthcare.

EPF has used its prior work on access to shape the messages of the campaign; in particular looking at the [definition](#) of access to healthcare, and the statement on [pricing](#) and reimbursement of innovative medicines.

Why a campaign on access?

Disparities in access to healthcare predate the financial crisis in Europe, but against a background of austerity measures and falling healthcare spending in many Member States since 2009, inequalities have been made worse. Access to care is affected by austerity policies in response to the economic crisis, such as cuts in healthcare budgets and in insurance coverage, increased fees and co-payments, and cuts in social protection measures.

At the same time, healthcare systems are facing increasing demands as a result of demographic change. As the population ages, the number of patients with chronic diseases is growing. Patients who developed a chronic disease at a younger age are also living longer, thanks to modern medical treatments. Patients with chronic diseases develop specific needs which the healthcare systems need to adapt to.

Patients across the EU are reporting multiple barriers to access to healthcare, whether it's not available, not adapted to needs, or not affordable. EU Member States need to overturn the current trends of short sighted decisions on investment in healthcare, and commit to realising universal access by 2030 by taking concrete steps. EU Member States need to achieve universal health coverage and improve access to healthcare by 2030 according to the UN Sustainable Development Goals.

<http://www.eu-patient.eu/campaign/access-to-healthcare/>

In a climate of suspicion that currently exists around the way financial support is allocated to non-government organisations (NGOs), their role and added-value is too often misunderstood or not recognised.

NGOs, including patient groups, working on European issues are confronting with serious challenges in resourcing their organisations to be able to harness the experience of their members and contribute effectively to EU activities in the health and social sphere.

There is a broad commitment from patient organisations to transparency, one of EPF's core values. We would like to recall that NGOs benefiting from EU grants already need to state their sources of funding and financial statements.

We agree that the current system could be improved, through simplification of the application and reporting system for example.

Adverse events are underreported in cancer targeted therapy trials

Copenhagen, Denmark—More than half of 81 trials leading to the approval of a targeted therapy were judged to not be fully transparent about the risk for adverse events (AEs), according to a new study. The investigators suggested that the underreporting of AEs might be a more frequent occurrence with targeted treatments than conventional cytotoxic chemotherapies.

"Toxicities of targeted agents and immunotherapy are obviously different from the toxicities we are used to observing and treating due to chemotherapy, and there are some aspects of the toxicities of these newer agents for which we probably need more information," reported Paolo Bossi, MD, a research oncologist at the Fondazione IRCCS at Istituto Nazionale dei Tumori, in Milan.

In this study, presented at the 2016 European Society for Medical Oncology Congress (abstract 320P), the published manuscripts on targeted therapy trials in a variety of solid malignancies, including lung, breast and colon, were scored for AE reporting with a 24-point rating tool developed by the Consolidated Standards of Reporting Trials (CONSORT) Group. The CONSORT initiative was specifically founded to establish standards for clinical trial methodology.

The most common deficiency in AE reporting was in describing recurrent and late toxicities, which was suboptimal in 90% of the trials. Information about the duration of AEs also was frequently absent. In about 25% of cases, reporting of AEs included only those that occurred at a rate that exceeded a fixed threshold, such as 15%, and only about one-third of published studies that permitted dose adjustments for AEs provided data on when or whether changes were made.

Targeted agents, many of which are administered for extended periods, are typically better tolerated than cytotoxic therapies, but AEs—even if milder—have the potential to persist longer because of the longer treatment duration. For this reason, standard AE reporting by treating physicians may be insufficient, according to Dr. Bossi. Instead, an analysis of tolerability from the patient's perspective, using validated instruments now available for this purpose, is likely to provide better information for counseling patients.

These instruments "will allow physicians to collect symptoms [that] are reported by the patients, considering also the severity, intensity and influence of the symptoms on their quality of life," Dr. Bossi said.

Reinforcing this point, Nathan Cherny, MD, the head of palliative care at Shaare Zedek Medical Center, in Jerusalem, noted that there is substantial evidence that physicians underreport AEs and their severity compared with patients. Although Dr Cherny said data submitted to regulatory agencies are likely to be more complete than data in published studies that are not submitted for regulatory approval, he agreed that greater transparency in AE reporting for targeted therapies would be helpful in clinical decision making. "These findings," he said, "lend further support to the proposal to radically reevaluate the collection and reporting of adverse event data to give weighting to patient-reported data." Ted Bosworth

<http://www.clinicaloncology.com/Current-Practice/Article/02-17/AEs-Are-Underreported-in-Targeted-Therapy-Trials/40357>

American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network® (NCCN®) announce a joint collaboration to publish practical clinical guidance on the management of side effects caused by immunotherapy.

