

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

Enhanced quality and relevance of HTA through patient and citizen involvement

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

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Welcome to the April E-Bulletin

Chair Neil Bertelsen was recently part of a discussion panel at the DIA Euro meeting on patient involvement. DIA Vision: DIA is your essential partner in catalysing knowledge creation and sharing to accelerate healthcare product development.

The main areas I spoke about on the panel:

- Introduction to the PCIG and why our multi-stakeholder approach has been so successful (it amazes me that people from industry still don't know about us).
- Patient involvement in HTA strengthens decision making
- Patient participation and patient based evidence are two parallel strands of patient involvement and both are needed
- (In terms of patient-based evidence, I gave the example that we have formed a PRO work stream that is looking into how HTA uses and assesses PRO measures)
- There is no one-size fits all approach to this and systems, legislation, the agency remit and cultural/societal values shape the processes that have emerged
- We have to be vigilant about legislation passed today as it will affect the future for many years - specifically the proposed EU HTA Harmonisation proposal is unfortunately very light on patient involvement and this needs to be addressed now (I called on the participants who were mainly industry to keep flagging the need for patient involvement) - in particular, I stressed that we have to be careful that harmonisation does not lead to a dilution of the involvement or ignores the lessons we have learned on the importance of patient involvement
- I also brought up the issue that we are covering in our HTAi PCIG workshop - the resource burden on patient organisations to submit to HTA.

HTAi Matters

HTAi 2018 Annual Meeting at <https://www.htai2018.org/#>



Join HTAi 2018 to engage with an extensive network of leaders, experts and key policymakers in lively discussions.

Any questions regarding Registration? Please contact registration@htai.org

Highlighting two PCIG panel sessions panel session [the third, Patient Preference Data versus Patient Participation in HTA – Getting The Balance Right was last month]

The first is a panel discussion on Rapid Qualitative Evidence Synthesis. Moderated by Karen Facey, this panel involves Andrew Booth, Fiona Campbell, and two agency presenters Naomi Fearn and Laura Weeks.

Decision-makers are increasingly recognizing the usefulness of qualitative research evidence to inform patient-centred policy decisions, and are accordingly demanding qualitative evidence as part of HTA. Qualitative research can inform an understanding of how technologies are used by, or interact with, patients in their daily lives, and the impacts of those technologies both intended and unintended. Increasing interest in qualitative evidence synthesis can help ensure policy making is based on the best available evidence. Rapid qualitative evidence syntheses need to be relevant, rigorous, and meet standards for conduct and reporting. While already a familiar challenge for HTA researchers, this balance between time and rigour may be particularly salient in rapid qualitative evidence syntheses.

While CADTH has maintained a renowned Rapid Response service for over 10 years, it is now revising this service to produce rapid reviews of qualitative evidence. Laura Weeks will discuss the opportunities and challenges establishing this service brings. The Scottish Health Technologies Group is developing a framework that identifies the key themes that are known to arise and uses this as a basis to support rapid qualitative evidence synthesis by health services researchers with little prior exposure to qualitative research. Naomi Fearn will discuss experiences to date, focusing on the development and use of a framework synthesis approach to speed up the analytic process.

Participants will leave this panel discussion: with an understanding of the need and opportunities for rapid qualitative evidence syntheses in HTA; an understanding of diverse methodological challenges within the conduct of rapid qualitative evidence syntheses; having been able to discuss with leading researchers in HTA agencies how novel rapid qualitative evidence synthesis approaches could be applied within their own setting; encouraged to participate in a new HTAI Interest Group workstream on rapid qualitative evidence synthesis.

Innovative Methods for Patient Evidence in a World of Real-World Evidence

Panellists include Lindsay Lockhart of SMC; Kyle Nicholls Cobb, National Quality Forum; Emil Chiauzy, Research Director of PatientsLikeMe; and Patient Involvement and Education Working Group members.

