

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

From our Chair

Welcome to another edition of the PCIG e-bulletin and thank you to Janney Wale for her consistent dedication to ensuring this valuable resource is compiled and distributed each month.

On August 4, PCIG will be holding its first 'virtual' Annual Business Meeting. This year the focus will be on providing updates from our six current projects. These include the International Summary of Information for Patients which is the first HTAi non-webinar product to go through the Society's new accreditation project. If you haven't registered yet, you can do so [here](#).

The papers were circulated on our list serve in the final week of July. Just a reminder, that if you want to circulate information on our list serve, if you contact me, I can arrange that. My apologies, the new list serve does not allow anyone to do that and nor can you reply to it. So, if you have hit reply, thinking it reaches me, please contact me directly on the email linked to my name below.

PCIG patient preference webinars

Members you can watch the first two webinars from this series if you missed them [here](#). Still to come:

Webinar Three: Patient Preferences in HTA Decision-Making, *Sept 2020*

Webinar Four: Patient Preferences and Values Studies in Oncology and Rare Diseases—Redefining Patient Advocacy in the HTA, *Oct 2020*

Patient-based evidence webinars for patient groups

The Patient Voice Initiative invites patient groups and communities to join us for a three-part webinar series on patient-based evidence.

10:00-11:30 am (AEST) 7 August – Patient preference for PBAC/MSAC

Including:

Data that makes a difference and what patient-based evidence can add (Jo Watson, PBAC Deputy Chair)

What is patient preference research and what can it do? (Dr Simon Fifer, CaPPRe and PVI)

How and why Myeloma Australia uses patient preference research (Steve Roach, CEO, Myeloma Australia & Nella Combe, Nurse, Myeloma Australia)

10:00-11:00 am (AEST) 14 August – PROMs for PBAC/MSAC

What is PROMS research and what can it do? (Prof Rachel Morton, The University of Sydney)

How and why the Unicorn Foundation uses PROMs research (Simone Leyden, CEO and Co-Founder)

10:00-11:00 am (AEST) 21 August – PROMs for PBAC/MSAC

What is qualitative research and what can it do? (Dr Stephen Holden, Adjunct Professor, Macquarie Graduate School of Management)

How and why a patient group used qualitative research (Dr John Rule, Senior Research Manager, National Association of People with HIV Australia)

You can register for the individual webinars [here](#).

Valuing and paying for combination regimens in oncology

Challenges in valuing and paying for combination regimens in oncology. Report of an international workshop convened by Bellberry, held on November 18-20, in Sydney, Australia. Latimer N, Pollard D, Towse A, Henshall C.

<https://bellberry.com.au/challenges-in-valuing-and-paying-for-combination-regimens-in-oncology/>

Combination therapies are often expensive, especially when multiple on-patent treatments are combined, which makes paying for them challenging for health systems around the world. This is particularly the case when different companies own the on-patent treatments that are combined, because this may inhibit flexibility in pricing. This report primarily considers the case where combination therapies consist of two or more on-patent treatments, owned by two or more companies. Importantly, one of the three areas recommended for development was that of increasing the value of the combination therapy through improved clinical development and design, including measures of outcomes important to patients.

Stay safe

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

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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

Online PCIG Annual Business Meeting, 4 August 2020

05:00 – 06:00 MDT (UTC -6). To register: <https://htai.org/interest-groups/pcig/htai-2017/>

This year, due to COVID, the Patient and Citizen Involvement in HTA Interest Group (PCIG) Annual Business Meeting will be held online. Join us as we provide an update on the Interest Group's activities in our new project structure.

Projects include:

- Patient participation at the organizational level
- Stakeholders perspectives of impact in patient involvement in HTA
- International Summary of Information for Patients
- Low and Middle Income Countries
- Patient Preferences
- Tools for patient engagement in Early Dialogue/Scientific Advice – PARADIGM

HTAi Disinvestment and Early Awareness Interest Group Alert

<https://htai.org/interest-groups/disinvestment-and-early-awareness/ig-resources/>

We are happy to inform you that the June 2020 (issue 5) of the *Disinvestment & Early Awareness Interest Group Alert* is now available.

This alert is a collaboration between HTAi, the Norwegian Institute of Public Health, and CADTH to provide quarterly updates on new publications relevant to disinvestment, reassessment, early awareness, and horizon scanning. We hope you find it useful!

