

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, September 2019

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 the September E-Bulletin – from our Chair

Thank you to all those who contributed comments to our PCIG response to the *MDIC White paper: Best practices for communicating benefit, risk and uncertainty*. PCIG members highlighted additional relevant work and issues relating to terminology, scope, audience and transparency. We are very grateful to Sam Thomas for compiling this response. The plan is to share submissions, such as this, on the HTAi website. Updating our online information will be a key priority following PCIG's face to face meeting hosted by KCE in Brussels in November. This year, we've invited Steering Committee members, project sub-committee leads and several local patient representatives to attend the meeting, which will focus on turning our new Terms of Reference into practical ways of working, including ensuring the success of our new projects. We'll share a report about the meeting before the end of 2019.

Meanwhile, don't forget the following dates for Beijing 2020:

Friday 4 October: Deadline for panel and workshop abstracts seeking PCIG endorsement. Email abstracts to Rebecca.Addo@chere.uts.edu.au.

Thursday 10 October: Deadline for HTAi 2020 panel and workshop abstracts (note if you submit your abstract to PCIG for endorsement, you still must submit the abstract to HTAi. See details on the website).

Thursday 21 November – Deadline for HTAi 2020 orals, posters and vignettes.

Ann Single, Chair – HTAi Patient and Citizen Involvement Interest Group
singlehaworth@gmail.com

PCIG Matters

Gap Analysis and Central Resource for Patient Involvement in HTA Project

In our project we are identifying the specific steps in the HTA process and potential needs/opportunities for patient involvement in each – as part of developing a framework to assess gaps in patient involvement across the spectrum of HTA processes worldwide.

We are wondering if anyone knows of existing published or unpublished work in this area that you could share with us?

Our present starting point is: Gauvin FP, Abelson J, Giacomini M, Eyles J, Lavis JN. "It all depends": conceptualizing public involvement in the context of health technology assessment agencies. *Soc Sci Med.* 2010 May;70(10):1518-26. doi: 10.1016/j.socscimed.2010.01.036

And Abelson, et al. Public and patient involvement in health technology assessment: a framework for action. *Int J Tech Assess Health Care* 2016;32(4):256-264, specific for Ontario, Canada.

Janney Wale (socrates111@bigpond.com), Sam Thomas (Samuel.thomas@roseliassociates.com)

Call for Project Participation in PCIG-LMIC Project

We are inviting interested stakeholders from Low- and Middle-Income Countries (LMIC) to join this joint project between the Patient- and Citizen Involvement Interest Group (PCIG) and the Developing Countries Interest Group (DCIG).

The objectives of this project are to (1) explore the current routes of patient involvement in LMICs, (2) collaborate with LMIC stakeholders to define LMIC-specific needs for patient involvement, and (3) develop and adapt guidance and tools to support patient and citizen involvement in HTA in emerging economies. We are looking for individuals from LMICs across the world who are interested in this subject and who bring a background in health technology assessment, as patient advocate, or have experience in this subject from another perspective. After formation of the full team, we will proceed with interactively developing a full project plan, which should help us to achieve our objectives as outlined above.

If you are motivated to work with us on this subject and are member (or are willing to become a member) of the PCIG or the DCIG, please send a letter of intent to the project leads (Jani Mueller and Anke-Peggy Holtorf) which specifies what your specific interests are, why you feel qualified and enthusiastic to work with us on this subject, and what your engagement background is. Altogether, we are looking for a maximum of 12 team members with mixed backgrounds from Latin America, Asia, the Middle East or Africa. If we receive more applications, we will select the team to have the broadest possible geographic, cultural and stakeholder representation. In addition, we are looking for a wider group of interested members, who will serve as advisers, sounding board, and reviewers to the project team.