This panel outlines strengths of patient engagement and challenges to integrating input into HTAs. We explore use of large patient-managed databanks to collate and analyze data and design outcome performance measures that reflect health outcomes and can provide HTAs with patient evidence. Patient groups have a right to provide input and can improve the quality, completeness, and practical implementation of HTA decision-making. Yet the ability to present and integrate patient input in ways that directly supplement the evidence at hand is a major hurdle. The power of large datasets for facilitating HTA is increasingly cited, and beginning to be implemented, for such functions as developing adaptive, more sensitive and relevant quality of life measures and generating real-world evidence on effectiveness, safety, and economic impacts. Patient perspectives on health outcomes can be collated from electronic capture of patient experiences by or in partnership with patient organizations. Can these methods be used to inform HTAs, and in what form would this data be best integrated and presented?

Quality clinical care, clinical trials, registries, and performance outcome measures can inform improvements in healthcare and health outcomes through the use of data. Powerful electronic-based technologies include computer-adaptive tests, e-measures, e-patient reported outcome measures (PROs) and poll methodologies. Patient-driven organizations like PatientsLikeMe (PLM) have demonstrated that they can collect and analyze patient perspectives on patient experiences in living with and treating diseases. PLM has more than 500,000 members and defines health outcomes relevant to patients using their own language and terminology, considering how patients conceptualize and apply their own data. Patients can more accurately reflect their experiences, inclusive of vulnerable, disabled and often under-represented populations. These activities readily expand beyond national borders. Payers want to pay for the right

treatments at the right time, and that healthcare is value-based. PLM has worked with National Quality Forum to turn real-world data into quality performance measures and real-world evidence on health outcomes. HTA is not just about the technology but how it fits within the health system to improve health outcomes. The patient perspective on healthcare outcomes is an important consideration for HTA agencies. The objectives of this panel are to: look at what patient engagement in HTA presently looks like when it is done well, the attributes and challenges, and to explore how patient perspectives in HTA could be developed to assess value-based care, by patient organizations and in partnership.

The PCIG also has a workshop: WS13: Building A Shared Resource of Patient Experience And Preferences To Improve HTA

8.30 am – 4.30 pm, Saturday 2 June 2018

This full-day workshop presents the issue of the burden of patient input in HTA and seeks to identify solutions by developing participants’:

- knowledge of common gaps, issues and overlaps in patient input sought for HTAs
- awareness of existing sources of patient experience and how they function
- ability to identify potential collaborators and approaches to building shared such as repositories.

HTA Agency activities

CADTH symposium 2018: Patient Engagement Highlights, April 15-17

Travel Support for Patients: This is the third year of CADTH’s Patient Group Travel Award program and we were able to support attendance for 32 patients.

Welcome to the Symposium: Patient representatives Meet and Greet

The *Meet and Greet* took place just before the poster session and welcome reception. It officially lasted 45 minutes, but people lingered for about 90 minutes, enjoying the food and conversation before heading to the poster session. The CADTH Symposium has met the criteria for the [Patients Included](#) designation. Part of the criteria is patient involvement in the planning of the symposium, and CADTH had 2 patient group representatives on the planning committee: Jamie Myrah (Pulmonary Hypertension Association of Canada) and Susan Tilley-Russell (Arthritis Society). Susan welcomed all the delegates and explained how the *Meet and Greet* was created based on input from patients that it would be helpful to have an opportunity to meet others early in the proceedings. In addition, in response to requests from patients, a quiet room was made available for the duration of the Symposium. CADTH’s activities meet all the Patients Included criteria and are outlined here: <https://www.cadth.ca/2018-cadth-symposium/patients-included>

Livestream and Webinar Content

Although we were able to support participation at the Symposium by more than 30 patient group representatives, we recognize that not everyone is able to attend. Canada’s unpredictable spring weather also made travel difficult and there were many last minute scheduling changes. Luckily all three plenary sessions were livestreamed and will soon be available at: <https://www.cadth.ca/2018-cadth-symposium>
Photos: <https://www.flickr.com/photos/124034028@No6/sets>

Conference Activity Highlights: Making Tough Decisions: An Interactive Deliberative Exercise

On the Sunday afternoon, 13 delegates attended a 3 hour workshop modelling a CADTH expert committee meeting. After an introduction on the role CADTH drug reviews, a fictional case study, with details drawn from a real rare disease assessment were presented by a CADTH clinical manager and health economist.

