



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

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

Welcome to this month's E-Bulletin.

### October meeting of PCIG members in Manchester



Members of the PCIG active in two of our working groups, the Methods and Impact Working Group (WG) and Patient Involvement and Education (PIE) WG, together with some of the members of the Patient Panel met at the NICE offices in Manchester UK from 17-19 October for an update on current activities and to workshop plans for moving forward. We also found time to discuss plans for the Rome HTAi Annual Meeting, with abstracts due soon. The meeting was made possible through an unrestricted grant from PhRMA, the Pharmaceutical Research and Manufacturers of America, managed through HTAi.

The Methods and Impact WG have a well-defined work plan while PIE is to concentrate in the coming months on mapping existing resources for patient involvement in HTA on HTA agency, industry, patient organization and other web pages. Watch for more details of this work and calls for information. If you would like to be involved please let us know.

We were fortunate to have past President Carol Longson talk with us as well as a NICE Chair. Some of us also attended part of a NICE Diagnostics meeting. The meeting was expertly managed by our Chair Neil Bertelsen together with Neil McGregor Paterson. We thank them both for their efforts, as well as NICE, making this a very successful meeting.

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### HTAi Annual Meeting 2017: Explore how the global HTA community is evolving towards an integrated ecosystem

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

#### Deadlines



#### Abstract Submissions

Workshops & Panels, December 2, 2016

Posters & Oral Presentations, January 16, 2017

**Travel Grants:** Application, January 16, 2017

**Registration:** Early Bird, March 3, 2017

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### Patient Panel members meet in Manchester

At the PCIG face-to-face meeting in Manchester, the Chair of our Patient Panel Nick Meade (Director of Policy, Genetics Alliance UK) spoke about initial thinking among panel members on its purpose and possible principles for involvement, such as working collegially and visibility of impact. Nick stated that the Panel is there for the patient advocates to talk among each other, share experiences, and for collaboration:

1. For the PCIG: either commenting or consulting (2-way and even if not asked)
2. Communication and education activities: terminology is dense in HTA, need for common language, a need to raise awareness of HTA/HTAi and to help demystify it, shine a spotlight on successes of engagement
3. Policy and practice: conflicts of interest, visibility of patient input, transparency of HTA

Overall, the Patient Panel is a good idea and is needed to provide the patient voice (although members are not convinced about its name)

The members liked being involved in the WG discussions, and agreed that a source of patient opinions is needed in these discussions

The Patient Panel now needs to work out how to communicate within the PCIG; and how to be of most value to the patient community

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### Patient Panel member Kevin Hsu in Taiwan



Kevin Hsu has let us know that Taiwan Alliance of Patients' Organizations (TAPO) has recently had a successful international round table meeting on HTA and patients' rights in Taipei, led by TAPO Chairman Dr Yaung Chih Liang. Invited were experts from other countries including patient advocates Pharmaceutical Benefits Advisory Committee (PBAC) consumer

representative Dr Jo Watson from Australia and IAPO Former Chairman KP Tseng from Hong Kong, as well as legislators. The special guests were invited to meet the National Health Insurance (NHI) authority to discuss the issues of patient representatives on committees.

"We lack experience in participation in health policy, decision making, and collecting evidence. We hoped the experts from Hong Kong and Australia could give us some know how for a kick start."

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### The Innovative Medicines Initiative (IMI) is funding a new patient centred initiative: IMI PREFER, a patient preferences project, which commenced on 1 October

Sent in by Nigel Cook of Novartis, Switzerland

#### Giving patients a voice in drug development

*The patient perspective is important in all medical research, and particularly in drug development. This month, a five year project funded by the Innovative Medicines Initiative (IMI), is launched to assess when and how patient preferences on benefits and risks should be incorporated in decisions on medicinal products.*

PREFER, or The Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle project, will evaluate different preference elicitation methods and test them in a clinical setting. The end result will be recommendations for HTA, payers and regulatory authorities on when and how to include the patient perspective.

PREFER will conduct patient preference studies in three disease areas where patient and clinical research partners have expertise: cancer, rheumatoid arthritis and neuromuscular disorders. Industry partners will provide additional patient preference studies, covering disease areas from their fields of expertise.

