

## HTAi Patient and Citizen Involvement in HTA Interest Group (PCiG) E-Bulletin, May 2017

*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 from the Chair

Dear PCiG members,

The HTAi congress in Rome is fast approaching and I am looking forward to meeting many of you there. This is the one opportunity of the year where so many of us can get together at the same time, hear from each other about the evolving landscape of patient and citizen involvement, and share ideas and thoughts. Most members of the interest group steering committee will be at the congress, and you know that there is nothing we like more than hearing about your work, your ideas and sharing your passion. So don't be shy, and do come and see us at the various events we are planning, at our Annual Business Meeting, or as we attend the same events together.

Attached is a schedule of events that we have visibility of. These are a combination of official PCiG activities as well as panels that some of us are taking part in. Please take a look and note that the PCiG Annual Business Meeting is on Monday Afternoon, and as usual, we will be organising an informal dinner that Monday evening, close to the HTAi venue. On the Sunday before the main conference begins, we will be hosting a workshop on the Why, When and How of patient involvement in HTA. This workshop is very special to us, because it is built from the tireless work that went into a new book that will be launching in Rome on patient involvement in HTA, and I know that many of you have been involved in the chapters for this book. For those that want to learn more about this book, which has been edited by Karen Facey, Ann Single and Helle Ploug Hansen, the workshop is the best place to hear and meet the various authors of its chapters.

I am sure that many of you will also be presenting at the conference, and we don't want to miss any of your great work. So, if you are attending the congress, we would be grateful if you could complete the short survey below, it should only take a few moments, which will allow us to understand who from our membership we should be looking out for, and what sessions you may be presenting at during the conference.

<https://www.surveymonkey.de/r/LMH6Mz7>

Wishing you a sunny June and a successful conference  
Neil Bertelsen

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**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 14<sup>th</sup> Annual Meeting June 17-21, 2017 at the Ergife Palace Hotel in Rome, Italy.

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## Endorsement of PCIG resources

The HTAi Board has approved the Patient Group Submission templates for HTA of diagnostic technologies. These will be launched at the PCIG Annual Business Meeting on Monday 19 June in Rome.

The HTAi Board has confirmed that the Values and Quality Standards for Patient Involvement in HTA are endorsed. We have requested a letter of endorsement – and would appreciate any ideas from you on how they can best be promoted.

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Patient Preferences in HTA workstream has held an interesting first meeting. To coordinate the workstream, a researcher working in the field is now needed to join Eric Low, who will be the patient representative leader. If any academic is interested, please contact Karen Facey on [k.facey@btinternet.com](mailto:k.facey@btinternet.com) to find out more.

*Provided by Karen Facey*

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## Patient Involvement in HTA – the book

The first comprehensive book on patient involvement in HTA will be released at the HTAi annual meeting in Rome on Sunday 18 June. Over 80 authors, including many PCIG members, have contributed to the book which contains detailed explanations of methods for conducting patient aspects research, approaches to participation and 15 international case studies. *Patient Involvement in HTA* is aimed at researchers, postgraduate students, HTA professionals and experts in the HTA community.

*Patient involvement in HTA* is available in hardcopy or ebook from Springer:

<http://www.springer.com/gb/book/9789811040672> and Amazon: [https://www.amazon.com/Patient-Involvement-Health-Technology-Assessment/dp/9811040672/ref=sr\\_1\\_fkmr1\\_1?s=books&ie=UTF8&qid=1495583998&sr=1-1-fkmr1&keywords=patient+involvement+in+HTA](https://www.amazon.com/Patient-Involvement-Health-Technology-Assessment/dp/9811040672/ref=sr_1_fkmr1_1?s=books&ie=UTF8&qid=1495583998&sr=1-1-fkmr1&keywords=patient+involvement+in+HTA)

At the annual meeting there will be fliers offering a 20% discount on the book for the first month (up to 500 copies).

*Provided by Ann Single*

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*WELL DONE ERIC!*

## DFN Foundation donates £1m to Myeloma UK. May 30, 2017

Today we are delighted to announce a £1 million donation to Myeloma UK. The funds will allow the development of advanced genomic and genetic research tools to better characterise, monitor and treat myeloma over time. This news closely follows the appointment of former Myeloma UK CEO Eric Low as Trustee of the Foundation, with the responsibility of managing and maximising the funds...