OPENING PLENARY: Health Priorities in a Changing Health Care Landscape
In this opening plenary, senior policy-makers from across the country discussed their priorities, including improving health outcomes for Indigenous Canadians, better care in the community, home care, and mental health. They reported on



their progress and plans, and discussed the implications of these priorities for patients.

PLENARY SESSION 2: Beyond HTA: What Does Health Technology Management Mean for Patients and



the Health System? For many, this session was an introduction to the concept of health technology management (HTM) defined as a more active process to influence innovation, adoption, and disinvestment decisions throughout the life cycle of technologies to better support healthcare decision-makers. Brian Huskins offered a patient perspective on this plenary panel challenging delegates to meaningfully involve patients. Craig Mitton emphasized the

importance of patient engagement activities, and mentioned CADTH's Optimal Use reports as a model of patient engagement in medical devices.

CLOSING PLENARY: Appropriate, Affordable, and Accessible Drug Therapy: Can We Have It All?

Concurrent Session B7 — Patient and Public Engagement

Understanding the Perspectives of Patients' and Family Members' Experience With Treatment:

Engaging Patients in the Medical Devices and Clinical Interventions Portfolio at CADTH:

- Tamara Rader, CADTH

- Andrea Smith, CADTH

Managing Screening Technologies in the Face of Uncertainty: Results From a Population Survey and Deliberations With Ontario Citizens:

- Dr Julia Abelson, McMaster University

Co-Designing and Conducting a Scoping Review With Patients:

- Tamara McCarron, University of Calgary

Making Fair and Sustainable Decisions About Funding for Cancer Drugs in Canada:

- Dr Stuart Peacock, Canadian Centre for Applied Research in Cancer Control.

Concurrent Session C5 — Panel Discussion: Patients, Patient Groups, and Patient Engagement: Blockbuster or Boondoggle?

- Dr Sharon Batt, Dalhousie University

- Kevin McNamara, retired (former Deputy Minister of Health, Nova Scotia)

- Bill Swan, Faces of Pharmacare

- Dr Dilini Vethanayagam, University of Alberta

- Kerri MacKay, Patient Advisors Network

- Dia Sue-Wah-Sing, Canadian Severe Asthma Network

Concurrent Session D6 — The Patient's Experience

The Reality of Health Technology Access in Canada: Understanding the Patient's Experience in Drug Coverage Navigation and Early Access Coordination - Mary Lou Robertson, M.L. Robertson

Consulting Patient Voices: Whose Stories Are Missing? Why? And, So What? - Dr Sharon Batt, Dalhousie University

Using LEAN Tools to Improve the Patient's Experience - Luciana Lot, University of Campinas, Brazil

Summary of Qualitative research sessions:

In a lively panel discussion moderated by Andrea Smith, Qualitative Research Officer at CADTH, three qualitative researchers and decision makers explored the potentials for "thinking qualitatively" to further patient-informed health policy. Dr Jeremy Petch spoke from his experience as the public member of CADTH's Health Technology Expert Review Panel and reflected on the usefulness of qualitative evidence on patients' perspectives and experiences to guide recommendations about the appropriate use of health technologies, to identify and implementation considerations. Elijah Herington, Qualitative Research Officer at CADTH, used his training as a medical anthropologist to reflect on the many opportunities to use qualitative approaches evidence in HTA: moving beyond descriptions of patients' perspectives and experiences to more empathetically place care, in its many dimensions, at the centre of health care policy and decision making. Prof Janice Graham spoke from her experiences producing and presenting qualitative research to national and international health regulators and reinforced the need for reflexivity and the continued incorporation of knowledge produced from different paradigms. Overall, this panel

demonstrated an emergence of qualitative research in HTA and left the audience with many ideas for the future potential of qualitative research in multi-disciplinary HTA.

