NEWS

HTAi:
An International Society
for the Promotion of
Health Technology Assessment

HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG)
E-Bulletin, December 2017

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 last E-Bulletin for 2017!

We wish you the very best for the New Year, and look forward to working with many of you in 2018! And do have a very happy and relaxing holiday season, for those who have time off.

Message from the Chair

Dear Members

It has been a busy year with the PCIG and I thank you all for your continued engagement, the advice and knowledge you bring to us, and the way that many of you get involved in our activities and promote the concepts and methodologies of patient and citizen involvement around the world.

Next year is likely to be even busier for us. We have a very ambitious set of work plans covering the mapping of resources around patient and citizen involvement; the role of PROs in the evidence that is considered by HTA, our involvement in an upcoming Innovative Medicines Initiative project; and our continued involvement in the HTA annual meeting - to name but a few of our activities.

As ever, we are always keen to hear from those of you who would like to get more involved in the group's activities. And expect further emails from me in the coming days on ways that you can offer your support.

Neil Bertelsen

Expressions of interest in upcoming EURORDIS event sought by HTAi

Does the following event align with a specific interest of yours? If so, could you let us know and also indicate how you think you could best contribute to the event?

On behalf of EURORDIS-Rare Diseases Europe and Karen Facey, we are writing to explain why we believe an associate partnership for HTAi with our 9th European Conference on Rare Diseases & Orphan Products (ECRD 2018) to be held at the Wien Messe Congress Center in Vienna, Austria from 10 to 12 May 2018, is of value and relevance to our respective organisations.
ECRD is a biennial event that has allowed the rare disease community to gather since 2001 to monitor and benchmark relevant initiatives, drive the policy framework around rare disease diagnosis, treatment and care and empower the rare disease community to drive change where it is needed most. Outputs from these conferences have informed national and local policy initiatives and are referenced in decision-making around the provision of services for the community. It is important that all rare disease stakeholders are 'at the table' during these discussions and all perspectives taken into consideration.
The overarching theme of ECRD 2018 is **Rare Diseases 360° - Collaborative strategies to leave no one behind.** There is one entire theme (5 sessions) entitled 'Breakthrough medicines on the horizon' that will specifically address the changes envisaged at a European level for health technology assessment and other related topics. The co-theme leaders for those sessions have been confirmed as Wim Goettsch, Executive Board Chair, EUNetHTA, Jordi Llinares, Head of Product Development Scientific Support Department, EMA and François Houyez, Treatment Information and Access Director, Health Policy Advisor, EURORDIS.
Please visit our official website here: https://www.rare-diseases.eu/. If you scroll to the bottom of the homepage you will see the list of full and associate partners already confirmed for ECRD 2018 to give you an idea of their scope, outreach and diversity.
Sharon Ashton, EURORDIS - UK office

Rebecca Trowman
Policy Forum and Interest Group Manager, Health Technology Assessment international (HTAi)

What's happening – in the world of patient and public involvement and access

In Wales, UK
See this great 5 minute video that explains different mechanisms to medicines access in Wales – explaining the range of routes with great infographics.
https://youtu.be/47tcgnF3Wwg

Karen Facey

In Belgium

The Belgian Health Care Knowledge Centre (KCE), the HTA body in Belgium, is leading the HTA input into the Innovative Medicines Initiative (IMI) PREFER project. See their latest update here:
https://tinyurl.com/yc2fwkmx

PREFER looks at how and when it is best to perform and include patient-preference in decision making during the drug life cycle. We include patient stakeholders at every level of the project. The end-result will be recommendations to support development of guidelines for industry, regulatory authorities and HTA bodies (http://www.imi-prefer.eu/).
The PREFER consortium includes four patient organisation: the European Cancer Patients Coalition (ECPC), Muscular Dystrophy UK (MDUK), European Patients Forum (EPF), and International Alliance of Patients' Organizations (IAPO). Together they form the PREFER Patient Advisory Group.

Karen Facey

In US

FDA public workshop, "Patient-Focused Drug Development: Guidance 1 – Collecting Comprehensive and Representative Input," on December 18, 2017.
https://www.fda.gov/downloads/Drugs/NewsEvents/UCM586195.pdf
FDA is to develop a series of four guidance documents describing in a stepwise manner how stakeholders can collect and submit information from patients and caregivers to be used for medical product development and regulatory decision making. These documents will focus on practical approaches and methods to collect and utilize robust and meaningful patient and caregiver input that will ultimately inform the development of clinical studies that measure what matters most to patients. The science of patient input is constantly evolving and gathering robust and meaningful *patient experience data* to inform medical product development is a collaborative process.

Neil Bertelsen

In healthcare quality

EPF participates in international effort to assess health systems' performance from a patient perspective
http://www.eu-patient.eu/News/News/epf-participates-in-international-effort-to-assess-health-systems-performance-from-a-patient-perspective/
European Patients Forum (EPF) has developed close cooperation with the Organisation for Economic Co-operation and Development (OECD) in the last years, namely on healthcare quality indicators. We are delighted to see that the patient perspective is more and more considered as added value to their work, and we will continue this collaboration in the hope that new indicators are actually meaningful for patients and co-designed with them.
Countries acknowledge: patients' views matter
In January 2017, the health ministers of OECD Member States mandated the OECD to develop tools for assessing health systems performance from the patient's perspective, in a Ministerial statement titled "The Next Generation of Health Reforms".
The aim of collecting data is to support health systems to become more knowledge-based and person-centred; to achieve better governance, particularly by reducing waste; to understand and plan for complex care needs; and to understand and manage the impact of new technological developments, such as personalised medicine.
The essence of the initiative – called Patient Reported Indicators Surveys or PaRIS – is the collection of comparable cross-country indicators on patient-reported outcome measures (PROMs) for different conditions, and patients' experiences of care (PREMs). The first areas to be explored are breast cancer and hip/knee replacements. OECD will lead the development of internationally comparable indicators where they do not already exist. An important future area will be looking at "generic" PROMs that could be applicable for any person living with one or more chronic conditions.

