

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

*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
- Responses to Issues, FAQ

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### Welcome to the June E-Bulletin – from our new Chair

It was great to see so many of you at HTAi Cologne this month. The topic of patient and citizen involvement in HTA was a key part of the Annual Meeting with PCIG members leading at least 12 panels in addition to presenting numerous orals, posters and vignettes and running the PCIG workshop. The PCIG Annual Business Meeting was also well attended with nearly 50 new and existing members taking part. At that meeting, Neil Bertelsen handed over the Chair to myself. Neil has been a hard-working, thoughtful and inclusive Chair. As a result of his work with the dedicated members of the Steering Committee (SC), we now not only have recognition for our credibility and productivity, we also have expanded networks and a reach of over 400 members, along with more sustainable processes, including better funding.

As part of preparing for the next decade, PCIG is transitioning from its working group structure to a project based structure. On behalf of us all, I'd like to thank the following Working Group Chairs and Coordinators for their tireless work and dedication:

- Karen Facey – Methods and Impact Coordinator
- Sophie Staniszewska – Methods and Impact Chair
- Sally Wortley – Citizens and Community Involvement Chair
- Sophie Werkö – Methods and Impact Chair
- Tania Stafinski – Citizens and Community Involvement Chair
- Jackie Street – Citizens and Community Involvement Chair
- Melissa Sullivan – Patient Involvement and Education Coordinator
- Lizzie Thomas – Patient Involvement and Education Chair
- Janney Wale – Patient Involvement and Education Chair

For the short-term, all our current SC members will continue to guide the work of the PCIG. We are delighted that Todd Stephenson has accepted the role of PCIG Finance Secretary – after being co-opted to undertake funding work for PCIG last October – and that Anke Holtorf will be joining the SC as our Project Coordinator

Our call for Expressions of Interest for a few additional Steering Committee members closes on **22 July** (as does our first call for project sub-committees) so please act quickly if you are interested.

I look forward to providing further updates on our transition and new projects new month.

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

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## **Governance**

### **Steering Committee members – Expressions of Interest. Deadline: Monday 22 July 2019**

Following the approval of the HTAi PCIG's new Terms of Reference at our Annual Business Meeting in Cologne last week, the Steering Committee now invites Expressions of Interest from those wishing to join the Steering Committee.

Due to the new structure, the Steering Committee is currently:

- Ann Single (Chair), Patient Voice Initiative, Brisbane, Australia
- Valentina Strammiello (Deputy Chair), European Patients Forum, Brussels, Belgium
- Neil Bertelsen (outgoing Chair), Independent Consultant, Berlin, Germany
- Todd Stephenson (Finance Secretary), Janssen, Sydney, Australia
- Anke-Peggy Holtorf (Project Co-ordinator), Health Outcomes Strategies GmbH, Basel, Switzerland
- Heidi Livingstone (member), NICE, London, England
- Hervé Nabarette (member), AFM-Téléthon, Paris, France
- Rebecca Addo (Technical Officer), appointed by HTAi

We seek several more Steering Committee members to achieve our minimum of 10. We particularly encourage Expressions of Interest from people offering different perspectives to those already on the Committee, such as stakeholders from different jurisdictions (e.g. those outside of Europe and Australia as well as low- and middle-income countries) or disciplines (e.g. different methods, citizen involvement). We are also keen to appoint a Secretary to lead the work of the Technical Officer.

### **Criteria**

- Able to demonstrate active participation in the field of patient or citizen involvement in health technology assessment
- Able to meet the expectations of Steering Committee membership as set out in the Terms of References, e.g. commit to take an active role in driving the work of the Interest Group and providing practical assistance to activities undertaken by the group as appropriate and complete a three-year term
- Preference will be given to those members who have actively participated in the Interest Group.