Myeloma UK is the only organisation in the UK dealing exclusively with myeloma whose goal is to find a cure. They work to ensure patients get access to the right treatment at the right time, and provide a range of support and information services to patients and their family and friends aimed at helping them to deal with a myeloma diagnosis. Myeloma UK receives no government funding and relies almost entirely on voluntary donations and fundraising activities.

The £1 million donation will be provided to Myeloma UK to fund research at their Centre for Myeloma Research at The Institute of Cancer Research in London to conduct Whole Genome Sequencing (WGS) on up to 2,000 patient samples collected from the pivotal Myeloma XI clinical trial...

<http://www.dfnfoundation.org/news-and-events/dfn-foundation-donates-1m-to-myeloma-uk.html>

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## Publications

### Measuring Value Based On What Matters To Patients: A New Value Assessment Framework

By Josh Seidman et al. Health Affairs Blog, 23 May 2017

<http://healthaffairs.org/blog/2017/05/23/measuring-value-based-on-what-matters-to-patients-a-new-value-assessment-framework/>

Through a process that included significant public input and collaboration with other value framework developers, Avalere and FasterCures published [version 1.0 of the PPVF](#) (Patient-Perspective Value Framework) version 1.0 on May 11, 2017. The value assessment is viewed through the lens of patient preferences.

The PPVF: considers outcomes that matter to patients and incorporates real-world data necessary to measure those outcomes, instead of limiting the measures considered to those tracked in randomized clinical trials; measures the true cost to the patient and family instead of focusing on financial cost to the system alone; acknowledges that different evidence applies to different patients and uses subgroup data where possible.

*Submitted by Deb Maskens*

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**ICER's Value Assessment Framework: Capturing the Patient Experience.** By David M. Rind; and Sarah K. Emond  
The Institute for Clinical and Economic Review (ICER), has established a robust health technology assessment strategy for engaging patients so that the entire process is informed by the patient experience and what "value" means to them

Assessing the value of new drugs, diagnostics, or other health system interventions, often called health technology assessment (HTA), can become an academic exercise that loses sight of the fact that these technologies ultimately have a single purpose: to help patients. The patient perspective should therefore be central to HTA. The Institute for Clinical and Economic Review (ICER), a leading HTA research group in the United States, has established a robust strategy for engaging patients so that the entire process is informed by the patient experience and what "value" means to them.

<http://www.ajmc.com/journals/evidence-based-oncology/2017/peer-exchange-spring-2017-oncology-stakeholders-summit/icers-value-assessment-framework-capturing-the-patient-experience>

**Patient Centricity In Clinical Trials: Lessons Learned From Big Pharma.** Clinical Leader, Guest Column, May 25, 2017 <https://www.clinicalleader.com/doc/patient-centricity-in-clinical-trials-lessons-learned-from-big-pharma-0001>

*Submitted by JoAnne Zaborowski*

### **Why clinical trial outcomes fail to translate into benefits for patients**

A commentary by Carl Heneghan, Ben Goldacre and Kamal R. Mahtani. *Trials* 2017;**18**:122.

Clinical research should ultimately improve patient care. For this to be possible, trials must evaluate outcomes that genuinely reflect real-world settings and concerns. However, many trials continue to measure and report outcomes that fall short of this clear requirement. We highlight problems with trial outcomes that make evidence difficult or impossible to interpret and that undermine the translation of research into practice and policy. These complex issues include the use of surrogate, composite and subjective endpoints; a failure to take account of patients' perspectives when designing research outcomes; publication and other outcome reporting biases, including the under-reporting of adverse events; the reporting of relative measures at the expense of more informative absolute outcomes; misleading reporting; multiplicity of outcomes; and a lack of core outcome sets. Trial outcomes can be developed with patients in mind, however, and can be reported completely, transparently and competently. Clinicians, patients, researchers and those who pay for health services are entitled to demand reliable evidence demonstrating whether interventions improve patient-relevant clinical outcomes.

<https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-017-1870-2>

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### **Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap.**

By Jan Geissler, Bettina Ryll, Susanna Leto di Priolo, and Mary Uhlenhopp.

