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

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 our November E-Bulletin!

From our Chair

Welcome to our November 2020 edition. I trust by now you have submitted your abstracts for posters, orals and vignettes for HTAi Manchester 2021. At this stage it is envisaged as a mixed in-person and virtual meeting, and it's shaping up to have a strong patient focus. Not only is 'patients at the heart of innovation' one of the three plenary themes, there is also a working group focusing on ensuring that patients are welcomed and supported in Manchester and virtually. PCIG is pleased to be part of this group which is led by Dr Karen Facey and includes representatives from each of the host bodies as well as the patient representatives on the Local Organising Committee.
I'm also pleased to see so many patients involved in panels and workshops. These include the following submitted by PCIG members:

Panels

- Evaluation Of A Vital Part: Innovative Approaches to Evaluate Patient and Public Involvement in Health Technology Assessment (Lead: Aline Silveira Silva)
- Patient Engagement in Early Dialogues – Experiences, Tools And Resources For HTA bodies (Lead: Neil Bertelsen)
- Patient Participation At The Organizational Level in Health Technology Assessment (Lead: Hervé Nabarette)

Workshops

- Putting Patients At The Heart: Resources And Good Practice For Patient Involvement In Health Technology Assessment (Lead: Ann Single)
- Conceptualizing patient-involvement in countries with expanding healthcare coverage: Identifying opportunities in Low- and Middle-Income Countries (Lead: Anke-Peggy Holtorf)

Finally, on behalf of PCIG, especially the Steering Group, I want to say a huge thank you to Rebecca Addo who finishes her time as the PCIG Technical Officer this year. It has wonderful getting to know Rebecca and having her support to assist in the smooth running of the Interest Group. We hope we will continue to

interact with you, Rebecca, throughout your career in HTA and especially hope you enjoy not having to stay up late in Sydney for those summertime Steering Committee meetings. Very best wishes Rebecca.

Stay safe
Ann Single, Chair – HTAi Patient and Citizen Involvement Interest Group
singlehaworth@gmail.com

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

PCIG Matters

Call for HTAi Technical Officers
Are you new to HTA? Are you interested in connecting with the global HTA community and in learning more about the activities and discussions of one of the HTAi Interest Groups? As part of our engagement and educational development strategy, the Interest Group Steering Committee (IGSC) has created the opportunity for individuals keen about pursuing or advancing career prospects in the field of HTA.

PCIG is looking for dedicated and enthusiastic individuals who are willing to provide one to two days a month to administratively support their Chair(s) and Executive Committee as a Technical Officer (TO), from January 1 – December 31, 2021.
Responsibilities vary but are guided by the Interest Group Chair and Executive Committee. Examples of responsibilities include defining agendas, setting calls and taking minutes, writing reports, supporting project work and scientific papers, drafting press releases and other similar activities. If this is something of interest to you, please complete and submit the HTAi Technical Officer Application Form and your CV to interestgroups@htai.org by **Friday, December 4, 2020**. Your application will be reviewed by the Interest Group and candidates will be notified in December.
Please note that you must be a paid member of HTAi to apply for this position. If you have not renewed your membership, you can do so at https://htai.org/membership/2020-membership/

If you have any questions, please contact Sydney Ruller at sruller@htai.org.

Update from Sophie Staniszewska
I am part of this ISPOR taskforce where we have been involving patients in the study to ensure health economic evaluation reports patient and the public involvement in studies if it has happened. The study is still underway so nothing to say at the moment. But maybe just highlight it's happening.
https://www.ispor.org/member-groups/task-forces/consolidated-health-economic-evaluation-reporting-standards-(cheers)-2
My paper on PPI in mathematical and economic modelling is now in press in the journal called The Patient.
Staniszewska S et al. Developing a Framework for Public Involvement in Mathematical and Economic Modelling: Bringing New Dynamism to Vaccination Policy Recommendations. Forthcoming, in The Patient.

