

## HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, August 2018

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

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

- Welcome to this August E-Bulletin
- HTAi Matters
- What’s Happening – in patient and public involvement
- Publications

### Welcome to the August E-Bulletin

And welcome to the change of season, to autumn in the northern parts of the world and spring in the south. The following activity is both much needed and of great interest to us:

#### An International Collaboration to Update the Definition of HTA

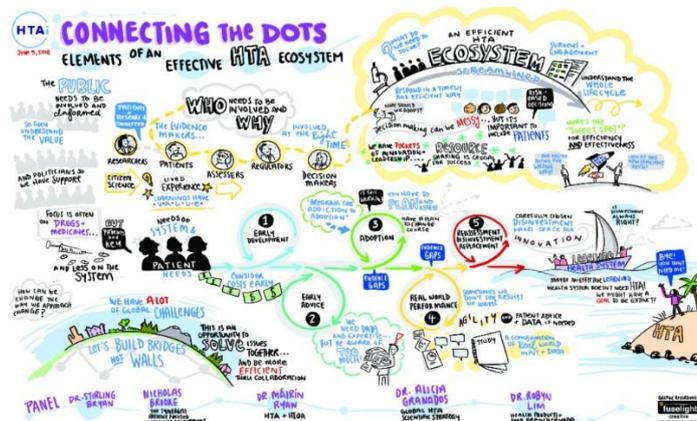
Brian O'Rourke from INAHTA and Wija Oortwijn from HTAi are co-Chairs of an international initiative involving representatives from the regional HTA networks (RedETSA, HTAsiaLink, and EUnetHTA), the World Health Organization and ISPOR along with representatives from the HTA Glossary to update the definition of health technology assessment. There are many different variations of the HTA definition used today, and it is in the interest of the international HTA community to create a consolidated definition that reflects the current and future role of HTA to support health system sustainability.

If members have ideas or suggestions to offer on this work, you are encouraged to contact [Gert Jan van der Wilt](#) and/or [Dr. Wija Oortwijn](#), both representing HTAi

### HTAi Matters

#### HTAi Annual Meeting 2018 in Vancouver

We are pleased to advise that the HTAi 2018 Annual Meeting oral, vignette and poster presentations for which we have received consent from the primary presenter to post are now available on the [HTAi Website](#). Additional materials are:



## 2018 Annual Meeting Illustration Video - Click the Image to Watch!

### Idea Factory Summary

The HTAi 2018 Annual Meeting featured dozens of sessions on best practices in health technology assessment (HTA) from around the world. As a novel format and pilot project, the Idea Factory was introduced at one of the sponsored sessions and aimed to directly involve delegates in the generation of ideas, recommendations and solutions to tackle current challenges in HTA and healthcare.

Focusing primarily on oncology treatments, delegates were challenged to generate ideas to address budget predictability and access, clinical and patient outcomes and patient/clinician engagement in HTA. The Queen's Executive Decision Centre facilitated the session by using an electronic meeting system to collect and support the idea generation and real-time review by all delegates.

**A one-page summary of the session can be accessed following this [LINK](#)**

We are hopeful that this year's Idea Factory marks a successful start in building further on program components that will provide HTAi Annual Meeting delegates with exciting sessions to engage and collaborate. If you have any input or feedback on this year's Idea Factory or other interactive sessions, please send them to the HTAi Annual Meeting Team at [annualmeeting@htai.org](mailto:annualmeeting@htai.org)

---

### HTAi Annual Meeting 2019

The 2019 Annual Meeting is in Cologne, Germany, June 15 – 19<sup>th</sup>. Visit [www.htai2019.org](http://www.htai2019.org) for more information.

### Call for abstracts



---

### What's Happening

#### Health Care Partner Perspective: Bringing Patient Voices into Health Technology

Health technology is a hot topic, particularly when it comes to patient engagement! The Canadian Health Technology Assessment (HTA) team at C2E2, is an independent academic group contracted by the British Columbia (BC) Ministry of Health to produce Health Technology Assessments. The team will carefully look at the strengths and weaknesses of health care technologies and processes, old or new, and recommend whether they should be used across the province.