In an oral session focused exclusively on qualitative evidence, Andrea Smith (Qualitative Research Officer, CADTH) opened with a thought provoking presentation during which she interrogated the use of standard methods for systematic reviews for synthesizing qualitative evidence often focused on patients' and caregivers' perspectives and experiences. Considering each stage of the evidence synthesis process (i.e., question development, literature searching, screening, data extraction, quality appraisal, data synthesis, developing conclusions), Andrea explored the epistemological disjunctures when synthesizing clinical effectiveness data and qualitative literature and used this as an opportunity to suggest methodological refinements with qualitative evidence synthesis and opportunities to enhance rigor. In a separate presentation, Dr Laura Weeks (Manager, Scientific Affairs, CADTH) described increasing requests to conduct qualitative evidence syntheses quickly, which has given rise to a new study design: rapid qualitative reviews. Understanding that standard methods for rapid clinical reviews may not transfer to the conduct of rapid qualitative reviews, Laura described a scoping review to identify existing methodological guidance, and characteristics of published rapid qualitative reviews. The research team found that, with rare exception, the methods of rapid clinical reviews are being used to likewise conduct rapid qualitative reviews, which further highlighted the need for methodological work to ensure the rigorous conduct and delivery of qualitative evidence to decision makers.

Contributed by Tamara Rader, Laura Weeks, Ken Bond

Welcome to NICE 2018, June 26 in Manchester

NICE 2018: Improving health, improving lives showcases the latest developments in clinical improvement, health technologies and patient-centred quality care.

Providing clinicians, managers and leaders of the NHS and life sciences sector with unrivalled insight into the innovations reshaping healthcare, the event will explore topics ranging from digital technology and patient empowerment to real world evidence and big data.

NICE 2018 packs 15 hours of content into just one day:

- Renowned keynote speakers, including conference host, clinician and broadcaster Dr Phil Hammond
- Case studies from the frontline of quality improvement
- Plenary debates on the big issues facing healthcare in the UK
- Super-fast 'lightning learning' talks on everything from Devo Manc to cancer drugs, quality improvement, and apps and wearables

Why you should attend

- Come along to our Shared Learning Awards and hear about practical case studies from health and care professionals successfully implementing NICE standards and guidance across the country
- Gain insight into how industry and the NHS are working together to improve the uptake of innovations in healthcare, what's changed since the Accelerated Access Review and what's next for life sciences
- Hear from key organisations shaping the healthcare landscape and share an invaluable opportunity to get involved, shape the debate and keep up to date with the changes

NICE 2018 is the only event of its kind, bringing together the clinical, pharmaceutical and health technology communities to share the latest in evidence-based excellence and innovation.

What's Happening



PARADIGM
Patients Active in Research and Dialogues
for an Improved Generation of Medicines

[PARADIGM](#) is a new IMI project to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and

sustainable patient engagement and demonstrates the 'return on the engagement' for all players. PARADIGM will be implemented with plenty of input from EUPATI and other previous initiatives, and we wish good luck to the new project with [this blog entry from EUPATI alumni](#) who participated at the kick-off conference.

From EUPATI - April newsflash, contributed by Marleen Kaatee

FDA draft guidance

The FDA draft guidance on "Pregnant Women: Scientific and Ethical Considerations for Inclusion in Clinical Trials" has been issued and is available at:

<https://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM603873.pdf>

ISPOR events

'the leading educational and scientific organization for health economics and outcomes research (HEOR) and its use in healthcare decisions'

Webinar - open to all, ISPOR members and non-members

Wednesday, May 2, 2018, 11:00 AM EDT | 5:00 PM CEST for 1 hr

ISPOR will be offering a new, complimentary educational webinar, *Using the Patients Voice to Bring BIG Data to Life*. . How can PRO data be collected at scale in the real world? How can patient-centered evidence be combined with information drawn from clinical or claims sources? How can we truly evaluate health care and real world outcomes from the patient's point of view?

If you would like to participate in this webinar, be sure to register via the link provided below!