Also look out for the special issue of the International Journal of Technology Assessment in Health Care special issue on patient and public involvement in HTA.

Professor Sophie Staniszewska

On behalf of the Hospital-Based HTAi Interest Group
The Hospital Based Interest group works to support those who are developers and users of Health Technology Assessment (HTA) in a hospital setting; supporting managerial and clinical decision-making processes in a hospital. It has been created to share information and insights; proposing and discussing best practices and methodologies and to work on collaborative projects.

The aim of the group is to promote awareness and increase the knowledge of hospital based HTA.
This group is also open to all members of the HTAi with an interest in HTA in a hospital setting.
The interest group is created to represent its members as a collective action, in order to work more efficiently and with influence on the decision making, to bring issues and to provide solutions in a hospital setting.
We are actively organizing educational tools, for example: webinars, workshops, debates, methodologies and cooperation on articles. The HB-HTAi IG has started to cooperate with other HTAi interest groups, as HTA is not only extended into one base and decision-making and collaboration can be diverse depending on the setting, for example a particular country.
Please if you are interested in participating as a panelist, member, author on an article/ report as a hospital based HTA expert or you are interested in this, we welcome you to join us. This can be done through the following e-mail: interestgroups@htai.org or through the website.

Hospital-Based HTAi IG

HTAi Matters

Beijing Annual Meeting 2020 – Register for sessions!
https://htai.org/annual-meetings/htai-2020-beijing/
Program: https://htai.eventsair.com/htaibeijing2020/#program

OnAIR Virtual Event Portal to view over 100 Orals and Posters.
https://portalapp.htai.eventsair.com/VirtualAttendeePortal/htaibeijing2020/htai2020/

For information on HTAi webinars, log in as member and go to the introductory webpage.
https://htai.org/?CFID=22448258&CFTOKEN=cc5e0cbe520f6d9a-F7E6050D-B0CC-CD69-EB3E4EEEDF869FEA

HTAi 2021 Innovation through HTA - Manchester UK, June 19-23, 2021
https://htai.eventsair.com/htai-manchester-2021-am/
Co-hosts NICE, the All Wales Therapeutics and Toxicology Centre (AWTTC) and Healthcare Improvement Scotland (HIS) are looking forward to welcoming you to Manchester in 2021 and are taking full advantage of the opportunity to showcase the UK's expertise in HTA. A hybrid event is being planned, which will give delegates the option to participate both in person and virtually.
The 2021 Annual Meeting will focus on how adaptive approaches to HTA can continue to provide the cornerstone in leading health systems innovation particularly as technologies advance and novel interventions rapidly emerge. As our technological world evolves and new challenges emerge, we will need to adapt HTA to ensure it continues to be a conduit to support technology innovation.
The main theme is supplemented by three plenary themes:
Evidence for HTA: Innovative Methods for Challenging Times
Patients at the Heart of Innovation
Innovating HTA to support Novel Interventions
Visit the HTAi 2021 Annual Meeting website for a full description of the theme.

Call for abstracts
Submissions for Workshops and Panels; Orals, Posters and Vignettes are now complete.

To gain a better understanding of your level of comfort with our conference design, as well as the feasibility of you being able to travel and attend an in-person event, we would kindly ask you to fill out the following short survey until December 10, 2020: https://www.surveymonkey.com/r/AM21Pre-Conference-Survey

Twitter: twitter.com/HTAiOrg @HTAiOrg
Facebook: www.facebook.com/HTAiOrg @HTAiOrg
LinkedIn: www.linkedin.com/company/htai

What's Happening

2nd Asia Pacific Patient Congress – 3-4 December
Registration is free for patients and this year's theme is 'Patient Leadership in Health Systems Strengthening'.
IAPO's Asia-Pacific Patients Congress aims to bring together patient experts and health stakeholders including researchers, nurses, health financiers, regulators, health service providers and pharmaceutical industry representatives to map out how we can all harmonise and align our agendas with national health policies and plans on Universal Health Coverage in the region.
The Congress is organised by IAPO and co-presented by Dakshayani and Amaravati Health and Education and Indian Alliance of Patient Groups.
The 2020 Congress Programme will reflect on the impact of COVID-19, the ongoing developments and the next steps towards achieving UHC in the region in the midst of COVID-19.
Link here for registration and more information.

