HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG)
E-Bulletin, October 2018

Enhanced quality and relevance of HTA through patient and citizen involvement

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

Welcome to the October E-Bulletin

From our Chair

It has been a busy month for those of us that are active on the projects within the PCIG working groups. At the beginning of October, we held our annual face-to-face working meeting in Stockholm, Sweden. Special thanks go to the Swedish Agency for Health Technology Assessment and Assessment of Social Services, SBU, and in particular to Sophie Werkö, who hosted this meeting and provided excellent facilities for us to work together in.

On the first day we heard from SBU and the important work they are doing in bringing stakeholder, and particularly patient insight into their work and their assessments. This was a fantastic start to the event and led to a session where all the attendees could share their experiences and help define some of the opportunities and challenges on furthering the integration of patient involvement in HTA. On the second day, the working groups, 'Methods and Impact', 'Patient Involvement & Education' and 'Citizens and Community' held all-day sessions to further their work plans for this year and next. Finally, on the last day, we took a deep-dive into the current status of the EU proposal on a harmonised HTA process for Europe as well as thinking about our plans for the HTAi Annual Meeting in 2019.

Our active members take three valuable days out of their daily work to attend this event every year, and I thank each of them for devoting their time, their energy and their critical thinking to how we continue to advance patient and citizen involvement in HTA. One of the outputs for this meeting was to look at ways that we can structure the group so that it is easier for members to identify projects that they may want to contribute to. We will keep you posted as we work out what this may look like.

Neil Bertelsen, Chair - HTAi Patient and Citizen Involvement in HTA Interest Group

HTAi Matters

HTAi 2019 Meeting to be held in Cologne, Germany from Saturday 15 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.

Abstract Submission Deadlines – for details please visit the HTAi 2019 website

Workshops & Panels: Complete

Orals, Vignettes & Posters: November 16, 2018

Do not forget the travel scholarships for patient advocates, people from low or middle-income countries, students!
Deadline: November 16, 2018, at 11:59 PM Mountain Standard Time
Notification of acceptance: February 8, 2019
Confirmation of acceptance: February 22, 2019

Please review the Travel Grant Guidelines before submitting an application. Consecutive applications and applications from individuals from the same organisations are welcome. However, additional scoring points will be granted to those applicants who have not received a Travel Grant in the last two years and there may be only one recipient from each organisation
http://htai2019.org/register/travel-grants/

Setting Priorities Fairly: Sustainable Policies for Effective Resource Allocation

This was a two-day program organised by HTAi and iDSi in Ghana in collaboration with the Ghanaian Ministry of Health. The aim of the program was to raise awareness of the importance of using HTA for decision making in health especially in resource constrained systems like LMICs. Participants included stakeholders from academia, research, policy, patient advocates and industry from sub Saharan African countries such as Nigeria, Uganda, Zimbabwe and Kenya. Other representatives were from the UK and Australia.
The first day consisted of workshop sessions, which provided an overview of HTA. Core technical components and how HTA could be integrated within a broader decision-making process were discussed. The second day consisted of a plenary and parallel sessions. Speakers presented on a range of issues concerning HTA by sharing their experiences of HTA in SSA nations.
One of the parallel sessions included a presentation titled 'Patients' voice in Global Health care decision making' presented by Regina MN Kamoga, a patient advocate. She focused on the issue of HTA serving as a scientific tool for health decision making that could ensure better patient outcomes in a process where patients were part of the decision making process. She highlighted the importance of involving patients in the HTA processes and clearly defined the role of patients in the process. Educating patients about HTA was also explained. She shared some experiences in Uganda where patient advocates had facilitated a major decision concerning stocking of antiretroviral drugs for HIV/AIDS patients in the country.
Key messages from the program were developing national strategies for health, educating all stakeholders on HTA and involving them in the decision making processes. Here is a link to all the presentations given during the workshop.

