

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

Enhanced quality and relevance of HTA through patient and citizen involvement

Welcome!

We are obtaining helpful information from your responses to our questionnaire (see end of E-Bulletin) that will guide some changes in future editions. If you want to voice your views, please send your responses to Janney Wale, e-mail: socrates111@bigpond.com



A Message from the Chair

I will be writing a note to you all in each of the future E-Bulletins. This is to update you on activities of the group, to alert you to any upcoming consultations, and to encourage you to feedback to us with your thoughts, ideas, activities or observations on the evolving nature of patient and citizen involvement in HTA. Do feel free to contact me at any time.

It has been a busy month across the interest group. The consultation on the patient group submission template for diagnostics was closed and work has begun to revise this following your input. Your engagement in these consultations is very important to us as it strengthens the work that we do and the resources we create, so thank you to all who contributed. Outside of the interest group, there has been a period of consultation organised by the European Commission on 'strengthening EU cooperation on HTA'. This consultation ended in January, and we have heard from many of you that you have input into this process. We will be watching closely for any announcement on the outcome of this consultation and share this with you when it becomes available.

We are now in the lead up to the HTAi 2017 congress in Rome. Members of the working groups and steering committee have been planning for their panels, workshops and oral sessions, and I know that some of you are involved in these. As we get closer to the event, we will send round a calendar of the patient and citizen involvement sessions and meetings that we have visibility of. It would be useful to know who is coming to Rome from our membership and we will be sending round a very short doodle poll to capture this in the coming weeks. If you have a patient or citizen session at the meeting and would like this added to our calendar, then please forward the details to us. Please make a note that our interest group AGM will be held in Rome on Monday 19th June at 16:30.

Last but not least, the interest group is potentially embarking on a new adventure. We have been invited to join a public consortium to answer the Innovative Medicines Initiative call on 'Patient Perspectives in the medicines lifecycle'. It will be several months before we know if this particular consortium has been successful, but we are excited at the prospect of bringing the patient and citizen involvement in HTA perspective into this important project. We will keep you updated.

Neil Bertelsen
Chair - HTAi Patient & Citizen Involvement in HTA Interest Group
nb@neilbertelsen.com

PCIG News

See the photo of some of the PCIG team on our webpages
<http://www.htai.org/index.php?id=545>

HTAi Annual Meeting 2017: Explore how the global HTA community is evolving towards an integrated ecosystem – from local needs to global opportunities

Join us for HTAi's 14th Annual Meeting June 17-21, 2017 at the Ergife Palace Hotel in Rome, Italy.

New Associate Editor of the International Journal of Technology Assessment in Health Care

Editor: Dr Wendy Babidge

Sally Wortley has recently been appointed to Associate Editor of IJTAHC. Ken Bond is already an Associate Editor

Submitted by Jackie Street

IMI GetReal

Sure-Real tool online: visually design & explore multiple trial scenarios when creating evidence development plans.

<https://www.imi-getreal.eu/Tools/Sure-Real>

Health Technology Assessment in the European Union. State of Art and Future Scenarios

February 2017. Authors: Davide Integlia and Eleonora Mazzoni

This paper provides a well-researched report on the purpose of HTA in the EU, EUnetHTA, cross-country comparisons, challenges and policy considerations.

<http://www.astrid-online.it/static/upload/7787/7787e169a7foafc63221153a6636c63f.pdf>

Provided by Kathi Apostolidis

Highlights from the European Patients' Forum (EPF) March newsletter

In the course of 2016, EPF ran a survey among patients' representatives to understand their perception of *quality of care*. The featured report shows how the image of quality very much depends on the context where healthcare is provided and that it encompasses many dimensions of health and social care. The survey's results are telling and should encourage policy-makers to invest in more qualitative methods to capture patients' feedback.

In 2017, EPF will develop a formal position statement on quality of care, based on the results of this survey and other work we have undertaken with our member patient organisations.

<http://www.eu-patient.eu/News/News/epf-survey-results---what-does-quality-care-mean-to-patients/>

Active Citizenship Network Newsletter highlights

Patient's involvement in the National Medicine Agencies: let us know what is happening in your country!

Active Citizenship Network designed a short survey on the involvement of patients associations in each Member State. The collected data will be presented in occasion of the next European Patients' Rights Day. Please let us know the different patients' engagement approaches in the national medicines agencies processes! Active Citizenship Network will be glad if you give us your precious opinion about the situation in your Country. [Click here to fill the questionnaire](#). There is also a version of the questionnaire dedicated to the National Medicine Agencies. If you work in one of them, please use [this questionnaire](#).

10 May 2017, Brussels (Belgium): 11th European Patients' Rights Day on "The European & National Medicines Regulatory Systems: the challenges for an equitable, timely and suitable access to innovation"

Active Citizenship Network will celebrate the 11th European Patients' Rights Day with a multi-stakeholder conference to be held on 10 May 2017 at the European Economic and Social Committee. The aim of the convention is to discuss, inform and suggest new approaches to the existing European and National Medicines Regulatory Systems, for better management of access to innovation. Indeed, the access to innovative therapies strongly contributes to define the quality of life of patients and the quality of healthcare services provided, respecting the fundamental values recognized by the [European Charter of Patients' Rights](#).