Visit the PREFER website at [www.imi-prefer.eu](http://www.imi-prefer.eu)

Written by Josephine Fernow, communications manager for the PREFER project

#### Working together:

PCIG Steering Committee member Kathi Apostolidis of the European Cancer Patient Coalition (ECPC) writes:

Thanks for sharing the great work that the IMI-PREFER project has to tackle in the coming months! Indeed, at ECPC we believe that PREFER will be a great opportunity for collaboration of all stakeholders to elicit patient preferences and find the best method to integrate them in the development, approval, and post-market entry of new treatments.

From a press release by Kalliopi Christoforidi, ECPC:

Patient input is crucial to PREFER's success. On September 1st, we formed the patient stakeholder advisory group to make sure the patient perspective is included at all levels of the project. The group is co-ordinated by the European Cancer Patients Coalition (ECPC),

The PREFER Patient Advisory Group consists of the European Cancer Patients Coalition (ECPC), Muscular Dystrophy UK (MDUK), European Patients Forum (EPF), and International Alliance of Patients' Organizations (IAPO) and EURORDIS.

Patient Advisory Group members are directly involved in activities within all work packages of PREFER, sharing common expectations and ensuring that the methodologies identified correspond to the patient views, experiences and preferences. We also have a number of individual patients with rheumatoid arthritis on board through the clinical research partners at the University of Birmingham. The patient perspective is complemented by the presence of EURORDIS, who are members of a broader stakeholder advisory board.

<http://www.ecpc.org/pressroom/news/427-prefer-project-giving-patients-a-voice-in-drug-development>.

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#### *Related literature*

#### Age, education and health literacy affects how people understand risk

We know that people have difficulties interpreting risk information correctly. This is a challenge for researchers who want to know how people weigh possible risks against benefits. A study shows that age, education and health literacy affect the ability to understand risks. This means researchers need to have strategies in place for accurately measuring preferences regarding risk.

One way to measure how people weigh risks and benefits when making decisions about treatments is discrete choice experiments (DCE's). These DCE questionnaires allow researchers to see the relative importance of certain treatment characteristics for respondents when they make a treatment decision. But if people do not understand risks, the accuracy of their trade-offs and the relative importance they assign is limited.

Jorien Veldwijk is the academic co-lead for the case studies that will be conducted in PREFER. She is also one of the authors of the following and has worked with DCE's for several years. According to her, age, education and health literacy should be included in DCE questionnaires as a standard measure. She also recommends a thorough pilot testing phase the questionnaire is developed, including think-aloud testing.

The study is based on structured interviews with 70 participants that evaluated and completed four discrete choice tasks aloud. According to the authors, researchers who want to use DCE's should take some preventative steps to avoid bias based on the participants' age, education and health literacy. The authors recommend a kind of mini-lab setup, where participants can complete the questionnaire in the presence of a researcher who can explain the questionnaire and answer questions. In online research setups, they believe researchers should provide explanations of the attributes in pop-up texts or audio, and offering the option to repeat explanations when participants complete the choice tasks.

Read article BMC Medical Research Methodology: [Exploring how individuals complete the choice tasks in a discrete choice experiment: an interview study](#)

#### **The latest issue of Value in Health includes a themed section on the incorporation of patient preferences into health care decision making.**

The focus of this themed section is the use of patient-centred benefit-risk assessment to support regulatory decision making and other decision making settings.

"This is very timely issue for the PREFER project that is launching this month" says Ardine de Wit from the University Medical Center Utrecht and one of the leaders for our clinical case studies.

Many of the papers are directly relevant for the project. If you are interested, please have a look at the current issue: [Volume 19 Issue 6 - September/October 2016](#)

By Josepine Fernow, Uppsala University

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

JA-CHRODIS has developed 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 assess practices, interventions and policies using assessment criteria established by JA-CHRODIS (<http://www.chrodis.eu/our-work/o4-knowledge-platform/wpo4-activities/delphi-process/>).

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. If you are interested in joining, contact [helpdesk@chrodis.eu](mailto:helpdesk@chrodis.eu) and we will give you further details.