### **Role**

The Steering Committee is responsible for providing governance, strategy and oversight of the plans and deliverables of any Project Sub-Committee. Additionally, it:

- Develops the overarching strategy for the Interest Group
- Develops and implements the Interest Group external communications
- Assesses collaboration opportunities with other organisations working in the field
- Approves funding requests and reports to the HTAi Board
- Organises sessions for the HTAi annual meeting
- Organises face to face meetings
- Agrees on projects to be delivered by the Interest Group
- Approves membership and the project plan of any Project Sub-Committees (provided in Project Template).

Expressions of interest should be no longer than 200 words and emailed to the Chair ([singlehaworth@gmail.com](mailto:singlehaworth@gmail.com)) no later than Monday 22 July 2019.

### **Further information**

- Ann Single ([singlehaworth@gmail.com](mailto:singlehaworth@gmail.com)) or Valentina Strammiello ([valentina.strammiello@eu-patient.eu](mailto:valentina.strammiello@eu-patient.eu))
- PCIG Terms of Reference will be made available on the PCIG website.

## **PCIG Project Proposals. Deadline: Monday 22 July 2019**

Following the approval of the HTAi PCIG's new Terms of Reference at our Annual Business Meeting in Cologne, the Steering Committee now invites project proposals from any PCIG member.

### ***Project criteria***

There are no set criteria. The key requirement is to identify a need related to patient involvement in HTA and then put together a sub-committee to scope and complete the project with appropriate oversight from the Steering Committee and consultation with the wider Interest Group. The projects can be short or long and with large or small goals. Typically, PCIG projects address areas such as developing involvement and educational materials and processes, exploring methodological issues, developing resources and tools which can be used or adapted by others.

The PCIG Steering Committee will approve up to eight projects at any one time. Each Project Sub-Committee shall have a lead and up to 12 members. Members of Project Sub-Committees must be members of PCIG and Project Sub-Committees must provide quarterly reports to the Steering Committee for publication on the website.

The PCIG Terms of Reference provide further information, including the PCIG Project Sub-Committee template for completion.

To make a proposal, complete the PCIG Project Sub-Committee template (available through Anke Holtorf) and return by email to the Project Co-ordinator, Anke-Peggy Holtorf (anke.holtorf@health-os.com) no later than Monday 22 July 2019.

If you have a project in mind but are unable to make this deadline, please consider submitting a few sentences describing a project you wish to propose in the future, by 22 July.

### ***Current project – Call for impact stories***

#### **Impact of Patient Involvement in HTA or Early Scientific Advice – an online survey**

You are invited to take part in research into the difference patient involvement has made in the assessment of health technologies, or in decisions about access, pricing and/or reimbursement.

Please complete the online survey platform: <http://survey.health-os.com/index.php?r=survey/index/sid/834771/lang/en>

The template is also being made available at: <https://htai.org/interest-groups/pcig/resources/> and <https://htai.org/interest-groups/pcig/working-groups/impact-stories-template/>

Submitted by Anke-Peggy Holtorf

### ***Date claimer***

The PCIG will hold its face-to-face meeting in Brussel's on 6-8 November 2019. This is a by invitation only working meeting for members of the PCIG Steering Committee and those particularly active in PCIG projects. We are very grateful to Irina Cleemput and the Belgian Health Care Knowledge Centre (KCE) for hosting the meeting.

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## **HTAi Matters**



### **HTA Beyond 2020: Ready For The New Decade?' HTAi Meeting in Cologne, Germany, June, 2019**

Thank you for attending the HTAi 2019 Annual Meeting in Cologne, Germany. Now that you've had time to process the meeting content and follow up with colleagues, we would like to find out about your experience. We value your time and completing the survey shouldn't take longer than a few minutes.

Your feedback will be thoughtfully considered and used to assess preparations for HTAi 2020 in Beijing,

China. In particular, we welcome any impact stories you may have about the meeting, any partnerships formed and how these relationships have been of benefit to you.

The attendee survey is anonymous; however, we will draw one lucky respondent to get a \$100 USD discount for next year's registration to the 2020 Annual Meeting in Beijing. If you wish to enter the draw please provide your name and email address in the survey form: [HTAi 2019 Attendee Survey](#)  
A speaker survey is also available for completion.

