

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

Enhanced quality and relevance of HTA through patient and citizen involvement

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

- Welcome – from our Chair
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Welcome to our January E-Bulletin!

NEW YEAR GREETINGS - it's the year of the metal Ox, celebrated 12 to 26 February

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From our Chair

2021 has kicked off with a flurry of activity for patient involvement in HTA. In the first few weeks of the year, we've seen a great range of papers published in the field (see below) especially with the Society's journal, International Journal of Technology Assessment in Health Care, publishing its special issue on patient involvement (edited by Sophie Staniszewska and Sophie Werkö). There you will find two papers from our project teams which are open access (to encourage sharing) thanks to grants from HTAi. Don't forget that your HTAi membership gives you free access online to the journal too.

Additionally, plans are underway to hold more virtual meetings across the wider interest group membership for sharing and networking, and early in February, the PCIG Steering Committee will meet to focus on our Strategic Plan. Preparing for this session, has highlighted just how far the area of patient involvement in determining the value of health technologies has come, but also how far we still want to go. We look forward to sharing work on the Strategic Plan with you all for your expert input.

The program for HTAi 2021 Manchester is looking like a great one for patient and public involvement. The HTAi Participation Grants have now closed and will be awarded in February. PCIG will also once again offer a PCIG PASS to support patient participation at the Annual Meeting, so please keep an eye on our [social media](#) and this list serve for details of that late February/March.

As always, if you have any questions or concerns, please contact me.

Stay safe

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

singlehaworth@gmail.com

Ann also would like to share with you:

We've gone soft

Just a note to let you know that [Patient Involvement in Health Technology Assessment \(Springer 2017\)](#) is now available in softcover which makes it a bit cheaper than the hardback. The ebook is, of course, still available. If you are new to the field and have not seen the book, do check it out. Its chapters drew on the wealth of expertise of more than 80 authors around the globe (many PCIG members) to provide a comprehensive guide to involving patients in HTA. Part I includes chapters discussing the ethical rationale, terminology, patient-based evidence, participation and patient input. Part II sets out methodology including: Qualitative Evidence Synthesis, Discrete Choice Experiments, Analytical Hierarchy Processes, Ethnographic Fieldwork, Deliberative Methods, Social Media Analysis, Patient-Reported Outcome Measures, patients as collaborative research partners and evaluation. Part III contains 15 case studies setting out current activities by HTA bodies on five continents, health technology developers and patient organisations.

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

Our members have been very busy publishing

So many papers by PCIG members that we have decided to present them upfront!

If you have been missed please let me know and that will be corrected next month.

Starting with:

Low E. (2021). Letter of support for the special issue of IJTAHC from Eric Low, Director, Eric Low Consulting, Edinburgh, UK. *International Journal of Technology Assessment in Health Care*, 37, e32.

doi:10.1017/S0266462321000027

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/letter-of-support-from-eric-low-director-eric-low-consulting-edinburgh-uk/5234233CF177D2C92615331D6BE3EC5F>

I am delighted that the IJTAHC is focusing on the important issue of patient involvement in health technology assessment (HTA).

Over the past decade or so, there has been an increasing spotlight on the involvement of patients in health technology appraisals. Rightly so. The ultimate value proposition of any new or existing health technology can be comprehensively understood only when it is viewed through a patient lens.

Stakeholders including HTA bodies, patient organizations, advocates, and researchers around the world should be congratulated for their efforts in making patient involvement in technology appraisals a reality. HTA is better for it....

One of the PCIG projects:

Pilot approach to analyzing patient and citizen involvement in health technology assessment in four diverse low- and middle-income countries

Holtorf A-P, Mueller D, Sousa MSA, Pretorius L, Wijaya KE, Adeyemi S, et al. *International Journal of Technology Assessment in Health Care*, 37. 2021.

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/abs/pilot-approach-to-analyzing-patient-and-citizen-involvement-in-health-technology-assessment-in-four-diverse-low-and-middle-income-countries/F9E8A4AD2DD19409C1C9FA861DF3A4B9>

Through a collaborative, international multi-stakeholder initiative, a questionnaire was developed for describing each LMIC's healthcare system context and the emergence of opportunities for PCI relating to HTA. The questionnaire was piloted in the first set of countries (Brazil, Indonesia, Nigeria, and South Africa). The questionnaire was successfully applied across four diverse LMICs, which are at different stages of using HTA to inform decision making. Only in Brazil, formal ways of PCI have been defined. In the other countries, there is informal influence that is contingent upon the engagement level of patient and citizen advocacy groups (PCAGs), usually strongest in areas such as HIV/AIDS, TB, oncology, or rare diseases. The questionnaire can be used to analyze the options for patients and citizens to participate in HTA or healthcare decision making.

