

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, July 2019

Enhanced quality and relevance of HTA through patient and citizen involvement

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

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Welcome to the July E-Bulletin – from our Chair

Following our call for Expressions of Interest in joining the PCIG Steering Committee, we are delighted to welcome Sarah Berglas and Barry Liden to the Committee. Seven valued PCIG members expressed an interest in joining. The Committee selected Sarah and Barry because they bring skills and experience which address gaps in the current Committee composition and are experienced in working on PCIG projects. In addition to contributing to the balance of the Committee, we showed preference to those experienced in PCIG projects as we believe this will be a great asset during this time of transition, particularly as new projects come online. We will keep you up to date on those projects through this e-bulletin and with emails on this listserv.

PCIG Matters

Our 29 July meeting was the final Steering Committee for some extremely dedicated members who have served with enormous energy and untold wisdom, many for more than a decade. We are deeply indebted to Karen Facey, Janney Wale, Lizzie Thomas, Sophie Staniszewska and Sally Wortley and look forward to continuing to work with them in PCIG projects.

We will work to address the remaining skills/experience gaps and balance of our multi-stakeholder group. Below is our Steering Committee membership as of 29 July 2019:

Name	Organisation	Country	Role/Area	Year appointed to role
Ann Single	Patient Voice Initiative	Australia	Chair	2019
Valentina Strammiello	European Patients Forum	Belgium	Deputy Chair	2019
Neil Bertelsen	Independent consultant	Germany	Outgoing Chair	2019
Todd Stephenson	Janssen	Australia	Finance Secretary	2019
Anke-Peggy Holtorf	Health Outcomes Strategies GmbH	Switzerland	Project Co-ordinator	2019

Sarah Berglas	CADTH	Canada	PPI in HTA body	2019
Barry Liden	Edwards Lifesciences	USA	Medical devices Patient preferences	2019
Heidi Livingstone	NICE	England	PPI in HTA body	2018
Hervé Nabarette	AFM-Téléthon	France	Patient group	2018
Rebecca Addo	CHERE, University of Technology Sydney	Australia/Ghana	Technical Officer	2018

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

HTAi Matters

Cologne Presentations Now Available



We are happy to advise that the presentations from the 2019 Annual Meeting in Cologne are now available on the HTAi website under the Resource area. These presentations may be accessed by HTAi members only.

Please note that only those presentations for which permission was received from the primary presenters are on the website. Any presentations that are not on the website are due to not having received consent and we are therefore not able to share them.

From the HTAi Annual Meeting Team

Publication as result of PCIG Annual Conference Workshop in 2017:

Stories of patient involvement impact in health technology assessments: A discussion paper by Ann Single, Karen Facey and Aline Silva. *Int J Tech Assess in Health Care* July 2019, 1-7.

Doi:10.1017/S0266462319000552

Drawing on experiences presented at the PCIG Workshop in Rome (2017), this paper uses the stories of people working in HTA bodies in the field of patient involvement to encourage discussion about the way patient involvement can impact HTAs. The stories link patient involvement to better decisions about how and when a technology is used, not just by addressing gaps, but by influencing the questions that are asked about a technology and the evidence that is used. The authors emphasise the need for HTA bodies to document the use and influence of patient involvement.

HTAi members can access the article for free via the journal link on the HTAi website or use the link.

<https://www.cambridge.org/core/journals/international-journal-of-technology-assessment-in-health-care/article/stories-of-patient-involvement-impact-in-health-technology-assessments-a-discussion-paper/F86C5196F3011F640274D87012873B7F>

AQuAS Spanish templates for patient submissions are now on our webpages

These accompany the French versions of the templates (medicines and non-medicines)

<https://htai.org/interest-groups/pcig/resources/for-hta-agencies-and-policy-makers/>

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

Xavier Garcia Cuscó and Emmanuel Gimenez from AQuAS

What's Happening

Measuring Patient Preferences: An exploratory study to determine how patient preferences data could be used in health technology assessment (HTA)

Project report

<https://www.myeloma.org.uk/wp-content/uploads/2019/07/NICE-Patient-Preferences-Report.pdf>

Myeloma UK and the National Institute for Health and Care Excellence (NICE) have released a report outlining the findings from a research project which examined how patient preference data could be more formally incorporated in HTA. Recently the NICE Scientific Advice team have also piloted providing scientific advice for a patient preferences study.

Submitted by Sally Wortley

Qualitative evidence and the Sustainable Development Goals (SDGs) symposium, Brasilia Brazil

<https://qesymposium.org/>

On behalf of the Organisation and Scientific Committees from the QESymposium (9-11 Oct, Day Zero 8 Oct is for workshops) I would like to extend the invitation to people on the HTAi-PCIG whom I know may be interested in the themes we are approaching - mainly qualitative evidence and how to bridge the know-do gap amongst those who know and those who act so that we can tackle the SDGs.

We will explore the tools and methods needed to support the translation of qualitative evidence into policy and practice, and we will examine ways of strengthening capacity particularly in the global South.

As well as face-to-face participation, we will provide virtual participation options through a linked 'virtual Symposium'.

Sharmila Sousa, Fiocruz

NICE to undertake regular 'health technology evaluation methods' review

The National Institute for Health and Care Excellence (NICE) has announced details of its health technology evaluation methods review, with a purpose to optimise NICE's evaluation methods to support the ambition of the NHS and provide high quality care that offers good value to patients and to the NHS.