*Ann Single says:* This is a great chance to provide positive feedback as well as suggestions for improvement. As members of PCIG, you may be able to offer different insights such as thoughts about the program, travel grants or venue accessibility. So please take the time to feedback.

The Annual Meeting started with an excellent Keynote Address by Francesca Colombo of OECD, based in France. For an example of some of the OECD work see the last item in the next section. The plenary sessions over the three days were:

- HTA Beyond 2020: One Size Fits All? Will Joint International Assessments Improve Or Hinder HTA?
- HTA Beyond 2020: The Era Of Digital Health?
- HTA Beyond 2020: Need For Smart Capability Building?

The plenary speakers were excellent and gave us considerable food for thought.

The various other sessions throughout the meeting were also high quality. It is unfair to pick out one or two but I do want to highlight the popular panel sessions led by Sophie Staniszewska: The Value Of Patient-Based Evidence In HTA Beyond 2020 (joined by Nigel Cook, Sarah Garner, Andreas Hager, and Sophie Werkö); and Social Media Analysis - An Essential Part Of HTA Beyond 2020? (joined by Francois Cadiou, Nigel Cook, Sophie Werkö).

The PCIG workshop entitled 'Listen, Exactly What Do We Each Want from Social Engagement in HTA Assessments' was led by Sam Thomas, assisted by Janney Wale and Heidi Livingstone. It provided an opportunity for HTA agencies, patient advocates, industry and others to get together to share on current patient involvement practices; how effectiveness of patient involvement is being assessed; what 'works'; common problems (pitfalls) in patient participation; what types do decision makers want more of from patient involvement; and future plans and hopes. Lively discussions followed on ways forward. A report and activities are being prepared.

#### **Policy Forum Scientific Secretary – vacant position**

<https://htai.org/blog/2019/06/26/vacancy-htai-global-policy-forum-scientific-secretary/>

Call for Applications for the position of Scientific Secretary to the 2020 [HTAi Global Policy Forum](#).

Closing date for applications: 10<sup>th</sup> July 2019, 17.00 CET

To submit an application and for all inquiries, contact: [policyforum@htai.org](mailto:policyforum@htai.org)

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#### **What's Happening**

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##### **Notice of NICE public consultation**

NICE is inviting comments on a 'statement of intent' for broadening the sources of evidence used to develop guidance and evaluate its effects. The statement applies to the range of NICE guidance including HTA and guidelines. The [public consultation](#) closes on 13 September.

<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/how-we-develop-nice-guidelines/consultation-data-and-analytics-statement-of-intent>

Submitted by Jane Cowl

##### **ABPI publishes new guidelines on pharma working with patients**

The Association of the British Pharmaceutical Industry (ABPI) has published a new guide for

pharmaceutical companies working with patients, which provides companies with new guidance on "working successfully, collaboratively and ethically with patients and patient groups and in line with the ABPI Code of Practice."

The sourcebook covers six topics, which were identified as areas where further guidance would be of assistance, such as principles and agreements, stating that companies must have written agreements when working with patient organisations, and principles of clarity, integrity, independence and transparency should underpin all collaborations. Companies must disclose details of the patient organisations that they provide financial support to.

The code also has strict guidance on the purpose of the meetings and what can and can't be included, for example, meetings must have a clear educational purpose.

The guide is being launched at the joint ABPI, AMRC, NIHR conference: Pioneering Partnerships.

From PharmaTimes online

### **IMI2 18th Call for proposals**

There are three topics, which could be of interest to members of our group:

Health Outcomes Observatories – empower patients with tools to measure their outcomes in a standardised manner creating transparency of health outcomes;

Improving patient access, understanding and adherence to healthcare information: an integrated digital health information project;

Establishing international standards in the analysis of patient reported outcomes and health-related quality of life data in cancer clinical trials.

