

## HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, January 2018

*Enhanced quality and relevance of HTA through patient and citizen involvement*

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

新 X n 年 nián 快 kuài 乐 lè!



The Chinese year of the Dog will begin in February. A Dog's most defining characteristic is their loyalty. They will never abandon their friends, family or work. Honest and just, they are popular in social circles. Everyone needs a Dog friend for advice and help. They are worried and anxious inside. However, they will not let this stop them. Once they decide on something, no one can persuade them against it.

- Welcome to Rebecca Addo, our technical officer
- Patient Involvement and Education Working Group news
- President Sean Tunis writes about the HTAi Asia Policy Forum in 2017
- What's happening – in the world of patient and public involvement
- Interesting Publications

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### Welcome to this E-Bulletin - and

#### 'Welcome' to Rebecca Addo as our Technical Officer for 2018/19!

Rebecca is from Ghana and has a background in nursing and public health. At present she is completing her PhD in Sydney Australia. Rebecca started on 1 January has started as Technical Officer for the PCIG and we are at present developing our working relationship with her. We are keen that the relationship is mutually beneficial. This should not be difficult as Rebecca is keen to learn about patient and citizen involvement and explore how it can be applied in non-Western countries. She will be providing us with technical support for our Steering Committee meetings and with communication.

This is a new initiative by the HTAi Secretariat and Interest Group Steering Committee (IGSC) as part of its engagement and educational development strategy.

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#### Other Technical Officer positions

Now the Assessment of Vaccination Programs; Disinvestment and Early Awareness; Ethics in HTA, and Information Retrieval Interest Groups are looking for someone keen about pursuing or advancing career prospects in the field of HTA: The person needs to be dedicated, enthusiastic and willing to provide one to

two days a month to administratively support their Chair(s) and Executive Committee as a Technical Officer (TO), from April 1, 2018 to December 31, 2019. There is a stipend of \$1,750 CAD for this TO position.

Technical Officer Position Guidelines are available and submissions due by Wednesday, February 21, 2018 to [interestgroups@htai.org](mailto:interestgroups@htai.org). You must be a paid member of HTAi to apply for this position. If you have not renewed your membership, you can do so at <https://www.xcdsystem.com/htai/member/>.

If you have any questions, please contact Rebecca Trowman, Policy Forum and Interest Group Manager, at [rtrowman@htai.org](mailto:rtrowman@htai.org)

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### **PIE Working Group has its first teleconference for 2018**

The PCIG Working Group on Patient Involvement and Education (PIE) has expanded its membership for 2018. It is keen to further its work on a Resources Directory for resources to inform patients and patient groups about HTA and patient involvement and was successful in obtaining 2017 HTAi funding for Interest Groups to develop the Directory on the website. If your organization has not completed our questionnaire you can still do so by emailing Melissa at [htai.pie@gmail.com](mailto:htai.pie@gmail.com)  
If you are keen to work on a project with PIE please let us know!

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### **Register now for the HTAi 2018 Annual Meeting**

Follow this [LINK](#).

Join HTAi 2018 to engage with an extensive network of leaders, experts and key policymakers in lively discussions around the theme of the meeting: **"Strengthening the Evidence-to-Action Connection"**. HTAi welcomes those invested in the production and implementation of HTA from Canada, neighbouring countries and around the world.

### **Early Bird Registration ends on March 31, 2018**

Any questions regarding Registration, contact [registration@htai.org](mailto:registration@htai.org)

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### **HTAi looking for one engaged, motivated and enthusiastic Board Director for a three-year term between 2018 and 2021.**

HTAi is seeking active members of the Society for nomination to the Board of Directors. At the time of appointment, the Society will be at the mid-point of implementing our 2015 – 2020 Strategic Plan and will be busy working towards achieving our current goals while looking ahead.

Nominees should be prepared:

- To chair at least one of the new advisory board committees,
- To sit as a member of at least two committees or working groups,
- To travel and attend two face-to-face Board meetings, and
- To perform other duties, as requested.