Lilisbeth Perestelo-Perez and Maria Jose Vicente-Edo  
Servicio de Evaluación y Planificación, Dirección del Servicio Canario de la Salud, Red de Investigación en Servicios de Salud en Enfermedades Crónicas (REDISSEC)

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## **2nd Multi-Stakeholder Symposium on Improving Patient Access to Rare Disease Therapies** **Objectives of the 2nd Multi-Stakeholder Symposium**

22 - 23 February 2017, Hotel Le Plaza, Brussels, Belgium

EURORDIS and partners will bring together patient advocates, payers, HTA bodies, academics, clinicians, policy makers, investors and industry representatives to provide a platform for dialogue, a neutral ground and open environment for discussion. All stakeholders will have the opportunity to express their views and observations in order to reach sustainable and durable solutions to improve patient access to rare disease therapies across Europe.

The event aims to:

- Identify common conditions to facilitate increased uptake of therapies for rare diseases;
- Build and seek convergence on current and emerging initiatives;
- Recognise the need and nurture the willingness for flexibility within the healthcare system;
- Discuss how to work together and where there are differences of opinion;
- Investigate reasonable ways to resolve rare disease patient access issues in an equitable way for society and
- Pave the way to a fair approach with acceptable compromises from each stakeholder.

<http://www.eurordis.org/publication/2nd-multi-stakeholder-symposium-improving-patient-access-rare-disease-therapies#Register>

Submitted by Marleen Kaatee, PCIG Patient Panel

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## **Enhancing regulatory decision tools to support drug development and review: Enhancing the Incorporation of the Patient's Voice in Drug Development and Decision-Making**

To facilitate the advancement and use of systematic approaches to collect and utilize robust and meaningful patient and caregiver input that can more consistently inform drug development and, as appropriate, regulatory decision making, the FDA will develop a series of guidance documents to focus on approaches and methods to bridge from initial patient-focused drug development meetings, like those piloted under PDUFA V, to fit-for-purpose tools to collect meaningful patient and caregiver input for ultimate use in regulatory decision making. Prior to the issuance of each guidance, as part of the development, FDA will conduct a public

workshop to gather input from the wider community of patients, patient advocates, academic researchers, expert practitioners, industry, and other stakeholders.

FDA plans for the next iteration of patient focused drug development, announced as part of the PDUFA (Prescription Drug User Fee Act) Reauthorization performance goals and procedures, fiscal years 2018 through 2022. The relevant text begins on page 27 of the linked PDF file, <http://www.fda.gov/downloads/ForIndustry/UserFees/PrescriptionDrugUserFee/UCM511438.pdf>

Submitted by Mark Skinner

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### Days Spent at Home — A Patient-Centered Goal and Outcome

Adam C Groff, Carrie H Colla, and Thomas H. Lee. N Engl J Med 2016; 375:1610-1612 October 27, 2016\_DOI: 10.1056/NEJMp1607206

Most measures of the quality of healthcare delivery focus on what healthcare providers do, not what patients want. If “high-value, patient-centered care” is to be more than rhetoric, health care organizations need to measure outcomes that matter to patients. Only when they do so will care be designed and organized in ways that improve those outcomes.

To understand how this approach differs from business as usual, consider “days spent at home in the last 6 months of life.” The [map](#) “Mean Number of Days Spent at Home in the Last 6 Months of Life, by Hospital Referral Region, for Medicare Beneficiaries Who Died in 2012 or 2013” shows the mean number of days spent at home by Medicare beneficiaries who died in 2012 or 2013, by hospital referral region (HRR). “Days at home” was calculated as 180 days minus the number of inpatient days in an acute care facility, an inpatient rehabilitation facility, a skilled nursing facility, or an inpatient hospice unit.

Free full text at <http://www.nejm.org/doi/full/10.1056/NEJMp1607206?query=TOC>

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### An article published by Julia Abelson and her team in Canada

Abelson, J., Wagner, F., DeJean, D., Boesveld, S., Gauvin, F.-P., Bean, S., Axler, R., Petersen, S., Baidoobonso, S., Pron, G., Giacomini, M. and Lavis, J. (2016) ‘PUBLIC AND PATIENT INVOLVEMENT IN HEALTH TECHNOLOGY ASSESSMENT: A FRAMEWORK FOR ACTION’, *International Journal of Technology Assessment in Health Care*, sep 27, pp. 1–9. doi: 10.1017/S0266462316000362.

As health technology assessment (HTA) organizations in Canada and around the world seek to involve the public and patients in their activities, frameworks to guide decisions about whom to involve, through which mechanisms, and at what stages of the HTA process have been lacking. The aim of this study was to describe the development and outputs of such a framework.