You can find further information on the topic descriptions and Call conditions on the IMI website: <https://www.imi.europa.eu/apply-funding/open-calls/imi2-call-18>

Submitted by Anke-Peggy Holtorf

### **European Patients Forum (EPF) Congress on patient involvement 2019 Newsletter**

<https://epfcongress.eu/>

The Congress is being held in Brussels, 12 to 14 November

To make sure that you receive the newsletters, contact [congress@eu-patient.eu](mailto:congress@eu-patient.eu)

Submitted by Valentina Strammiello

### **Further EPF information**

EUPATI FUNDAMENTALS: Patient engagement training for the pharmaceutical industry and academia:

Next Training: 21 November 2019

Address: EPF Office - Chaussée d'Etterbeek 180, 1040 Brussels, BE

Price: €988 excl. VAT

Register: <https://www.eupati.eu/fundamentals/register>

This training on Patient Engagement is necessary to address the gap preventing effective patient engagement. EUPATI will ensure that in the future both patients and professionals have fruitful engagement that meets the expectations of all parties.

### **Patient-Reported Indicators Surveys (PaRIS)**

<https://www.oecd.org/health/paris.htm>

Health systems know very little about whether the health care delivered seeks to improve people's well-being and their ability to play an active role in society. The success of health care is typically measured by survival rates after treatment or mortality or hospital utilisation. Often, though, differences between the best and worst performing hospitals are small. It is only when we measure outcomes reported by patients themselves – such as quality of life – that important differences in the outcomes of care emerge.

We need to better understand what patients themselves think of health care and whether it improves the outcomes that matter to them:

- The OECD benchmarks some aspects of patient experience in 19 countries, in ambulatory care... but we need to expand this survey to other care settings (such as in-patient and mental health care facilities), and to more countries
- Patient-reported outcome measures are in use for some conditions, such as hip and knee surgery... but different measures in different countries make international comparisons difficult
- And the biggest users of health care – people with multiple, long-term conditions – are not being asked at all

The Patient-Reported Indicators Surveys (PaRIS) initiative addresses these critical information gaps and aims to develop international benchmarks of health system performance as reported by patients themselves.

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## Publications

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### *A must read:*

Booth K 2019. "Getting to the table": Changing ideas about public and patient involvement in Canadian drug assessment. *J Health Politics, Policy and Law* 44(4) August. Are patient submissions providing the information needed for HTAs...

Submitted by Sally Wortley

Vanstone M, Abelson J, Bidonde MJ, Bond K, Burgess R, Canfield C, Schwartz L, Tripp L. Ethical challenges related to patient involvement in Health Technology Assessment. (2019). *International Journal of Technology Assessment in Health Care*. E-pub before print. <https://doi.org/10.1017/S0266462319000382> Including information and values from patients in HTA has the potential to improve both the process and outcomes of health technology policy decisions. Accordingly, funding and structural incentives to include patients in HTA activities have increased over the past several years. Unfortunately, these incentives have not yet been accompanied by a corresponding increase in resources, time, or commitment to responsiveness. In this Perspectives piece, we reflect on our collective experiences participating in, conducting, and overseeing patient engagement activities within HTA to highlight the ethical challenges associated with this area of activity. While we remain committed to the idea that patient engagement activities strengthen the findings, relevance, and legitimacy of health technology policy, we are deeply concerned about the potential for these activities to do ethical harm. We use this analysis to call for action to introduce strong protections against ethical violations that may harm patients participating in HTA engagement activities.

<https://twitter.com/MGVanstone/status/1144645668016971776>

Submitted by co-author Carolyn Canfield, Independent Citizen-Patient

### Looming Challenges for ICER in Assessing the Value of Rare Disease Therapies

By Dr William Smith. Pioneer Institute white paper looking at QALYs and ICER model in the US and its inappropriateness in rare disease situations; Clinical Trial Data Too Limited to Evaluate Ultimate Value; ICER's Definition of "Ultra-Rare Disease" is also Arbitrary

<https://pioneerinstitute.org/featured/new-report-addresses-distinct-challenges-in-utilizing-icer-to-assess-value-of-rare-disease-treatments/>

Another publication on use of online community boards. This is a chronic obstructive pulmonary disease (COPD) online community study.

