

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

From our Chair

We are receiving a lot of enquiries regarding HTAi 2020 in Beijing and the coronavirus disease (COVID-19). PCIG is currently acting in accordance with the advice we have received from HTAi (published below). The PCIG resources workshop is scheduled for the full day of Sunday 21 June and our joint workshop with the Low and Middle Income Countries Interest Group has been scheduled for the afternoon session on the same day. We recognise that now is a particularly challenging time for patients and care givers to travel and are being mindful of this as we plan.

Please watch for emails with updates on HTAi 2020.

I'd also like to draw your attention to a survey we're doing to make sure these E-bulletins meet your needs. While newsletters struggle for attention in this era of information overload, the PCIG E-Bulletin maintains a relatively high readership (on average around a third of people on the distribution list open the newsletter). If you can spare 5 minutes, please complete this quick survey.

E-Bulletin survey

Please follow the link to complete our survey on the PCIG E-Bulletin (this monthly newsletter) **by 31 March**:

<https://www.surveymonkey.com/r/PY922SJ>

Why? PCIG is updating its communications strategy. This includes working with HTAi to introduce a new email group, increasing our use of our [LinkedIn](#) page (and [Twitter](#) account, and making sure the E-Bulletin meets your needs. While the PCIG E-Bulletin maintains a solid readership, we don't know which information you value the most. We'll share what we learn in the E-Bulletin and use it to guide our work.

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HTAi Matters



HTAi 2020 Annual Meeting Beijing
*Attaining, maintaining and sustaining
healthcare systems in a changing World:
the role of HTA* HTAi2020.org
20-24 June

HTAi is aware of the global news regarding the Coronavirus (COVID-19) and the evolving advisories regarding travel to China. We will continue to closely monitor the situation and its impact on our stakeholders. We will provide updates on the Annual Meeting in the travel tab of the Annual Meeting website, found here: <https://htai2020.org/traveling-to-china/>.

As of the end of February planning for the meeting continues to go ahead. The HTAi Board will provide supplementary communications on or before March 20, 2020.

Registration

HTAi continues to encourage our stakeholders to review the advice of their local authorities. In recognition of current barriers to travel, the Early Bird Deadline for registration will be extended to April 20, 2020, giving delegates more flexibility in determining their travel arrangements.

The Annual Meeting [refund policy](#) remains in effect and HTAi confirms it will offer a full refund on registration to any delegates who are prevented from attending the Annual Meeting due to COVID-19.

HTAi has been working with our local hosts, Fudan University and China National Health Development Research Centre (CNHDRC), over the past two years with the goal of expanding our ability to mobilize and strengthen the global HTA community. Despite local logistical challenges, all parties remain committed to this goal and are seeking solutions to make the conference successful.

Travel grants

Congratulations to successful applicants for travel grants – please quickly let our Chair know of any problems you may have in taking up these grants so that we can try to address them.

Follow us on social media and re-post our messages: #HTAi2020Beijing

Twitter: twitter.com/HTAiOrg @HTAiOrg

Facebook: www.facebook.com/HTAiOrg @HTAiOrg

LinkedIn: www.linkedin.com/company/htai

What's Happening

International Women's Day 8 March 2020

Championed by UN Women for advancing gender equality and the empowerment of all women and girls. As part of this year's events, the global community will take stock of progress made for women's rights since the adoption of the Beijing Platform for Action and will also mark several other galvanizing moments in the gender equality movement: a five-year milestone towards achieving the Sustainable Development Goals; the 20th anniversary of UN Security Council resolution 1325 on women, peace and security; and the 10th anniversary of UN Women's establishment.

Patient Focused Medicines Development: Patient Engagement Industry Training (L1 Awareness - full version) <https://learning.pfmd.org/cstart/course/182>

Learn about WHY patient engagement is the right thing to do and WHY it also makes business sense. After this course, you will be able to define when patient engagement happens, who should do it and when patients should be involved. This first level of Patient engagement training for industry professionals will provide case examples as well as introduce you to the next level of training that focuses specifically on HOW to operationalise patient engagement systematically and effectively.

From the European Patients Forum February newsletter:

Project ImmUniverse: Transforming Diagnosis and Therapy of Immune-Mediated Diseases

<https://www.immuniverse.eu/>

ImmUniverse has been formed as a European trans-disciplinary consortium to tackle unmet needs and pave the way towards a truly personalised disease understanding of two different diseases, Ulcerative Colitis and

Atopic Dermatitis. The project will run for a period of five years with a total budget of EUR 31 million provided by the Innovative Medicines Initiative (IMI 2), a Joint Undertaking of the European Union and the European Federation of Pharmaceutical Industries and Associations (EFPIA). Of the total budget, 50% are contributed by the EFPIA partners and 50% by the EU. EPF is an important part of this initiative.

Médecins du Monde (MdM) <https://www.eu-patient.eu/News/News/state-of-universal-healthcare-coverage-in-europe-epfs-view-on-medecins-du-mondes-recent-report2/>

On 11 December, EPF was honoured to be invited to moderate a panel at an event in the European Parliament organised MdM. This was to launch MdM's [2019 observatory report](#) on the state of universal healthcare coverage in Europe. The report sheds the light on healthcare exclusion experienced by people in vulnerable situations such as homelessness, migration and poverty especially for children, providing a unique insight into the state of Universal Healthcare Coverage (UHC) in Europe. Included are data and testimonies from 29,359 people in seven countries (Belgium, France, Germany, Luxembourg, Sweden, Switzerland, and United Kingdom). Some member states of the European Union are not meeting United Nations and the World Health Organization standards on UHC, nor respecting the human rights frameworks that protects UHC. The [State of Health in the EU](#) Country Health Profiles and companion report published by the Commission, WHO European Observatory and OECD at the end of November 2019 echo the findings that gaps in the accessibility of health care and a lack of data are undermining UHC across the European Union.

ASCO GU 2020: Financial toxicity and quality of life: Understanding and improving patient centered outcomes in genitourinary malignancies

https://www.urotoday.com/conference-highlights/asco-gu-2020/asco-gu-2020-bladder-cancer/119188-asco-gu-2020-financial-toxicity-and-quality-of-life-understanding-and-improving-patient-centered-outcomes-in-genitourinary-malignancies.html?utm_source=newsletter_7482

Publications

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