In their recently published scientific article (<http://journals.sagepub.com/eprint/6J5ErcVqeCi4BDdCE7FD/full>), EUPATI contributors detail the rationale and benefits for all parties of involving patients and patient organisations at all stages of medicines' development. The article also lays out patient input as becoming increasingly important in pharmacovigilance, i.e. in monitoring the safety and reliability of medicines once on the market.

The value of patient involvement (PI) in medicines research and development (R&D) is increasingly recognized by all health stakeholders. Despite numerous ongoing PI initiatives, PI so far lacks structure and consistency in approach. Limited formal documentation of PI activities further hampers the sharing of experience and learnings, preventing timely and systematic implementation. This article summarizes the outcomes of several multi-stakeholder discussions during 2013-2016 in a practical roadmap for PI in medicines R&D. The roadmap highlights specific opportunities for PI along the 4 key stages of the medicines R&D life cycle and is illustrated with concrete examples. This roadmap's aim is to provide a tool to facilitate PI during medicines research and development and is being shared to encourage implementation and further refinement.

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## Useful Resource

### Plain Language Medical Dictionary

<https://www.lib.umich.edu/taubman-health-sciences-library/plain-language-medical-dictionary>

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### HTA: Advancing Towards EU Collaboration

The results of the recent HTA consultation confirmed the need for a sustainable EU collaboration on HTA beyond 2020, echoing EPF's recommendations on stronger and deeper cooperation between Member States. Will this be taken over by the coming Commission's proposal?

The results of the consultation came out as an emphatic call for more EU collaboration. Responding to the 87% who expressed themselves in favour of a more collaborative approach, the Health Commissioner Vytenis Andriukaitis declared that the coming Commission's proposal on HTA would foresee provisions on the definition and specifics of the yet-to-be-defined cooperation. EPF strongly welcomes this statement, as it mirrors our calls for a mandatory collaboration between national HTA agencies.

Involving patients and patient organisations in the HTA process can prove to be challenging due to the diverse and conflicting interests represented in this multi-disciplinary process. However, behind these challenges lays a silver lining. We see a window of opportunities for the patient community across Europe to rethink patient involvement in HTA...

Another potential good practice is the initiative developed by the Spanish Network of HTA Agencies that recently celebrated its [10<sup>th</sup> anniversary](#). Launched in March, this initiative called [Patient Involvement Strategy](#) includes short, medium and long-term actions and foresees an incremental involvement of patients with the long-term objective to achieve involvement in all HTA reports. The initiative includes many other tools, like training materials, adaptation of methodologies, production of lay summaries and also plans on initiating some interactions with the Network of Health Schools for Citizenship.

Valentina Strammiello

<http://www.eu-patient.eu/News/News/hta-advancing-towards-eu-collaboration/>

*From the EPF Newsletter*

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### Call for applications for CIHR-CADTH-McMaster Health System Impact post-doctoral fellowship

McMaster's [Health Policy PhD program](#) is inviting interested PhD graduates, or near-graduates, to apply for a one-year post-doctoral fellowship in health services and policy research (HSPR) with a focus on public and patient engagement in health technology management.

This impact-oriented fellowship will have the successful applicant spend half of their time at McMaster with the Centre for Health Economics and Policy Analysis ([CHEPA](#)), Programs for Assessment of Technology in Health ([PATH](#)) and the Department of Health Evidence and Impact ([HEI](#)); the other half will be spent with the fellowship partner organization, the Canadian Agency for Drugs and Technologies in Health ([CADTH](#)).

Applications will be accepted until June 15<sup>th</sup>, and will be reviewed as they are received. The one-year position will begin no later than Sept. 1, 2017.

For more information about how to apply, go to <http://www.chepa.org/news/2017/05/01/call-for-applications-for-cihr-cadth-mcmaster-health-system-impact-post-doctoral-fellowship>

*Submitted by Julia Abelson*

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## AllTrials

Major global funders and international NGOs have agreed to adopt the WHO's strong standards on clinical trial transparency. This means all clinical trials they fund or support will be registered and the results reported. This is a big step forward.