The project leaders are:

Debjani (Jani) Mueller (DCIG) email: dbmueller7@yahoo.de

Anke-Peggy Holtorf (PCIG) email: anke.holtorf@health-os.com

PCIG Steering Committee Annual Meeting abstract endorsement process

The PCIG Steering Committee (SC) will endorse abstracts for up to two panels and one workshop for Beijing 2020. This endorsement will result in the abstract receiving 1 extra point when it is peer reviewed for possible acceptance for the annual meeting. If you are submitting a panel or workshop abstract and want it to be considered for endorsement, please:

1. Submit your abstract to PCIG Technical Officer, Rebecca Addo, no later than Friday 4 October (23:59 Mountain Standard Time), email Rebecca.Addo@chere.uts.edu.au, noting the PCIG Endorsement Criteria (below).
2. Make sure that you submit your abstract to HTAi no later than 10 October (23:59 Mountain Standard Time) regardless of PCIG endorsement outcome as PCIG SC does not submit the abstracts. Ensure you take account of the HTAi criteria. Note that this year's submission systems and guidelines have changed. Further information: <https://www.htai2020.org/abstracts/>.

The PCIG SC is trialling a structured process for endorsing abstracts this year. SC members will review and score abstracts in survey monkey according to endorsement criteria (below). As part of this process, SC members will indicate if they are part of the group submitting the abstract. Before 10 October, the PCIG Chair will advise the HTAi International Scientific Program Committee (ISPC) and PCIG members of the abstracts PCIG endorsed.

PCIG criteria:

- a) The concept is appropriate to HTAi and aligns with the main themes of the Annual Meeting Beijing 2020.
- b) The abstract addresses a pressing issue in patient and/or citizen involvement in HTA.

- c) The workshop or panel is comprised of people with appropriate expertise about the subject matter and collectively represent a variety of perspectives or settings.
- d) The workshop or panel is structured to achieve its deliverables.
- e) Workshop or panel abstract meet quality and style requirements.
- Additional consideration: The panel is connected to or supports a PCIG project (Note, SC will take account of current projects but also wishes to encourage innovative work not covered by current project program).

Ann Single, PCIG Chair

HTAi Matters



HTAi 2020 Annual Meeting Beijing
Attaining, maintaining and sustaining healthcare systems in a changing World: the role of HTA [HTAi2020.org](https://www.htai2020.org)

Details are available for the main theme [https://www.htai2020.org/the-role-of-hta/and plenaries](https://www.htai2020.org/the-role-of-hta/and-plenaries)
<https://www.htai2020.org/the-role-of-hta/>

Abstract submission is open: <https://www.htai2020.org/abstracts/>

Submission deadlines are different based on submission type. Please note below the important dates regarding abstract submissions and be advised that no extensions to these deadlines will be made.

Deadline for Workshop and Panel submissions: October 10, 2019

Acceptance notification: November 11, 2019

Deadline for Oral, Vignette and Poster Presentation submissions: November 15, 2019

Acceptance notification: February 1, 2020

Travel grants <https://www.htai2020.org/travel-grants-2/>

Travel Grant Applications will open: October 4, 2019

Deadline to submit a Travel Grant Application: November 15, 2019

Successful/Unsuccessful Application Notification: February 3, 2020

HTAi offers Travel Grants to support HTA stakeholders who would otherwise not be able to attend the HTAi Annual Meeting for the purpose of contributing their expertise, presenting their work or otherwise benefitting from participation in the global HTA community. These grants are funded directly by HTAi and in some cases, are sponsored by external parties on an unconditional basis.

To be eligible for an HTAi Travel Grant, applicants must qualify to represent one of the following groups:

a. Resides in a low or middle-income country (as defined by the World Bank Link);

Please note: Individuals temporarily residing in a high-income country but maintaining permanent residence in a low or middle-income country may apply for an HTAi Travel Grant. However, preference may be given to individuals currently residing in low or middle-income countries.

b. A patient or care-giver who can provide patient insights relevant to health policy and health technology assessment and is associated with a not-for-profit patient engagement network. (necessary to provide a letter of confirmation from organization represented);

c. Full-time student enrolled in a post-secondary education program or course for HTA (necessary to provide a certificate of enrollment).