Contributed by Ann Single

Scottish Medicines Consortium (SMC) moves its HTA meetings online
SMC has published two blogs explaining how it has taken complex HTA meetings and made then work online, in response to the Covid-19 pandemic. In the first blog Lindsay Lockhart, SMC's Public Involvement Advisor, explains the approach SMC took to enable this. In the second blog Daniel Cairns, patient group representative from Myeloma UK, provides insight as to how this has impacted patient engagement in HTA and access to new medicines.

Jennifer Dickson, Public Involvement Coordinator

WHO website
The following link is to a new WHO website which might be of interest https://decidehealth.world
In an HTAi webinar by the WHO it was described as a "Dating platform for everybody with an interest in HTA"

Contributed by Anke-Peggy Holtorf

Talking about research
The Patient Voice Initiative has launched a video series especially for health consumers and their organisations who are not sure why they might get involved with reimbursement decision processes, especially patient-based evidence (robust research into patients' needs, preferences and experiences). This series complements PVI's 2020 webinar series for health consumer organisations on patient-based evidence for HTA, but aims to introduce the area to those who may not have considered it, let alone registered for a webinar on it.
You can find the three introductory videos along with the three webinars on PVI's YouTube channel. They are there to be watched and shared.

Contributed by Ann Single

Quality Improvement in a large Canadian health service

Foothills Medical Centre (FMC) is one of the three large hospitals in Calgary. As part of an ongoing quality improvement (QI) program, the FMC is reviewing processes around cardiac services including the catheterization lab. Here are the FMC Cardiac QI Project goals.
Primary Goal:
• Implementation of Safe Surgical Checklist briefing, timeout, and debriefing process.
Secondary Goals:
• Decrease complications
• Decrease waste, and
• Increase patient satisfaction
Two patient advisors provide input, as full committee members, around the project terms of reference, patient care, and study methods. Our role has recently expanded to include taking input directly from patients. It is felt that some patients may prefer to share their experience with fellow patients rather than clinicians, due to a perceived power imbalance. The project has been slowed due to Covid, but the target date remains March 31, 2021.

Chris Hylton, Patient Advisor, Alberta Health Services, Calgary, Canada chris@hylton.ca
QI Reference: https://www.ahrq.gov/ncepcr/tools/pf-handbook/mod4.html

Exploring the potential of citizen science
https://www.thisinstitute.cam.ac.uk/podcast/exploring-the-potential-of-citizen-science/?utm_campaign=Listen%20to%20THIS&utm_content=146879164&utm_medium=social&utm_source=twitter&hss_channel=tw-896251529245716480
THIS Institute, UK podcast
Want to hear about an unusual approach to engaging thousands of people in dementia research?
Jenni Burt talks to Michael Hornberger, the co-creator of Sea Hero Quest. Sea Hero Quest is a smartphone game that gathers data on how people find their way around their environment, in Episode 6 of Listen to THIS.

Covid-19

WECAN article on 'Covid-19's twin threat for cancer patients'
https://patientfocusedmedicine.org/covid-19s-twin-threat-for-cancer-patients/
Covid-19 presents threats as shown with data on psychosocial and financial pressures, limited access to services and a surge in demand for patient organisation's services while their financial base is eroding