Job opportunities

EUnetHTA vacancy
http://www.eunethta.eu/vacancies
EUnetHTA is looking for: a Senior Scientific Officer (1,0 FTE), with the National Health Care Institute in the Netherlands.

The National Health Care Institute (ZIN) is an independent, non-departmental government organisation. The tasks of ZIN include providing advice about and implementing statutory Dutch health insurance. ZIN has a major role in maintaining the quality, accessibility and affordability of health care in the Netherlands. The objective of the EUnetHTA Joint Action 3 (JA3) is to support voluntary cooperation at scientific and technical level between Health Technology Assessment Bodies to validate the model for joint work to be continued after EU funding under the Health Programme ends. The cooperation between national and regional HTA Bodies is essential to meet the provisions set out by Article 15 of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare (5) and to create synergy with the strategic HTA Network set up under this Directive.
JA3 is divided into seven functional Working Packages (WP) of which the first (WP1) is responsible for the overall management.
ZIN is the designated partner organisation to lead EUnetHTA JA3 from 2016 – 2019. For this task ZIN established the EUnetHTA Directorate to manage the cooperation amongst the 80+ partner organisations of the EUnetHTA consortium.

From: Marleen Kaatee
Date: Wed, Dec 13, 2017

University Professor (Full Professor) for Quantitative Methods in Public Health and Health Services Research, Austria

We are happy to announce that as part of the further development of the Institute for Public Health, Medical Decision Making and Health Technology Assessment (IPH), UMIT - University for Health Sciences, Medical Informatics and Technology in Hall in Tirol, Austria, seeks to fill the full-time position (100%) at the earliest time possible. The professor will also be the Head of the new Division for Quantitative Methods in Public Health and Health Services Research at the IPH.
Interested candidates are kindly requested to electronically send their applications, along with the usual documents, to UMIT's Rectorate, Email: rektorat@umit.at; code word: Quantitative Methods PH+VF, **by January 31, 2018, at the latest.**
For full details: https://www.umit.at/page.cfm?vpath=universitaet/die-universitaet/berufungsverfahren

Prof. Dr. Uwe Siebert, President, Society for Medical Decision Making (SMDM), Professor of Public Health and Health Technology Assessment (UMIT), Adjunct Professor of Health Policy and Management (Harvard University), Chair, Dept. of Public Health, Health Services Research and HTA, UMIT - University for Health Sciences, Medical Informatics and Technology, Eduard-Wallnoefer-Zentrum 1, A-6060 Hall i.T., AUSTRIA

Publications

A new use for patient preference studies to understand weightings in composite endpoint studies.

JAMA Guide to Statistics and Methods. The "Utility" in Composite Outcome Measures. Measuring What Is Important to Patients by Telba Z Irony. JAMA November 14, 2017 Volume 318(18), 1820-21
Composite end points may be used in a clinical trial (or in observational studies) if the target disease has several clinically important consequences and the study is intended to examine the effects (or association) of an intervention on (or exposure with) more than 1 consequence or end point. If patients perceive the importance of individual components differently (eg, death being a much worse outcome than having a myocardial infarction), then using a singular composite end point to represent a study result may be misleading. This can be corrected using weighting or utility, which can be determined using patient preference studies.

Nigel Cook

A Health Plan's Investigation of Healthy Days and Chronic Conditions

Tristan Cordier, S. Lane Slabaugh, Eric Havens, Jonathan Pena, Gil Haugh, Vipin Gopal, Andrew Renda, Mona Shah, and Matthew Zack. Am J Manag Care. 2017;23(10):e323-e330
Humana, the Centers for Disease Control and Prevention (CDC), and the Robert Wood Johnson Foundation joint study links higher incremental unhealthy days to the presence of certain chronic conditions and to Non-compliance with certain quality measures
Results of the study found a relationship between patient-reported, health-related quality of life (HRQoL) and multiple objective measures of health in elderly Medicare Advantage patients with chronic conditions.
The researchers used the survey instrument Healthy Days to evaluate HRQoL, a CDC measure that assesses the total burden of disease in a population, including physical, emotional, and mental health and social functioning. Healthy Days uses four questions to assess how individuals perceive their recent health and how many days over the previous month they felt physically or mentally unwell.
Those who were compliant with certain quality measures related to their chronic conditions, such as diabetic eye exams or medication adherence, reported fewer unhealthy days.
Patients who reported more unhealthy days had higher health care utilization (doctor visits and hospitalizations).
The study evaluated 55,681 individuals who had a mean age of 75 years, were 56 percent female and 87 percent white. Humana is creating population-level health care interventions that can potentially reduce the burden of chronic disease and improve overall wellbeing.

Nigel Cook

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