[Register Here](#)

Please note: On the day of the scheduled webinar, the first 500 registered participants will be accepted into the webinar. For those who are unable to attend, or would like to review the webinar at a later date, the full-length webinar recording will be made available at the [ISPOR Educational Webinar Series webpage](#) approximately 2 weeks after the scheduled Webinar.

ISPOR Educational Webinars *provide ISPOR Members the opportunity to learn about [ISPOR Good Practices for Outcomes Research](#) methods and other current topics directly from the authors themselves.*

All of our past webinars and [Upcoming Educational Webinars](#) are posted at the ISPOR website.

Be on the lookout for upcoming webinars on newly published Good Research Practice Reports!

ISPOR Europe 10-14 November, 2018 in Barcelona

Call for abstracts and proposals: Deadline 13 June 2018

For more information on abstract submissions, including instructions, examples, and specific evaluation criteria: [Abstract Submission Information](#) »

If you have any questions concerning submissions, please contact abstractreview@ispor.org.

[#ISPORBarcelona](#)

EURORDIS www.eurordis.org



Eurordis political statement on the Regulation proposal for European cooperation on HTA

On March 29th, Eurordis's Board of Directors adopted a statement on the Regulation proposal for a European Cooperation on HTA: *Transparency and Health Technology Assessment cooperation as proposed by the Regulation are the only real antidote to secrecy and political games*

And Annexe:

<https://www.eurordis.org/publication/eurordis-statement-proposal-regulation-hta-cooperation-europe>

In this statement, Eurordis:

1. Details why patients need decision-making to be based on scientific and medical evidence, transparent processes and facts, everywhere in the EU
2. Reminds that Solidarity between Member States is a funding principle of the European Union
3. Explains that HTA cooperation on a voluntary basis has its limits
4. Comments on fairness, equity, high scientific standards and efficiency in the decision-making process, in the interest of all patients, as provided for by the proposal
5. Welcomes the synergy with the European policy to create and develop European Reference Networks

François Houyez
EURORDIS

McMaster Health Forum Update <https://www.mcmasterforum.org/newsletter>

The McMaster Health Forum is proud to announce that John Lavis, our Director, has recently been appointed as a Distinguished Visiting Professor at the Africa Centre for Evidence (ACE) in the Faculty of Humanities at the University of Johannesburg (UJ). Joining him in this five-year role will be Sandy Oliver from the EPPI-Centre at University College London.

"This appointment at UJ offers the opportunity to both share our lessons learned in supporting evidence-informed health policymaking, and to learn from colleagues working at the leading edge of similar efforts beyond the health sector. With the creation of Forum+ and Social Systems Evidence, we're very keen to build a strong partnership among three organizations (ACE, EPPI-Centre and McMaster Health Forum | Forum+) committed to working across sectors."

Carlos Eduardo Pinzón-Flórez, the Deputy Director of Health Technology Assessment at the Instituto de Evaluación Tecnológica en Salud (IETS) in Colombia, spent the past six weeks at the McMaster Health Forum as part of a hands-on learning experience in the field of evidence-informed policymaking, stakeholder engagement, and patient-oriented research. During this time, he received training and access to our resources while he worked to develop and implement a framework to integrate social values and patients' perspectives in health technology assessment and coverage decisions. This collaboration will continue with a knowledge translation and a capacity building component that will culminate in a two-day workshop to be hosted by François-Pierre Gauvin in Columbia during the month of May for 12 participants from the Institute.

UK INVOLVE Guidance on co-producing a research project

March 2018

<http://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/>

Key Principles:

Sharing of power – the research is jointly owned and people work together to achieve a joint understanding
Including all perspectives and skills – makes sure the research team includes all those who can make a contribution

Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance

Reciprocity – everybody benefits from working together

Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.