Contributed by Anke-Peggy Holtorf

From patient advocate members:

Patients and public are important stakeholders in health technology assessment but the level of involvement is low – a call to action

Janet L Wale, Samuel Thomas, Dominique Hamerlijnck and Ronald Hollander

<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00248-9> Open Access

In this 'Call to action', we present ideas from three HTA expert commentaries calling for collaborative learning and to share innovative ideas for changes in HTA. We also draw on examples of HTA agencies creatively pursuing this goal. We propose a 'Call to action' for HTA stakeholders to undertake serious dialogue with patient advocates aimed at creating shared goals. HTA agencies can use these goals to ensure meaningful patient involvement at every step of the HTA process. Five elements are explored. A wide variety of patients and HTA practitioners came together to discuss efforts during a 2019 HTAi workshop in Cologne. While several promising examples of patient involvement were examined, the consensus of the patient leaders in attendance was that much more needs to be done. Following that workshop, the authors did additional research and continued the conversation with colleagues. This article reviews some promising initiatives. It proposes a 'Call to action' for collaboration among HTA agencies and stakeholders to develop a robust framework for patient involvement at all stages of the HTA process.

Contributed by Dominique Hamerlijnck

And more:

The representation of public values in health technology assessment to inform funding decisions: The case of Australia's national funding bodies

Haji Ali Afzali H, Street J, Merlin T, Karnon J. (2021). International Journal of Technology Assessment in Health Care, 1-4. doi:10.1017/S0266462320002238

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/abs/representation-of-public-values-in-health-technology-assessment-to-inform-funding-decisions-the-case-of-australias-national-funding-bodies/6697D7BC9DC865D98AE39C1F8FEDFB3B>

How do we bring public values into HTA and HTA-supported funding decisions? Over the past few years, there has been an increasing recognition of the value of public involvement in health technology assessment (HTA) to ensure the legitimacy and fairness of public funding decisions. However, important challenges remain, in particular, how to reorient HTA to reflect public priorities. In a recent international survey of thirty HTA agencies conducted by the International Network of Agencies for HTA (INAHTA), public engagement in HTA was listed as one of the "Top 10" challenges for HTA agencies. Historically, Australia has been at the forefront of the application of HTA for assessing the effectiveness and cost-effectiveness of new health technologies to inform public funding decisions. However, current HTA processes in Australia lack meaningful public input. Using Australia as an example, we describe this important limitation and discuss the potential impact of this gap on the health system and future directions.

Contributed by Jackie Street

Building on: Street J, Stafinski T, Lopes E, Menon D. Defining the role of the public in Health Technology Assessment (HTA) and HTA-informed decision-making processes. *Int J Technol Assess Health Care*. 2020;36:87–95.

O'Rourke B, Werko SS, Merlin T, Huang LY, Schuller T. The “Top 10” challenges for health technology assessment: INAHTA viewpoint. *Int J Technol Assess*. 2020;36:1–4.

Strengthening patient outcome evidence in health technology assessment: a coproduction approach

Mark Rasburn, Heidi Livingstone, Sarah E Scott (2021)

International Journal of Technology Assessment in Health Care, 37.

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/strengthening-patient-outcome-evidence-in-health-technology-assessment-a-coproduction-approach/B6B15E9A05F02E820270BCB40A184898>

The National Institute for Health and Care Excellence (NICE) worked with patients and staff from six patient organizations to review existing health technology assessment (HTA) methods and coproduce proposals to improve the following: patient involvement, how patient evidence is identified and considered by committees, and the support offered to patient stakeholders. This engagement identified important factors that HTA bodies need to understand to enable meaningful patient and public involvement (PPI), such as having clearly documented processes, appropriate evidence submission processes, transparent decisions, and suitable support. This work demonstrated the benefits of HTA bodies working collaboratively with patient stakeholders to improve PPI. By doing so, HTA bodies can increase their knowledge and understanding of the barriers faced by patient stakeholders to develop appropriate solutions to remove them. The coproduction approach improved stakeholder engagement methods, provided a better analysis of data, supported the development of meaningful conclusions, and improved stakeholder relationships.

