



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

Enhanced quality and relevance of HTA through patient and citizen involvement

Welcome to this month's E-Bulletin

[HTAi 2016 Presentations Online \(Members Only\)](#)

Several HTAi 2016 presentations are now available online to HTAi members.
And make sure you get your Tokyo feedback in!

HTAi 2017 Rome, from 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

Ethical issues for patient groups collecting or reporting information for HTA submissions

To complete submissions for HTAs, patient groups may gather information about patients' and caregivers' experiences of living with a condition, preferences and unmet needs for treatment. This may involve conducting interviews, focus groups and surveys and collecting input using social media. As a result, patient groups need to think about the ethical and legal issues involved when engaging with people and using their personal information.

The PCIG has worked with the Ethics Interest Group to create two online documents to help patient groups identify and respond to those issues. Following consultation, these documents are available at:

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

Ann Single

The link to the non-medicine submission template has been updated

Available from: <http://www.htai.org/interest-groups/patient-and-citizen-involvement/resources/for-hta-agencies-and-policy-makers.html>

Values and Quality Standards for Patient and Citizen Involvement in HTA

Available as [two page PDF](#) and [PDF Poster](#)

Patient Group Submission Templates

Generic patient submission templates for an HTA, with useful prompts

- [Medicine's HTA](#) (Word doc) & [Cover Note](#) (Word doc)
- [Non-medicine's HTA](#) (Word doc) & [Cover Note](#) (Word doc)

Guidance for providing patient input using the templates

Guidance for patient organisations to completing a patient group submission template: For health technology assessment and appraisal of medicines. Available as [PDF](#) and [Word doc](#)

From the Belgian Health Care Knowledge Centre (KCE)

Our report "Multi-criteria decision analysis for the appraisal of medical needs" has been published today. You can find a link to the full report [here](#). On the same page, you will find the templates and tools, including the HTAi tool for collecting information from patient organisations.

We recommended the use of these tools and templates to the experts at the national health insurance institute. The language will probably be an issue. We hope they will put a little effort into translating the document into French and Dutch.

Thank you for the useful work
Irina Cleemput

Patient advocate and HTAi Patient Panel member Deb Maskens of Kidney Cancer Canada receives award

On June 23rd, Deb was awarded a Meritorious Service Medal from Canada's Governor General for her work for cancer patients in Canada. This award was also presented posthumously to the wife of the other co-founder of Kidney Cancer Canada who died in 2010.

See: <http://ikcc.org/article/canada-honours-deb-maskens-late-tony-clark/>

The latest edition of the DIA Global Forum magazine focuses on patients and patient advocacy, including an article from Karen Facey in relation to patient involvement in HTA on page 32.

<http://globalforum-online.org/>

The US Patient Organisation, the National Health Council, takes lead in patient centred development of value frameworks

With the emergence of a plethora of "value frameworks" in the past few years, it's great to see a US Patient Organisation, the National Health Council, taking the lead to promote patient-centred methods for their development. This suggests some good principles and practices that could also support patient involvement in HTA.

To inform work in value models (also known as frameworks), emerging as the latest tools to help healthcare stakeholders assess the value of new treatments, the National Health Council (NHC), with stakeholder input, has created this Patient-Centered Value Model Rubric. The purpose of the Value Model Rubric is to provide a tool that the patient community, physicians, health systems, and payers can use to evaluate the patient centeredness of value models and to guide value model developers on the meaningful incorporation of patient engagement throughout their processes.

<http://www.nationalhealthcouncil.org/sites/default/files/Value-Rubric.pdf>

Karen Facey

A joint initiative to develop a universal and best practice approach to patient involvement in drug development

Patient Focused Medicine Development (PFMD) <http://patientfocusedmedicine.org>, is a joint initiative between the patient community and industry to develop a universal and best practice approach to patient involvement in drug development.