<http://www.activecitizenship.net/patients-rights/projects/234-european-patients-rights-day-2017.html>

Changing Current Practice in Urology: Improving Guideline Development and Implementation through Stakeholder Engagement

[http://www.europeanurology.com/article/S0302-2838\(17\)30097-0/fulltext?rss=yes](http://www.europeanurology.com/article/S0302-2838(17)30097-0/fulltext?rss=yes)

The International Kidney Cancer Coalition has been working to ensure that there is a robust patient voice in the development of guidelines for kidney cancer. Our involvement in the European Urology Association (EAU) Guidelines is considered best practice.

A relevant quote: "Here, we propose a model that addresses all the different agents (patients, carers, charitable organisations, and health care funders, in addition to specialists) involved in health-related decisions. Importantly, our proposed model incorporates key stakeholders as non-tokenistic panel members with clearly defined responsibilities."

Deb Maskens, Vice Chair and PCIG Panel member

Patient View: 'Corporate Reputation of Pharma in 2016—The Patient Perspective'

<http://createsend.com/t/j-F9E5E5647E345B15>

A report from a survey conducted: November 2016 to early-February 2017.

Patient groups surveyed: 1,463 patient groups; 46+ specialties; 105 countries.

The survey was conducted in 16 languages.

The seven indicators of corporate reputation used to assess the 47 pharma companies are:

1. Patient centricity, 2. Patient information, 3. Patient safety, 4. Useful products, 5. Transparency, 6. Integrity, 7. Effectiveness of patient-group relationships.

Of the activities assessed, fair pricing ranked lowest

The highest ranking companies for 'corporate reputation' were (1-10): ViiV Healthcare, AbbVie, Novartis, Novo Nordisk, Gilead Sciences, Grifols, Janssen, Roche, Lundbeck, Shire, UCB

Submitted by Nigel Cook

McMaster Health Forum: Update, March 2017

Canadian Cochrane Center Symposium

This year's Cochrane Canada Symposium is taking place in Hamilton, Ontario. The Symposium will be held at McMaster University's David Braley Health Sciences Centre 11-12 May 2017. This year's theme is - *Evidence and Impact* – and will be shared with consumers, healthcare and public health practitioners, health program managers, health policy decision makers, systematic reviewers and other researchers, guideline developers, trainees, workplace wellness professionals and health research evidence end users.

<http://canada.cochrane.org/symposium-2017>

Other citizen focused materials

Search or browse the [McMaster Optimal Aging Portal](#) for citizen-focused content (Blog Posts, Evidence Summaries, and Web Resource Ratings) on depression

Advance care planning and palliative care consultations can help patients clarify their preferences for end of life care.

- Read more on this topic from the [McMaster Optimal Aging Portal](#)
- Read the briefs and summaries from our [citizen panel](#) and [stakeholder dialogue](#) on Improving End-of-life Communication, Decision-making and Care in Ontario
- Read the brief and summary from our [citizen panel](#) on Improving Access to Palliative Care in Ontario

UK Biobank attracts backing from GSK and Regeneron

24 March 2017, PharmaTimes reporter

GlaxoSmithKline and Regeneron have given their backing to a new project that will use patient data held by the UK Biobank.

The firms will get free access to the samples in return for covering the cost of genetic sequencing it and, after a period of exclusivity, they will then allow the data to be plugged back into the resource for wider use.

http://www.pharmatimes.com/news/uk_biobank_attracts_backing_from_gsk_and_regeneration_1189980?utm_source=Viridis+Newsletter&utm_medium=email&utm_campaign=viridis+news+alert

Publications

Involving Patients in Hospital-Based HTA: Experiences, Approaches, and Future Directions
Chapter by Marie-Pierre Gagnon, Janet Wale, Durhane Wong-Rieger, Russel McGowan – in Hospital-Based Health Technology Assessment

https://link.springer.com/chapter/10.1007%2F978-3-319-39205-9_30

An editorial on the IMI PREFER project

Patient. 2017 Feb 28. doi: 10.1007/s40271-017-0222-3. [Epub ahead of print]

Giving Patients' Preferences a Voice in Medical Treatment Life Cycle: The PREFER Public-Private Project [de Bekker-Grob EW²](#), Berlin C, Levitan B, Raza K, Christoforidi K, Cleemput I, Pelouchova J, Enzmann H, Cook N, Hansson MG

Bulletin du Labo du partenariat / Partnership Lab Bulletin, Mars/March 2017

Engagement dans la transformation des systèmes de santé / Engagement in health-system transformation
[Patient and family engaged care — Going beyond tactical buzzwords](#) (Accès libre/Open access)

Allen et al. (2017) *British Medical Journal*

[Industry links with patient organisations](#) (Accès libre/Open access)