Deadline: Thursday, February 15, 2018, 23:59 MST (GMT +7). [info@htai.org](mailto:info@htai.org)

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### **President Sean Tunis reports on the 5<sup>th</sup> HTAi Asia Policy Forum: Momentum Continues to Build**

Excerpts from a blog at: <https://www.htai.org/htai/presidents-blog/december-2017/>

This Forum brought together nearly 50 individuals from public and private sector organizations, with representatives from 11 countries, including China, Thailand, South Korea, Malaysia, Vietnam, Japan, Taiwan, Singapore, Philippines, Indonesia, and Iran. For the latter three countries, it was the first time they had participated in the HTAi Asia Policy Forum. We also had active participation from the World Health Organization global and regional offices, along with staff from 11 pharmaceutical and device companies. Several senior officials from the Chinese government also attended and spoke at the Forum ... Each speaker emphasized the essential role that they see for HTA as a part of their efforts to expand access to health care across their population of 1.34 billion people.

At a very high level, the two-day conversation explored the role of HTA in the context of progress toward Universal Health Coverage (UHC) in Asia. Healthcare systems in Asia are experiencing tremendous

pressures exerted, in part, by increasing urbanization, aging populations and a dramatic increase in chronic non-communicable disease... They need to find ways to strike the right balance in providing essential health care services, while increasing access to care, and also reducing health inequalities and out-of-pocket expenditure.... There was a particular focus on the potential role that real-world data (RWD) can play in this context.

There were a remarkable number of insightful comments made by presenters and during the plenary discussions, many of which have been summarized in the latest Policy Forum series newsletter, and further detail will be available in journal publications in the next several months. A selection of a few particularly noteworthy comments included:

- HTA is one priority setting tool that can be used to overcome some of the barriers to achieving UHC, but it must be used appropriately to the local context while also taking account of the budget impact and affordability within the Asia region.
- Countries in the region need to define their healthcare priorities, identify technologies that address these priorities and then conduct HTA. HTA should be used to prioritize and evaluate services of all technologies in a pathway of care, rather than focus on single technologies in isolation.
- There is a disconnect between what RWD the HTA agencies collect, and what industry and academics have knowledge of, and access to, in the Asia region. This could be improved by greater collaboration and trust between agencies, private sector experts and stakeholders.

By the end of the second day, there was a palpable appetite in the room to find ways to move from dialogue to action on some of the ideas discussed...

Sean would welcome your feedback on this message. Comments or suggestions for future topics, or highlights of noteworthy activity within the wide world of HTA also welcome [sean.tunis@cmtpn.org]

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## What's Happening:

### **ISPOR Establishes New Patient Council, an advisory group to the ISPOR Board of Directors**

In early January, ISPOR, the professional society for health economics and outcomes research, announced the establishment of the sponsored advisory council devoted to patient engagement. The ISPOR Patient Council serves as a platform for dialog and information sharing among the Society's global patient engagement groups, as an advisory body to the Board of Directors, and as a main contributor to the development and implementation of ISPOR patient initiatives. Chairs from each of the Society's Patient Representatives Roundtables (Europe, North America, Latin America, and Asia Pacific) will be on the Council.

Qualifications for advisory members include: Expertise in patient research; ISPOR member; Invited experts from different stakeholders, such as, academic, payers, industry, government, and HTA, when necessary.

The mission of the ISPOR Patient Council is to determine how best to engage patient representatives in research and decision making processes and in ISPOR strategy.

<http://press.ispor.org/index.php/isp-or-establishes-new-patient-council/>;

<https://www.ispor.org/councils/PatientCouncil.asp>

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### **Theme issue on INTEGRATE-HTA published**

In December 2017, a theme issue on INTEGRATE-HTA was published in the International Journal of Technology Assessment in Health Care.

