

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

#### **We invite you to participate in the open consultation on an updated draft definition of HTA!**

<https://htai.org/blog/2019/03/20/open-consultation-updated-definition-of-hta/>

An international joint task group co-led and convened by the International Network of Agencies for Health Technology Assessment (INAHTA) and HTAi proposes an updated definition of HTA that consolidates and simplifies the various definitions in existence and which reflects the current and emerging realities of HTA.

*Health Technology Assessment (HTA) is defined as:*

"A multidisciplinary process that uses explicit and scientifically robust methods to assess the value of using a health technology at different points in its lifecycle. The process is comparative, systematic, transparent and involves multiple stakeholders. The purpose is to inform health policy and decision-making to promote an efficient, sustainable, equitable and high-quality health system."

Note 1: A [health technology](#) is an intervention, health product or service developed to prevent, diagnose or treat medical conditions; promote health; provide rehabilitation; or organize healthcare delivery. The intervention can be a test, device, medicine, vaccine, procedure, program or system.

Note 2: The dimensions of value for a health technology may be assessed by examining its clinical effectiveness and safety, costs and economic implications, wider implications for the patient and caregivers, and any ethical, social, cultural, or legal issues, as well as organisational and environmental aspects. The overall value may vary depending on the perspective taken, and the decision context.

Note 3: HTA is a process that may include several activities related to the lifecycle of a health technology. This comprises identification (e.g. horizon scanning), prioritisation of what to assess, assessment (evaluation of effects and impacts), appraisal (determining overall value), and implementation and monitoring (e.g. re-assessment).

Comments on the definition are welcomed from individuals as well as official comments on behalf of organizations. Comments are to be provided in writing and sent to the task group secretariat at [HTAdefinition@ihe.ca](mailto:HTAdefinition@ihe.ca). The deadline for comments is April 30, 2019.

Submitted by Anke-Peggy Holtorf

## Resources Directory added to our Resources webpages

<https://htai.org/interest-groups/pcig/resources/for-patients-and-patient-groups/>

These are resources to involve individual patients and patient groups in HTA.

The tools are to assist Patient Groups in providing HTA agencies with information on patient and caregiver experiences, living with the disease, its management and any harms and unmet needs.

**Online Resource Directory** – Links to government and organization resources to assist patients and citizens in HTA in their countries.

**Questionnaire** – Help us continue to develop our online directory of patient involvement in HTA resources. You can add your resources by completing this questionnaire.

### *Some of the other resources you will find on the webpage:*

**Health Equality Europe: A Guide to Understanding HTA for Patients and the Public** – Written for patient organizations who want to represent the views of patients but may not clearly understand what HTA is and how they can contribute. Mentoring is also referred to.

**HTAi Glossary for Consumers and Patients** – HTA terms explained in plain language.

Some resources are available in a number of languages

**Patient Group Submission Templates** – Generic patient submission templates for an HTA, with useful prompts

**Guidance** on giving patient input, including ethical guidance

**Values and Standards for HTA**

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## HTAi Matters



**HTAi Meeting to be held in Cologne, Germany from Saturday June 15 to Wednesday 19 June, 2019**

Supported by the Institute of Quality and Efficiency in Health Care (IQWiG) and the German Institute of Medical Documentation and Information (DIMDI) as host organisations.

**HTA Beyond 2020: Ready For The New Decade?'**

**Regular:** March 23 – June 9, 2019

**Onsite:** June 15 – 19, 2019

Visit the [HTAi 2019 website](http://HTAi2019.org) for currently available information and for registration.

Registration inquiries: [registration@htai.org](mailto:registration@htai.org)

The HTAi PCIG is excited to have many panels and a pre-conference workshop in Cologne and we know that some of you are doing oral presentations. So we hope to see you there. PCIG is at present finalising its full day workshop, which is on the Saturday.

We would be happy to let people know about your session in this E-Bulletin, so please contact us.

<https://www.htai2019.org/>

## Election of Vice-President and 4 HTAi Board Directors

Electoral Reform Services is administering the Board of Directors Elections 2019 on behalf of HTAi. There are four Director positions to vote for as well as the Vice-President position.

People who are current HTAi members and eligible to vote will have received an email.

Voting closes on Friday 26 April 2019 at midnight (MDT)

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## What's Happening

## **2019 CADTH Symposium, 14 – 16 April, Edmonton: Supporting Health System Transformation**

There are a number of patient sessions at this upcoming CADTH conference, which is a ‘Patients included’ event.