#### How HTA engages patients

These assessments require the help of patient partners, who can share their experiences and weigh in on whether they have found these technologies to be effective and useful. The HTA team works with PVN (as

well as one of our health care partners, the [BC SUPPORT Unit](#)) to ensure they're including a wide variety of voices in their projects. Patient partners are involved in the work of the Health Technology Assessment team in two important ways: using their specific experiences as patients, and as individuals.

#### **Why it's important to involve patients as decision makers**

Patient partner knowledge is a valuable resource for health care partners: "Having a patient who has gone through similar experiences with the health care system, they can find areas of importance that I may not be able to see as well. It is because of our patient partners, that we consider all aspects of the technology. Not just cost effectiveness, but quality of life, length of hospital-stay, risk of relapse, mental health status, costs for the patient and how technology can help patients deal with their condition." Working with patients directly gives the HTA team a more well-rounded idea of how the public will interact with a technology.

A new blog piece at <https://patientvoicesbc.ca/2018/08/15/health-care-partner-perspective-bringing-patient-voices-into-health-technology/>

Submitted by Selva Bayat as the research coordinator in scoping and engagement for the Health Technology Assessment team at the Centre for Clinical Epidemiology and Evaluation, British Columbia, Canada

---

#### **Australia's Patient Voice Initiative has released *Recommendations to improve patient voice in health technology assessment in Australia***

<http://www.cappre.info/PVI/Patient%20Voice%20Initiative%20Recommendations%20to%20Improve%20Patient%20Voice%20in%20Health%20Technology%20Assessment%20in%20Australia.pdf>

The report recommends improving consumer/patient involvement in health technology assessments conducted by the Pharmaceutical Benefits Advisory Committee (PBAC), Medical Services Advisory Committee (MSAC) and Prostheses List Advisory Committee (PLAC) in four key areas:

- Legislation and procedures
- Communication
- Training and guidance
- Evidence generation.

The recommendations are based on the needs expressed by patients and patient groups at workshops convened by the Patient Voice Initiative. The report contains practical suggestions for how these needs can be met and examples of how HTA bodies do it in other countries. The Patient Voice Initiative is an incorporated association which brings together patients, researchers and industry driven to improve the patient voice in HTA in Australia.

Our next series of workshops for patients will be held in late October and November 2018 in Sydney, Adelaide and Perth. Workshops will also be held in Hobart, Melbourne and Brisbane in early 2019. Our website [www.patientvoiceinitiative.org.au](http://www.patientvoiceinitiative.org.au) is still under construction however, if you or your organisation would be interested in attending please email [contact@patientvoiceinitiative.org.au](mailto:contact@patientvoiceinitiative.org.au).

Ann Single for Patient Voice Initiative

*Around Australia considerable expertise about living with conditions and using services and treatments resides within patients. However, it remains largely untapped throughout the life span of treatments.*

---

#### **Two more weeks to influence the patient engagement landscape in Europe and elsewhere**

As you already know, we are currently running a [public consultation](#) to help identify specific patient engagement (PE) activities that should or could be done in each phase of medicine research, development phases and life cycle.

Due to numerous requests, we have decided to extend the survey deadline to **September 14th** - giving you two more weeks to influence the future patient engagement work at PFMD.

### [I want to give feedback](#)

Please share it within your network with PE experience. Every response will provide us with insights of potentially missing activities or other recommendations that have not been mentioned in the publications so far.

### [Answer the public consultation](#)

Your input is extremely valuable for us, so on behalf of our members and contributors, thank you for taking the time to complete the survey  
Nicholas Brooke on behalf of PFMD

---



## ARE PAYERS & REGULATORS REALLY LOOKING AT PRO DATA?

Why PRO are an important part of your product submission  
**Learn how patient experience data can help to**

### **demonstrate product value**

Join our upcoming webinar on September 12th to learn how payers and regulators are looking at PRO as part of the product approval process. Using case studies in oncology and rare disease, you gain insights on how PRO data can impact your new drug approval process.