Rebecca Addo
http://www.idsihealth.org/setting-priorities-fairly-sustainable-policies-for-effective-resource-allocation-in-africa/

HTAi Capacity Building Working Group - we have requested patient involvement to be included in this work!
PCIG Patient Involvement and Education Working Group member Anna Scott (Australia) is on the group, and on the Scientific Development and Capacity Building Committee together with Ken Bond. The objective of the Scientific Development and Capacity Building (SDCB) Committee is to streamline the Scientific Direction of the Society, providing guidance at the highest of levels. The priority is to do this in low and middle income countries, working with the HTA in Developing Countries Interest Group (IG) and other IGs, industry and academia.

https://htai.org/about-htai/committees-and-working-groups/scientific-development-and-capacity-committee/

HTAi Ethics Interest Group meeting
The Ethics Interest Group (IG) is having its face-to-face methodology meeting in Amsterdam December 6-7. The meeting will bring together approximately 12-15 of the IG members to address emerging issues in ethics in HTAi and to chart projects that the IG may tackle collectively. Some of the topics that will be addressed are competencies for conducting ethics in HTA, ethics of disinvestment, and new approaches to identifying and addressing ethical issues with emerging technologies. The meeting is being funded by HTAi. The previous face-to-face meeting in Cologne in 2013 was very productive and led to several publications and important new collaborations. Hopes are high for a similarly productive meeting this time around. The report from the previous meeting can be found on the HTAi IG webpage: https://htai.org/interest-groups/ethics/ethics-resources/

Submitted by Ken Bond

What's Happening

EU Joint clinical assessment reports and the role of patient organizations
This is an area where our Steering Committee and its European Patients' Forum representative Valentina Strammiello as well as other members continue to be active in.

From Eurordis - Advocating for patients' active participation in new EU cooperation on health technology assessment
The European Parliament voted in favour of a new legislation to bring into place an EU-level cooperation on health technology assessment (HTA), the process through which European experts assess what a health technology adds to patient care and prepare the information Member States need to decide on whether the technology should be reimbursed. By pooling the best European expertise, the new EU HTA cooperation will contribute to increasing the scientific quality of HTA reports and will avoid duplication of work in the 28 EU Member States.
Over the last four years, EURORDIS has advocated on behalf of members to prepare a future EU HTA cooperation in which patients actively participate. In total, seven amendments proposed by EURORDIS were adopted by the European Parliament, improving the legislative text.
We are almost there! EURORDIS congratulates MEPs for voting in favour of the legislative proposal. However, and despite the fact that patients are best placed to know if a health technology is useful to them or not, MEPs rejected amendments supported by EURORDIS to ensure patients' adequate participation in the cooperation.
The legislative proposal will now pass through a reading of the Council of the European Union. EURORDIS continues to push for patients' participation in the new EU HTA cooperation. Read the press release in which we call on the Council to recognise patients' role in HTA. Any questions about HTA? Please contact francois.houyez@eurordis.org and matteo.scarabelli@eurordis.org.

Submitted by Marleen Kaatee

Surveys

Survey on actual needs and continuous education opportunities in HTA and HTA related topics

Jani Mueller (INAHTA Board Director) would like to invite you to participate in a research study on the current educational and training capabilities of institutions. Jani is currently enrolled as a doctoral candidate at the Department of Health Care Management, Technical University in Berlin.

The purpose of this survey is to collect information on actual needs and continuous education opportunities in HTA and HTA related topics and hence to identify individual and institutional capacity.
Your responses will be attributable to your organization, the results of the survey will be made publicly available, and inferences will be drawn in an aggregate manner. Please note that this survey questions have been adapted and adopted from the survey conducted by the ECHTA/ECAHI Project – Working Group 5. 2001. View the report.
Your participation is voluntary and you are free to withdraw your participation from this study at any time.
The survey can be found online at https://goo.gl/forms/QlXponS1m8jNfWPI2 and should take 15-20 minutes to complete.
If you have any questions regarding the survey or the project in general, please contact Jani - dbmueller7@yahoo.de
Thank you for taking the time to participate in this survey your response would be appreciated – almost immediately.

HTAi Secretariat

Measuring the user friendliness of national healthcare systems
Health Consumer Powerhouse's mission is to analyse health care systems and countries care provision, health policies implementation to create free user-friendly tools (disease-specific indexes) to empower citizens, physicians, patient organizations, politicians and professionals working at different national bodies (website HCP)
Currently HCP is asking health campaigners, including patient organisations, across the 35 European countries to help it compile the annual *EURO HEALTH CONSUMER INDEX*. The 2018 *INDEX* will measure the user friendliness of national healthcare systems.
If you would like to contribute your views (anonymously) on the condition of your country's healthcare system in 2018, you will find a live link below to the 16-question survey online questionnaire: 2018 Euro Health online questionnaire
[http://www.surveymonkey.com/r/EURO-HEALTH-INDEX-2018]
Please complete the survey by Monday, December 10th 2018.