Scottish Health Technologies Group: Enhancing patient engagement

Stewart J, Clifton E, Macpherson K, Angelova N, Morrison G. (2021). *International Journal of Technology Assessment in Health Care*, 37. doi:10.1017/S026646232000224X

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/scottish-health-technologies-group-enhancing-patient-engagement/40B7AEE6F555B7B2D13BE5313515FA8C>

The Scottish Health Technologies Group (SHTG) provides evidence support and advice to the National Health Service in Scotland on the use of new and existing health technologies, which, although not medicines, are likely to have significant implications for people's care. The purpose of this paper is to highlight the developments that have taken place in the SHTG's patient involvement processes in the years 2017 to 2019, focusing primarily on specific engagement with patient organizations and considering how the new approaches have been received by stakeholders.

Lessons learned from the reimbursement policy for immune checkpoint inhibitors and real-world data collection in Taiwan

Li Ying Huang, Churn-Shiouh Gau

International Journal of Technology Assessment in Health Care, First View

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/lessons-learned-from-the-reimbursement-policy-for-immune-checkpoint-inhibitors-and-realworld-data-collection-in-taiwan/526F539DA0D0ACC3F61D87AD2F8AFD2C>

The Health Technology Assessment Team plays an important role in drawing upon the evidence to support policy making. Under an implemented cost-management mechanism, Taiwan's high-cost drug policy has enabled patients to access new medicines and maximized patient benefits.

Creating a patient and community advisory committee at the Canadian Agency for Drugs and Technologies in Health

Sarah Berglas, Nadine Vautour, Daryl Bell (2021). International Journal of Technology Assessment in Health Care, 37. doi: 10.1017/S0266462320002251

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/creating-a-patient-and-community-advisory-committee-at-the-canadian-agency-for-drugs-and-technologies-in-health/5B01BBF6A0C89F7CA5C57B56A1AA6328>

In recognition of patients' roles using, and contributing to, a publicly funded health system, the Canadian Agency for Drugs and Technologies in Health (CADTH) created a Patient and Community Advisory Committee. Twelve members bring lived experiences of chronic illness, progressive illness, mental illness, trauma, traveling long distances for treatment, and caregiving to an ill child, parent, or spouse. Members contribute their own insights and ideas but do not represent specific organizations or viewpoints. This paper explores how CADTH determined the committee's role, whether to have individuals or organizations as members, and how to recruit for diversity. The creation of this committee is changing how CADTH engages with patients.

Patient involvement in relative effectiveness assessments in the European Network for Health Technology Assessment

Elvsaa I, Ettinger S, Willemsen A (2021). International Journal of Technology Assessment in Health Care, 37, e24. doi:10.1017/S0266462320002226

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/patient-involvement-in-relative-effectiveness-assessments-in-the-european-network-for-health-technology-assessment/C363442716B4C67961DC9D9F8F32446F>

Patient involvement in the process of producing health technology assessments has become increasingly important. In the European Network for Health Technology Assessment (EUnetHTA), several approaches to patient involvement were explored. The outcome was a document on "Patient Input in Relative Effectiveness Assessments" that is available for access and was published in 2019. Patients were involved in twenty-three of thirty-six pharmaceutical and other technology EUnetHTA assessments from June 2016 until the end of November 2019. Approaches to patient involvement included using a patient input template, one-on-one conversations, group conversations, scoping meeting with patients, and other approaches.

Although it is recognized that patient involvement is important to understand the needs of the target patient population, challenges remain with timely patient involvement. Additionally, further efforts are needed to guide assessment teams on how to implement and enhance the visibility of patient input in assessments.

My autobiography "Surviving hemophilia"

This has been nominated for the rare disease Black Pearl Written Media Award 2021. You can now vote for me at <https://blackpearl.eurordis.org/written-media-voting/>

At the end of February 2021, the Dutch version of my autobiography "Surviving with hemophilia, a journey through the world of healthcare" will be published. Final editing by Annemarie de Knecht - van Eekelen and design by Suzan Beijer. With a foreword by Marcel Levi.

The book or ebook can be ordered via <http://www.overlevenmethemofilie.nl>

For orders of the Dutch, English version and the ebook, see <http://www.survivinghemophilia.com>

Contributed by Cees Smit

HTAi Matters



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. The format of the meeting is being decided, and how much will be presented 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.](#)

The 2021 Board elections are approaching

Would you like to join the HTAi Board of Directors or do you have a Society member you'd like to nominate?

The nominations are open February 3 – 17, 2021, with the following positions available for nominations:

1. [Vice-President](#) for the two-year term 2021-2023. At the end of this term, the Vice-President succeeds typically to the President (two-year term) and, finally, advances to the Past President (two-year term).