Active Citizenship Network: Therapeutic adherence: value the impact for patients and healthcare system
23rd May 2018, 09:30 – 13:00 in Brussels

<http://activecitizenship.net/primopiano/254-xii-european-patients-rights-day-2018.html> (Register here)

In line with the topic of healthcare systems' sustainability, addressed in the previous conferences of the European Patients' Rights Day, the twelfth edition will contribute to the current policy debate on how to achieve a more sustainable provision of care. The poor adherence to treatments has, in fact, significant implications for the expenditures of healthcare and it is estimated to increase costs of approximately €80 billion a year. The event will be an occasion to foster communication among different partners/actors in the healing and caring process to improve adherence to treatments and take commitments to increase the respect of patients' rights and their involvement as fundamental active partners with health professionals in their own care, respecting the fundamental values recognised by the [European Charter of Patients' Rights](#).

Publications

The Patient Reported Outcomes, Burdens and Experiences (PROBE) Project: development and evaluation of a questionnaire assessing patient reported outcomes in people with haemophilia

has now been published as part of a special thematic series in Pilot and Feasibility Studies. The journal series includes a collection of peer-reviewed papers reporting on the pilot and testing phases of Patient Reported Outcome Measures (PROMS) during their development, evaluation and implementation.

Through the PROBE Study we have demonstrated the feasibility to engage diverse patient communities globally in the structured generation of real-world outcome research at all stages. For more information: www.probestudy.org. The full article is available in open access at:

<https://pilotfeasibilitystudies.biomedcentral.com/articles/10.1186/s40814-018-0253-0>

Mark has presented on PROBE at the last 3 HTAi meetings. This is the first manuscript published, several more publications are in their final stages and will be out soon.

Contributed by Mark Skinner

Impact of patient involvement on clinical practice guideline development: a parallel group study.

Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Implement Sci. 2018 Apr 16;13(1):55. doi: 10.1186/s13012-018-0745-6. PMID: 29661195 DOI: [10.1186/s13012-018-0745-6](https://doi.org/10.1186/s13012-018-0745-6) [Free Article](#)

Patient and public involvement (PPI) is recognized as a key component of clinical practice guideline development with important implications for guideline implementability. The impact of PPI on guidelines, however, has not been rigorously assessed. Better understanding of the impact of PPI must start with guideline question formation, which drives all subsequent development steps. The aim of this study was to investigate the effect of PPI on guideline question formation and validate a conceptual model of patient and public contributions to guidelines. We convened two parallel guideline development groups, one with and one without patient representatives. Participating physicians were randomized to group assignment. Each group developed Population, Intervention, Comparator, Outcome, Time (PICOT) questions and identified key benefits and harms to incorporate in guideline development. Analysis included a descriptive comparison of proposed PICOT questions, benefits, and harms between groups and a qualitative analysis of discussion themes from audio recordings of the question development retreats.

Proposed guideline questions, benefits, and harms were largely similar between groups, but only the experimental group proposed outcomes relating to development of cognitive impairment at specific time points and rate of progression. The qualitative analysis of the discussions occurring during guideline question development demonstrated key differences in group conduct and validated the proposed conceptual model of patient and public contributions to guidelines. PPI should be considered an essential element of trustworthy guideline development for purposes of development and funding.

Contributed by Sally Wortley

A New Framework for Patient Engagement in Cancer Clinical Trials Cooperative Group Studies

PA Deverka, R Bangs, K Kreizenbeck, DM Delaney, DL Hershman, CD Blanke, SD Ramsey. *JNCI: Journal of the National Cancer Institute*, djyo64, <https://doi.org/10.1093/jnci/djyo64>

Published: 18 April 2018. A PCORI funded study

For the past two decades, the National Cancer Institute (NCI) has supported the involvement of patient advocates in both internal advisory activities and funded research projects to provide a patient perspective. Implementation of the inclusion of patient advocates has varied considerably, with inconsistent involvement of patient advocates in key phases of research such as concept development. Despite this, there is agreement that patient advocates have improved the patient focus of many cancer research studies. This commentary describes our experience designing and pilot testing a new framework for patient engagement at SWOG, one of the largest cancer clinical trial network groups in the United States and one of the four adult groups in the NCI's National Clinical Trials Network (NCTN). Our goal is to provide a roadmap for other clinical trial groups that are interested in bringing the patient voice more directly into clinical trial conception and development. We developed a structured process to engage patient advocates more effectively in the development of cancer clinical trials and piloted the process in four SWOG research committees, including implementation of a new patient Advocate Executive Review Form that systematically captures patient advocates' input at the concept stage. Based on the positive feedback to our approach, we are now developing training and evaluation metrics to support meaningful and consistent patient engagement across the SWOG clinical trial life cycle. Ultimately, the benefits of more patient-centered cancer trials will be measured in the usefulness, relevance, and speed of study results to patients, caregivers, and clinicians.