Submitted by Marleen Kaatee

Seminars and webinars

Fiocruz Brasilia will host the first Brazilian seminar on patients' rights (6-7 Nov 2018)
They will launch a document entitled "palliative care and human rights" produced by the Observatory of Bioethics and Patients' Human Rights.
https://campusvirtual.fiocruz.br/gestordecursos/mod_hotsite/cvf-node-30225-submission-747/apresentaaao/929

Submitted by Sharmila Sousa

3rd EURORDIS Multi-Stakeholder Symposium on Improving Patients' Access to Rare Disease Therapies
13-14 Feb 2019, Brussels
https://www.eurordis.org/3rd-access-symposium

Submitted by Marleen Kaatee

FDA Patient Engagement Advisory Committee Meeting 15 November 2018 8am to 5pm
Hilton Washington DC North, Gaithersburg, MD

The general function of the Committee is to provide advice to the Commissioner, or designee, on complex issues relating to medical devices, the regulation of devices, and their use by patients. The meeting will be open to the public. The Committee will discuss and make recommendations on the topic "Connected and Empowered Patients: e-Platforms Potentially Expanding the Definition of Scientific Evidence." The recommendations will address how FDA can leverage patient-driven platforms, such as social media and registries, to better engage patients and consumers as empowered partners in the work of protecting public health and promoting responsible innovation. Social media and other web platform enablers are facilitating the growth of virtual patient communities. Increasingly, patients and health care consumers are using these platforms to share their health experiences and seek information from other patients and consumers, rather than their health care providers alone. Novel approaches and methodologies are being used to tap into some of these platforms as potentially rich sources of patient-generated health data, which could be used as relevant and reliable real-world evidence (https://www.fda.gov/ucm/groups/fdagov-public/@fdagov-meddev-gen/documents/document/ucm513027.pdf).
This meeting will help advance FDA's objective to assure the needs, experiences, and perspectives of patients are included as part of FDA's deliberations involving the regulation of medical devices and their use by patients.
Interested persons may present data, information, or views, orally or in writing, on issues pending before the Committee. Oral presentations from the public will be scheduled for one hour.
https://www.fda.gov/AdvisoryCommittees/Calendar/ucm621239.htm

Patient-Reported Outcomes and Patient-Centered Outcomes: Is There a Difference?
US National Health Council webinar, Wednesday 7 Nov, 7 from 1 pm ET to 2 pm ET/ 10 am PT to 11 am PT
In patient-centered research and care, we focus on the outcomes most important to patients. These outcomes are referred to in research as patient-reported outcomes or PROs. Patient-reported outcomes are not the same as patient-centered outcomes. In this webinar, you will learn about the differences, and why we need patient-centered PROs in research and care.
In 2019, the Food and Drug Administration will release two, new draft guidance documents on clinical outcome assessment (COA). Patient-reported outcomes are one type of COA tool that will be covered in these guidances. Patient groups should be familiar with PROs so they and their constituents can become fully engaged in the development and use of the patient-centered PROs important to their community.
We suggest you read this short pre-read before the webinar.
http://www.nationalhealthcouncil.org/nhc-webinar-patient-reported-outcomes-and-patient-centered-outcomes-there-difference?_cldee=a3Jpc3RpLmxlbmd5ZWxAdWNiLmNvbQ%3d%3d&recipientid=contact-3b3ec9c3b2c3e611891fd4ae52850932-ce56672ced714e6182541dd9e43ac3c7&esid=f6b7b558-eec7-e811-a2c9-000c2959e3d7

Submitted by Thomas Morel

Other items of interest

IPPOSI Newsletter http://www.ipposi.ie/category/newsletters/
IPPOSI continues to work with patient members to finalise the Patient Charter for Involvement in Medicines Assessment & Reimbursement with a view to publishing this charter by the end of November.

Access to Medicines
The National Centre for Pharmacoeconomics (NCPE Ireland) launched its Patient Organisation Submission of Evidence process in 2016. It recently completed reviewing the process and has identified priority areas for improvements around communication and guidance.
http://www.ncpe.ie/for-patients/patient-submission-process-overview/development-of-the-patient-organisation-submission-process-in-the-ncpe/