Sign up now for our webinar to learn how to build an effective PRO strategy to help demonstrate your product's value.

[Register Now](#)

---

## **CADTH Webinar: Ensuring Patient Voices Are Heard/ À l'écoute des patients**

CADTH webinars are excellent. So I suggest you all sign up to this one to learn from one the HTA bodies that has led thoughtful and innovative developments in their patient involvement processes over the past few years and has now turned its attention to engaging patients in conference preparation.

### **Ensuring Patient Voices Are Heard: How Patients Can Contribute to the CADTH Symposium**

**THURSDAY, SEPTEMBER 13, 2018 12:00 p.m. to 1:00 p.m. EDT**

Patients are involved in every aspect of CADTH's annual Symposium — from planning to reviewing abstracts to presenting relevant work. We even offer financial support to facilitate participation by patients and patient group representatives.

Since 2016 the CADTH Symposium has achieved Patients Included status. To meet and exceed the Patients Included standards in 2019, our goal is to encourage and support more people from the patient community to be involved. In particular, we would like to have more patient representatives submit abstracts to the CADTH Symposium and invite more patient representatives to serve on the Abstract Review Committee in the hopes that the 2019 program will then reflect more topics of interest to the patient community.

This webinar will outline the process for submitting abstracts and offer tips and ideas to increase the chances for success. We will explain the process for the selection of presentations, posters, and panel sessions and describe a volunteer opportunity to be part of the Abstract Review Committee. Panellists Peter Chinneck, Maureen Smith, and Linda Wilhelm will answer your questions about the CADTH Symposium including topics such as submitting an abstract, presenting at the symposium, or volunteering for the abstract selection committee.

Developed with patient group representatives and members of the public in mind, this webinar will also be of interest to anyone interested in contributing to the 2019 CADTH Symposium.

Registration Information: Registration is required for this webinar.

Please [click here](#) or the link below to register:

<https://attendee.gotowebinar.com/register/4763128744915211521>

Submitted by Karen Facey

---

### **From Ireland: Billion dollar ORPHANS**

By Susan Mitchell

There is a widespread perception that new drugs will only be made available to those patients who shout the loudest. The process lacks transparency. The industry's morals are questionable.

As the medicines watchdog predicts an avalanche of expensive orphan drugs, what does the future hold for those with a rare disease?

It is almost impossible to turn on the radio or open a newspaper without hearing about the "miraculous" benefits of the latest drug. New cancer therapies, and treatments for cystic fibrosis, Duchenne muscular dystrophy and rare developmental conditions have all come on-stream in recent years. The world is full of stories of sick patients who have either been given a second chance by these new drugs, or who are being denied access to a possible life-saving treatment. In recent times, campaigners have taken to the streets to urge the state to fund drugs including Orkambi (to treat cystic fibrosis) and Respreeza (genetic emphysema). As an increasing number of orphan drugs become available to treat rare diseases, policymakers are concerned at the budget implications. Orphan drugs typically come with eyewatering price tags...

Because pricing is decided at national, not EU level, not enough pressure has been exerted on firms to lower prices...

<http://www.ipposi.ie/wp-content/uploads/2018/04/Sunday-Business-Post-Orphan-Drugs-April-8th-2018.pdf>

### **Patient education programme in health innovation**

This IPPOSI-led programme delivers training for Irish patients on health research and innovation including modules on clinical trials, medicines regulatory affairs and HTA.

In March 2018, 19 students participating in the [IPPOSI Pilot Patient Education Programme](#) completed the Health Technology Assessment (HTA) module of the Programme, which was delivered by a combination of the Dept. of Pharmacology & Therapeutics, Trinity College Dublin, the National Centre for Pharmacoeconomics and Health Information and Quality Authority, all in partnership with IPPOSI.

<http://www.ipposi.ie/our-work/education/patient-education-programme/>

### **Developing a Patient Charter**

IPPOSI is working with its patient organisation members to develop a Patient Charter for Involvement in the Medicines Assessment & Reimbursement Process in Ireland. The Charter will be informed by international perspectives ([IPPOSI webinar in May](#)), including an upcoming Sept. 11th 'Study Trip' - with the National Centre for Pharmacoeconomics - to a number of Scottish Medicines Consortium's [PACE \(Patient And Clinician Engagement\)](#) meetings.