In addition, the applicant must meet at least one of the following criteria:

a. Be a participant in the submission of an abstract for a panel or workshop or have an abstract submitted for an oral, vignette or poster presentation;

- b. Demonstrate a current link (volunteering, employment or academic) to an HTA agency, government body, or academic research center, or to another area of the health system with clear relevance to the field of HTA;
- c. Demonstrate clear interest in becoming involved in the field of HTA (e.g. through study or the establishment of HTA activities in the applicant's jurisdiction). Applicants must provide a letter of support in relation to becoming involved in the present or the future.

Make sure you let PCIG know so we can provide you with a letter of endorsement for the work you do with us.

Please do follow us on social media and repost our messages: #HTAi2020Beijing

Twitter: twitter.com/HTAiOrg @HTAiOrg

Facebook: www.facebook.com/HTAiOrg @HTAiOrg

LinkedIn: www.linkedin.com/company/htai

Call for Interest Group technical officers

Deadline for applications – October 4, 2019.

We are looking for dedicated and enthusiastic HTAi members willing to provide coordination support to the Chairs and Executive Committees of the following Interest Groups (IGs), on a two-year term, commencing January 1, 2020.

- Hospital-Based HTA
- HTA in Developing Countries
- Medical Devices

A total of three positions are open— one per listed Interest Group. Responsibilities will vary by Interest Group and will be guided by respective IG Chair(s), IG Executive Team or IG Steering Committees.

Examples include defining agendas, setting calls and taking minutes, writing reports, supporting project work and scientific papers, drafting press releases, and other similar activities.

To find out more about these positions and how to apply, visit the HTAi

website: <https://htai.org/blog/2019/09/05/vacancy-interest-group-technical-officer-2020/>

If you have any questions regarding the role or application process, please email interestgroups@htai.org

Rebecca Stiffell, Coordinator, Scientific and Health Policy Initiatives

The Disinvestment & Early Awareness Alerts (Issue 2, September 2019)

<https://htai.org/interest-groups/disinvestment-and-early-awareness/ig-resources/>

This alert is a collaboration between HTAi, the Norwegian Institute of Public Health, and CADTH to provide updates on a quarterly basis on new studies relevant to disinvestment, reassessment, early awareness, and horizon scanning. We welcome your suggestions on how we can further improve this service to help meet the needs of your organization.

A special thanks to Julie Polisena and Vigdis Laurvraak, our past DEA-IG co-chairs, for their hard work and dedication to launching these alerts.

What's Happening

IMI PARADIGM holds open forum

Recently the Patient Engagement Open Forum from the PARADIGM project was held in Brussels. In the following link you have information (<https://twitter.com/PEOForum>). See the PARADIGM website (<https://imi-paradigm.eu/>) for further information.

Submitted by Maria Jose Vicente Edo

Evidera webinar: Patient Preferences in Health Technology Assessment in Europe: Recent Advances and Future Potential October 15, 2019 | 10:00 - 11:00AM EDT

<https://www.evidera.com/news-events/upcoming-webinars/>

The use of quantitative patient preference information (PPI) in decision-making has developed substantially over the past few years, particularly in the regulatory setting. There is also a growing interest in incorporating PPI into HTA. While the extent to which these data are useful from an HTA agency perspective has not always been clear, recent advances suggest that agencies are more interested than ever before. This is exemplified by NICE's recent promotion of their scientific advice on a patient preference study.

The presenters are both active in recent efforts to understand and extend the use of PPI in HTA. Kevin Marsh (Evidera) recently co-chaired an ISPOR working group that reviewed the use of preference information in HTA across Europe. Nigel Cook (Novartis) is a member of IMI PREFER and was the sponsor Principal Investigator on NICE's recent scientific advice on a patient preference study.