Anna Lien Espeland for the alert team and the DEA-IG Executive Team



Beijing Annual Meeting 2020 – Register for sessions!

<https://htai.org/annual-meetings/htai-2020-beijing/>

Anke-Peggy Holtorf would like to remind you that the panel session 'Involving Patients in HTA in LMICs: Making the Ends Meet' is on: 19 August, 13:00 - 14:15 CET

15 September

Development of a 'Summary of Information for Patients' Template for International HTA Adoption

6 October

Patient Involvement Impact Stories - Adapting HTA?

7 October

Patient Access To Cell and Gene Therapies – Issues & Potential Solutions

HTAi Patient Preferences Webinar Series

<https://register.gotowebinar.com/register/7320216772546285840>

HTAi Patient and Citizen Involvement Interest Group has created an exciting new webinar series, running from June to October 2020. This webinar series includes four 60-minute webinars providing an introduction to patient preference research that over the series will explore its use in HTA.

Patient preference studies could help identify the outcomes and improvements that are most important to patients, while potentially addressing some of the perceived challenges with patient participation approaches, including the robustness, quality, partiality and consistency of input. However, the role of patient preference evidence in HTA is as yet undetermined and remains a subject of continued interest and debate: how can we best embrace new forms of patient-based evidence alongside more traditional forms of input, and will patient preference evidence redefine the future of 'the patient voice' in HTA?

Webinar Three: Patient Preferences in HTA Decision-Making, Sept 2020

Webinar Four: Patient Preferences and Values Studies in Oncology and Rare Diseases—Redefining Patient Advocacy in the HTA, Oct 2020

For information on HTAi webinars, log in as member and go to the introductory webpage.

<https://htai.org/?CFID=22448258&CFTOKEN=cc5e0cbe52of6d9a-F7E6050D-BoCC-CD69-EB3E4EEEDF869FEA>

HTAi COVID-19 Response webinar series

<https://htai.org/hta-support-for-covid-19/webinars-2/>

Webinar Five: Health Economics Methods in Rapid HTAs in Response to COVID-19

21 September 2020, 07:30 – 09:00 MDT (UTC -6)

Many countries have responded to COVID-19 without having the right tools and information to properly assess the health economic impact of the imposed interventions due to lack of time and/or resources. This could have resulted in suboptimal health outcomes and/or higher costs. However, rapid decision making is required under these circumstances and compared to doing nothing, it can save lives and high related health costs and productivity losses due to death and sick days. To be able to assess different intervention strategies, the use of HTA tools, and solid and reliable data is required. Over the past months, multiple tools

and datasets related to COVID-19 are made available which can be of great value when evidence-based policy decisions need to be made.

The objective of this webinar is to show the usefulness of several tools and data sources and the potential impact on outcomes of policies to control COVID-19.

Panellists:

Maarten Postma, PhD, MSc, *University of Groningen (Netherlands)*

Jovana Stojanovic, PhD, MSc, MPharm, *Concordia University (Canada)*

Dan Ollendorf, PhD, *Tufts University Medical Center (United States)*

Arnold Hagens, MSc, *University of Groningen (Netherlands)*

View Previous Webinars

<https://htai.org/hta-support-for-covid-19/webinars-2/>

All HTAi COVID-19 Response webinar recordings are available online. These webinars are open access. Access past webinars under the 'all previous sessions' tab at the bottom of the page.

HTAi Position Statement on Evidence Standards

<https://htai.org/hta-support-for-covid-19/>

The HTAi COVID-19 Response Team has released a position statement on Evidence Standards and Quality Assessment in COVID-19 Therapeutic Interventions. A brief introduction:

Confidence in HTA findings, recommendations, and policy decisions is directly impacted by the quality and rigor of the evidence submitted. Researchers around the globe are working tirelessly to assess early evidence on therapeutic interventions to treat patients with COVID-19, with the twin goals of speed and maintenance of the standards HTA bodies have been known for.

At the same time, those designing studies to assess the efficacy and safety of COVID therapeutic interventions need guidance on study design, outcome definition and measurement, and mitigation of bias that will meet HTA standards. This will reduce uncertainty in HTA reviews and help informing decision-making on effective treatment options.

Read the entire statement on the webpage.