PFMD is a not-for-profit, multinational coalition made up of representatives from both industry and patient organisations. Founding members include the European Patients Forum, the National Health Council, EUPATI (the European Patient Academy on Therapeutic Innovation), Parkinson's Disease Foundation, Cancer 101 Foundation, the Society of Participatory Medicine and a number of large pharma companies; including Amgen, Astra Zeneca, GSK, MSD, UCB, Pfizer and Novartis.

The Joint Action on Chronic Diseases and Healthy Ageing (JA-Chrodis) across the Life Cycle - the European joint action on chronic diseases <http://www.chrodis.eu/>

Launched January 2014, the main objective of JA-CHRODIS is to promote and facilitate a process of exchange, transfer and implementation of good practices between European countries and regions, addressing [chronic conditions](#), with a specific focus on the area of: Health Promotion and Primary Prevention, Organizational interventions focused on dealing with chronic patients with multiple conditions, Patient's empowerment interventions and Diabetes (Please, find more information in:).

JA-CHRODIS is developing a CHRODIS Platform to collect, assess and exchange practices, interventions or policies affecting chronic conditions, where decision-makers, caregivers, patients, and researchers across the

EU can find and share the best practice on chronic diseases. The platform includes criteria agreed by experts across the EU and an online tool to allow users to evaluate practices, interventions and policies using assessment criteria established by JA-CHRODIS.

We would like to invite you to be part of the CHRODIS Platform by submitting your own practices or inviting your acquaintances to submit practices. CHRODIS Platform will be open for practices submission on the 4th of July.

Please, if you are interested in joining, contact us on chrodis.iaes@aragon.es. Once we get your expression of interest, we will give you further details.

Finally, let me kindly ask you to share this info with any other colleagues who might be interested in submitting practices.

Lilisbeth Perestelo Pérez

EMA publishes new guidance on the use of patient-reported outcome measures in oncology studies

<http://www.esmo.org/Oncology-News/Integrating-Patients-Views-in-Clinical-Studies-of-Anticancer-Medicines>

The new guidance is an [appendix to the guideline](#) on the evaluation of anticancer medicinal products in man. This guidance document issued by the Committee for Medicinal Products for Human Use (CHMP) and its Oncology Working Party (ONCWP) describes the use of PROs and health related quality of life (HRQL) measures in clinical studies. It acknowledges the importance of bringing the perspective of patients on their disease and the treatment they receive to the assessment of benefits and risks of cancer medicines. The experience of patients of how a treatment impacts on their well-being and everyday life is an important aspect of the evaluation of the clinical benefits of new medicines.

The EMA also released terms of reference for the new EMA/FDA cluster on patient engagement

http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_ooo655.jsp&mid=WC0b01ac0580953d98

http://www.ema.europa.eu/docs/en_GB/document_library/Other/2016/06/WC500209197.pdf

Recent publications - highlighted

Measuring impact

By Sarah Berglas, Lauren Jutai, Gail MacKean and Laura Weeks at CADTH, Patients' perspectives can be integrated in health technology assessments: an exploratory analysis of CADTH Common Drug Review. Research Involvement and Engagement 2016;2:21.

In Canada, the CADTH Common Drug Review helps ensure that scarce health care resources are used to fund the most effective drugs. Clinicians, researchers, payers, and patients all have important, but potentially different, ideas on what should be considered, to determine a drug's value. Since 2010, CADTH has invited patient groups to contribute their perspectives to the Common Drug Review. We explored whether, and how, insights offered by patient groups are integrated into assessment reports and Recommendations by the CADTH Canadian Drug Expert Committee.

After examining 30 completed drug assessments, we found that:

- Patient insights are used by CADTH reviewers to frame an assessment and are used by the expert committee to interpret the evidence.
- Drug trials do not always measure outcomes that patients consider important.
- Survival, symptom relief, the process of recovery, and maintaining health are all important aspects to consider when determining value during health technology assessments.

These findings had been used to modify the submission template, along with other changes.