INTEGRATE-HTA, a FP7 research project, aimed to adapt and develop concepts and methods for HTA to enable an integrated assessment of issues of complex technologies as follows:

- Assessment of effectiveness and economic, socio-cultural, ethical, and legal issues of complex technologies
- Assessment of patient preferences and patient-specific moderators of treatment
- Assessment of context, setting, and implementation
- Integrating all issues in a comprehensive patient-centred assessment

- Closing existing methodological gaps in the assessment of complex technologies
- Palliative care was used as a case study to test the methodology developed within the framework of the INTEGRATE-HTA project. Insights from the case study were subsequently used to refine the developed methodology and enhance its applicability to other complex technologies. This resulted in six guidances:
- Guidance on the integrated assessment of complex health technologies – The INTEGRATE-HTA Model
  - Guidance for assessing effectiveness, economic aspects, ethical aspects, socio-cultural aspects and legal aspects in complex technologies
  - Guidance for the assessment of treatment moderation and patients' preferences
  - Guidance for the Assessment of Context and Implementation in Health Technology Assessments (HTA) and Systematic Reviews of Complex Interventions: The Context and Implementation of Complex Interventions (CICI) Framework
  - Guidance on the use of logic models in health technology assessments of complex interventions
  - Guidance on choosing qualitative evidence synthesis methods for use in health technology assessments of complex interventions

Parts of these guidance documents have been applied by the Canadian Agency for Drugs and Technologies in Health (CADTH). The theme issue contains an article about this application, as well as articles by members of the project team describing the results of the project, and several valuable contributions from international HTA experts on the usefulness of INTEGRATE-HTA.

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/issue/9155BC31AEBE05CA4DE4F3AF0D6B6D2A>

Submitted by Wija Oortwijn

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### **Evaluation of HTA for the Dutch government**

In April 2015, ZonMw published an evaluation report of the HTA methodology programme from August 2007 to December 2014. ZonMw then installed an external committee, in April 2015. The goal of the self-evaluation was to justify the programme budget to the Ministry of VWS. The more recent evaluation was to review the self-evaluation report and to formulate recommendations for the future. In this report, the external evaluation committee of the HTA methodology programme provides its conclusions and advice to ZonMw in accordance with its tasks.

The ZonMw HTA methodology programme has contributed to the development and improvement of HTA methodology for application in drug efficiency research and in other fields. It is, however, difficult to draw firm conclusions with regard to the actual impact of the HTA methodology programme on policy and practice at this point in time. This might be due to the fact that most of the impact is indirect (using better HTA methods that influence policy making). Measuring the actual impact of projects too soon after the completion of the research is problematic. It probably also would have been beneficial to engage relevant stakeholders more clearly (e.g. in selecting research themes, providing methodology training after completion of projects) as this stimulates translation of evidence in practice and policy.

The fact that the programme already has resulted in many international publications and contributions to international conferences shows clearly the success of the programme. It definitely has contributed both to the high international standard and quality of HTA research(ers) in the Netherlands, as well as to advancing the HTA methodology field.

[https://www.zonmw.nl/fileadmin/zonmw/afbeeldingen/Geneesmiddelen/121218\\_Evaluation\\_Health\\_Technology\\_Assessment\\_Methodology\\_Programma\\_DEF.pdf](https://www.zonmw.nl/fileadmin/zonmw/afbeeldingen/Geneesmiddelen/121218_Evaluation_Health_Technology_Assessment_Methodology_Programma_DEF.pdf)

Submitted by Marleen Kaatee

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### **FDA announcement on patient engagement**

The FDA announced the patient engagement collaborative and draft guidance regarding capturing patient experience data in submissions

<https://www.fda.gov/ForPatients/CommentonGuidance/ucm589787.htm>). This will have a big impact on pharmaceutical companies recognizing the need to engage in such activities since it is expected as part of

the FDA submission. It is not yet clear how the FDA will weight such patient-based evidence alongside other data, or what they will do when companies haven't fully engaged with patients.

Submitted by Nigel Cook

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### **EUPATI Webinar 8 February – no places available**

Registries a powerful tool in improving healthcare and treatment. What they are, what they contain, how patients can contribute.

This is a great opportunity to join the discussions, share your perspective and ask your questions in the Q&A sessions

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### **Research institute to gather evidence to better support health care and organisation decisions**

The University of Cambridge, England has opened a new, £42-million research institute. The Healthcare Improvement Studies Institute (THIS Institute) has been established with a 10-year grant from the independent charity the Health Foundation.

High quality evidence should be created by both users and providers of care. The THIS Institute will create a digital platform to crowdsource research ideas and collect data from NHS staff and patients, including their opinions on aspects of care.