The side effects of immunotherapy are generally mild and infrequent, but when they do occur, they can be serious and even life threatening if not identified and treated in a timely manner. They are often different from the side effects associated with other traditional cancer treatments, so it is important that clinicians know how to recognize and manage them.

https://connection.asco.org/magazine/society-member-news/guidelines-planned-management-immunotherapy-side-effects-asco-and-nccn?et_cid=38987841&et_rid=933006565&linkid=ASCO+Joins+C%2fCan+2025+Initiative+as+Founding+Partner

Bulletin du Labo du partenariat / Partnership Lab Bulletin
Février/February 2017

Engagement en recherche / Engagement in research

[Patient engagement evaluation tools](#) (Accès libre/Open access)

Patients Canada (2017)

[Patient-and community-oriented research: How is authentic engagement identified in grant applications?](#) (Accès libre/Open access)

Ramsden et al. (2017) *Canadian Family Physician*

[A critical discussion of patient engagement in research](#) (Accès libre/Open access)

Bombak & Hanson (2017) *Journal of Patient-Centered Research and Reviews*

[How are PCORI-funded researchers engaging patients in research and what are the ethical implications?](#) (Accès libre/Open access)

Ellis & Kass (2017) *AJOB Empirical Bioethics*

[Integrating consumer engagement in health and medical research: An Australian framework](#) (Accès libre/Open access)

Miller et al. (2017) *Health Research Policy and Systems*

[A 'work in progress'? UK researchers and participation in public engagement](#) (Accès libre/Open access)

Burchell et al. (2017) *Research for All*

[Changing what researchers' think and do': Is this how involvement impacts on research?](#) (Accès libre/Open access)

K Staley (2017) *Research for All*

[Stroke through a lens: Exposing the challenges of establishing a visual arts project as a research engagement activity](#) (Accès libre/Open access)

Cook et al. (2017) *Research for All*

[Public and patient participation in health policy, care and research](#) (Accès libre/Open access)

de Freitas (2017) *Porto Biomedical Journal*

[Engaging patients with heart failure into the design of health system interventions: Impact on research methods](#)

Newhouse et al. (2017) *Geriatric Nursing*

[Patient engagement in pharmacy practice research](#)

Adesanoye & Guirguis (2017) *Canadian Pharmacists Journal*

[Developing a patient and family research advisory panel to include people with significant disease, multimorbidity and advanced age](#)

Portalupi et al. (2017) *Family Practice*

[Patient-centred outcomes research: Brave new world meets old institutional policies](#)

Chung et al. (2017) *Family Practice*

[Patient and public involvement in emergency care research](#)

Hirst et al. (2016) *Emergency Medicine Journal*

[Involving patients in hospital-based HTA: Experiences, approaches, and future directions](#)

Gagnon et al. (2016) *Hospital-Based Health Technology Assessment*

Engagement dans la transformation des systèmes de santé / Engagement in health-system transformation

[Patient and Citizen Innovation Council in family practice](#) (Accès libre/Open access)

Garnett et al. (2017) *Canadian Family Physician*

[Can patient involvement improve patient safety?](#) (Accès libre/Open access)

Lawton et al. (2017) *BMJ Quality & Safety*

[Patient involvement can affect clinicians' perspectives and practices of infection prevention and control: A "post-qualitative" study using video-reflexive ethnography \(Accès libre/Open access\)](#)

Wyer et al. (2017) *International Journal of Qualitative Methods*

New book >> [Participation in Health and Welfare Services: Professional Concepts and Lived Experience](#)

Eide et al. (2017) Routledge

["What is "the patient perspective" in patient engagement programs? Implicit logics and parallels to feminist theories"](#)

Rowland et al. (2017) *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*

[The productive techniques and constitutive effects of 'evidence-based policy' and 'consumer participation' discourses in health policy processes](#)

Lancaster et al. (2017) *Social Science & Medicine*

[Healthcare leaders' views on successful quality improvement initiatives and context](#)

Barson et al. (2017) *Journal of Health Organization and Management*

[Les patients experts: Quelle réalité? Quel rôle?](#)

Avril (2017) *Médecine des Maladies Métaboliques*

Engagement en santé des communauté / Engagement in community health

[Blending qualitative, quantitative, and rhetorical methods to engage citizens in public deliberation to improve workplace breastfeeding support \(Accès libre/Open access\)](#)

Anderson et al. (2017) *Communication Studies and Theatre Faculty Publications*

[The role of policy coalitions in understanding community participation in healthy cities projects](#)

Clavier & O'Neill (2017) *Healthy Cities*

[Rural health services and the task of community participation at the local community level: A case study](#)

Wilson et al. (2017) *Australian Health Review*

Engagement en enseignement / Engagement in teaching

[Evaluation of a co-delivered training package for community mental health professionals on service user and carer involved care planning \(Accès libre/Open access\)](#)

Grundy et al. (2017) *Journal of Psychiatric and Mental Health Nursing*

[Participation des patients à la formation continue des professionnels](#)

Verheye & Devos (2017) *Soins: la revue de référence infirmière*

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