2. [Secretary](#) for a three-year term 2021-2024. This position is eligible for re-election to a total of six years of service.

3. [Treasurer](#) for a three-year term 2021-2024. This position is eligible for re-election to a total of six years of service.

Considering the high profile of these positions within the Society, and while not limited to these areas, the [Nominating Committee](#) is encouraging applications from Society members in good standing with experience in one or more of the following: organizational leadership, governance of not-for-profit organizations, business and finance, operations management, marketing, communications, sponsorship development, and content strategy.

Check our [website elections page](#) to find the job descriptions, time commitments, and what you will need for your nomination. We encourage you to run for office or nominate another member. Only through the volunteer efforts, each taking a turn, will we continue building a strong, active, and successful Society. HTAi Nominating Committee and Secretariat

Interestingly the HTAi journal IJTAHC was seeking new Associate Editors. The closing date for applications was Jan 31. Editor-in-Chief wendy.babidge@adam.com.au

Twitter: twitter.com/HTAiOrg @HTAiOrg

Facebook: www.facebook.com/HTAiOrg @HTAiOrg

LinkedIn: www.linkedin.com/company/htai

What's Happening

HTA resources for patient groups

The Patient Voice Initiative in Australia has updated its tip sheet for patient groups, [Preparing for PBAC Consumer Comments – Patient Groups](#). Aimed at groups who are considering whether they should get involved with the work of the Pharmaceutical Benefits Advisory Committee (PBAC), the tip sheet may be useful to any patient groups weighing up if and how they might want to provide input to an HTA body.

Patient Voice Initiative also provides similar guides for [patients and health consumers](#) and [carers and family members](#).

Contributed by Ann Single

Virtual CADTH Symposium 2020

You can re-watch all the recorded sessions from the Virtual CADTH Symposium for the next 3 months. Login in here <https://web.cvent.com/attendee-login> and follow the quick instructional video

IPPOSI in Ireland is organising a 2021 Citizens' Jury

It launched a campaign to identify and recruit 25 members of the public, broadly representative of the Irish population, willing to step up as members of a Citizens' Jury to deliberate on the matter of Access to Health Information. Health information can be valuable for making decisions about individual care, but also for managing the future of health services more broadly. Health leaders, researchers and companies are all keen to have access to this information. But this is information about people, and those people should have a say in how it is viewed, shared and used. This jury aims to let you have your say! A cross-section of 25 adults from different communities to meet online in April 2021 to hear from and ask questions of experts, and to deliberate. The jury is overseen by a multi-stakeholder oversight panel, and is supported by a number of IPPOSI academic and industry member organisations. See full details [here](#).

Inspired by chance: valuing patients' informal contributions to research | The BMJ

BMJ 2020; 371 doi: <https://doi.org/10.1136/bmj.m4478> (Published 14 December 2020) BMJ 2020;371:m4478 Sebastian Crutch, Daniel Herron, James Pickett, Simon Rosser, Martin Rossor, on behalf of the Created Out of Mind team

Helle Ploug Hansen from the Southern University in Denmark sent in this article from the Christmas edition of the BMJ about the value of informal contributions from patients that have impacted research and medical breakthroughs. Important for us all to remember how often patients can give us those "light bulb" moments that totally change the way we think about things... We need to create spaces for them to reflect and for us to listen.

Serendipitous contributions from patients that influence the research agenda should be better recognised and acknowledged, argue Sebastian Crutch and colleagues..Collectively the stories of informal as well as formal involvement constitute an appeal to enable people affected by health conditions to influence the research which ultimately may affect them. In a world where research can often feel sanitised, these stories also encourage researchers to recognise how subtle interactions can influence emerging ideas. As Arends and Thackara wrote: "Science is hypothesis driven ... but the first step on this journey—namely, the generation of the hypothesis itself, is rarely discussed... This early and ill-described stage entails a 'methodology gap'. It is at this messy and amorphous juncture, where the creation of knowledge starts, that scientists must find their inspiration."

In our experience, that inspiration often emerges through the experiences, questions, and uncertainties of those with a lived experience of a health condition.

