

## HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, March 2020

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

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

- Welcome
- PCIG Matters
- HTAi Matters
- What's Happening – in patient and public involvement
- Publications

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Welcome to our March E-Bulletin!

### From our Chair

What happened to our plans for 2020? You will be aware that HTAi has cancelled its Annual Meeting scheduled for Beijing in June. We are exploring which parts of the program may be adapted for other formats, such as webinars. At the PCIG Steering Committee on 25 March, we agreed to adjust our plans for 2020 and ensure we are supporting our members at this time rather than adding to their load.

It's a time of enormous stress, sorrow and uncertainty. We share a common foe in COVID-19, but each of us will have a unique experience of this time. I'm mindful that for our patient and carer members there is nothing new about living with stress, sorrow and uncertainty, but COVID-19 has made life much harder. It has created familiar, but new, challenges in having your voice heard and your needs recognised.

Thank you to those in the patient community who have been able to advocate for these needs, provide condition-specific COVID-19 information to their communities, or share practical advice from lived experience about self-isolating and coping.

Thank you to all in our membership who are working hard to provide essential healthcare, research, management, administration or social support.

Thank you to all our members who have put health first and stayed home.

### *New Steering Committee member*

At the PCIG Steering Committee on 25 March 2020, members voted unanimously to appoint Aline Silveira Silva to the Steering Committee. Aline, who is with the Brazilian Ministry of Health, has worked with PCIG on a variety of projects over the past four years. For her PhD, she has been researching perspectives, attitudes and guidance on what successful patient engagement in HTA looks like. We are delighted to have Aline as a Steering Committee member.

### *E-Bulletin survey - REMINDER*

Due to some issues with our email distribution list, we have extended our E-Bulletin survey. Please follow the link to complete our 5 minute survey on PCIG E-Bulletins (this monthly newsletter) **by 30 April**:

<https://www.surveymonkey.com/r/PY922SJ>

*Why?* PCIG is updating its communications strategy. This includes increasing our use of our [LinkedIn](#) page (and [Twitter](#) account, and making sure the E-Bulletin meets your needs. While the PCIG E-Bulletin maintains a solid readership, we don't know which information you value the most. We'll share what we learn in the E-Bulletin and use it to guide our work.

NOTE:

If, when trying to do the survey, you receive the message "you have already taken this survey"....

- we have been informed that it is a cookie issue and if you clear your browser history it should work. If that does not work, you can be sent a unique link and your responses added manually to the set but your anonymity would not be possible.

We are also fixing Question 3 so that multiple responses can be given.

Ann Single, Chair – HTAi Patient and Citizen Involvement Interest Group

[singlehaworth@gmail.com](mailto:singlehaworth@gmail.com)

### **New HTAi PCIG mailing list.**

Your email address has been transferred over to this new distribution list. Please note if you no longer wish to receive these emails, you can unsubscribe at any time by following the link in the footnote of emails sent. Messages sent to the list are moderated, so there may be a short lag in between messages you send to the email list and when someone reviews your email, accepts the content and it goes out to the full group.

Please note this is a new list with a new system, internal testing has been thorough, however the PCIG is the first group to start using this. There may be some expected bugs that we didn't catch during internal testing, thank you for your patience in advance. We always welcome feedback as we work to support our members' ability to connect and collaborate.

If you'd like any more information about the HTAi Interest Groups: <https://htai.org/interest-groups/> or, at any time you'd like to get in touch with the Secretariat regarding the IGs: [interestgroups@htai.org](mailto:interestgroups@htai.org)

The HTAi Team

NOTE:

This email list is different to the list used for the E-Bulletin

Present and past issues of the E-Bulletin can also be accessed on the website <https://htai.org/interest-groups/pcig/e-bulletins/>

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## **HTAi Matters**



### **HTAi 2020 Annual Meeting Beijing**

*Attaining, maintaining and sustaining healthcare systems in a changing World: the role of HTA* [HTAi2020.org](http://HTAi2020.org)

### **Important message from the Annual Meeting Team**

Thank you for your patience and understanding as we have continued to monitor the evolving global situation with COVID-19 (coronavirus) for impacts to our delegates, speakers, partners, volunteers, staff, and many other key stakeholders. As part of our commitment to keeping our stakeholder community fully informed, the Board of Directors requests the following 2020 Annual Meeting status update be communicated.

Based on the balance of the evidence before the Board, and with the strong support of our local hosts, HTAi has determined the 2020 Annual Meeting can no longer safely proceed as planned in June; the health and safety of our stakeholders was paramount in arriving at this decision.

We appreciate your support and understanding while additional contingency plans are finalized and HTAi continues to investigate options to deliver our valuable services to our members.

### **The HTAi 2020 Board of Director election**

This is quickly approaching. In preparation, HTAi is seeking active members of the Society for nomination to the Board of Directors. Board Directors play a key role in the direction of the Society.