The framework was informed by a synthesis of international practice and published literature, a dialogue with local, national and international stakeholders, and the deliberations of a government agency’s public engagement subcommittee in Ontario, Canada.

Results: The practice and literature synthesis failed to identify a single, optimal approach to involving the public and patients in HTA. The resulting framework is structured around four actionable elements: (i) guiding principles and goals for public and patient involvement (PPI) in HTA, (ii) the establishment of a common language to support PPI efforts, (iii) a flexible array of PPI approaches, and (iv) on-going evaluation of PPI to inform adjustments over time.

<https://www.ncbi.nlm.nih.gov/pubmed/27670693>

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### Meet the new Editor-in-chief, the International Journal of Technology Assessment in Health Care



HTAi has announced the appointment of Associate Professor Wendy Babidge as the Editor-in-chief of [The International Journal Of Technology Assessment In Health Care](#). Dr Babidge is the Director of the Research, Audit and Academic Surgery Division of the Royal Australasian College of Surgeons, which manages the Australian Safety and Efficacy Register of New Interventional Procedures—Surgical (ASERNIP- S). She is also the past chair of the International Network of Agencies for Health Technology Assessment (INAHTA) board and for several years was a deputy editor for the journal.

This is the official Journal of HTAi, for health policy makers and professionals interested in the economic, social, ethical, medical and public health implications of health technology.

The Editor-in-chief is responsible for the quality and timely output of articles, as well as the scope of the Journal's output in discussion with the Journal's proprietors, the Editorial Board, and the publishers.

Contact Information: wendy.babidge@adam.com.au

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### Interesting to listen to an audio of what industry is doing to involve patients, early in development – panel sessions at EyeforPharma, US event

#### ***This is the year of the patient! But what does that mean?***

Elizabeth Turcotte, Director, Patient Hub, **BMS**, Ramana Sonty, Director of Strategy, **Janssen** and Lisa Egbuonu-Davis, *VP Global Patient Centered Outcomes and Solutions*, **Sanofi** on what it takes to drive patient-centered transformations.

[Click here to download the audio \(https://s3.amazonaws.com/efpharma/Philadelphia2017/2016-10-11+1500+Panel.mp3\)](https://s3.amazonaws.com/efpharma/Philadelphia2017/2016-10-11+1500+Panel.mp3)

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### Working together

<https://www.eupati.eu/advocacy/interaction-patients-regulators-industry/>

EUPATI recently welcomed participants from regulatory authorities, patient organisations, academia, non-profit organisations and industry to reflect on patient involvement and engagement

Participants from regulatory authorities, patient organisations, academia, non-profit organisations and industry joined together in Berlin to advance and foster the interaction of us all on patient involvement and engagement in medicines Research and Development (R&D).

Director, Jan Geissler, shared some preliminary data on the impact of EUPATI from a survey among EUPATI fellows who participated in the Patient Expert Training Course: they have increased their advisory roles significantly, comparing their engagement before and after the course:

- providing advice to the pharmaceutical industry increased from 8% to 52%,
- to regulatory agencies from 12% to 40%, and
- to HTA bodies from 4% to 8%.

Despite this progress, challenges still remain, such as the lack of mutual learning, the lack of mutual trust, the lack of standardised metrics to measure benefits and impact, perceived and/or real barriers around conflict of interest as well as the lack of capacity in patient organisations...

Isabelle Moulon, from EMA, highlighted that patients can engage in various ways in regulatory processes: they can be members of committees, act as representatives of an organisation or be individual experts, and she clarified how declarations of interests are evaluated for each of these roles. EMA has established a network of European patients' and consumers' organisations for collaboration on various topics. The EMA Patients' and Consumers' Working Party (PCWP) plays a key role in enabling these interactions. To support the best possible cooperation EMA recognises that patients involved with the Agency need to have adequate knowledge of the work of the Agency and therefore provides various training opportunities, also referencing EUPATI initiatives.

Matthias Gottwald, from Bayer, presented a practical "roadmap" for patient involvement in all steps of the R&D process. He also shared some preliminary findings from a DIA-Tufts University study:

- out of 20 pharmaceutical companies, only three consider themselves "very patient-centric" and
- four "not very patient-centric",
- most are "somewhat patient-centric".