---

### **For the Chance to tell your story**

EFPIA wants to raise awareness of different medical conditions, and the positive impact new medicines and treatments have had or could have on them. We aim to create a platform to discuss topics that are important to patients.

We've also asked patients to provide us with their "for the chance to" quote, as well as to answer some other questions which will help us create the story behind their quote. The story would be published through social media such as twitter, LinkedIn and Facebook with a link to a blog based on answers to the questions. It gives an opportunity to start an online dialogue on the issues important to you with industry, researchers, healthcare providers and politicians.

### **Building patient impact stories into #WeWontRest**

We Won't Rest has become the industry-wide platform to tell the story of dedication, passion and commitment to discovering and developing treatments that transform the lives of patients. What EFPIA will do, how national associations can engage and how companies can participate in the patient story elements form 3 elements:

1. Illness Never Sleeps tells our innovation story, underlining our commitment to tackling disease.
2. Brighter Tomorrow underlines the hope that the endeavour and innovation can create.
3. For the Chance to gives the patient perspective both on the challenges they face but also the impact new medicines can have on their lives.

### **#ForTheChanceTo**

Launching in Q3-2018, the *For the Chance to* story is focused on the patient, and aims to appeal to a broader audience than Illness Never Sleeps and Brighter Tomorrow. *For the Chance To* highlights how many patients have grasped another chance at life because of treatments developed by our industry.

EFPIA will trans-create the core resources of #ForTheChanceTo into local languages for use in their own campaigns. In addition, national associations can use the patient story form to generate patient stories through their own contacts in local languages

Submitted by Nigel Cook

---

### **Shared Decision Making: essential but hard to measure**

Richard Lehman, Professor of the Shared Understanding of Medicine at the University of Birmingham, reflects on the latest Cochrane evidence on shared decision making and what might be needed to see it become a reality in all health care settings. Read more at

<http://www.evidentlycochrane.net/shared-decision-making-essential-but-hard-to-measure/>

---

### **European Medicines Agency approval for CAR-T cell therapy**

CAR T (chimeric antigen receptor T cell) immunotherapies work by using a patient's own immune system to fight certain types of blood cancer. T cells are drawn from a patient's blood and genetically modified in the lab to create T cells that are genetically coded to target the patient's cancer cells. European regulators have now approved Novartis' Kymriah and Gilead's Yescarta. In the US Gilead set a list price of \$373,000, for the therapy, a single shot of a patient's own T-cells, harvested and genetically modified to destroy certain types of blood cancer.

[http://www.pharmatimes.com/news/eu\\_approves\\_first\\_car-](http://www.pharmatimes.com/news/eu_approves_first_car-t_therapies_1250347?utm_source=Viridis+Newsletter&utm_medium=email&utm_campaign=viridis+news+alert)

[t\\_therapies\\_1250347?utm\\_source=Viridis+Newsletter&utm\\_medium=email&utm\\_campaign=viridis+news+alert](http://www.pharmatimes.com/news/eu_approves_first_car-t_therapies_1250347?utm_source=Viridis+Newsletter&utm_medium=email&utm_campaign=viridis+news+alert)

<https://www.reuters.com/article/novartis-cancer/novartiss-kymriah-wins-eu-approval-for-blood-cancer-treatment-idUSFWN1VH026>

---

### **Publications**

---

**A cancer label and low-risk conditions**

Labelling very low-risk conditions as cancers can cause unnecessary anxiety and lead to overtreatment. An article from The Conversation at [https://theconversation.com/is-it-time-to-remove-the-cancer-label-from-low-risk-conditions-101331?utm\\_source=twitter&utm\\_medium=twitterbutton](https://theconversation.com/is-it-time-to-remove-the-cancer-label-from-low-risk-conditions-101331?utm_source=twitter&utm_medium=twitterbutton)

---

### **"But this is a good cancer:" Patient perceptions of endometrial cancer in Denmark**

Anne Sidenius, Lenore Manderson, Martin Rudnicki, Helle Ploug Hansen. *Journal of Clinical Nursing* July 2018. DOI: 10.1111/jocn.14615

Patients retain the idea of a close connection between cancer and death, while also adopting the notion of endometrial cancer as "good". This influenced how women responded to treatment and care. Framing endometrial cancer as "good" is not always helpful, as the impact of a cancer diagnosis per se is rarely favourable.