Taylor & Denegri (2017) *British Medical Journal*

[Influencing health policy through public deliberation: Lessons learned from two decades of citizens'/community juries](#)

Degeling et al. (2017) *Social Science & Medicine*

[The untapped potential of patient and family engagement in the organization of critical care](#)

Haines et al. (2017) *Critical Care Medicine*

[Families as partners in hospital error and adverse event surveillance](#)

Khan et al. (2017) *JAMA Pediatrics*

[Value to whom? The patient voice in the value discussion](#)

Perfetto et al. (2017) *Value in Health*

Engagement en recherche / Engagement in research

[Our commitment is to patient partnership](#) (Accès libre/Open access)

Godlee (2017) *British Medical Journal*

[The PCORI Engagement Rubric: Promising practices for partnering in research](#) (Accès libre/Open access)

Sheridan et al. (2017) *The Annals of Family Medicine*

[Process and impact of patient involvement in a systematic review of shared decision making in primary care consultations](#) (Accès libre/Open access)

Hyde et al. (2017) *Health Expectations*

[Public consultation changes guidance on the use of health-care interventions: An observational study](#) (Accès libre/Open access)

Campbell et al. (2017) *Health Expectations*

[Engaging patients in health research: Identifying research priorities through community town halls](#) (Accès libre/Open access)

Etchegary et al. (2017) *BMC Health Services Research*

[Recommendations for patient engagement in guideline development panels: A qualitative focus group study of guideline-naïve patients](#) (Accès libre/Open access)

Armstrong et al. (2017) *PLOS ONE*

[Community recommendations on biobank governance: Results from a deliberative community engagement in California](#) (Accès libre/Open access)

Dry et al. (2017) *PLOS ONE*

[Methods guiding stakeholder engagement in planning a pragmatic study on changing stroke systems of care](#) (Accès libre/Open access)

Gesell et al. (2017) *Journal of Clinical and Translational Science*

[The Delphi consensus consultation method: Using community engagement to identify effective self-management strategies for bipolar disorder](#) (Accès libre/Open access)

Lapsley et al. (2017) *Bipolar Disorder*

['Science Tikkun': Repairing the world through the science of neglected diseases, science diplomacy, and public engagement](#) (Accès libre/Open access)

Peter (2017) *Scowcroft Institute of International Affairs*

[The patient voice in research — Supporting actor or starring role?](#)

Rowbotham et Smyth (2017) *Journal of Cystic Fibrosis*

[Early assessment of the 10-step patient engagement framework for patient-centred outcomes research studies: the first three steps](#)

Sofolahan-Oladeinde (2017) *Family Practice*

[A research note on the benefit of patient and public involvement in research: The experience of prostate cancer patients regarding information in radiotherapy](#)

Gordon et al. (2017) *Radiography*

[Why public engagement matters in science](#)

Srinivas (2017) *Trends in Biotechnology*

[Partnering with parents in interprofessional leadership graduate education to promote family-professional partnerships](#)

Margolis et al. (2017) *Journal of Interprofessional Care*

[Les patients experts: Quelle réalité? Quel rôle?](#)

Avril (2017) *Médecine des maladies métaboliques*

Institute for Peace & Dialogue (IPD) Summer Academy, Switzerland

It's a pleasure for us to invite you to join the next **10-20 Days International Summer Academy** and **3 Month CAS-Research Program** which will be held in Switzerland.

During the Summer Program 2017 experienced experts of IPD will share with you professional and academic skills about Peacebuilding, Conflict Resolution, Mediation, Security, Intercultural Dialogue & Human Rights topics.

VII International Summer Academy: 11 - 20 August, 2017 (10 Days)

VIII International Summer Academy: 20 - 29 August, 2017 (10 Days)

Deadline for Applications: 01 June, 2017

Please note that there have early registration and reduced fee amount payment deadline till the **01 May, 2017**

Program Link: <http://www.ipdinstitute.ch/VII-VIII-Summer-Academy-2017-3-Month-CAS-Research-Program/>

Scholarship: IPD offer several type of scholarship support to reduce the participation fee amount for most needed potential participants from all over the world countries.

If you will be any more questions or suggestions, please feel free to write us by email to fhuseynli@ipdinstitute.ch

Submitted by JoAnne Zaborowski

Janet Wale, HTAi PCIG

E-mail: socrates111@bigpond.com

Short questionnaire to guide future e-Bulletins

- please answer in terms of how you usually respond to the HTAi PCIG E-Bulletin e-mail in your Inbox.

1. Do you open the e-mail:

Soon after receiving it...

When you have more time to go through it...

If the latter, when is this most likely to be (eg Friday afternoon, over weekend, other)...

2. What would you like to see more of in the E-Bulletin...

3. What would you like to see less of....

4. What, if anything, do you always try to read...
5. How can we improve the presentation of the E-Bulletin...
6. How often do you want to receive an E-Bulletin....
7. Do you have any other comments you would like to make....