...Corporate drivers to create a patient engagement function are company commitment and clear benefits for process improvement. Challenges for patient involvement in R&D are:

- concerns of patient independence,
- need for comprehensive guidance addressing all stakeholders,
- no infrastructure for "matchmaking",
- no consolidated approach for patient involvement in industry, and
- no metrics for impact assessment.

### **Two working groups – one on industry, the other on regulatory bodies**

According to the Industry group, there is a need to gain more clarity on the conflict-of-interest question in order to be able to engage patients in an appropriate way....

#### **The take home messages:**

More clarity and common understanding is needed on the demands, expectations and restrictions on patient representatives in different roles as members of committees, acting as representatives of an organization, or being individual experts.

Should the EUPATI training be expanded to other target groups in addition to patients? And can IMI involve patients more proactively, e.g., through its new IMI Patient Engagement Strategy?

The very different approaches to patient involvement in national competent authorities and in EMA need to be aligned on the basis of more knowledge of current experiences and best practices, leading potentially to a more systematic involvement in the daily work of the national and European agencies. This will be taken forward in the European medicines regulatory network.

The processes of patient involvement in industry have evolved, but the evolution of frameworks, mechanisms, metrics and processes happens ad hoc without much alignment and sharing. Establishing a neutral platform, e.g., DIA, to enable pre-competitive sharing and alignment is needed and will be explored further.

Both regulators and industry identified a need for clarity and alignment on compensation. This can be taken forward in multi-stakeholder discussions.

Both regulators and industry identified a need for development of commonly accepted metrics on outcome of patient involvement. Such an initiative could/should be taken forward by IMI.

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### **The European Federation of Pharmaceutical Industries Association (EFPIA) has produced a Health Collaboration Guide**

This guide showcases best practice in collaboration between stakeholders in the healthcare sector. .

[https://gallery.mailchimp.com/144770e74471b2695c19422dc/files/EFPIA\\_Health\\_Collaboration\\_Guide.pdf?mc\\_cid=99f2038cdf&mc\\_eid=bc77b3ee01](https://gallery.mailchimp.com/144770e74471b2695c19422dc/files/EFPIA_Health_Collaboration_Guide.pdf?mc_cid=99f2038cdf&mc_eid=bc77b3ee01)

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### **EUPATI**

The final EUPATI conference is in Brussels on Dec. 14th, and includes the graduation ceremony for the first wave of EUPATI fellows.

EUPATI will continue beyond its current funding model as a European Patients Forum-led programme. At national levels, EUPATI has initiatives in 18 countries. The national teams offer workshops and tutorials for patient communities, interacting with professionals from clinical research, ethics committees, regulators and the pharmaceutical industry.

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### **AllTrials campaign**

Last month Dr Sile Lane delivered a fantastic talk at TEDx Madrid. It is a clear and compelling introduction to the AllTrials campaign which calls for all clinical trials – past, present and future – to be registered, and their methods and results to be fully reported.

The absence of trial information on many drugs we prescribe and use today is a shocking story that many have yet to hear. Please share the video with your friends, family and colleagues – on Facebook, on Twitter (using #AllTrials), on your website, by email – so that they, too, understand what we are calling for and why. The campaign is now a global force, we appreciate all your help in spreading the word.

Dr Till Bruckner

AllTrials campaign manager

Sense about Science - *Because evidence matters*

[www.senseaboutscience.org](http://www.senseaboutscience.org) | [@senseaboutsci](https://twitter.com/senseaboutsci) | [Facebook](https://www.facebook.com/senseaboutsci)

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### **ICER Convenes Broad Group of Stakeholders to Inform Update to Value Assessment Framework**

On September 30, 2016, the Institute for Clinical and Economic Review (ICER) convened a one-day meeting with over [40 health care stakeholders](#) to review ICER's current Value Assessment Framework and provide input to help inform a planned 2017 update.

The insights discussed at the meeting will inform the 2017 update to the methods that underpin ICER's evidence reports on new drugs and other health care interventions. Participants in the discussion included patients and representatives from patient organizations, clinical specialty societies, insurers and pharmacy benefit managers, pharmaceutical and biotech companies, and methodologic experts.

Earlier this year, ICER had invited written suggestions on how to improve its value assessment framework. Over 50 interested parties provided [comments](#).

The current iteration of the framework has been in use for over a year. An updated version of the value framework will be posted for additional public comment in December before being finalized and used for ICER reports beginning in early 2017.