- Understand when and how patient preference information can support HTA submissions
- Learn how to collect patient preference information to support HTA
- Learn about possible future developments in the use of preference information in HTA

IAPO Asia-Pacific Patients Congress

<https://www.iapo.org.uk/>

Harmonisation for Patient-Centred Universal Health Coverage in Asia, 13 - 14 November 2019
Sheraton Grand Taipei Hotel, Taiwan (Republic of China)

A plain language consideration of the complexities of 'crossover' in oncology clinical trials

<https://www.cancer.net/blog/2019-09/what-treatment-switching-cancer-clinical-trials>

This is a blog post by an international team that was recently posted on the American Society of Clinical Oncology (ASCO) [Cancer.net](https://www.cancer.net).

Information about Standardised Data on Initiatives - STARDIT

In plain English it's a proposed way of sharing data about 'interventions', 'research', 'projects' and other similar words that describe any kind of 'initiative' or action, standardising data about initiatives and reporting impacts in multiple human languages.

We're keen to work with people from lots of different disciplines to talk about how we can report data in a similar way. It has been designed so it can help inform HTA processes, including reporting on how people have been involved in the process.

It is being hosted by the Wikimedia Foundation and we've just published a preprint, with authors from Cochrane, Campbell Collaboration, Health Research Authority UK, Poche Centre for Indigenous Research and La Trobe University. <https://osf.io/preprints/5q47h/>

We're looking to involve as many people as we can in the next stage of creating a peer-reviewed version.

More information here: <https://scienceforall.world/stardit/>

We'll be managing that process using this online discussion forum which anyone interested can [join here](#).

We're running an event in London on 1st October to discuss STARDIT and ways of improving it.

<https://www.eventbrite.com.au/e/standardised-data-on-initiatives-sharing-the-who-how-and-what-tickets-70595223213>

Jack Nunn, Director and Founder, *Science for All* scienceforall.world

Twitter: [@JackNunn](#) [@campfirescience](#) [@scifall](#)

Facebook: [Science for All](#) and [Campfires and Science](#)

Instagram: [@Campfiresandscience](#)

Email: info@scienceforall.world

ClinicalTrials.gov to modernise

<https://clinicaltrials.gov>

A short blog article outlining actions

<https://nlmdirector.nlm.nih.gov/2019/08/13/engaging-users-to-support-the-modernization-of-clinicaltrials-gov/>

EPF Transparency Guidelines now available

<http://www.eu-patient.eu/globalassets/library/toolkits/epf-transparency-guidelines.pdf>

Patient organisations are under increasing pressure to demonstrate transparency and good governance. They deal with health, which is a highly sensitive topic. They also operate in a complex external environment which includes relationships with regulators, healthcare professionals, and industry with high potential for real or perceived conflicts of interest. This calls for a high degree of integrity and accountability.

EPF is proud to announce that our Transparency Guidelines are now available online for your download, absolutely free. These guidelines aim at providing guidance on sound and ethical practices in the following fields: governance, cooperation with industry, membership, and communications.

EPF September Newsletter

Having the right tools & skills is key to make patient engagement happen and not be left behind

<https://patientfocusedmedicine.org/pe-training/>

Patient focused Medicines Development has launched Patient Engagement Industry Training. The program - requested and endorsed by pharma companies from the PFMD partnership and co-created together with other stakeholders - is now available to all.

The first module on what is meaningful patient engagement is now available for free, with others to follow soon.

CADTH Lecture Series – on cancer drugs

<https://www.youtube.com/watch?v=dNFga1iQ4B4&feature=youtu.be>

Video: Why Oncology Needs More Common Sense and Less Cheerleading, by Bishal Gyawali
With a global perspective

Interview with Dr Michael Raphael of Toronto, Ontario on progression-free survival

<https://podcasts.apple.com/au/podcast/2-15-bonus-value-progression-free-survival-as-treatment/id1429998903?i=1000451340700>

From his new paper in JAMA Oncology: "The value of progression-free survival as a treatment endpoint among patients with advanced cancer: a systematic review and qualitative assessment of the literature".
jamanetwork.com/journals/jamaonco...-abstract/2751879

