



## HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, July 2016

*Enhanced quality and relevance of HTA through patient and citizen involvement*

Welcome to this month's E-Bulletin.

We have included information that is not specifically HTA but which helps create our community and strengthens what we do. You will also find the very helpful literature update provided by François-Pierre Gauvin.

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### **An update from the Taiwan Alliance of Patients' Organizations (TAPO)**



The medical media connected a recent TAPO seminar and the HTAi conference in Japan, so we have too. The new TAPO was formed earlier this year to provide a more consolidated patient voice particularly in This was their first seminar – “Our seminar went well. At first, the Board and I were very concerned that some of the patient group leaders would stand alone with their own perspective. Because this is our first step, anything could happen. But they didn't, they worked with the issues within a macrostructure... They were very impressive individually.

I really thank you guys, thanks for the invitation to be part of the PCIG. So that I could witness the appearance of Taiwan's new patient new era...”

Kevin Yeh

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### **An interesting Capacity Building Programme by European Patients Forum (EPF)**

As part of its Training on Transparency and Ethics, EPF is holding a workshop in Brussels in September. The EPF concept document states that:

Because of the intrinsic nature of patient organisations, the complex external environment with potential and/or perceived conflict of interests demanding a high degree of integrity and accountability, ethics and transparency are therefore an absolute priority for them.

The need for transparency applies across all of an organisation's activities, from membership criteria and governance rules, to their cooperation agreements, through their financial resources. This training module aims to review transparency and ethics guidelines for patient organisations, through the exchange and building of good practices. It will also provide an opportunity to initiate a collective reflection within EPF on the ways for patient organisations to increase their credibility and strengthen their position on the public health scene.

This training module aims at reviewing transparency and ethics guidelines for patient organisations, through the exchange and building of good practices with an improved understanding of what constitutes good governance and accountability for patient organisations; awareness and knowledge of ethical principles and how these can be applied in the organisations; and in the longer-term, improved reputation for patient organisations.

It will also provide an opportunity to initiate a collective reflection within EPF on the ways for patient organisations to increase their credibility and strengthen their position on the public health scene, to develop

a common understanding of what constitutes an ethically sound patient organisation and the legitimacy criteria patient organisations should fulfil; to reflect on the accountability of patient organisations, and how to demonstrate it; and to establish guidelines and principles for cooperating with other stakeholders, with a focus on donors.

[http://www.eu-patient.eu/globalassets/events/2016\\_cbp\\_transparency/cbp2016-tr-conceptnote.pdf](http://www.eu-patient.eu/globalassets/events/2016_cbp_transparency/cbp2016-tr-conceptnote.pdf)

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### **A Rapid Evidence Report on Effectiveness of Digital Surveys to Collect Patient Feedback on Experiences**

Melissa Sullivan, Canada, was part of the team at pCODR who developed their guidance on patient organisation HTA submissions:

I recently completed a Rapid Evidence Report on the Effectiveness of Digital Surveys to Collect Patient Feedback on Experiences with the Healthcare System. Although it does not specifically speak to HTA - it may be of interest to some.

[http://www.nlcahr.mun.ca/CHRSP/PATIENT\\_FEEDBACK\\_RER.pdf](http://www.nlcahr.mun.ca/CHRSP/PATIENT_FEEDBACK_RER.pdf)

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Katelyn Pretzlaff is working as Administrator Assistant | Health Technology Assessment international (HTAi) in Edmonton. She shares a little of what she does as a result of her own personal experiences – “as we hope that it will help bring awareness to the need for more research on brain cancer”.