An interesting paper exploring relationships with the public in relation to health research – from trust to trustworthiness....

<http://spp.oxfordjournals.org/content/early/2016/05/11/scipol.scv075.full>

The Scottish Health Informatics Programme (SHIP) was a Scotland-wide research programme exploring ways of collecting, managing and analysing electronic patient records for health research. A series of eight focus groups and a stakeholder workshop were conducted to explore perceptions of the role, relevance and

functions of trust (or trustworthiness) in relation to research practices. The findings demonstrate that the public's relationships of trust and/or mistrust in science and research are not straightforward. The bases of public trust/mistrust in science, what trust implies and equally what it means for research/researchers to be trustworthy are explored in focus groups and a stakeholder workshop.

Written by Deidre DeJean and fellow Canadian researchers, comparing search filters to identify qualitative research studies

<https://www.ncbi.nlm.nih.gov/pubmed/27117960>

Karen Facey

Bulletin du Labo du partenariat / Partnership Lab Bulletin, Juin/June 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

[Giving voice to older adults living with frailty and their family caregivers: Engagement of older adults living with frailty in research, health care decision making, and in health policy](#) (Libre accès/Open access)
Holroyd-Leduc et al. (2016) *Research Involvement and Engagement*

[What's in a 'research passport'? A collaborative autoethnography of institutional approvals in public involvement in research](#) (Libre accès/Open access)
Laterza et al. (2016) *Research Involvement and Engagement*

[Study protocol: Determining what young people with rheumatic disease consider important to research \(the Young People's Opinions Underpinning Rheumatology Research - YOURR project\)](#) (Libre accès/Open access)
Parsons et al. (2016) *Research Involvement and Engagement*

[Patients' perspectives can be integrated in health technology assessments: An exploratory analysis of CADTH Common Drug Review](#) (Libre accès/Open access)
Berglas et al. (2016) *Research Involvement and Engagement*

[Moving beyond the rhetoric of consumer input in health technology assessment deliberations](#) (Libre accès/Open access)
Wortley et al. (2016) *Australian Health Review*

[Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: A UK-based qualitative interview study](#) (Libre accès/Open access)
Crocker et al. (2016) *Health Expectations*

[Public consultation changes guidance on the use of health-care interventions: An observational study](#) (Libre accès/Open access)
Campbell et al. (2016) *Health Expectations*

[Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives](#) (Libre accès/Open access)
Woolley et al. (2016) *BMC Medical Ethics*

[Public engagement is key for the future of science research](#) (Libre accès/Open access)
Pham (2016) *Nature - Science of Learning*

[Patient involvement in clinical research: Why, when, and how](#) (Libre accès/Open access)

Sacristan et al. (2016) *Patient Preference & Adherence*

[Engagement practices that join scientific methods with community wisdom: Designing a patient-centered, randomized control trial with a Pacific Islander community](#)

McElfish et al. (2016) *Nursing Inquiry*

[Effect of public deliberation on attitudes toward return of secondary results in genomic sequencing](#)

Gornick et al. (2016) *Journal of Genetic Counseling*

[Implementing a pragmatic framework for authentic patient-researcher partnerships in clinical research](#)

Fagan et al. (2016) *Journal of Comparative Effectiveness Research*

[Lay and professional stakeholder involvement in scoping palliative care issues: Methods used in seven European countries](#)

Brereton et al. (2016) *Palliative Medicine*

[Creating patient engagement infrastructure in bladder cancer research prioritization.](#)

Smith et al. (2016) *ASCO Annual Meeting Proceedings*

[Patient and public involvement \(PPI\) in research is perceived to benefit stroke survivors and the research process. Barriers and facilitators exist which can be addressed to enable PPI in stroke research](#)

Wallen & Gerrand (2016) *Australian Occupational Therapy Journal*

[Participatory research ideals and practice experience: Reflections and analysis](#)

D'Cruz (2016) *Journal of Social Work*

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

[NHS Confederation: Public and patient partnerships: How they can address the inequality and finance gap in health and care](#) (Libre accès/Open access)