Dutch Minister of Health writes open letter to pharma – on drug pricing

<https://medicineslawandpolicy.org/2019/08/dutch-minister-of-health-writes-open-letter-to-pharma-threatens-to-name-and-shame/>

EMA: From laboratory to patient: the journey of a centrally authorised medicine

https://www.ema.europa.eu/en/documents/other/laboratory-patient-journey-centrally-authorized-medicine_en.pdf

Publications

Coming from the IMI-PARADIGM project, a literature review on the benefits and costs of patient engagement in medicine development:

Vat LE, Finlay T, Jan Schuitmaker-Warnaar T, et al. Evaluating the “return on patient engagement initiatives” in medicines research and development: A literature review. *Health Expect.* 2019;00:1–14. <https://doi.org/10.1111/hex.12951>
<https://onlinelibrary.wiley.com/doi/10.1111/hex.12951>

Submitted by Nigel Cook

Marianne Botoft Hansen, Lotte Stig Nørgaard, Christine Erikstrup Hallgreen. How and Why to Involve Patients in Drug Development: Perspectives From the Pharmaceutical Industry, Regulatory Authorities, and Patient Organizations.

<https://journals.sagepub.com/doi/abs/10.1177/2168479019864294>

Submitted by Sophie Staniszewska

Special issue on Patient and public involvement and engagement

Health Expectations September 2019 Volume 22, Issue 4

<https://onlinelibrary.wiley.com/toc/13697625/2019/22/4>

Some interesting topics, including:

Puerta LL, Bartlam B, Smith HE. Researchers' perspectives on public involvement in health research in Singapore: The argument for a community-based approach. Pages: 666-675 First Published: 19 July 2019 Singapore is becoming a world-class research hub, promoting the advancement of patient care through translational clinical research. Despite growing evidence internationally of the positive impact of public involvement (PPI), in Singapore PPI remains unusual beyond patient participation as subjects in studies. The cultural reluctance of individuals to question perceived authority figures such as researchers may be overcome by adopting an approach to PPI that is closer to family and local community values, and which facilitates patients and the public collectively engaging in research.

Kuehn CM. (2019). A Proposed Framework for Patient-Focused Policy at the U.S. Food and Drug Administration. *Biomedicines*, 7(3). doi: <https://doi.org/10.3390/biomedicines7030064>

Cowley A, Kerr M, Darby J, Logan P. (2019). Reflections on qualitative data analysis training for PPI partners and its implementation into practice. *Research Involvement and Engagement*, 5(1), 22. doi: <https://doi.org/10.1186/s40900-019-0156-0>

Rahimi SA, Zomahoun HTV, Legare F. (2019). Patient Engagement and its Evaluation Tools—Current Challenges and Future Directions: Comment on "Metrics and Evaluation Tools for Patient Engagement in Healthcare Organization-and System-Level Decision-Making: A Systematic Review". *International Journal of Health Policy and Management*, 8(6), 378. <https://doi.org/10.15171/ijhpm.2019.16>

Keenan J, Poland F, Boote J, Howe A, Wythe H, Varley A, Vicary P, Irvine L, Wellings A. 'We're passengers sailing in the same ship, but we have our own berths to sleep in': Evaluating patient and public involvement within a regional research programme: An action research project informed by Normalisation Process Theory. *PLoS One*. 2019 May 14;14(5):e0215953. doi: 10.1371/journal.pone.0215953.

Gholamreza Roshandel et al. Effectiveness of polypill for primary and secondary prevention of cardiovascular diseases (PolyIran): a pragmatic, cluster-randomised trial. *Lancet* 24 August 2019.

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(19\)31791-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)31791-X/fulltext)

A cohort study with 50 045 participants aged 40–75 years from the Golestan province in Iran.

DOI: [https://doi.org/10.1016/S0140-6736\(19\)31791-X](https://doi.org/10.1016/S0140-6736(19)31791-X)

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