Message from HTAi Director, Scientific Initiatives

If you're working on COVID-19 related projects, in any capacity, we would like to hear from you. We invite you to respond to this email and submit your concerns, suggestions, bright ideas, general thoughts at this time. All suggestions will be collated and reviewed, and where possible plans formulated to respond to priority needs of our global community.

Lucy Henry

Joint HTAi - ISPOR Task Force: Deliberative Processes for HTA

<https://htai.org/blog/2020/06/29/joint-htai-ispor-task-force-deliberative-processes-for-hta/>

<https://www.ispor.org/member-groups/task-forces/joint-htai---ispor-deliberative-processes-for-hta>

HTAi and ISPOR have announced a new joint task force to develop a consensus definition for a deliberative process from an HTA perspective and internationally recognized good practice recommendations on the use of deliberative processes in HTA. The HTAi-ISPOR Task Force aims to provide direction and recommendations on international good practices of deliberative process.

“The task force will consider all of the interrelated components of the HTA process: governance and structure of the process, scoping, assessment, appraisal, implementation and monitoring. It will discuss considerations for decisions on which approaches to the various components of a deliberative process might be more appropriate for HTA and under what contexts. The task force will also provide direction for those deciding on how and what to implement as well as practical recommendations on the evaluation and monitoring of a deliberative process.”

Launch of the INAHTA international HTA database 2.0

The International Network of Agencies for Health Technology Assessment ([INAHTA](#)) announces the launch of the new and improved international HTA database, which provides single platform to search records of completed and ongoing health technology assessments (HTAs) from around the world. The database was [previously produced by the CRD](#) and this new rebuild by INAHTA includes:

Streamlined and strengthened search function

Expanded records containing more abstract information

Records from 120 HTA producers including INAHTA member agencies and other organizations

Currently more than 16,000 records of ongoing and completed HTAs from around the world dating back to 1989

For more information and to search the international HTA database visit: <https://database.inahta.org/>

Does your organization produce HTA reports? Become a contributor to the database. Contact the INAHTA secretariat for more information (INAHTA@ihe.ca)

Twitter: twitter.com/HTAiOrg @HTAiOrg

Facebook: www.facebook.com/HTAiOrg @HTAiOrg

LinkedIn: www.linkedin.com/company/htai

What's Happening

Patient Engagement Open Forum, 25 June to end November online

<https://patientengagementopenforum.org/>

PARADIGM, Patient Focused Medicines Development (PFMD) and EUPATI welcome you to the Patient Engagement Open forum – a series of virtual events where we will work together, in a multi-stakeholder context, to turn patient engagement into reality.

The Forum aims to provide a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation and silos that are often present in patient engagement work.

Topics range from tools and recommendations for effective patient engagement, methods for monitoring and evaluation of impact and outcomes in patient engagement activities, and fair market compensation for patient input to interactive sessions on assessing good practices in patient engagement and more.

European Patients Forum newsletter: The Value and Pricing of Innovative Medicines Summary Report

<https://www.eu-patient.eu/globalassets/documents/executive-summary---pricing---finalversion.pdf>

<https://www.eu-patient.eu/globalassets/documents/position-paper---pricing---finalversion.pdf>

On 1 July 2020, the European Patients' Forum published and presented its position paper on 'The Value and Pricing of Innovative Medicines.' during an event which took place virtually. The event was moderated by EPF President Marco Greco and featured a keynote speech from European Commissioner for Health and Food Safety, Stella Kyriakides.

Data Saves Lives wants to hear from you!

Share with us your quotes on responsible health data sharing and your views on why data saves lives. Your quote will be featured on the Data Saves Lives social media pages, and will help us in our goal to promote greater awareness of how health data can be used in trustworthy ways to improve health and care, and to establish a trusted environment for dialogue about responsible health data use and good practices across Europe. dsl-info@eu-patient.eu

On 1 July 2020, Data Saves Lives (DSL) held its first deep-dive webinar all about the initiative. The webinar featured a panel of experts from the four DSL working groups, which presented the initiative from their perspective. At the end of the webinar, attendees had the opportunity to ask the panel of speakers' questions, to be published in a blog post on the DSL website. You can watch a video of the highlights

<https://www.youtube.com/watch?v=-Z6qzDniBRg&feature=youtu.be>.