The Taite Boomer Memorial Brain Tumor Foundation is a local non-profit foundation in Edmonton that aims to raise funds for, and awareness of, brain tumors in honor and memory of Taite Boomer. Taite was a bright student, an excellent athlete, a true friend and an amazing son, who developed a brain tumor at the age of 20 and succumbed to it before turning 21. Since we started in November of 2012, we have succeeded in raising over \$82,000! Through our affiliation with the Brain Tumour Foundation of Canada, we have been able to fund five Research Studentships and a Youth Education Award. On top of this, our team has contributed over \$32,500 to the national Brain Tumour Walk. In Canada, brain tumors are the leading cause of solid cancer death in persons under the age of 20 and third in persons age 20-30. We believe that in order to promote and fund further research on brain tumors, we need to bring more awareness to brain cancer and its many forms. We encourage everyone to learn more about brain cancer and find ways to get involved with the search for the cure. Visit us at [www.TaiteBoomer.com](http://www.TaiteBoomer.com).

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### **Report from the Tinder Foundation and NHS England on the positive health and wellbeing outcomes derived from a programme to get vulnerable people digitally engaged, July 2016**

Tinder Foundation worked in partnership with NHS England on the three year Widening Digital Participation programme as a way to reduce health inequalities among older people, disabled people and those on low incomes. The programme ran from September 2013 to March 2016, and used local community networks. Our Health Flagship centres developed and trialed innovative new ways to engage people in digital health, while the wider Digital Health Network helped people throughout the UK to improve their digital skills and access health information online.

The programme reached 387,470 people, and trained 221,941 to improve their digital health literacy. It found that as a result pressure on frontline services was relieved, with more people going online before contacting their GP, 111, or going to Accident&Emergency. That could save the NHS more than £6 million every year. Meanwhile, health practitioners found that participants were more active and engaged in their own healthcare, and digital health support was recognised for its potential role in prevention, in improving the ongoing management of chronic health conditions, and in facilitating patient trust and interaction with health and social care services.

8,138 volunteers have been trained to support the programme.

<http://www.tinderfoundation.org/our-thinking/news/widening-digital-participation-health-report-launches-today>

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Highlighted by Neil McGregor-Paterson

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### **European Organisation for Rare Diseases, EURORDIS, study on the impact of rare diseases on daily life**

EURORDIS is a non-governmental patient-driven alliance of patient organisations. Rare Barometer Voices is a community of people living with a rare disease who are willing to participate in EURORDIS surveys and

studies. The objective is to transform opinions and experiences about topics that directly affect participants into figures and facts that can be shared with a wider public. People are emailed the results of surveys when they do one.

<http://www.eurordis.org/voices>

Yann Le Cam, the CEO of EURORDIS, has been appointed to the Management Board of the European Medicines Agency (EMA). The EMA Board is made up of representatives of each of the 28 EU Member States, the European Commission, the European Parliament, two civil society organisations, and doctor and veterinarian organisations. Yann has been a patient representative on the Committee for Orphan Medicinal Products for nine years.

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### **European Medicines Agency (EMA) Consultation**

[http://ec.europa.eu/health/human-use/clinical-trials/developments/index\\_en.htm](http://ec.europa.eu/health/human-use/clinical-trials/developments/index_en.htm)

#### **Public consultation on the 'Summary of Clinical Trial Results for Laypersons'**

From 1 June 2016 to 31 August 2016.

This document is for sponsors and investigators to provide a templated summary of clinical trial results for laypeople. Citizens and organisations are welcome to contribute to this consultation.


The consultation document can be downloaded [here](#)  (649 KB).

Contributions should be sent by 31 August 2016 to: [SANTE-B4-GL-results-laypersons@ec.europa.eu](mailto:SANTE-B4-GL-results-laypersons@ec.europa.eu)

#### **Public consultation on 'Risk proportionate approaches in clinical trials'**

From 1 June 2016 to 31 August 2016.

The main objective of these recommendations is to provide further information on how a risk proportionate approach can be implemented in clinical trials and also highlights the areas identified in the clinical trials

The consultation document can be downloaded [here](#)  (215 KB).

Contributions should be sent by 31 August to: [SANTE-B4-GL-risk-proportionate-approach@ec.europa.eu](mailto:SANTE-B4-GL-risk-proportionate-approach@ec.europa.eu)

**The Patients' and Consumers' Working Party (PCWP)** provides a platform for exchange of information and discussion of issues of common interest between EMA and patients and consumers.