---

### **Association of Preferences for Papillary Thyroid Cancer Treatment With Disease Terminology: A Discrete Choice Experiment**

Nickel B, Howard K, Brito JP, Barratt A, Moynihan R, McCaffery K. *JAMA Otolaryngol Head Neck Surg.* 2018 Aug 22. doi: 10.1001/jamaoto.2018.1694.

Given recent evidence of overdiagnosis and overtreatment of small papillary thyroid cancers (PTCs) and other low-risk cancers, strategies are needed to help patients consider less invasive treatment options. Preferences in PTC treatment were evaluated using a discrete choice experiment (DCE) conducted as a web-based survey using an existing public online research panel. Participants were randomized to receive 1 of 2 frames of information based on the terminology used to describe the condition: "cancer" or "lesion." Participants chose between 3 treatment options for PTC (thyroidectomy, hemithyroidectomy, and active surveillance). The DCE was completed by 2054 participants (993 [48.3%] men and 1061 [51.7%] women; mean [SD] age, 46.0 [16.5] years) with no history of thyroid cancer. Participants preferred options with less frequent follow-up, lower out-of-pocket costs, lower chances of having voice and calcium level problems, and a lower risk of developing invasive thyroid cancer and of dying of thyroid cancer. When trading benefits against harms, participants were willing to accept a higher number of extra patients experiencing adverse effects to avoid a thyroid cancer death when the condition was described as a cancer compared with a lesion. For both the cancer and lesion terminology, health literacy consistently was associated with preferences for treatment options. **Those with lower health literacy had a significantly lower preference for less invasive treatment options.**

---

### **Uncertain times: A survey of Canadian women's perspectives toward mammography screening.**

Abelson J, Tripp L, Brouwers MC, Pond G, Sussman J. *Prev Med.* 2018 Jul;112:209-215. doi: 10.1016/j.ypmed.2018.04.021. Epub 2018 Apr 18.

Evolving scientific evidence about mammography has raised new questions about the net benefits of organized screening, yet gaps remain about women's current screening practices, knowledge, attitudes and values toward screening to support informed decision making in this area. We addressed this gap through an online survey of 2000 screen-eligible women from Ontario, Canada in January 2016. Likert-scaled and categorical questions were used to collect information about screening practices, knowledge of benefits and risks of screening and underlying attitudes and values toward screening. Results for all responses were summarized using descriptive statistics. Comparison of results between ever screened versus never screened respondents was performed using chi-squared tests. Most women felt informed about screening yet had doubts about how informed their decisions were. They were more confident in their knowledge of the benefits than the risks which aligned with the emphasis given to benefits in discussions with health care providers. The benefits of screening were linked with lowered anxiety about breast cancer. The never screened were less likely to overstate the benefits of screening, more likely to give weight to the risks, and less likely to report anxiety or worry about breast cancer. Findings highlight the need for improved communication strategies and decision supports that emphasize the provision of current, balanced information about the benefits and risks of screening, both at the population-level (through mass media)

and within patient-provider interactions. Sensitivity to the psychosocial factors that shape women's attitudes toward mammography screening should be central to any strategy.

---

### **How do health consumer organisations in Australia manage pharmaceutical industry sponsorship? A cross-sectional study**

Edith Lau, Alice Fabbri and Barbara Mintzes. Australian Health Review 2018.