N Cook, J Gey, B Oezel, et al. Impact of cough and mucus on COPD patients: primary insights from an exploratory study with an Online Patient Community. *International Journal of Chronic Obstructive Pulmonary Disease* 2019;14 1365–1376.

[https://www.dovepress.com/articles.php?article\\_id=46598](https://www.dovepress.com/articles.php?article_id=46598)

Cook N, Mullins A, Gautam R, et al. Evaluating Patient Experiences in Dry Eye Disease Through Social Media Listening Research. *Ophthalmol Ther*. 2019 Jun 3. doi: 10.1007/s40123-019-0188-4. [Epub ahead of print]

<https://rdcu.be/bFyfH>

RM Merchant, DA Asch, P Crutchley et al. 2019. Evaluating the predictability of medical conditions from social media posts. *PLoS One* 14(6):e0215476. doi: 10.1371/journal.pone.0215476.

We identified that patients' Facebook status updates can predict many health conditions, suggesting opportunities to use social media data to determine disease onset or exacerbation and to conduct social media-based health interventions.

Submitted by Nigel Cook

Boylan AM, Locock L, Thomson R, Staniszewska S. "About sixty per cent I want to do it": Health researchers' attitudes to, and experiences of, patient and public involvement (PPI) - A qualitative interview study. *Health Expect*. 2019 Mar 29. doi: 10.1111/hex.12883. [Epub ahead of print]

Staniszewska S, Mockford C, Chadburn G, et al. Experiences of in-patient mental health services: systematic review. *Brit J Psych* 2019 doi: 10.1192/bjp.2019.22

Submitted by Sophie Staniszewska

As demonstrated by Benjamin Sylvestre's film 'Measure of Time/ Le Temps Retranché' detailing life for people with renal failure requiring dialysis

Trailer: <https://vimeo.com/301827984> Facebook: <https://www.facebook.com/letempsretranche/>

"The idea to make this film came to me when I returned to dialysis 18 months ago. Shifting from the world of people to transplants to that of people on dialysis, I felt the need to make an account of the chronic illness that is kidney failure and the daily treatments that it involves..."

VT Tran, C Barnes, VM. Montori, et al. Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions. *BMC Medicine* (2015) 13:115

DOI 10.1186/s12916-015-0356-x

Insights gained from living 24/7 with cancer. A humbling, cautionary story for all of us in cancer clinical care, research and advocacy...

<https://ascopubs.org/doi/full/10.1200/JCO.19.00666>

### **Putting Patient Centricity On Trial**

Clinical trials are broken and only patients can help us fix them. If we let them.

Havas Lynx Group, Spring 2019. Edition #19

<https://www.patientcentricityontrial.com/>

### **Enhancing patient engagement in health technology assessment of medicines in Australia (with special consideration of oncology medicines)**

<http://www.biointelect.com/>

BTE Report, May 2019. Biointelect for Bristol-Myers Squibb (BMS)

Broadening the Evidence.

### ***Food for thought:***

**If doctors have a duty of care to all, why crowd fund for surgery?**

Ranjana Srivastava, Mon 17 Jun 2019

<https://www.theguardian.com/commentisfree/2019/jun/17/if-doctors-have-a-duty-of-care-to-all-why-crowdfund-for-surgery>

It is rare in Australia that any intervention with proven benefit would be denied a patient, even when cost is a barrier

How much money would you give to save the life of a terminally ill patient? It turns out a lot – enough to restore one’s faith in humanity that, even in this crazy world, we can stop to care for the plight of a stranger. But are you entitled to know how your money is spent?