<https://icer-review.org/announcements/value-assessment-meeting/>

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## Bulletin du Labo du partenariat / Partnership Lab Bulletin, Octobre/October 2016

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.

### Engagement en recherche / Engagement in research

[At your next conference ask where the patients are](#) (Accès libre/Open access)

Godlee (2016) *BMJ*

["Nothing about us without us" — Patient partnership in medical conferences](#)

Chu et al. (2016) *BMJ*

[Partnering with consumers to develop and evaluate a Vietnamese Dementia Talking-Book to support low health literacy: A qualitative study incorporating codesign and participatory action research](#) (Accès libre/Open access)

Goeman et al. (2016) *BMJ Open*

[Determining priorities for research to improve fundamental care on hospital wards](#) (Accès libre/Open access)

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

[Participation: Power to the patients](#) (Accès libre/Open access)

Bourzac (2016) *Nature*

[Successful stepwise development of patient research partnership: 14 years' experience of actions and consequences in outcome measures in rheumatology](#) (Accès libre/Open access)

de Wit et al. (2016) *The Patient : Patient-Centered Outcomes Research*

[Engaging patient advocates and other stakeholders to design measures of patient-centered communication in cancer care](#) (Accès libre/Open access)

Treiman et al. (2016) *The Patient : Patient-Centered Outcomes Research*

[It IS about us! Patient engagement in health research](#) (Accès libre/Open access)

Tran et al. (2016) *Arthritis Research Canada*

[Involvement of general public in biomedical research](#) (Accès libre/Open access)

Pramesh et al. (2016) *Perspectives in Clinical Research*

[Participatory methods for research prioritization in primary care: an analysis of the World Café approach in Ireland and the USA](#) (Accès libre/Open access)

MacFarlane et al. (2016) *Family Practice*

[Public and patient involvement in health technology assessment: A framework for action](#)

Abelson et al. (2016) *IJHTAC*

[Using stakeholder engagement to develop a patient-centered pediatric asthma intervention](#)

Shelef et al. (2016) *Journal of Allergy and Clinical Immunology*

[Tokenism in patient engagement](#)

Hahn et al. (2016) *Family Practice*

[Developing a patient-centered benefit-risk survey: A community-engaged process](#)

Hollin et al. (2016) *Value in Health*

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

[Journal of Public Deliberation](#) >> Special Issue: Equality, Equity, and Deliberation

[Promoting inclusion, equity and deliberation in a national dialogue on mental health](#) (Accès libre/Open access)

Campbell et al. (2016) *Journal of Public Deliberation*

[CJCheck Stage 1: development and testing of a checklist for reporting community juries – Delphi process and analysis of studies published in 1996–2015](#) (Accès libre/Open access)

Thomas et al. (2016) *Health Expectations*

[Co-creating health: More than a dream](#) (Accès libre/Open access)

Richards (2016) *BMJ*

[From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement](#) (Accès libre/Open access)

Ocloo & Matthews (2016) *BMJ Quality and Safety*

[Who truly represents the patient perspective?](#) (Accès libre/Open access)

Crompton (2016) *Cancer World*

[Social change and public engagement with policy and evidence](#) (Accès libre/Open access)

Stewart et al. (2016) *Rand Corporation*

[Consumer co-creation in health: Innovating in Primary Health Networks](#) (Accès libre/Open access)

Randall (2016) *Consumers Health Forum of Australia*

[The experience of patients engaged in co-designing care processes](#)

Lavoie-Tremblay et al. (2016) *The Health Care Manager*

[More than just a chat: Bringing service user involvement to an online community of practice](#)

Potter et al. (2016) *Journal of Health Visiting*

[Engaging patients and families beyond the point of care: An emergent model](#)

Washington (2016) *Journal of Nursing Administration*

Engagement en santé des communauté / Engagement in community health

[Community engagement for identifying cancer education needs in Puerto Rico](#)

Jiménez et al. (2016) *Journal of Cancer Education*

Engagement en enseignement / Engagement in teaching

[Participation of patient community members in communication classes for dental students at Tokyo dental college](#) (Accès libre/Open access)

Takahashi et al. (2016) *The Bulletin of Tokyo Dental Coll.*

[Identifying key areas for active interprofessional learning partnerships: A facilitated dialogue](#)

Steven et al. (2016) *Journal of Interprofessional Care*

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