<https://doi.org/10.1071/AH17288>

We identified 230 health consumer organisations that received pharmaceutical industry support from 2013 to 2016 according to reports published by Medicines Australia, the industry trade association. A random sample of 133 organisations was selected and their websites assessed for financial transparency, policies governing corporate sponsorship and evidence of potential industry influence. 130 of the 133 organisations evaluated received industry funding. Of these 130, 68 disclosed this funding - 98.5% reported the identity of their industry donors, 52.9% how it was used. 13.2% the amount and 4.4% the proportion of income from industry. Industry-funded health consumer organisations in Australia have low transparency when reporting industry funding and few have policies governing corporate sponsorship. Relationships between health consumer organisations and the industry require effective actions to minimise the risks of undue influence.

---

### **How to strengthen the presence of patients in health technology assessments conducted by the health authorities**

Mamzer, M.F., Dubois, S., Saout, C., Albin, N., Béhier, J.M., Buisson, A., Diebolt, V., Delaitre, O., Duguet, C., Fagon, J.Y. and Gaillard, S., 2018 *Thérapie*, 73(1), pp.95-105.

The constant development of health technologies, combined with the increase in the cost of treatment, means that States must continually make choices about the introduction of new technologies into their healthcare system and how they are to be funded. In France, the systematic participation of patients in these processes is one of the targets to be met in terms of healthcare democracy. Given the scope and complexity of the subject, and the difficulty involved in understanding all the different aspects of health technologies and innovations, the members of the Round Table chose to concentrate on health technology assessments (medicinal products and medical devices) to develop national recommendations on all possible types of patient involvement in the health technology assessment processes conducted by the health authorities in France.

---

### **Decision making in NICE single technological appraisals: How does NICE incorporate patient perspectives?**

F Hashem et al. *Health Expectations* 2018;21(1):128-37.

The National Institute for Health and Care Excellence (NICE) has an explicit mandate to include patient and public involvement in the appraisal of medicines to be available for funding on the NHS. NICE involves an appraisal committee who are required to take on board experiential evidence from patient experts alongside population-based evidence on clinical and cost-effectiveness when making a decision whether to fund a drug. This paper considers how NICE Single Technological Appraisal (STA) committees attempt to incorporate the views of patients in making decisions about funding medicines on the NHS.

Three data collection methods were used: analysis of documentary evidence sent by NICE, non-participant unstructured observations of the open and closed sessions of meetings and qualitative interviews.

Our analysis showed how the committees displayed a preference for an ideal-type of patient representative, disagreement among the committee when weighing-up patient statements in the STA process and more pre-preparation support for patient involvement.

---

### **What does meaningful look like? A qualitative study of patient engagement at the Pan-Canadian Oncology Drug Review: perspectives of reviewers and payers**

Rozmovits, L., Mai, H., Chambers, A. and Chan, K., 2018. *Journal of Health Services Research & Policy*, 23(2), pp.72-79.

Determining what constitutes meaningful (as opposed to tokenistic) engagement is complex through 24 semi-structured telephone interviews. Submissions from patient advocacy groups were seen as meaningful when they provided information unavailable from other sources. This included information not collected in clinical trials, information relevant to clinical trade-offs and information about aspects of lived experience such as geographic differences and patient and carer priorities. In contrast, patient submissions that relied on emotional appeals or lacked transparency about their own methods were seen as detracting from the meaningfulness of patient engagement and by failing to provide credible information relevant to deliberations. Misalignment of stakeholder expectations remains an issue even for a well-regarded health technology assessment process that has promoted patient engagement since its inception. There is a fundamental tension between the evidence-based nature of health technology assessment and the experientially oriented culture of patient advocacy.

---

### **Patient vs. Community Engagement: Emerging Issues**

Kimminau KS, Jernigan C, LeMaster J, Aaronson LS, Christopher M, Ahmed S, Boivin A, DeFino M, Greenlee R, Salvalaggio G, Hendricks D, Herbert C, Mabachi NM, Macaulay A, Westfall JM, Waitman LR.