We are looking for up to **three (3)** engaged, motivated and enthusiastic **Board Directors for a three-year term between 2020 and 2023**. Nominees should be prepared to:

Chair at least one of the advisory board committees,  
Sit as a member on at least two committees or working groups,  
Travel and spend time attending two face-to-face Board meetings, and  
Carry out other duties as requested.

When considering potential nominees, and based on current Board composition, experience with the following skills are preferred:

Life sciences industry experience

Data sciences

Finance, budget, and accounting

Board governance

Business development

Marketing and communications

**\*Please note:** while these are preferred attributes when considering who to nominate, the attributes themselves do not form part of the standard Nomination Committee evaluation process. All nominees are welcome.

Participation in the election process as a nominee, nominator, or voter can only be done by **active members** of the Society.

The nominations form can be found [here](#).

We request that applicants provide a biography, vision statement and a photograph along with supporting signatories.

All nominations should be submitted by email to [info@htai.org](mailto:info@htai.org). The deadline for receiving nominations has been extended to **Friday, April 3, 2020, 23:59 MST (GMT +7)**. The Nominations Committee, in collaboration with the Secretariat, will ensure that all nominations meet eligibility stipulations as outlined in the Society bylaws.

The voting process will be administered by Civica, a neutral third-party electoral service. All HTAi members in good standing are eligible to vote and will be contacted by Civica via email with instructions once voting opens. Voting will remain open 24 hours a day, closing on **Friday, May 1, 2020, 23:59 MST (GMT +7)**.

Elected candidates are expected to attend the HTAi June Board meeting at their (or their organization's) own expense. Appointments will be pending the approval of the Membership at the Society's Annual General Meeting following the June Board meeting. Should you have any question, please email [info@htai.org](mailto:info@htai.org).

Twitter: [twitter.com/HTAiOrg](https://twitter.com/HTAiOrg) @HTAiOrg

Facebook: [www.facebook.com/HTAiOrg](https://www.facebook.com/HTAiOrg) @HTAiOrg

LinkedIn: [www.linkedin.com/company/htai](https://www.linkedin.com/company/htai)

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## What's Happening

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### How is patient/carer engagement changing with COVID-19 for you?

The following news item is an example. Let us know at [pcig.htai@gmail.com](mailto:pcig.htai@gmail.com) what you are doing so we can share experiences...

### The Foothills Medical Center (FMC) Cardiac Cath Lab and Short Stay Cardiology units, located in Calgary, Canada, were interested in involving patients in its Quality Council

In choosing the Patient Advisor, the FMC was looking for advisors that had experience relevant to the purpose of the program (e.g. patient or family of patient admitted to hospital who had catheter laboratory procedures or similar experiences).

The Patient Advisors support the goals of the project, which are focused on Quality Improvement and important initiatives to patient centred care, including the use of Health Technology. All aspects of the

project are now being co-led by representatives from all the functional areas, and Patient Advisors, in a cooperative team. Meetings have been held monthly since October. Initial meetings focused on developing the projects key study parameters, while later meetings have been involved in developing study teams, including Patient Advisors, which will review specific aspects. The Patient Advisors have proven helpful in lending a patient voice to augment the clinical one. [Staff and Patient Advisors look forward to continuing this important project when the pandemic permits.](#)

More information: Tanya Federico, [Tanya.Federico@albertahealthservices.ca](mailto:Tanya.Federico@albertahealthservices.ca), and Chris Hylton, [crisilton@gmail.com](mailto:crisilton@gmail.com)>>

Can we learn from the following for [https://htai.org/wp-content/uploads/2019/03/Resource-Directory-for-Patients\\_7Mar19.pdf](https://htai.org/wp-content/uploads/2019/03/Resource-Directory-for-Patients_7Mar19.pdf)

### **IPPOSI launch of an online repository of tools and guidances on Patient/Public Involvement in clinical research**

In order to help establish good practice in PPI in Clinical Research in Ireland and to provide guidance for interested clinical researchers and the public, an online repository of relevant PPI documents has been launched at the IPPOSI website <https://www.ipposi.ie/our-work/research/ppi-clinical-research/>

The repository was created by a multi-stakeholder Clinical Research PPI Working Group (CR-PPI-WG), which works collaboratively under the HRB-CRCI and IPPOSI umbrellas. Working Group members include representatives and staff members from IPPOSI, HRB-CRCI, Clinical Research Facilities and Centres, Hospitals, Universities, Patient Groups/Charities and the Healthcare Industry.

Health Research Board Clinical Research Coordination Ireland (HRB CRCI) is an independent integrated national clinical research network, providing centralised support in the conduct of multicentre clinical trials (both commercial and academic) across Ireland. The tools and resources available on the repository are accessible in six key folders: How to do PPI; Planning for PPI; Working with the public; Evaluating and measuring impact; Designing Patient Information; Guidance for Public.