The PCWP was established in 2006, and provides recommendations to EMA and its human scientific committees on all matters of interest in relation to medicines.

[http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners\\_and\\_networks/general/general\\_content\\_000708.jsp&mid=WC0b01ac0580028d32](http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000708.jsp&mid=WC0b01ac0580028d32)

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### **European Patients' Academy on Therapeutic Innovation (EUPATI)**

<http://www.patientsacademy.eu/index.php/en/>

Karen Facey recently drew your attention to this consultation, as PCIG has had substantial input into the guidance for patient involvement in HTA, but you may also be interested in the other guidance documents too. Karen would appreciate being copied in when you make comments on the HTA framework.

Review of guidance for patient involvement in the medicines research and development process. The guidance is provided as distinct frameworks: Patient involvement with industry; with health technology assessment (HTA) bodies; with regulatory bodies. A fourth framework on ethics committees is to follow (by the end of July). The frameworks have been developed in response to the increasing need to draw on the experience and specific knowledge of patients, and their day-to-day use of medicines, in order to improve medicines development and evaluation. The frameworks suggest approaches to allow structured interaction with patients, and thereby facilitate the exchange of information and constructive dialogue at national and European level where the views from users of medicines can and should be considered.

These three frameworks have already received feedback from a number of partners of the EUPATI consortium (including patient organisations) but further evaluation and feedback from patient organisations and other key stakeholders are essential in order to validate the guidance. The internal review resulted in some suggestions that require more discussion (applies namely to patient involvement with industry, but also with regulators).

If you have significant expertise and knowledge in patient interaction with industry, HTA, or regulatory bodies, please consider contributing to this review; please add your suggestions (in track change) and comments directly on the three documents at:

[www.patientsacademy.eu/consultation](http://www.patientsacademy.eu/consultation)

Once you have reviewed the documents, please forward them to: [consultation@eupati.eu](mailto:consultation@eupati.eu)

This public consultation will end on September 15. Following the consultation all comments will be carefully evaluated, and the guidance will be revised and released.

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## **Bulletin du Labo du partenariat / Partnership Lab Bulletin**

Juillet/July 2016

Le [Labo du partenariat](#) (dirigé par Dr. Antoine Boivin) produit une veille électronique mensuelle qui vise à faciliter l'accès aux nouvelles publications sur l'engagement des patients et du public. Si vous ne souhaitez pas recevoir le bulletin, n'hésitez pas à nous écrire.

The [Partnership Lab](#) (lead by Dr. Antoine Boivin) is producing a monthly electronic newsletter that seeks to facilitate access to new publications on public and patient engagement. If you do not wish to receive the newsletter, please send us an email.

### **Engagement en recherche / Engagement in research**

[Including patients in core outcome set development: Issues to consider based on three workshops with around 100 international delegates](#) (Libre accès/Open access)

Young & Bagley (2016) *Research Involvement and Engagement*

[Development of a decision guide to support the elderly in decision making about location of care: An iterative, user-centered design](#) (Libre accès/Open access)

Garvelink et al. (2016) *Research Involvement and Engagement*

[Citizen science, engagement and transformative learning: A study of the co-construction of a neuroscience research project in Catalonia](#) (Libre accès/Open access)

Ruiz Mallen et al. (2016) *Universitat Oberta de Catalunya*

[Participation levels in 25 community-based participatory research projects](#)

Johnson et al. (2016) *Health Education Research*

[From 'trial community' to 'experimental publics': How clinical research shapes public participation](#)

Montgomery & Pool (2016) *Critical Public Health*

[Patients as key partners in rare disease drug development](#)

Bronstein & Kakkis (2016) *Nature Reviews Drug Discovery*

[The citizen scientist: Community-academic partnerships through Translational Advisory Boards](#)

Patel et al. (2016) *Patient Education and Counseling*

[How are PCORI-funded researchers engaging patients in research and what are the ethical implications?](#)