Med Care. 2018 Aug 2. doi: 10.1097/MLR.0000000000000772. [Epub ahead of print]

The value proposition of including patients at each step of the research process is that patient perspectives and preferences can have a positive impact on both the science and the outcomes of comparative effectiveness research. Qualitative methods were used to collect perspectives and models of engagement from a diverse group of patients, researchers and clinicians. The project culminated with a workshop involving these stakeholders. The workshop used a novel approach, combining World Café and Future Search techniques, to compare and contrast aspects of patient engagement and community engagement. Participants developed and refined a framework that compares and contrasts features associated with patient and community engagement.

### **Patient and public engagement in research and health system decision making: A systematic review of evaluation tools.**

Boivin A, L'Espérance A, Gauvin FP, Dumez V, Macaulay AC, Lehoux P, Abelson J. Health Expectations 1<sup>st</sup> published 30 July 2018.

Patient and public engagement is growing, but evaluative efforts remain limited. Reviews looking at evaluation tools for patient engagement in individual decision making do exist, but no similar articles in research and health systems have been published.

Only 11% of tools were explicitly based on a literature review, and just 7% were tested for reliability.

Patients and members of the public were involved in designing 56% of the tools, mainly in the piloting stage, and 18.5% of tools were designed to report evaluation results to patients and the public.

---

### **What will it take to get the evidential value of lay knowledge recognised?**

Popay J. Int J Public Health. 2018 Jul 26. doi: 10.1007/s00038-018-1145-z. [Epub ahead of print] No abstract available. PMID: 30046850

---

### **Engaging patients to improve quality of care: a systematic review**

Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, Onate K, Denis JL, Pomey MP.

Implement Sci. 2018 Jul 26;13(1):98. doi: 10.1186/s13012-018-0784-z. Review.

To identify the strategies and contextual factors that enable optimal engagement of patients in the design, delivery, and evaluation of health services.

Strategies and contextual factors that enable patient engagement were thematically grouped and related to techniques to enhance design, recruitment, involvement and leadership action, and those aimed to creating a receptive context. Reported outcomes ranged from educational or tool development and informed policy or planning documents (discrete products) to enhanced care processes or service delivery and governance (care process or structural outcomes). The level of engagement appears to influence the outcomes of service redesign-discrete products largely derived from low-level engagement (consultative

unidirectional feedback)-whereas care process or structural outcomes mainly derived from high-level engagement (co-design or partnership strategies). A minority of studies formally evaluated patients' experiences of the engagement process. While most experiences were positive-increased self-esteem, feeling empowered, or independent-some patients sought greater involvement and felt that their involvement was important but tokenistic, especially when their requests were denied or decisions had already been made.

Patient engagement can inform patient and provider education and policies, as well as enhance service delivery and governance. Additional evidence is needed to understand patients' experiences of the engagement process and whether these outcomes translate into improved quality of care.

---

### **Why do the public support or oppose obesity prevention regulations? Results from a South Australian population survey**

Jackie Street: LC Farrell et al 2018. Health Promotion J of Australia

Australian policymakers have acknowledged that implementing obesity prevention regulations is likely to be facilitated or hindered by public opinion. Accordingly, we investigated public views about possible regulations in a cross-sectional survey of 2732 persons, designed to be representative of South Australians aged 15 years and over. Questions examined views about four obesity prevention regulations (mandatory front-of-pack nutrition labelling for packaged foods; zoning restrictions to prohibit fast food outlets near schools; taxes on unhealthy high fat foods; and taxes on sugar-sweetened beverages).

Views about the regulations were mixed: support was highest for mandatory nutrition labelling (90%) and lowest for taxes (40%-42%). High levels of support for labelling were generally underpinned by a belief that this regulation would educate "Other" people about nutrition. Lower levels of support for zoning restrictions and taxes were associated with concerns about government overreach and the questionable effectiveness of these regulations in changing behaviours. Levels of support for each regulation, and reasons for support or opposition, differed by gender and socioeconomic status.

Sociodemographic differences in support appeared to reflect gendered responsibilities for food provision and concerns about the material constraints of socioeconomic deprivation. Resistance to regulations amongst socioeconomically disadvantaged target populations warrants attention from public health advocates.

---

Janet Wale, HTAi PCIG

E-mail: [pcig.htai@gmail.com](mailto:pcig.htai@gmail.com)

---