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### **Publications**

Value-based pricing: L'Enfant terrible? A response to a Commentary written by S Garner, A Rintoul, SR Hill. *PharmacoEconomics* 2018;36(1),5-6.

<https://link.springer.com/article/10.1007%2Fs40273-017-0567-4>

Value-based pricing: Do not throw away the baby with the bath water. Commentary by Mattias Neyt. *PharmacoEconomics* 2018;36(1),1-3.

<https://link.springer.com/article/10.1007/s40273-017-0566-5>

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### **A New Way of Presenting Health States in Valuation Studies**

<https://www.ohe.org/news/new-way-presenting-health-states-valuation-studies>

In health state valuation studies, health states are typically presented as a series of sentences, each describing a health dimension and severity 'level'. Differences between the severity levels can be subtle, and semantic confusion about which is 'worse' can lead to logically inconsistent valuation data.

The paper examines how using the EQ-5D-5L – a patient-reported outcome (PRO) measure – to present PRO health states 'in context' may provide a way of helping respondents more readily differentiate between the pairs of health states they are being asked to value in discrete choice experiments. The new approach could offer even more advantage in time trade-off studies, where health states are presented one at a time.

Cole A, Shah K, Mulhern B, Feng Y and Devlin N. 2017. Valuing EQ-5D-5L health states 'in context' using a discrete choice experiment. *European Journal of Health Economics*. DOI: 10.1007/s10198-017-0905-7.

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### **A review exploring patient and family involvement**

Exploring patient and family involvement in the lifecycle of an orphan drug: a scoping review

Andrea Young, Devidas Menon, Jackie Street, Walla Al-Hertani and Tania Stafinski

*Orphanet Journal of Rare Diseases* 2017;12:188. Open Access

<https://doi.org/10.1186/s13023-017-0738-6>

<https://ojrd.biomedcentral.com/articles/10.1186/s13023-017-0738-6>

Existing and proposed opportunities for involving patients, families, and patient organizations were reported throughout the orphan drug lifecycle and fell into 12 themes: research outside of clinical trials; clinical trials; patient reported outcomes measures; patient registries and biorepositories; education; advocacy and awareness; conferences and workshops; patient care and support; patient organization development; regulatory decision-making; and reimbursement decision-making.

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Recommendations from two citizens' juries on the surgical management of obesity. PA Scuffham, R Krinks, K Chaulkidou, P Littlejohns et al. Obesity Surgery 2018. First online  
<https://link.springer.com/article/10.1007/s11695-017-3089-4>

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**Preferred Reporting Items for a Systematic Review and Meta-analysis of Diagnostic Test Accuracy Studies. The PRISMA-DTA Statement**

Matthew DF McInnes, David Moher, Brett D Thombs, et al; and the PRISMA-DTA Group  
JAMA. 2018;319(4):388-396. doi:10.1001/jama.2017.19163  
<https://jamanetwork.com/journals/jama/fullarticle/2670259>

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**What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences**

Munn Z, Stern C, Aromataris E, Lockwood C, Jordan Z. BMC Medical Research Methodology 2018,18:5. This paper presents a really helpful table, which organises review type, aim and question format together with example questions for ease of identification - a very handy tool for EBM and search skills trainers who want to steer participants towards more appropriate conceptualisation formats than the traditional PICO(S) or PICOT.  
<https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-017-0468-4>

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**Translating search jargon - a new glossary of terms about literature searching**

A comprehensive and sensible glossary of terms about literature searching produced by the Canadian Search Standards Working Group. I think this source will be a boon when communicating about searching, methods and why-we-do-what-we-do to non-searchers

[http://hlwiki.slais.ubc.ca/index.php/Canadian\\_Search\\_Standards\\_Working\\_Group\\_%E2%80%94\\_Glossary\\_of\\_Search\\_Terms\\_2017](http://hlwiki.slais.ubc.ca/index.php/Canadian_Search_Standards_Working_Group_%E2%80%94_Glossary_of_Search_Terms_2017)

From Kate Misso

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Janet Wale, HTAi PCIG

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