Ellis & Kass (2016) *AJOB Empirical Bioethics*

### **Engagement dans la transformation des systèmes de santé / Engagement in health-system transformation**

[Guidelines on public engagement](#) (Libre accès/Open access)

Health Canada & Public Health Agency of Canada (2016)

[Patients as partners: Building collaborative relationships among professionals, patients, carers and communities](#) (Libre accès/Open access)

The King's Fund (2016)

[Supporting quality public and patient engagement in health system organizations: Development and usability testing of the Public and Patient Engagement Evaluation Tool](#) (Libre accès/Open access)

Abelson et al. (2016) *Health Expectations*

[Whose voices? Patient and public involvement in clinical commissioning](#) (Libre accès/Open access)

O'Shea et al. (2016) *Health Expectations*

[Patient participation: Are we far from fulfilling the vision of patient-centred care?](#) (Libre accès/Open access)

Souliotis (2016) *Health Expectations*

[A structuration framework for bridging the macro–micro divide in health-care governance](#) (Libre accès/Open access)

Bodolica et al. (2016) *Health Expectations*

[Collaborative learning framework for online stakeholder engagement](#) (Libre accès/Open access)

Khodyakov et al. (2016) *Health Expectations*

[Patient involvement in rheumatology outpatient service design and delivery: A case study](#) (Libre accès/Open access)

Souza et al. (2016) *Health Expectations*

[Healthcare professional and patient codesign and validation of a mechanism for service users to feedback patient safety experiences following a care transfer: A qualitative study](#)

Scott et al. (2016) *BMJ Open*

[Concept mapping as a method to engage patients in clinical quality improvement](#) (Libre accès/Open access)

LaNoue et al. (2016) *The Annals of Family Medicine*

[Improving healthcare for Aboriginal Australians through effective engagement between community and health services](#) (Libre accès/Open access)

Durey et al. (2016) *BMC Health Services Research*

[Health policy dialogue: Experiences from Africa](#) (Libre accès/Open access)

Dovlo et al. (2016) *BMC Health Services Research*

[Consumers as partners: Including consumers as reporters to learning systems](#) (Libre accès/Open access)

Sheridan & Hatlie (2016) *Patient Safety & Quality Healthcare*

[Engaging patients as partners in practice improvement: A survey of community health centers](#) (Libre accès/Open access)

Willard-Grace et al. (2016) *Journal of Clinical Outcome Management*

[Implementing and using a patient portal: A qualitative exploration of patient and provider perspectives on engaging patients](#) (Libre accès/Open access)

Ryan et al. (2016) *Journal of Innovation in Health Informatics*

[Patient engagement: Opportunities and challenges for nursing and health care professionals](#) (Libre accès/Open access)

Abdelhak (2016) *Studies in Health Technology and Informatics*

[Evidencing impact: The challenges of mapping impacts from public engagement and communication](#) (Libre accès/Open access)

Wilkinson & Weitkamp (2016) *Impact of Social Sciences Blog*

[Leveraging community participation through health committees to achieve health rights: The role of power](#) (Libre accès/Open access)

Hasson (2016) *University of Cape Town*

[The patient's voice: Patient involvement in medical product regulation](#)

von Tigerstrom (2016) *Medical Law International*

[Co-production in healthcare: Moving patient engagement towards a managerial approach](#)

Gilardi et al. (2016) *Co-Production in the Public Sector*

[Introduction: Priority setting, equitable access and public involvement in health care](#)

Weale et al. (2016) *Journal of Health Organization and Management*

[Public involvement in health priority setting: Future challenges for policy, research and society](#)

Hunter et al. (2016) *Journal of Health Organization and Management*

[Patterns of public participation: Opportunity structures and mobilization from a cross-national perspective](#)

Slutsky et al. (2016) *Journal of Health Organization and Management*

[The use of patient and family advisory councils to improve patient experience in radiology](#)