Contributed by Karen Facey

Controlling how their real world data is shared in health systems

[JMIR - Sharing Patient-Controlled Real-World Data Through the Application of the Theory of Commons: Action Research Case Study | Hager | Journal of Medical Internet Research](#)

Andreas Hager from Sweden has recently published a paper in collaboration with the Karolinska Institute to show how patients with long term conditions, such as cystic fibrosis, can control how their real world data is shared in health systems to develop individualised high quality care and to support post HTA monitoring of new drugs. This parent led project combines the best digital technology with a true understanding of the issues faced by patients and payers to develop a system that benefits all. We need more win-win projects like this....

Contributed by Karen Facey

Whither Medical Professionalism

by Daniel Skinner

https://blogs.bmj.com/medical-humanities/2021/01/19/whither-medical-professionalism/?utm_campaign=shareaholic&utm_medium=twitter&utm_source=socialnetwork

The ongoing pandemic and the many failures of leadership we've witnessed over the past few months have moved me to reflect on the meaning of so-called professionalism. We've certainly seen the [heroization](#) of medical professionals working in hospitals around the U.S. But, as this translates to the training of future physicians, are we sure we know what it means to be a professional?

The famed sociologist Paul Starr, author of *The Social Transformation of American Medicine*, argues that medicine is among the most deeply socialized professions in the U.S. But what he means is far from what we tend to mean when we tell somebody to be professional. What Starr means, at least in part, is that physicians in training are initiated into a world of stakeholder interests and shared historical perspectives... Students are shown the ropes of this worldview in medical school, which is then reinforced during residency so that it can be perfected by the time one enters into longer term practice. As a result, professionalism in medicine is too often reduced to a form of stakeholding rather than an other-focused advocacy for patients or populations. It is, in a sense, a guide for survival.

It's also a form of discipline, in both the positive and negative senses ...

Completing the Picture

By Laila Hallam, Health Consumer Advisor, Honorary Affiliate The University of Sydney

<https://www.patientlibrary.net/cgi-bin/library.cgi?page=Blog;top=191>

..Perspective in medicine and health care is an interesting thing. Clinical perspectives and patient perspectives are two sides of the same coin. Each real. Each valid. Yet only one is recognised as truth. Only one contributes to 'evidence'.

Clinicians are recognised for their expertise in disease and treatment. In contrast, patients and families are rarely acknowledged for their expertise in managing and living with illness.

This has led to an over-estimation of our doctors, and an under-estimation of patients.

As I've travelled through our health system as an involved family member, I have seen beautiful, gentle and attentive care. I have also seen lapses. Lapses so obvious to our family, yet invisible to the system providing care. Some of which led to unnecessary and avoidable pain and suffering and wasted resources.

And all in the course of my father's illness. My observations. My experiences. Indelibly etched. Never asked for. Never collected. Absent in the established evidence...they remain stories, anecdotes, whispers in the winds, but mostly they stay silently in the shadows.

The evidence is incomplete.

Covid-19

How and why patients made Long Covid

Felicity Callard, Elisa Perego. *Social Science & Medicine* 268 (2021) 113426

Patients collectively made Long Covid – and cognate term 'Long-haul Covid' – in the first months of the pandemic. Patients, many with initially 'mild' illness, used various kinds of evidence and advocacy to demonstrate a longer, more complex course of illness than laid out in initial reports from Wuhan. Long Covid has a strong claim to be the first illness created through patients finding one another on Twitter: it moved from patients, through various media, to formal clinical and policy channels in just a few months. This initial mapping of Long Covid – by two patients with this illness – focuses on actors in the UK and USA and demonstrates how patients marshalled epistemic authority. Patient knowledge needs to be incorporated into how COVID-19 is conceptualised, researched, and treated..

Patient Engagement in the COVID-19 Pandemic. Evaluating Remote & Online Methods

<https://medium.com/knowledgenudge/engaging-during-covid-19-evaluating-remote-online-methods-bd60ab8d1b5a>

By Leanne Dunne & Ashley Struthers

As most people on this planet can relate, life looks very different now than it did before COVID-19. When Manitoba saw its first case of COVID-19 in mid-March of 2020, staff at the [George & Fay Yee Centre for Healthcare Innovation \(CHI\)](#) began working remotely, and in-person interactions the way we knew them ceased to exist... We wanted to take a first step to understanding the impact that COVID-19 has had on engagement, the barriers and facilitators to creating a safe online space, and how online engagement affects roles and expectations, cost, time, equity, and work-life balance.