The review will cover NICE's technology appraisals (TA), highly specialised technologies (HST), medical technologies, and diagnostics assessment programmes. It will also look at how uncertainty - for example with the available evidence or the assumptions made within economic modelling - is explored or quantified, and what can be done to try and reduce that uncertainty. This will include thinking about how data analytics and real-world evidence can be used.

Other topics, scheduled for consideration in 2020 include "How quality of life is incorporated into economic analyses and considered by committees", "Technology-specific issues (for example, addressing the challenges of evaluating the new generation of treatments that have been developed to target tumours according to their genetic make-up rather than where they originate in the body)" and "the methods needed to assess the clinical and cost effectiveness of the position of technologies in the care pathway."

EPF Congress 2019 12-14 November 2019 / Brussels, Belgium

<https://epfcongress.eu/>

In order to meet future challenges, healthcare must urgently shift from a fragmented disease-focus to a person-centred, integrated, participatory approach. Patient involvement is an underused resource in the development of innovative, patient-centred healthcare design and delivery at all levels that has enormous potential for improving healthcare effectiveness, efficiency and long-term sustainability. The EPF Congress – developed by representatives of the patient community themselves – will start a process towards real and lasting change in attitudes, knowledge and resources, moving forward policies and practices that will really empower patients:

How can co-designing healthcare services and systems with those who use it be successful?

How does patient involvement contribute to the best value for money in healthcare?

Why must partnership with patients become the norm in health research?

How can patients and their families be empowered to improve patient safety?

EPF responds to public consultation on EMA Strategy

At the end of June, EPF submitted a response to the European Medicines Agency's consultation on its strategic priorities for the next years 'Regulatory Science to 2025'.

<http://www.eu-patient.eu/News/News/epf-responds-to-public-consultation-on-ema-strategy/>

From the European Patients' Forum (EPF) Newsletter - July 2019

IPPOSI Patient Charter

<https://www.ipposi.ie/our-work/health-innovation/patient-charter/>

This Charter represents a call to action from Irish patient organisations to the Irish Department of Health, the Health Service Executive (HSE) and the National Centre for Pharmacoeconomics (NCPE). It is an open invitation to these national agencies to explore how patients are currently involved in the process of assessing and reimbursing new medicines in Ireland, and how this can be improved.

AllTrials: UK writing a new strategy on clinical trial transparency

<https://www.hra.nhs.uk/about-us/consultations/make-it-public/>

The NHS's Health Research Authority (HRA) has said the aims of the strategy are to "make transparency easy, make compliance clear and make information public." It has opened a public consultation on the draft strategy and on its plans to achieve these aims.

The HRA is asking us all to indicate priorities from among the plans and to point out where we think the HRA should go further. AllTrials especially welcomes the plans to monitor research sponsors' compliance with reporting rules and to share good practice to make following the rules as easy as possible. We are also very glad to see the HRA is asking for thoughts on whether introducing the threat of sanctions (such as fining researchers who don't follow the rules and bringing a researcher's past behaviour into consideration in future approvals) would increase compliance.

The HRA is doing this on the recommendation of the Science and Technology Committee of MPs and needs lots of input into its consultation to ensure the government recognises the strong mandate for progress to happen. Please, if you can, read the background to the strategy and complete the short survey <https://www.hra.nhs.uk/about-us/consultations/make-it-public/>

Sile of Sense about Science

www.senseaboutscience.org

Publications

Are patient education materials about cancer screening more effective when co-created with patients? A qualitative interview study and randomized controlled trial.

NY Bashir, JE Moore, D Buckland et al. *Curr Oncol*. 2019 Apr; 26(2): 124–136. Published online 2019 Apr 1. doi: [10.3747/co.26.4621](https://doi.org/10.3747/co.26.4621)

After co-created patient education materials (PEM) exposure, intervention and control participants did not clearly differ in Decisional Conflict Scale scores; in SURE (Sure of myself, Understand information, Risk–benefit ratio, or Encouragement) scores; or in screening intention. The screening test was for prostate cancer.

Submitted by Nigel Cook

Position paper on digital health from a patient perspective

Funded by Novartis. GLNS/NEUR/0036(1) Date of Preparation: May 2019

Established in 2016, the European Patient Innovation Summit (EPIS) was a platform for patient advocates from across Europe to discuss all aspects of digital health and to achieve consensus on the patients' position

on different issues relating to the digital world. EPIS is an event organized by Novartis together with a Steering Committee, representing the patient community that uses an innovative multi-site and multi-lingual format to enable patient advocates to learn more about developments in digital health and discuss how to embed a stronger patient voice within the digital health ecosystem.

EPIS 2018, which took place on 15th November 2018, was attended by over 270 patient advocates, spread out across thirteen hubs in different European countries and linked. The recommendations represent a clear call to action on patient-relevant aspects of digital health, for patient advocates, technology developers, policy makers, payers and healthcare professionals.

As relevant now as 12 months ago

<http://nuffieldbioethics.org/wp-content/uploads/Genome-editing-and-human-reproduction-FINAL-website.pdf>

In July 2018, a report was published on the social and ethical issues raised by the use of genome editing as a technology that could influence inherited characteristics in humans. The potential development of genome editing applications in human reproduction was one of the areas identified as requiring urgent ethical scrutiny in our 2016 report *Genome editing: an ethical review*.

Janet Wale, for HTAi PCIG

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