This was the first in a series of webinars aimed at raising awareness about the importance of responsible data sharing, supporting patient organisations to communicate about the value of health data, and further stimulate discussions about health data issues with wider audiences. The next webinar is planned for this Autumn.

Association of the British Pharmaceutical Industry public consultation on a 'new-look, more user friendly' Code of Practice

http://www.pharmatimes.com/news/abpi_consults_on_new-look_code_of_practice_1342614?utm_source=Viridis+Newsletter&utm_medium=email&utm_campaign=viridis+news+alert

The Code is designed to help govern the pharma industry's conduct in the UK through self-regulation, and reflects the sector's commitment to operate in a professional, ethical and transparent manner. Essentially, the ABPI is proposing to update the Code to bring it closely in line with the 2019 European Code of Practice, and also its language to help ensure that it is accessible as possible.

A key change is to arrange the Code into six themed sections according to the activity or audience.

The consultation will run until September 8, with a view to publishing the new Code in January 2021 and making 'live' the following July.

Publications

'Surviving hemophilia, a roadtrip through the world of healthcare' – my autobiography

On July 31, 2020 my autobiography 'Surviving hemophilia, a roadtrip through the world of healthcare' will be published. Edited by Annemarie de Knecht – van Eekelen and designed by Suzan Beijer. With a preface from Marcel Levi. For more information, see survivinghemophilia.com.

An ebook will be available and advertised on survivinghemophilia.com from 10 August. The book contains a piece on my experiences in the Dutch Appraisal Committee from ZINL.

A Dutch version of the book will be ready at the beginning of 2021.

Cees Smit

Application of evidence-informed deliberative processes in health technology assessment in low- and middle-income countries

Oortwijn, W., Van Oosterhout, S., & Kapiriri, L. (2020). *International Journal of Technology Assessment in Health Care*, 1-5. doi:10.1017/S0266462320000549. Open Access

Wija Oortwijn

Vat LE, Warren M, Goold S, Davidge EB, Porter N, Schuitmaker-Warnaar TJ, Broerse JEW, Etchegary H. Giving patients a voice: a participatory evaluation of patient engagement in Newfoundland and Labrador Health Research. *Res Involv Engagem*. 2020 Jul 9;6:39. doi: 10.1186/s40900-020-00206-5. eCollection 2020. PMID: 32670610. The evaluation of the projects was driven by questions patients wanted answered. Participatory evaluation may increase the relevance and usefulness of information, but it also raises issues such as who defines and designs the content of evaluation tools. A co-creation process is required to develop appropriate monitoring and evaluation strategies.

Lybrand, S., & Wonder, M. (2020). Analysis of PBAC submissions and outcomes for medicines (2010–2018). *International Journal of Technology Assessment in Health Care*, 36(3), 224-231. doi:10.1017/S026646232000029X

Maynou, L., & Cairns, J. (2020). Disagreement on cancer drug decisions in Europe. *International Journal of Technology Assessment in Health Care*, 36(3), 232-238. doi:10.1017/S026646232000032X

Kristina Staley, Sally Crowe, Joanna C. Crocker, Mary Madden and Trisha Greenhalgh. What happens after James Lind Alliance Priority Setting Partnerships? A qualitative study of contexts, processes and impacts. *Research Involvement and Engagement* 2020 6:41. Published on: 11 July 2020

Journal of Participatory Research Methods

<https://jprm.scholasticahq.com/about>

A new peer-reviewed, open-access, trans-disciplinary journal focused on the methods, techniques & processes of participatory research.

Achieving Person-Centred Health Systems: Evidence, Strategies and Challenges (2020)

https://www.euro.who.int/_data/assets/pdf_file/0010/455986/person-centred-health-systems.pdf

Edited by Ellen Nolte, Sherry Merkur and Anders Anell. Published by Cambridge University Press

European Observatory on Health Systems and Policies 2020 xxiv + 398 pages

ISBN 978 1 108 79006 2

This book brings together the world's leading experts in the field to present the evidence base and analyse current challenges and issues. It examines 'person-centredness' from the different roles people take in health systems, as individual service users, care managers, taxpayers or active citizens. The evidence presented will not only provide invaluable policy advice to practitioners and policy-makers working on the design and implementation of person-centred health systems but will also be an excellent resource for academics and graduate students researching health systems in Europe.

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