Staniszewska S, Hill EM, Grant R, Grove P, Porter J, Shiri T, Tulip S, Whitehurst J, Wright C, Datta S, Petrou S, Keeling M (2021). Developing a Framework for Public Involvement in Mathematical and Economic Modelling: Bringing New Dynamism to Vaccination Policy Recommendations. *The Patient*.
<https://doi.org/10.1007/s40271-020-00476-x>

Publications

The members of the International Network of Agencies for HTA (INAHTA) meet at their annual Congress where impact story sharing is one important activity - HTA can have a significant impact, irrespective of the health system and health technology being assessed." A great paper:

Demonstrating the influence of HTA: INAHTA member stories of HTA impact. Werkö S, Merlin T, Lambert L, Fennessy P, Galán A., Schuller T (2021). *International Journal of Technology Assessment in Health Care*, 37, E8. doi:10.1017/S0266462320000835

Patient involvement in health innovations: Necessary, but challenging. Tay E (2021). *Patient Education and Counseling*, 104(1), 47. <https://doi.org/10.1016/j.pec.2020.06.001>

Development of a decisional flowchart for meaningful patient involvement in Health Technology Assessment. Toledo-Chávarri A, Gagnon M.-P, Álvarez-Pérez Y, Perestelo-Pérez L, Triñanes Pego Y, Serrano Aguilar P (2020). *International Journal of Technology Assessment in Health Care*, 1-7.
<https://doi.org/10.1017/S0266462320001956>

Role of patients' organizations in Health Technology Assessment: a Habermasian system and lifeworld perspective

Neda Milevska-Kostova, Sita Ratna Devi Duddi, Richard J. Cooper (2021). *International Journal of Technology Assessment in Health Care*, 37.

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/abs/role-of-patients-organizations-in-health-technology-assessment-a-habermasian-system-and-lifeworld-perspective/420212683E52E3BCoCFCA105Co7E58FF>

Patient and public involvement in Health Technology Assessment (HTA) is gaining increased interest among research and policy communities. Patients' organizations represent an important link between individual patients and the health system. Social theories are increasingly being used to explain doctor-patient-system interactions, expanding understanding beyond the mere clinical perspective. In this sense, patient involvement in HTA can also be considered through the Habermas's theory of communicative action. From a Habermasian perspective, HTA as part of the instrumental rationality contributes to an increased efficiency of resource use within the system; however, such rationalization threatens to colonize the lifeworld by making it "increasingly state administered with attenuated possibilities for communicative action as a result of the commercialization and rationalization in terms of immediate returns." Using Habermasian system/lifeworld framework, this paper explores opportunities and obstacles to patient involvement in HTA, whereby trying to understand current and possible roles of patients' organizations as a mediating force between HTA as a function of the system and the lifeworld represented by patients.

Patient and caregiver engagement in the Patient-Centered Outcomes Research Institute (PCORI) Health Care Horizon Scanning System (HCHSS) process

Kelley Tipton, Jennifer De Lurio, Eileen Erinoff, et al. International Journal of Technology Assessment in Health Care, First View

https://www.cambridge.org/core/services/aop-cambridge-core/content/view/A94F49346CD53BBD494FC3083A992749/S026646232000207Xa.pdf/patient_and_caregiver_engagement_in_the_patientcentered_outcomes_research_institute_pcori_health_care_horizon_scanning_system_hchss_process.pdf

The Patient-Centered Outcomes Research Institute (PCORI) horizon scanning system is an early warning system for healthcare interventions in development that could disrupt standard care. The system involves broadly scanning many resources to identify and monitor interventions up to 3 years before anticipated entry into U.S. health care. As of March 2020, 312 monitored topics (some of which were archived) were derived.. perspectives informed analyst nominations for fourteen topics in two 2019 High Potential Disruption Reports. More research is needed to inform optimal patient and caregiver stakeholder recruitment and engagement methods and reduce barriers to participation

Qualitative comparative analysis of health economic evaluation guidelines for health technology assessment in European countries

Konstantinos Zisis, Panagiota Naoum, Kostas Athanasakis (2021). International Journal of Technology Assessment in Health Care, 37

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/abs/qualitative-comparative-analysis-of-health-economic-evaluation-guidelines-for-health-technology-assessment-in-european-countries/A4952B0D17111614E2A3CBE8C94FD44D>

Development of a checklist to guide equity considerations in health technology assessment

Maria Benkhalti, Manuel Espinoza, Richard Cookson, Vivian Welch, Peter Tugwell, Pierre Dagenais (2021). International Journal of Technology Assessment in Health Care. doi: 10.1017/S0266462320002275

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/development-of-a-checklist-to-guide-equity-considerations-in-health-technology-assessment/E07D86D1ED6CF2F7ED79758EB093B8A>