NHS Confederation (2016)

[At a crossroads? Key challenges and future opportunities for patient involvement in patient safety](#) (Libre accès/Open access)

O'Hara & Lawton (2016) *BMJ Quality & Safety*

[Interacting patients: The construction of active patientship in quality improvement initiatives](#) (Libre accès/Open access)

Vennik (2016) *Doctoral thesis, Erasmus University Rotterdam, the Netherlands*

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

de Souza et al. (2016) *Health Expectations*

[Consumer participation in co-creation: An enlightening model of causes and effects based on ethical values and transcendent motives](#) (Libre accès/Open access)

Martinez-Canas et al. (2016) *Frontiers in Psychology*

[Making ripples: Patient involvement in service planning](#) (Libre accès/Open access)

Caporn & Sawicka (2016) *Future Hospital Journal*

[Community involvement in development of evidence-informed recommendations for rehabilitation for older adults living with HIV](#) (Libre accès/Open access)

O'Brien et al. (2016) *Progress in Community Health Partnerships: Research, Education and Action*

["We Should Talk"—Moving knowledge into action by learning to engage patients, families, and healthcare staff to communicate for patient safety](#)

Dubrovsky et al. (2016) *Healthcare Management Forum*

[Moving from rational to normative ideologies of control over public involvement: A case of continued managerial dominance](#)

Croft et al. (2016) *Social Science & Medicine*

[Révolution tranquille: l'implication des usagers dans l'organisation des soins et l'intervention en santé mentale](#)

Godrie (2016) *Revue française des affaires sociales*

[Public participation in decision-making on the coverage of new antivirals for hepatitis C](#)

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

Engagement en santé des communauté / Engagement in community health

[We are all experts! Does stakeholder engagement in health impact scoping lead to consensus? A Dutch case study](#) (Libre accès/Open access)

Broeder et al. (2016) *Impact Assessment and Project Appraisal*

[Collaborating for community food security: Emerging scholar participation in a community–university partnership](#)

Nelson & Dodd (2016) *Action Research*

Engagement dans l'enseignement / Engagement in teaching

[Patient involvement in undergraduate curriculum development](#) (Libre accès/Open access)

Anderson (2016) *General Medical Council*

Bulletin du Labo du partenariat / Partnership Lab Bulletin, Mai/May 2016

Engagement en recherche / Engagement in research

[Consumer and community involvement in health and medical research: Evaluation by online survey of Australian training workshops for researchers](#) (Libre accès/Open access)

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

[Patient involvement in a qualitative meta-synthesis: Lessons learnt](#) (Libre accès/Open access)

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

[Patient and public involvement in patient safety research: A workshop to review patient information, minimise psychological risk and inform research](#) (Libre accès/Open access)

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

[The Ottawa Citizen Engagement and Action Model \(OCEAM\): A citizen engagement strategy operationalized through the Participatory Research in Ottawa, Management and Point-of-care of Tobacco \(PROMPT\) study: A community based participatory action research project in inner city Ottawa](#)

(Libre accès/Open access)

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

[On the path to a science of patient input](#) (Libre accès/Open access)

Anderson & McCleary (2016) *Science Translational Medicine*

[Patient involvement in clinical research: Why, when, and how](#) (Libre accès/Open access)

Sacristán et al. (2016) *Patient Preference and Adherence*

[Increasing patient involvement in drug development](#) (Libre accès/Open access)
Lowe et al. (2016) *Value in Health*

[Moving from trust to trustworthiness: Experiences of public engagement in the Scottish Health Informatics Programme](#) (Libre accès/Open access)
Aitken et al. (2016) *Science and Public Policy*

[Using participatory research methods to facilitate wide stakeholder involvement: Experiences from a community public health workshop](#) (Libre accès/Open access)
Brooks et al. (2016) *British Psychological Society Annual Conference*