Kuhn et al. (2016) *American Journal of Roentgenology*

[Levers for change: An investigation of how accreditation programmes can promote consumer engagement in healthcare](#)

Hinchcliff et al. (2016) *Journal for Quality in Health Care*

[Les ambiguïtés du « patient expert »](#)

Barrier (2016) *Médecine des maladies métaboliques*

[Perspectives démocratiques en santé mentale de la rhétorique à la pratique: le patient, usager ou partenaire?](#)

Alary (2016) *Pratiques en santé mentale*

[Un jeu de dupes? Contribution à une réflexion sur les pratiques de démocratie participative en santé mentale](#)

Letailleur (2016) *Pratiques en santé mentale*

[La participation des usagers, qu'est-ce que ça change?](#)

Joisin (2016) *Pratiques en santé mentale*

[Essor de la participation des usagers dans la dynamique associative en Rhône-Alpes](#)

Buffavand (2016) *Pratiques en santé mentale*

[Démocratie sanitaire, qu'est-ce à dire?](#)

Arveiller & Tizon (2016) *Pratiques en santé mentale*

**Engagement en santé des communautés / Engagement in community health**

[Improving HIV and STI responses through media and community engagement](#)

Cullen & Callaghan (2016) *Pacific Journalism Review*

[Using a community engagement process to explore how using an iterative approach and implementing user-driven designs may assist in the prevention of Lyme Borreliosis in Highland](#)

Morton et al. (2016) *Rural and Remote Health*

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**Palliative & End of Life Care: Supporting Patient Choice**  
**Thursday, 27th October 2016 at the Royal National Hotel in London**

The **Palliative & End of Life Care: Supporting Patient Choice** conference will examine how the delivery of care in the UK is evolving to support and fulfil need requirements, whilst respecting the choices expressed by patients and their families.

The event will feature a highly informative agenda, presenting speakers who are experts in their field, plus examples of best practice which delegates may feel appropriate to adopt into their own provision arrangements. Delegates will have the opportunity to question, discuss and debate the very latest policies, projects and emerging models of care, as well as share their own stories and experiences with the conference and contributing to wider thinking about end of life care.

The Palliative & End of Life Care: Supporting Patient Choice conference offers the thoughts of highly knowledgeable speakers, sharing both professional and personal experiences. It is ideally placed to update delegates on the latest findings from research conducted to give an accurate picture of the experiences of patients nearing the end of their lives and their families. The day will look to how future care can be improved for all and share some of the excellent examples of good practice.

Benefits of attending:

- Hear what improvements have been undertaken to improve care
- Learn about the areas that remain below an acceptable standard and what needs to be done to address them
- Gain insight into caring for a dying person
- How can we ensure those with learning disabilities have access to the same level of provision to the rest of the population?
- Hear about forward thinking practices in end of life care
- What can be done to help children, young people and their families in dealing with a terminal or life limiting illness
- How will the NICE guidelines improve the experiences of those nearing the end of their life
- What difference will Emergency Care and Treatment Plans in the decision making process to resuscitate
- Share best practice
- Benefit from the opportunity to question, discuss and debate current working practices and those for the future
- Take advantage of knowledge sharing and professional networking
- Gain CPD credits
- Make contacts

Topics of Discussion:

- Caring for the Dying with Choice and Compassion
- A Carer's Perspective
- Caring for those with Learning Disabilities
- Replacing DNR Orders with Emergency Care and Treatment Plans
- Meeting the Palliative Needs of Children, Young People and their Families
- The Guidelines to Improve Care for People at the End of Life
- The Award Winning CoSI team 'Coordinated, Safe, Integrated'



**HTAi 2017 Rome, June 17-21, 2017**

<http://www.htai.org/meetings/annual-meetings/htai-2017-rome.html>

**Abstract Submissions**

Workshops & Panels, December 2, 2016  
Posters & Oral Presentations, January 6, 2017  
**Travel Grants:** Application Deadline, January 6, 2017  
**Registration:** Early Bird Deadline, March 3, 2017

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