A New Way to Drive COVID-19 Vaccine Development
https://www.thinkglobalhealth.org/article/new-way-drive-covid-19-vaccine-development
How a "benefit-based advance market commitment" could build on existing Gavi COVAX and EU Joint Procurement initiatives, by Adrian Towse, Kalipso Chalkidou and Rachel Silverman
Around the world, countries are "going it alone" to make bilateral vaccine deals, threaten intellectual property protections, and generally use whatever means necessary to secure access for their citizens.
This creates - 'A risk that much of the world will be left behind—countries not funding their own vaccines, with no specialist manufacturing, and lacking buying power'
And, countries may end up "paying twice" for vaccines by using "push" funding, i.e. subsidising research and development (R&D) up front and then paying vaccine prices that do not account for public investment and/or exceed the health benefits delivered. It may also undermine the healthy pipeline needed to provide second- and third-generation vaccines.
An appropriate global response should balance development risk between countries, ensure access at cost to low- and lower–middle- income countries, incentivize private investment in vaccine R&D, and engage the "missing middle" of middle-income countries and the higher income countries without national candidates. Regional or global coordination will also send clearer demand signals to developers.

The Gavi COVAX Facility was launched in June as part of the WHO vaccine pillar. It is intended to add buying power to complement investments by the Coalition for Epidemic Preparedness (CEPI) in R&D and manufacturing capacity for vaccine candidates.
Drawing on Gavi's existing approaches and limited public communications, we anticipate that the facility will solicit expressions of interest from manufacturers to supply vaccines at pre-set prices and volumes. Gavi, in turn, will make legally binding commitments to purchase from specific manufacturers. It proposes a series of volume commitments to individual manufacturers for specific products, which will be triggered if and when they receive a license, and may result in too much or too little delivered vaccine.
The European Union has a regional mechanism for cooperation. It has proposed using its joint procurement powers to secure vaccine doses for its twenty-seven member states. Advance purchase agreements with vaccine producers will secure the right to buy a specified number of doses at a given price (as in the COVAX manufacturer-specific volume guarantees). In some cases, the European Union will secure this right by partially funding developers' upfront costs. Early engagement between the European Medicines Agency (EMA)—Europe's FDA equivalent—and manufacturers is already underway.
We propose a different approach to risk sharing, where the private sector retains most R&D risk and countries only pay for a successful vaccine. Countries assume market risk by guaranteeing an overall market for COVID-19 vaccines, even if the need for those vaccines decreases unexpectedly in future years (making such expenditure otherwise unnecessary).
A benefit-based advance market commitment (BBAMC) for a COVID-19 vaccine would work in a stepwise fashion. First, early health technology assessments by a country—or a regional or global purchaser acting on their behalf—would establish a value-based price for a product meeting the WHO target product profile. It would ensure risk sharing with payers, as the early health technology assessment is used to identify the size of each country's advance commitment based on the volume of vaccine needed and the price per dose.
There is no commitment on the part of participating countries to buy any particular vaccine—only to buy qualifying vaccines over a time period to meet the total market value commitment.

Analysis. Consideration Of Value-Based Pricing For Treatments And Vaccines Is Important, Even In The COVID-19 Pandemic. Peter Neumann, Joshua T Cohen, David D Kim, and Daniel A Ollendorf
HEALTH AFFAIRS Ahead of print, November 19, 2020. Free Access
https://doi.org/10.1377/hlthaff.2020.01548
Prices send signals about consumer preferences and thus stimulate producers to make more of what people want. Pricing in a pandemic is complicated and fraught. The policy puzzle involves balancing lower prices to ensure access to essential medications, vaccines, and tests, and adequate revenue streams to provide manufacturers incentives to make the substantial, risky investments needed to develop products in the first place. We review alternative pricing strategies (cost-recovery models, monetary prizes, advanced market commitments) for coronavirus disease 2019 (COVID-19) drugs, vaccines, and diagnostics. Hybrid pricing strategies are undoubtedly needed in a pandemic, but even in a public health crisis, value-based pricing is important. Cost-effectiveness analyses can inform pricing. Ideally, analyses would be conducted from both a health system and societal perspective.
....In July of this year, Clifford Lane and Anthony Fauci of the National Institute of Allergy and Infectious Diseases wrote, "It was once widely held that the setting of an outbreak is not an appropriate venue for conducting rigorous clinical research because when people are dying, any and all possible therapies should be "given a chance," rather than studied in rigorous ways." However, Lane and Fauci concluded: "Scientifically robust and ethically sound clinical research remains the quickest and most efficient pathway to effective treatment and prevention strategies for patients with COVID-19." In a similar vein, people may believe that the setting of a pandemic is not the appropriate venue for value-based pricing. However, robust and sound value assessments to inform product prices can help ensure that tests, treatments, and vaccines are available for this crisis and for crises yet to come.