Incorporating Quantitative Patient Preference Data into Healthcare Decision Making Processes: Is HTA Falling Behind?

DJ Mott. Published online March 2018. Patient <https://doi.org/10.1007/s40271-018-0305-9>

<https://link.springer.com/article/10.1007%2Fs40271-018-0305-9>

Contributed by Karen Facey

Emerging Good Practices for Transforming Value Assessment: Patients' Voices, Patients' Values.

Perfetto EM, Harris J, Mullins CD, dos Reis S. *Value in Health* [Internet]. 2018 [cited 2018 Apr 25];21:386–93.

Available from: <http://linkinghub.elsevier.com/retrieve/pii/S1098301518301931>

Patient engagement is a transformative strategy for improving value assessment. US value framework developers have increased engagement activities, but more needs to be learned about how to best achieve meaningful patient engagement in value assessment. The objective was to glean good practices in patient engagement emerging from patient community experiences, to be used in value assessment. The National Health Council Value Workgroup conducted a survey and held a focus group with its member advocacy organizations to gather experiences with value framework developers and views on emerging good practices. Ten of 13 organizations completed the survey; reporting 13 interactions with four framework developers. Most rated experiences as "good" to "very good." Emerging good practices included (1) engage

early; (2) engage a range of patients; (3) leverage patient-provided information, data resources, and outreach mechanisms; (4) be transparent; and (5) appreciate and accommodate resource constraints. Twelve of 13 organizations participated in the focus group, and this produced 30 emerging good practices in four areas: (1) timing; (2) methodology and data; (3) partnering; and (4) characterizing engagement. The growing pool of patient engagement experiences can be translated into good practices to advance a patient-centered, value-driven health care ecosystem.

Contributed by Anke-Peggy Holtorf

All Trials Campaign

[New research](#) has just revealed that most large charities and government bodies that fund clinical trials don't have a policy to ensure results are shared. And only half of them ask researchers to register their funded trials. It's disappointing to see charities and public bodies don't have strong policies on clinical trial transparency and as co-author of the study Dr Ben Goldacre put it "*We need these funders to show leadership, to tell their grant recipients very clearly that all trials must be registered and reported.*"

The new audit of non-commercial funders' policies is [published in JAMA](#) by Dr Goldacre's team at the EBMDDataLab at the University of Oxford. Out of 18 charities and federal bodies, who between them spend around \$40 billion on health research every year, the researchers found that only two had a strong policy that asked for trials they fund to be registered, results reported and data shared: the UK's Medical Research Council and Germany's DFG.

Last year, some of the world's major research funders, including some included in this audit, [joined the WHO's joint statement on public disclosure of clinical trial results](#). This means that they pledged to adopt a policy that asks their researchers to adhere to the WHO's strong standard on clinical trial transparency – that trials are registered and results publicly reported. The first group of funders joined the statement in May 2017 and the one-year deadline for adopting the new policy is coming up. The EBMDDataLab's team is going to audit or re-audit these funders in May 2018 to see whether they have fulfilled their commitments. AllTrials is continuing to highlight our [Unreported Clinical Trial of the Week](#) every week in the *BMJ*. This week it's a trial on pain relief for children who had tonsillectomies which was run with 64 children. It was sponsored by the Children's Hospitals and Clinics of Minnesota and is overdue to report results. Read about that and catch up on the unreported trials from previous weeks [here](#). Two of the trials we have shone a spotlight on since we started this in late February have now had results submitted to the register. This is working!

Sile Lane

Janet Wale, HTAi PCIG

E-mail: socrates111@bigpond.com