Related:

Tim Bell, Lidewij Eva Vat, Colleen McGavin, Malori Keller, Leah Getchell, Anna Rychtera and Nicolas Fernandez. Research Involvement and Engagement 2019 5:7 Co-building a patient-oriented research curriculum in Canada <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0141-7> *Foundations in Patient-Oriented Research* is a course designed and piloted in Canada to help patients, researchers, health care professionals and health system decision-makers gain an introductory understanding of patient-oriented research, the research enterprise, and how to work in a team. The course curriculum was co-developed by a diverse group of people with different lived experiences and relevant expertise in a 'co-learning format'. Our findings suggest that co-developing a patient-oriented research curriculum increases its quality, uptake and credibility.

European Patients' Academy on Therapeutic Innovation (EUPATI) training course <https://www.eupati.eu/download/>

INVOLVE <https://www.invo.org.uk/resource-centre/training-resource/>

According to the 70:20:10 Model for Learning and Development, people learn 70% from 'on-the-job training', 20% through others (peer to peer or social learning) and 10% from formal coursework 70:20:10 Institute, "Demystifying the 70:20:10 Framework" [https://www.70201olive.com/about-the-framework?r\\_done=1](https://www.70201olive.com/about-the-framework?r_done=1)

**The FDA opens up commercial coronavirus testing**

The agency is now allowing companies to proceed with their diagnostic tests without first submitting them for federal review or obtaining an official emergency clearance.

The FDA aims to expand the capacity as well as the variety of COVID-19 molecular diagnostics available—and that the agency is, essentially, trusting companies and labs to make sure their tests in the field are well-validated. The policy is a broad expansion in scope from the FDA's previous moves to accelerate testing, including allowing certain CLIA-certified, "high complexity" labs to proceed with their own tests while submitting their data and emergency use application to the agency for review within 15 days. Commercial developers will be held to the same paperwork requirement.

The Clinical Laboratory Improvement Amendments (CLIA) regulate laboratory testing and require clinical laboratories to be certified by the Center for Medicare and Medicaid Services (CMS) before they can accept human samples for diagnostic testing.

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## Publications

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Jackie Street, Tania Stafinski, Edilene Lopes, Devidas Menon. Defining the role of the public in Health Technology Assessment (HTA) and HTA-informed decision-making processes. *Int J Technol Assess Health Care* 2010. DOI: <https://doi.org/10.1017/S0266462320000094>  
<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/defining-the-role-of-the-public-in-health-technology-assessment-hta-and-htainformed-decisionmaking-processes/292CF251A57392C24EFF3E186E97A9E1>

Submitted by Sally Wortley

Nigel Cook, Andreas Geier, Andreas Schmid, Gideon Hirschfield, Achim Kautz, Jörn M. Schattenberg, Maria-Magdalena Balp. Assessing physician preferences on future therapeutic options and diagnostic practices in non-alcoholic steatohepatitis. *JHEP Reports*, Volume 2, Issue 2, 100081  
[https://www.jhep-reports.eu/article/S2589-5559\(20\)30015-X/fulltext](https://www.jhep-reports.eu/article/S2589-5559(20)30015-X/fulltext)  
DOI: <https://doi.org/10.1016/j.jhepr.2020.100081>

Submitted by Nigel Cook

Bird M, Ouellette C, Whitmore C, Li L, Nair K, McGillion MH, Yost J, Banfield L, Campbell E, Carroll SL. Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. *Health Expect*. 2020 Mar 10. doi: 10.1111/hex.13040. [Epub ahead of print] Review.

Wright K, Parker M; Nuffield Council on Bioethics Working Group. In emergencies, health research must go beyond public engagement toward a true partnership with those affected. *Nat Med*. 2020 Mar;26(3):308-309. doi: 10.1038/s41591-020-0758-y. No abstract available. Erratum in: *Nat Med*. 2020 Mar 4

Ruben MWA Drost, Aggie TG Paulus, Silvia MAA Evers. Five pillars for societal perspective  
DOI: <https://doi.org/10.1017/S026646232000001X>  
<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/five-pillars-for-societal-perspective/7DoFDE54E7BCBEB49C800876F75E5570>

In economic evaluation, the healthcare perspective has gradually given way to use of the societal perspective, as this perspective is often advocated for support in making optimal societal decisions. In practice, economic evaluations conducted from the societal perspective ignore, fail to measure and/or fail to monetize many of the costs that fall outside of the healthcare sector. To limit bias and increase decision-supportive power, researchers could strengthen their evaluations by adhering to a few basic principles. Five "pillars for the societal perspective" are proposed. First, who bears the cost and who does not is irrelevant. Second, it is imperative to consider including costs for sectors outside the healthcare sector. Third, both high frequent costs and costs with high unit prices should be considered. Fourth, double counting should be

avoided. And fifth, researchers should reflect on choices related to costs, i.e. cost omission and problems with identifying, measuring, and valuing costs.

AND, borrowed from an Indian newspaper website: 'Dear God, please reboot 2020. It has a virus'....

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