<https://symposium.cadth.ca/program/>

## **NICE 2019. 9 May, Manchester: Transforming Care**

<http://www.niceconference.org.uk/agenda>

## **EUnetHTA Stakeholder Forum, taking place on 11 April in Amsterdam**

Consisting of EUnetHTA Consortium partners, stakeholder groups, and other organisations involved in the activities of EUnetHTA JA3, the Forum provides a focal point for the open exchange of ideas and experience around Health Technology Assessment (HTA) and its European implementation. Live streaming of the event will ensure that, should you be unable to attend, you can participate remotely in the discussions that are helping to shape the future contours of the European HTA landscape.

<https://www.eunethta.eu/2019-eunethta-forum-2/>

Agenda

<https://www.eunethta.eu/wp-content/uploads/2019/03/2019-EUnetHTA-Forum-Agenda.pdf>

Submitted by Valentina Strammiello

## **New Leadership at the European Patients’ Forum Secretariat**

*Brussels, 15 March 2019* - The European Patients’ Forum is delighted to announce the appointment of our new Executive Director, Usman Khan, who will join us from the beginning of May. Usman has an established record in European health policy and practice and has significant knowledge of and commitment to patient engagement at all levels.

Usman is currently Executive Director of the European Health Management Association. *“...I am excited by the opportunity to lead EPF in its mission to ensure patient access, patient experience and patient involvement are core to health and social care provision across Europe.”*

Nicola Bedlington has stepped down as Secretary General after 13 years and will continue to support EPF in a part-time advisory function.

Dr Usman Khan has been Executive Director of the European Health Management Association since March 2016. A health policy and management professional with in excess of 25 years’ executive level experience within the public, private and not for profit sectors, Dr Khan spent over a decade working in academia, before moving into health and social care consulting in 2000. Dr Khan has held a number of high profile non-executive positions in health and social care and currently holds academic positions at the Milken Institute School of Public Health George Washington University and at New York University (London) as well as being a Member of the WHO European Region Primary Care Advisory Group.

## **From the European Patients Forum (EPF) Newsletter:**

### **Why aren’t medical devices regulated like drugs?**

BMJ 2018;363:k5032 <https://doi.org/10.1136/bmj.k5032> (Published 29 November 2018)

<https://www.bmj.com/content/363/bmj.k5032/rr-7>

A letter to the Editor in response to editorial published in the professional medical journal BMJ at the end of last year. EPF signed a joint letter with several patient and health professional organisations calling for increased transparency and access to incident reports on medical devices. The letter states that “transparency is important for informed decision making for both patients and doctors. For this reason, diminishing transparency to protect commercial secrets and to avoid scaring the public is an untenable argument.”

### **Data Saves Lives - an exciting new initiative hosted by the EPF secretariat**

<http://www.eu-patient.eu/News/News/data-saves-lives/>

Representatives from several organisations active in the field of digital health are combining forces to address the challenges and opportunities relating to health data.

### **EUPATI expanding training to other stakeholders**

<http://www.eu-patient.eu/News/News/eupati-launches-industry-training/>

In 2018, EUPATI expanded its scope to providing education on patient engagement for all stakeholders, to ensure the acceleration of effective patient engagement in Europe. The first step was launching a one-day crash-course on patient engagement for industry and academia in the second half of 2019. This expands a whole portfolio of educational offerings planned for all stakeholders involved in the EUPATI partnership including patient organisations, industry, HTA bodies, regulators, and academia.

### **Patients have different preferences - the need to explore diversity within preference research**

Center for Medical Technology Policy <http://www.cmtpnet.org/resource-center/view/march-excerpts-2019/>

#### **Putting the Patient Preference in Patient Research** by Ellen Janssen

In discussing research with our advisory board members...one of the patients spoke out - and said she didn't buy that in our survey patients assigned as much importance to a particular treatment benefit as our results indicated. One by one, the other patients joined in support and expressed their disbelief about our findings. Turns out, our local patient advisory board members represented a very different socio-demographic group than the national representative sample of patients that were surveyed.

This taught me some valuable lessons. Efforts to ensure diversity on an advisory board will greatly improve. We need to provide patients [and others] with the resources to be successful in their role as advisory board members and provide them information on certain research methods or definitions.

We need to treat patients as partners rather than research subjects. Since my first multi-stakeholder engagement study involving patients, we have learned a great deal. In our quest for higher quality and more relevant evidence, we are increasingly recognizing that patients are all unique and bring their individual views to the table. As we continue to conduct these types of studies, I'm sure we'll run into new challenges, but part of the beauty of a multi-stakeholder engagement process is that we can work together to overcome them.

Submitted by Nigel Cook

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## **Publications**

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Nigel Cook now has two papers on use of Online Bulletin Boards to add to his social media listening study

#### **Patient Needs, Perceptions, and Attitudinal Drivers Associated with Obesity: A Qualitative Online Bulletin Board Study** <http://link.springer.com/article/10.1007/s12325-019-00900-1>

Cook NS, Tripathi P, Weiss O, Walda S, George AT, Bushell A. Adv Ther. 2019 Apr;36(4):842-857. doi: 10.1007/s12325-019-00900-1. Epub 2019 Mar 11.