My patient was a foreign student when he became ill with a cancer whose size and virulence defied imagination. No number of expensive tests would change the first surgeon’s conclusion that it was inoperable. But this news seemed so unthinkable that we obtained multiple opinions to confirm that surgery would be futile and dangerous. My team and I tirelessly sorted out the tiniest details, including finding someone from the patient’s community to sit with him. The bottom line was brutally apparent – a young man lay dying without home or family to speak of. The hospital would be his home and the staff his family. What I failed to consider was that professionals knew how to process such tragedy, but an informal advocate was in over his head – soon he was sowing seeds of doubt in the patient’s mind that his condition might not be terminal.

The advocate who wanted to do good started a crowdfunding appeal. It featured a picture of my pallid patient attached to an IV with a heartrending plea urging generous donations now that his oncologist had given up. Money poured in. I was puzzled. What was the money for? I had never mentioned cost and in fact had sought assurances that the blow of his diagnosis would not be compounded by an unaffordable debt. But my discomfort felt uncharitable – who was I to know the exigencies of having terminal cancer? So, I kept focusing on caring for my deteriorating patient – and it wasn’t until a businessman discretely enquired if the funds were sufficient for my needs that the truth dawned on me. I was at once mortified and livid.

“You know that my care is entirely free?” I blurted. “No, I didn’t”, he replied politely.

The patient’s family flew in and the public hospital fed and sheltered them whenever it could. But long after his death, I was dogged by questions about the crowdfunding. Who spent the money and on what? Who inherited the rest? If the money was raised in the name of cancer treatment, shouldn’t the generous public hospital be repaid? And finally, didn’t donors deserve to know the truth? ...

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## Responses to Issues, FAQ

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Emmanuel Gimenez from AQUAS, the Agency for HTA of Catalonia, let us know on the listserv about their experience with using the PCIG non-pharmaceutical and diagnostics submission templates. As a result they have suggested some changes and translated the templates into Spanish. We will be following up with Emmanuel.

### **E-mail response to an excerpt from the April E-Bulletin**

A friend sent me a copy of your April E-Bulletin that includes an excerpt from an article I wrote in *Healthy Debate* in which I discussed the question of whether the experience of living with a condition necessarily makes one an expert about the condition itself or about the experience of living with that condition. I’m glad you included the part of the article in which I said that patients do, in fact, possess essential knowledge and important skills, but the short piece above the excerpt suggests, wrongly, that the piece reveals something about my thinking about patient input used in HTA contexts. It further seems to suggest that by articulating my views “now that [I am] retired” I was likely hiding or at least choosing not to express my views while I was a public member of the Canadian Drug Expert Committee.

At sessions at conferences of the Canadian Agency for Drugs and Technologies in Health (CADTH), at meetings (where the audience consisted almost entirely of patients) held by groups such as Diabetes Canada and the Canadian Organization for Rare Disorders, in short papers I wrote and shared widely with patient groups, at a meeting of Health Quality Ontario, and in a video made by CADTH I expressed views--such as the need to recognize the content of patient group submissions as actual evidence--I still hold about the value of those submissions.



And while the recent article was not about HTA, perhaps readers of the E-Bulletin will see some connection between the last sentences of the article and issues of particular concern to them:  
The final problem resulting from the idea that patients are experts is that it may not do justice to—and it may even obscure—the deep experiential knowledge nearly all of them possess. Many patients are eager to share this knowledge not just to improve their own health but to improve the quality of care for others or the relevance of research. They know what no one else knows: how a change in dosage affected their ability to perform certain daily activities, what exactly helped them endure an especially difficult phase of their illness or treatment, or why an outcome not previously of interest to researchers (e.g. quality of sleep or ability to climb stairs) matters more than the outcomes researchers think of first (e.g. length of stay in hospital or distance walked in six minutes). This knowledge is no less valuable for not being expert knowledge. We don't have to be experts to be equal.

Frank Gavin

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Janet Wale, for HTAi PCIG  
E-mail: [pcig.htai@gmail.com](mailto:pcig.htai@gmail.com)

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