On the role of cost-effectiveness thresholds in healthcare priority setting

Jonathan Siverskog, Martin Henriksson (2021). International Journal of Technology Assessment in Health Care doi: 10.1017/S0266462321000015, 5 pages. Published Online on 25 January 2021

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/on-the-role-of-costeffectiveness-thresholds-in-healthcare-priority-setting/C5DEF17BAD8793BF8C3BC9B3E3D428A9>

Reporting cost-effectiveness evidence as QALYs forgone per QALY gained has several advantages: (i) it frames the decision as assigning an equity weight to QALYs gained, which is more transparent about the trade-off between equity and efficiency than determining a monetary cost per QALY threshold, (ii) it makes it less likely that decision makers neglect taking the opportunity cost of reimbursement into account by making it explicit, and (iii) it helps communicate the reason for sometimes denying reimbursement in a way that might be less objectionable to the public than current practice.

Pomey M-P, Bush PL, Demers-Payette O, L'Espérance A, Lochhead L, Ganache I, Roy D (2020). Developing recommendations for the diagnosis and treatment of Lyme disease: The role of the patient's perspective in a controversial environment. International Journal of Technology Assessment in Health Care, 1-6.

<https://doi.org/10.1017/S0266462320002123>

The patient partners influenced decisions by sharing their experiential knowledge. The patient interviews and the literature review added an in-depth perspective on the disease and experience with the healthcare

system. The patient association members shared their perspectives and helped disseminate the recommendation to sustain a practice change.

The combination of methods to collect and integrate patients' knowledge and patient associations' perspectives helped develop a comprehensive understanding of a controversial object of evaluation.

Health technology assessment for the acute and preventive treatment of migraine: A position statement of the International Headache Society. Diener HC, Ashina M, Durand-Zaleski I, et al. *Cephalalgia*. January 2021. doi:10.1177/0333102421989247 <https://journals.sagepub.com/doi/full/10.1177/0333102421989247>
HTA considerations for migraine through a clinical society lens. The Clinical Trials Subcommittee of the International Headache Society presents the first Health Technology Assessment for the Acute Treatment of Migraine Attacks and Prevention of Migraine. Health technology assessments are systematic evaluations of the properties, effects, and consequences of healthcare technologies; this position statement is designed to inform decision makers about access to and reimbursement for medications and devices for the acute and preventive treatment of migraine. This position statement extends beyond the already available guidelines on randomized controlled trials for migraine to incorporate real-world evidence and a synthetic approach for considering multiple data sources and modelling methods when assessing the value of migraine treatments.

NICE's Discounting Review: Clear Thinking on Rational Revision Meets Obstacle of Industrial Interests. O'Mahony JF, Paulden M, McCabe C. *PharmacoEconomics* (2021). <https://doi.org/10.1007/s40273-020-00990-8>

NICE is reviewing its discounting guidelines and has mooted a discount rate reduction from 3.5 to 1.5%, which we believe justified given the real cost of government borrowing. The implications of a revision should be considered for other interventions such as screening and vaccination, even if they lie outside of NICE's remit, as appraisal methods should be consistent across all interventions. While any necessary accompanying reduction to the cost-effectiveness threshold is precluded by a current government agreement with industry, NICE could use the considerable flexibility within its £20,000–£30,000 per QALY threshold range to accommodate reform without formally adjusting the threshold.

Developing a Framework for Public Involvement in Mathematical and Economic Modelling: Bringing New Dynamism to Vaccination Policy Recommendations. Staniszewska S, Hill EM, Grant R, Grove P, Porter J, Shiri T, Tulip S, Whitehurst J, Wright C, Datta S, Petrou S, Keeling M (2021). *The Patient* <https://doi.org/10.1007/s40271-020-00476-x>

Funding of pharmaceutical innovation during and after the COVID-19 pandemic

Robinson JC (2021). *JAMA*. doi:10.1001/jama.2020.25384

https://jamanetwork.com/journals/jama/fullarticle/2775400?utm_source=silverchair&utm_campaign=jama_network&utm_content=covid_weekly_highlights&utm_medium=email

The COVID-19 pandemic is forcing experimentation throughout the health care system, including drug prices as a source of funding for innovation. Some of the new initiatives will recede as the pandemic ends. However, the changes observed reflect deeper trends that likely will persist.