Publications

The Patient journal call for editors
The Patient journal (specialising in patient preferences and PRO research), continues to build on its success and currently has an impact factor of 3.3. To ensure a high quality journal, new members of the Editorial Board are needed to:

- Undertake an occasional peer review (2-3 per year)
- Attend editorial board webinars (1-2 per year for 30 minutes)
- Offer input for the journals direction and content (normally via email)
- Write the occasional editorial piece or article (one every 2-3 years)

Membership of the Editorial Board is for a 2-year term, renewable upon members meeting the Editorial Board requirements and also depending on the requirements of the Journal.
They are particularly looking for people with expertise in PRO development and validation, qualitative research, shared decision making, medicine/device regulation and patient/public involvement (including patient advocates).

If you are interested in joining the Editorial Board, please send a half page statement of interest to the Editor, Chris Carswell at Chris.Carswell@springer.com by 18 December.

Ann Single

Measuring impact of public involvement in health research.
Russell, J., Fudge, N. & Greenhalgh, T. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it?. *Res Involv Engagem* 6, 63 (2020). https://doi.org/10.1186/s40900-020-00239-w
A commentary that calls "for a critical research agenda for public involvement that [a] considers public involvement not as an instrumental intervention but a social practice of dialogue and learning between researchers and the public; [b] explores how power relations play out in the context of public involvement in health research, what empowerment means and whose interests are served by it, and [c] asks questions about possible harms as well as benefits of public involvement, and whether the language of impact is helpful or not."

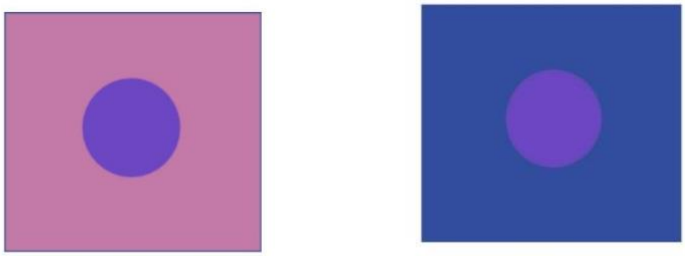
Contributed by Ann Single

Use of real-world evidence in cancer drug funding decisions in Canada: a qualitative study of stakeholders' perspectives. Clausen M, Mighton C, Kiflen R, Sebastian A, Dai WF, Mercer RE, Beca JM, Isaranuwatchai W, Chan KKW, Bombard Y. CMAJ Open. 2020 Nov 24;8(4):E772-E778. doi: 10.9778/cmajo.20200118. http://cmajopen.ca/content/8/4/E772
Real-world evidence (RWE) can provide postmarket data to inform whether funded cancer drugs yield expected outcomes and value for money, but it is unclear how to incorporate RWE into Canadian cancer drug funding decisions. This was a qualitative descriptive study with Canadian and international stakeholders who had experience with RWE and drug funding decision-making. Stakeholders indicated that a cultural shift is needed to adopt RWE in decision-making. Further, the Canadian infrastructure for real-world data is currently inadequate for decision-making, and there is a need for committed investment in building capacity to collect and analyze RWE. Finally, there is a need for increased collaboration among key stakeholders.