#### **Understanding Patient Preferences and Unmet Needs in Non-alcoholic Steatohepatitis (NASH): Insights from a Qualitative Online Bulletin Board Study** <https://www.ncbi.nlm.nih.gov/pubmed/30547371>

Cook NS, Nagar SH, Jain A, Balp MM, Mayländer M, Weiss O, Chatterjee S. Adv Ther. 2019 Feb;36(2):478-491. doi: 10.1007/s12325-018-0856-0. Epub 2018 Dec 13.

#### **Patients' perspectives on COPD: findings from a social media listening study**

<https://www.ncbi.nlm.nih.gov/pubmed/30775374>

Cook NS, Kostikas K, Gruenberger JB, Shah B, Pathak P, Kaur VP, Mudumby A, Sharma R, Gutzwiller FS. ERJ Open Res. 2019 Feb 11;5(1). pii: 00128-2018. doi: 10.1183/23120541.00128-2018. eCollection 2019 Feb.

**Learning as an outcome of involvement in research: what are the implications for practice, reporting and evaluation?** <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6416961/>

Staley K, Barron D. Res Involv Engagem. 2019 Mar 12;5:14. doi: 10.1186/s40900-019-0147-1. eCollection 2019.

Public involvement in research has evolved over the last two decades in a culture dominated by the principles of evidence-based medicine. It is therefore unsurprising that some researchers have applied the same thinking to involvement. This may explain why they tend to conceptualise involvement as an intervention, seek to evaluate its impact in the same way that treatments are tested, highlight the need for an evidence-base for involvement, and use the language of research to describe its practice and report its outcomes. In this article we explore why this thinking may be unhelpful. We suggest an alternative approach that conceptualises involvement as 'conversations that support two-way learning'. With this framing, there is no 'method' for involvement, but a wide range of approaches that need to be tailored to the context and the needs of the individuals involved. The quality of the interaction between researchers and the public becomes more important than the process.

We believe obtaining 'robust evidence' of the outcomes of involvement in ways that are consistent with the values of evidence-based medicine, may not be possible or appropriate. We argue that researchers' subjective accounts of what they learnt through involvement represent an equally valid way of knowing whether involvement has made a difference. Different approaches to evaluating and reporting involvement need to be adopted, which describe the details of what was said and learnt by whom (short term outcomes), what changes were made as a result (medium term outcomes), and the long-term, wider impacts on the research culture and agenda.

**Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative**

Katherine Deane, Laure Delbecque, Oleksandr Gorbenko, Anne Marie Hamoir, Anton Hoos, Begonya Nafria, Chi Pakarinen, Ify Sargeant, Dawn P Richards, Soren Eik Skovlund, Nicholas Brooke on behalf of the PFMD Patient Engagement Meta-framework Co-creation Team. Health IT, systems and process innovations. BMJ Innov March 2019. Epub ahead of print doi:10.1136/bmjinnov-2018-000317. <https://doi.org/10.1136/bmjinnov-2018-000317>  
<https://innovations.bmj.com/content/early/recent>

The Quality Criteria are presented in table 3 as: Shared purpose; Respect and accessibility; Representativeness of stakeholders; Roles and responsibilities; Capacity and capability for engagement; Transparency in communication and documentation; Continuity and sustainability.

Submitted by Ala Szczepura

**Opportunities and pathways for patient and public involvement**

Parisa Aslani. Health Expectations April 2019; 22(2):131-132. Open Access. Editorial <https://onlinelibrary.wiley.com/doi/10.1111/hex.12878>

**Optimizing patient and public involvement (ppi): Identifying its "essential" and "desirable" principles using a systematic review and modified Delphi methodology**

Baines RL, Regan De Bere S. 2018. Health Expectations, 21, 327-335. <https://doi.org/10.1111/hex.12618>

**Patient and public engagement in integrated knowledge translation research: Are we there yet?**

Banner D, Bains M, Carroll S, et al. 2019. Research Involvement and Engagement, 5, 8. <https://doi.org/10.1186/s40900-019-0139-1>

Evans D, Bird E, Gibson A et al. 2018. Extent, quality and impact of patient and public involvement in antimicrobial drug development research: A systematic review. *Health Expectations*, 21, 75-81.  
<https://doi.org/10.1111/hex.12587>

Hamilton CB, Hoens AM, Backman CL et al. 2018. An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expectations*, 21, 396-406.  
<https://doi.org/10.1111/hex.12635>

Harrison JD, Auerbach AD, Anderson W et al. Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. *Health Expectations* 2019 Feb 13. doi: 10.1111/hex.12873. [Epub ahead of print] Review. <https://doi.org/10.1111/hex.12873>

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