Building the next generation of patient advocates
by Irish health journalist Danielle Barron for an article as part of the Patient Focused Medicines Development (PFMD) initiative, speaking with Dr Derick Mitchell, Chief Executive of Irish Platform for Patient Organisations, Science & Industry (IPPOSI) about IPPOSI and the history of patient education.
https://patientfocusedmedicine.org/building-the-next-generation-of-patient-advocates/
IPPOSI is a unique, patient-led partnership in Ireland and internationally that has been in existence for almost 15 years.
It originated from a germ of an idea from an Irish patent advocate who saw a need for a neutral platform where patients, industry, and academia could collaborate and cooperate. Current CEO Dr Derick Mitchell explains that the goal was to open up space and a dialogue and get consensus about what patients actually need and want, and how stakeholders can work together to deliver that. Funded by a combination of Government money and industry fees, the organisation has close links with EUPATI, which has modelled much of its patient education offerings on the system originally developed by IPPOSI across different diseases.
IPPOSI was originally devised as a think-tank… Now "We have 105 patient organisation as members, and they give us the mandate to represent patients at the strategic level. This could be a decision made within a company, or a payer or HTA regulator – we operate at the regulatory and legislation level of policy."
Umbrella organisations such as IPPOSI can provide vital support for patient organisations who can often struggle with basic issues such as capacity, says Dr Mitchell. "The history of patient advocacy is based on individuals and individuals who self-train. They will have extensive experience of a condition or disease they have been experiencing for a number of years, and they know the healthcare system and where the gaps are in services and policy. This gives them great confidence to be advocates but there is no system behind the training, it's all down to the individual's motivation," he explains. What IPPOSI does is provide a framework, one that will create the next generation of patient advocates

Matthew Rehrl. An 'ikigai' Model For Healthcare Social Media
https://socialmedia.mayoclinic.org/2018/10/10/an-ikigai-model-for-healthcare-social-media/
The word ikigai (pronounced icky-guy) is an ancient Japanese term which roughly translates into 'the reason for which you wake up in the morning'. A westernized version of ikigai is the confluence of four elements, What you love to do; What you have the ability to do; What the world (however your world is defined) needs; What the world will pay you for
These four questions can be applied to a health care organization's ikigai to help evaluate and drive a health care organization's social media.
First, what are the fundamental evidence-based medical concerns contained in the "what your world needs" question? Second, what is the specific business model (the "how will you get paid?" question) surrounding a specific social media effort.
An example is a health care clinic sending a tweet about getting the flu vaccine. Answering the questions will help you better understand the true health and financial cost of your subject matter.

Submitted by Russell McGowan

Publications

FP Gauvin, 2018. Metrics and evaluation tools for patient engagement in healthcare organization- and system-level decision-making: A Systematic Review
http://www.ijhpm.com/article_3499_1967130d0349e7ae5eae493fe3321750.pdf …

Abelson J, Tripp L, Sussman J. I just want to be able to make a choice': Results from citizen deliberations about mammography screening in Ontario, Canada. Health Policy. 2018 Sep 28. pii: S0168-8510(18)30524-4. doi: 10.1016/j.healthpol.2018.09.013.

To support informed choice, mammography programs need to reflect the values of information sharing, trust and transparency, financial accountability, and allow for personal interactions and shared decision-making. Citizens are looking for balanced information about the risks and benefits of screening presented in an easy to understand, comprehensive, and transparent manner

Also: Abelson J, Tripp L, Brouwers MC, Pond G, Sussman J. Uncertain times: A survey of Canadian women's perspectives toward mammography screening. Preventive Medicine 2018 Jul;112:209-215. doi: 10.1016/j.ypmed.2018.04.021.

Sophie Staniszewska, Denegri S, Matthews R, Minogue V. Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. BMJ Open. **2018** Jul 30;8(7):e017124. doi: 10.1136/bmjopen-2017-017124. Free PMC Article
The importance of evidence to underpin practice and continuous improvement emerged. Co-production was identified as a concept central to strengthening public involvement in the future. The Vision and Mission are supported by four suggested measures of success, reach, refinement, relevance and relationships.

Wilson P, Mathie E, Poland F, Keenan J, Howe A, Munday D, Kendall S, Cowe M, Staniszewska S, Goodman C. How embedded is public involvement in mainstream health research in England a decade after policy implementation? A realist evaluation. J Health Serv Res Policy. 2018 Apr;23(2):98-106. doi: 10.1177/1355819617750688.

Price A, Schroter S, Snow R, Hicks M, Harmston R, Staniszewska S, Parker S, Richards T. Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study.
BMJ Open. **2018** Mar 23;8(3):e020452. doi: 10.1136/bmjopen-2017-020452.

CM Booth, AS Detsky. Why patients receive treatments that are minimally effective? Nature Reviews Clinical Oncology, 2018. https://www.nature.com/articles/s41571-018-0101-4 Not open access.

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