[The partnership of patient advocacy groups and clinical investigators in the rare diseases clinical research network](#) (Libre accès/Open access)
Merkel et al. (2016) *Orphanet Journal of Rare Diseases*

[A case study of community involvement influence on policy decisions: Victories of a community-based participatory research partnership](#) (Libre accès/Open access)
Williams et al. (2016) *Research and Public Health*

[Supporting youth and community capacity through photovoice: Reflections on participatory research on maternal health in Wakiso district, Uganda](#) (Libre accès/Open access)
Musoke et al. (2016) *Global Public Health*

[Patient participation in the development of a clinical guideline for inherited retinal dystrophies](#)
Serrano-Aguilar et al. (2016) *Expert Opinion on Orphan Drugs*

[Mener une recherche en partenariat avec les acteurs sociaux, économiques et politiques](#)
Petitpierre et al. (2016) *Contraste*

[Patients as research partners in chronic respiratory disease \(CRD\) research: Priorities, challenges and suggestions made by patients and caregivers](#)
Pakhale et al. (2016) *American Thoracic Society International Conference Abstracts*

[Let's talk about inclusion: A report on patient research partner involvement in the GRAPPA 2015 annual meeting](#)
de Wit et al. (2016) *The Journal of Rheumatology*

[Implementing a pragmatic framework for authentic patient-researcher partnership in clinical research](#)
Fagan et al. (2016) *Journal of Comparative Effectiveness Research*

[Patient and public involvement and the implementation of research into practice](#)
Foster et al. (2016) *Journal of Mental Health Training, Education and Practice*

[Research essentials: Developing and designing research through consultation and collaboration with children and young people](#)
Bray & Collier (2016) *Nursing Children and Young People*

["What do they really mean by partnerships?" Questioning the unquestionable good in ethics guidelines promoting community engagement in indigenous health research](#)
Brunger & Wall (2016) *Qualitative Health Research*

[Patient and other stakeholder engagement in Patient-Centered Outcomes Research Institute funded studies of patients with kidney diseases](#)
Cukor et al. (2016) *Clinical Journal of the American Society of Nephrology*

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

Livre >> [Promoting Patient Engagement and Participation for Effective Healthcare Reform](#)
[Graffigna](#) (2016) *Catholic University of the Sacred Heart of Milan, Italy*

[Community participation for transformative action on women's, children's and adolescents' health](#) (Libre accès/Open access)
Marston et al. (2016) *Bulletin of the World Health Organization*

[Difficult conversations? Engaging patients in reducing waste in health care](#)
Minogue et al. (2016) *International Journal of Health Governance*

[Regulatory decision making in Canada — Exploring new frontiers in patient involvement](#)
Klein et al. (2016) *Value in Health*

[Patient speaking for patients: What constitutes genuine patient input into pharmaceutical policymaking?](#)
Cassels & Birnbaum (2016) *International Journal of Health Governance*

[Engaging consumer voices in health care policy: Lessons for social work practice](#)
Law & Saunders (2016) *Health and Social Work*

[What is "the patient perspective" in patient engagement programs? Implicit logics and parallels to feminist theories.](#)
Rowland et al. (2016) *Health*

Engagement dans l'enseignement / Engagement in teaching
[L'application d'un modèle intégré de partenariat-patient dans la formation des professionnels de la santé : Vers un nouveau paradigme humaniste et éthique de co-construction des savoirs en santé](#)
Flora et al. (2016) *Journal international de bioéthique et d'éthique des sciences*

[A patient's view on helping to shape a career framework for community nurses](#)
Bliss & Upton (2016) *British Journal of Community Nursing*

[The patient educator presentation in dental education: Reinforcing the importance of learning about rare conditions](#)
Edwards et al. (2016) *Journal of Dental Education*

[Engaging persons with diabetes in nurse coaching with enabling technology to improve health](#)
Young (2016) *Sigma Theta Tau International's 2th International Nursing Research Congress*

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