The public and political resistance to high drug prices in the US is unlikely to abate. It is neither efficient nor equitable for US taxpayers and patients to pay drug prices substantially higher than those paid in other high-income countries, even though these prices likely help support drug development that benefits many individuals around the world. Postlaunch price increases not supported by new evidence of clinical benefit cannot be justified as either cost-based or value-based pricing principles...

High drug prices in the US compared with other countries constitute a direct subsidy to foreign competitors. The high prices allow non-US pharmaceutical companies to repatriate high profits from the US market and finance expanded research and production capabilities at home, whereas US pharmaceutical companies do not gain commensurate profits from their sales abroad. This contrasts with public funding mechanisms,

including grants and tax incentives, which are designed to favor research, product development, and manufacturing activities conducted in the US.

The limitations of pharmaceutical industry profits as a financing source extend beyond the scale of investment to include its direction. The traditional framework is concentrated on investments in therapeutic niches protected from competition, rather than those of the greatest social need...

The lesson of the COVID-19 experience is that, when innovation in the life sciences is imperative, the traditional reliance on pharmaceutical industry prices and profits is jettisoned in favor of governmental grants and procurement. Sustained public funding for product development and commercialization will permit the sustained financing of innovation, a renewed attention to major public health needs, and the global position of the US pharmaceutical industry.

Health Technology Assessment and Health Care Reimbursement in the European Union:

Permissive Dissensus and the Limits of Harmonization through the Backdoor, by Olga Loblova

Member states have consistently limited the European Union's competences in the area of health care reimbursement. Despite these efforts, there has been a slow but steady tendency toward harmonization of a key tool in reimbursement decision-making: health technology assessment (HTA), a multidisciplinary evaluation of "value for money" of medicines, devices, diagnostics, and interventions, which provides expert advice for reimbursement decisions. This article examines the origins of this paradoxical appetite for harmonization as well as of the dissensus that has, at the moment, somewhat stalled further integration in HTA. It finds that the prointegration neofunctionalist "permissive dissensus" is still present in decision making on HTA but potentially offset by dissensus or outright opposition from key actors, including member states and the medical device industry. These actors are able to decipher the potential consequences of highly technical issues, such as HTA, for national systems of social protection. Despite that, they have little interest in politicizing the issue, potentially opening the door to integrative policy solutions in the future.

BMJ Quality Improvement Series: A joint series of papers exploring how to improve the quality of healthcare delivery, produced by The BMJ in partnership with and funded by the Health Foundation.

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<https://www.bmj.com/quality-improvement>

Includes: *BMJ* 2018;362:k3617 doi: 10.1136/bmj.k3617 (Published 6 September 2018)

Getting more health from healthcare: quality improvement must acknowledge patient coproduction—an essay by Paul Batalden - Modelling healthcare as either a product or a service neglects essential aspects of coproduction between doctors and patients. Paul Batalden shares his learning from 10 years of studying change.

Development and evaluation of the measurement properties of a generic questionnaire measuring patient perceptions of person-centred care. Fridberg H, Wallin L, Wallengren C, Kottorp A, Forsman H, Tistad M. *BMC Health Serv Res.* 2020 Oct 20;20(1):960. doi: 10.1186/s12913-020-05770-w. PMID: 33081770; PMCID: PMC7574493.

People in the health service: Listen to your experiences of health and illness; Discuss how health and illness affect activities of daily living (ADL); you are: Encouraged to ask questions; Get responses that you understand, Enough information about care and treatment, Come to an agreement on the next step in care, Participate in care-related decisions; Important ADLs were considered in planning, Important goals set for the planning of care; Coordination of contacts within care; Discuss what you can do for yourself; Resources acknowledged and utilised; Opportunity to express when concerned and anxious; Feel as an equal person; Trust in the staff/caregiver; Treated with respect; Participate in the development of the plan; Understand the written plan.

Does the ICMJE guideline for authorship need revising to support and recognize patient partnership? A cross-sectional survey of journal editor-in chief

Kelly D Cobey, Zarah Monfaredi, Evelyn Poole, Laurie Proulx, Dean Fergusson, David Moher

Preprint <https://osf.io/n4rg6/>

Access to, and awareness of, appropriate authorship criteria is an important right for patient partners to recognize contributions to research. Our findings highlight gaps that may act as barriers to patient partner participation in research.

A very popular tweet from Trisha Greenhalgh

Doctor: Don't confuse your Google search with my 6y at medical school.

Patient: Don't confuse the 1-hour lecture you had on my condition with my 20y of living with it.

Janet Wale, HTAi PCIG

E-mail: pcig.htai@gmail.com