Translation, cultural adaptation and psychometric validation of the SF-6D measure of health-related quality of life for use in Arabic-Speaking countries. Dalia M Dawoud, Faris El-Dahiyat, Amjed Abojedi, et al. Research in Social and Administrative Pharmacy, Volume 16, Issue 12, 2020, 1754-1759, https://doi.org/10.1016/j.sapharm.2020.01.018. Available to download for free for 50 days https://www.sciencedirect.com/science/article/abs/pii/S1551741119310861?dgcid=author
The SF-6D is a generic, six-dimensional health-related quality of life (HRQoL) measure derived from a selection of items from the SF-36. We translated culturally adapted and validated the SF-6D for use in

Arabic-speaking countries. The International Quality of Life Assessment (IQOLA) methodology was followed. Two forward translations, one consensus and one backward translation were undertaken. Difficulties encountered were categorized as grammatical, idiomatic, semantic/conceptual, and cultural. The content validity of the final version was tested and Cronbach's alpha test of internal consistency was used for assessing reliability. Confirmatory factor analysis (CFA), was also used to assess construct validity and to test a pre-specified relationship of observed measures. A total of 470 participants from Jordan, Egypt, UAE, Qatar and Palestine completed the translated SF-6D. Reliability and validity have been confirmed as well as ability to assess the difference in quality of life between patients with chronic health conditions and healthy individuals.

The strange world of risk perception, and communicating risks - Alexandra Freeman, 18 November 2020
https://blogs.bmj.com/bmj/2020/11/18/alexandra-freeman-the-strange-world-of-risk-perception-and-communicating-risks/
Most of us simply do not think of colours in numerical terms. To us they are a purely qualitative, emotional experience. The same is true of "risk." Most people also do not think of risks in numerical terms. Even when we asked people to *put a number* on the chances of a person dying from covid-19 if they caught the virus, we found that people tended to have in their minds' eye a series of "personas" that represented the different levels of risk: a spectrum of risk from the lowest (young, female, ethnically white, no underlying health conditions) to the highest (very old, male, ethnically non-white, multiple underlying health conditions).
So, what made most sense to people when we were trying to help communicate risk from covid-19 was to make a visual scale, with number labels evenly spaced along it, and also spaced along it the "personas" that they naturally already had in their head.
A colour of a circle inside a square looks different depending on the colour of the surrounding square (figure provided)



You also wouldn't be surprised to hear that that same colour likely looks a little different to different individuals as well, even in the same context. Colour vision is an individual characteristic—and we struggle to describe our subjective experience of it to others. Importantly it brings home the fact that—just as with risks—there is no "right answer".
So when it comes to communicating risks with patients, perhaps think about it as if you were trying to communicate a colour. Words are not very useful where something needs to be quite precise; and can conjure up different mental images for different people. Just using a number on its own, is essentially meaningless in such an unfamiliar context, only giving us a sense of relative difference.
Our job as communicators is to try to show the risk as clearly as possible and under many different lights (contexts/ways of looking at it) so that they can see it objectively clearly and that their subjective perception is as little skewed as possible by the way we have shown it to them.

Health literacy and the quality of pharmacist-patient communication among those prescribed anticoagulation therapy Sean R King, Erica R King, David Kuhl, Lauren Peyton 2020. Research in Social and Administrative Pharmacy
https://doi.org/10.1016/j.sapharm.2020.04.026Get rights and content
Volunteers from cardiologist-supervised, pharmacists-staffed anticoagulation clinics completed telephone interviews to evaluate the relationship between health literacy and the perceived quality of patient-

pharmacist communication among those receiving anticoagulation therapy, in 220 participants. The primary outcome was patients' perceptions regarding the general communication process with pharmacists, according to the Interpersonal Process of Care questionnaire.
Patients receiving anticoagulation therapy and possessing inadequate health literacy appear more likely to perceive poorer communication with pharmacists. This seems especially true as it relates to the perceived time and attention pharmacist devote to the communication encounter, as well as the sense pharmacists provide patients concerning their ability to influence health outcomes.

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