Síle Lane, head of international campaigns and policy, Sense about Science said:

*This is great news. It's great news for the patients who volunteered for clinical trials that have never published results; for researchers re-running trials that they don't know already happened; and great news for all of us who expect our doctors to know whether our medicines work....*

It's especially important to see the signatories calling for the development of systems to monitor whether results are being shared. We need ways to monitor which results are missing. This will help us celebrate the organisations who are finding ways to share results, and to call out those who are letting us down.

<http://www.alltrials.net/news/funders-agree-to-who-standards/>

Anastasia Skamarauskas, Communications officer, Sense about Science

Janet Wale, HTAi PCIG

E-mail: [socrates111@bigpond.com](mailto:socrates111@bigpond.com)

Official PCIG activities in Rome		
Day / Date / Time	Session Title	Notes / Discussion Points
Sunday 18 June: 08:30 – 16:30	WS18: Patient Involvement In HTA – Why, When And How	This is the official PCIG workshop. <i>Note in the planner it says 'Tentative time slot'</i>
Sunday 18 June: 19:30 – 20:30	Welcome Reception	
Monday 19 June: 07:00 – 08:30	IG Steering Committee (Neil Bertelsen to attend)	A chance to bring PCIG related questions or points to the HTAi secretariat and other IGs
Monday 19 June: 11:30 – 13:00	HTAi Global Policy Forum panel – Neil B to bring the PCIG perspective to this panel	This is to reflect on the outputs of the annual policy forum meeting
Monday 19 June: 14:30-16:00	Panel discussion: Design of HTA systems: how to address decision makers' needs and recognize resource constraints?	Valentina Strammiello (EPF) involved as panelist
Monday 19 June: 16:30 to 18:00	PCIG AGM	Note, we need to check there are no clashes with other members of the PCIG presenting Oral Session 1 at this time!
Monday 19 <sup>th</sup> June: 19:00 – 20:00	HTAi AGM	
Tuesday 20 <sup>th</sup> June: 14:30 – 16:00	Panel Session: "Patient Involvement in HTA: Unique needs of developing countries"	This is an official PCIG panel session
Tuesday 20 <sup>th</sup> June: 20:30 – 22:30	Conference Dinner	

Other sessions that may be of interest (focused on patient and public involvement etc).		
Day / Date / Time	Session Title	Notes / Discussion Points
Saturday 17 June: 08:30 – 16:30	WS01: Measuring And Valuing Patient Preferences In HTA: Theories, Applications, And Guidelines	This is not a PCIG session but may be relevant to some of our members
Monday 19 June: 11:30 – 13:00	INAHTA Panel – Patient engagement strategies in INAHTA member agencies	Ken Bond (Steering Group) speaking
Monday 19 June: 11:30 – 13:00	Panel - Will the patient-centric approach of Value-based Healthcare drive innovation in HTA?	Karen moderating discussion of work from COMET and ICHOM with discussion from Mark Skinner, World Federation of Haemophilia
Tuesday 20 June: 10:30 – 12:00	Panel: HTA of Orphan Drugs	Karen moderating – discussion from Francois Houyez, Eurordis
Tuesday 20 June: 10:30 – 12:00	Panel: How to measure patient preferences and engage patients in value and access processes	Lizzie Thomas (Steering Group) and Durhane Wong-Rieger (former PCIG Chair) speaking

<b>Wednesday 21 June</b> 0830-1030	Panel: Joint HTA assessment: Is it worth the effort? An outlook to 2020 and beyond from various perspectives.	Gilliosa Spurrier-Bernard from MelanomeFrance will discuss challenges patients see in disparate HTA recommendations in different countries and the desire for HTA to be successful

#### DAY BY DAY VIEW

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	19:30 – 20:30	Welcome Reception	
Monday 19 June	07:00 – 08:30	IG Steering Committee (Neil B to attend)	
	11:30 – 13:00	HTAi Global Policy Forum panel – Neil B to bring the PCIG perspective to this panel	This is to reflect on the outputs of the annual policy forum meeting
	16:30 to 18:00	PCIG AGM	
	19:00 – 20:00	HTAi AGM	
	19:00 – 22:00	PCIG Dinner	At a restaurant local to the HTAi venue
Tuesday 20 <sup>th</sup> June	14:30 – 16:00	Panel Session: "Patient Involvement in HTA: Unique needs of developing countries"	This is an official PCIG panel session
	20:30 – 22:30	Conference Dinner	