



## HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) E-Bulletin, January 2017

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

Welcome to this month's E-Bulletin – and Happy Chinese New Year!



**HTAi Annual Meeting 2017: Explore how the global HTA community is evolving towards an integrated ecosystem – from local needs to global opportunities**

Join us for HTAi's 14<sup>th</sup> Annual Meeting June 17-21, 2017 at the Ergife Palace Hotel in Rome, Italy.  
**Registration:** Early Bird, March 3, 2017

### Two PCIG papers published in Research Involvement and Education, BioMed Central

One is on the formation of our Patient Panel: Strengthening international patient advocacy perspectives on patient involvement in HTA within the HTAi Patient and Citizen Involvement Interest Group &#8211; Commentary  
Authors: Wale Janet, Scott Anna, Bertelsen Neil, Meade Nick, on behalf of HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG)

And the second is on research done with Patient Panel members and others for the 2016 Pre-conference workshop in Tokyo: Patient advocate perspectives on involvement in HTA: An international snapshot

Research Involvement and Engagement.2017, 3:3  
DOI: 10.1186/s40900-016-0053-8  
<http://www.researchinvolvement.com/content/3/1/3>

### Call for HTAi Board of Director Nominations

Deadline: Wednesday, February 15, 2017, 23:59 MST (GMT +7)

HTAi is seeking active members of the Society for nomination to the Board of Directors. At the time of appointment, the Society will be at the mid-point of implementing its 2015–2020 strategic plan and will be working towards achieving current goals while looking ahead.

We are looking for three engaged, motivated and enthusiastic Board Directors for a three-year term, 2017-2020. Nominees must be prepared to:

- Chair at least one of the new advisory board committees
- Sit as a member on at least two committees or working groups
- Travel and attend two face-to-face Board meetings (January, June)
- Other duties as requested.

A fourth position is open for **Vice President**. Applicants must provide a biography, vision statement and photograph along with supporting signatories. The deadline for receiving the [nomination form](#) is Wednesday, February 15, 2017, 23:59 MST (GMT +7), submitted to [info@htai.org](mailto:info@htai.org). The Board Nominations Committee, in collaboration with the Secretariat, will ensure that all nominations meet the stipulations detailed in our bylaws with regards to eligibility.

Notification that the voting is open will be made to the membership, and will be open 24 hours a day, closing on Friday, March 31, 2017, 23:59 MST (GMT+7). Elections are administered by Electoral Reform Services, a neutral third-party. All HTAi members in good standing are eligible to vote and Electoral Reform Services will contact each HTAi member via email with further instructions on how to vote.

Questions? Please contact the [HTAi Secretariat](#)

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### PCIG releases draft patient group submission documents for diagnostics – for your comments

On behalf of Laura Norburn, Victoria Wurcel and the HTAi Patient Involvement Methods and Impact Working Group, I am delighted to share with you the draft patient group submission template for diagnostic technologies and its associated support documents for HTA bodies and patient organisations.

To receive the papers and comments: please send your comments on these documents electronically, either tracked or in comment boxes, to me at [k.facey@btinternet.com](mailto:k.facey@btinternet.com). Please indicate in your cover email, whether your comments are from you as an individual or on behalf of an organisation. **The deadline for comments is 17 March.**

The documents will then be revised and we hope to officially launch them at conference in June.

Karen Facey

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### Reimbursement issues for medical nutrition supplements – can you help

Since 2012 a number of European patient groups participate in the activities of the European Nutrition for Health Alliance (ENHA) focusing on disease-related malnutrition or undernutrition (DRM). One of the issues that regularly returns is the reimbursement of medical nutrition supplements, dietary foods and diagnostics to measure nutritional intake.

Also, healthcare insurance companies are actively involving the use of certain nutritional products above the use of others, as what they call 'preference products'. In some cases when patients use these 'preference products', they can receive a premium on their own payments for health care.

Most of the time, the use of these products is not discussed as a topic of HTA but Cees Smit is looking for information on the use of these products and patients' experiences with them, as well as publications or articles on these issues from a patient perspective.

Based on a request from New Zealand about problems perceived there, we are also looking for an experienced patient group in New Zealand or an HTA researcher or medical specialist in this area.

Cees Smit

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### Revised patient group submission form and guide for Scottish Medicines Consortium (SMC), Scotland

One year after launching its new simplified patient group submission form and accompanying guide for patient groups, SMC has taken feedback from patient groups and HTA committee members to improve the forms.

The Public Involvement Team worked closely with the SMC Public Involvement Network (PIN) Advisory Group during the review, resulting in minor amendments to optimise the accessibility and effectiveness of the form and guide.

New features include:

- MS word editable form format for maximum accessibility
- Increased word count for key questions

- Clear link for each question to the guidance document
- Space to include additional key information which isn't covered in any other questions.

The updated form and guide can be found on the [Submission form and guidance page](#) of the Public Involvement section of the website.

[http://www.scottishmedicines.org/About\\_SMC/Latest\\_news/News\\_Articles/Updated\\_submission\\_form\\_and\\_guide\\_for\\_Patient\\_Group\\_Partners?iru=UgZBIANLBB](http://www.scottishmedicines.org/About_SMC/Latest_news/News_Articles/Updated_submission_form_and_guide_for_Patient_Group_Partners?iru=UgZBIANLBB)

Submitted by Karen Facey

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### Review of access to end-of-life, orphan and ultra-orphan medicines in Scotland

The Scottish Government has published Dr Brian Montgomery's Review of Access to New Medicines, which assesses the impact of the new approach introduced by the Scottish Medicines Consortium (SMC) in 2014, with the aim of increasing access to end-of-life, orphan and ultra-orphan medicines.

<http://www.scot.gov.uk/Publications/2016/12/9192/downloads#res511595>

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### The Scottish approach to evidence. A discussion paper

An interesting paper from a Roundtable discussion: "... we hear qualitative evidence being pitted against quantitative evidence. However, both are valid, because what evidence is appropriate depends on what you want to know. This necessitates being clear about why you are going to use or gather evidence."

<http://www.alliance4usefulevidence.org/assets/AFUE-The-Scottish-Approach-to-Evidence-v7-1.pdf>

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### Update from EUPATI

The five-year Innovative Medicines Initiative (IMI) project funding supporting EUPATI has come to an end and it's great to see the wonderful tools and expertise they have developed.

- Since its launch last year, there are more than 100,000 unique users of the [EUPATI Toolbox](#), which is now available in seven languages as planned, but 3 additional languages are in the works. Thanks to a [robust production process](#), based on your feedback, the EUPATI content is widely acknowledged to be reliable, understandable and objective.
- [98 patient advocates from 51 disease areas and 31 countries have recently graduated](#) from our two EUPATI Patient Expert Training Courses, and the 3rd course will launch in September 2017 (Karen Facey is part of the selection process for that).
- [guidances on the interaction of patient organisations with regulators, HTA bodies, industry and ethics committees](#) have been published, the HTA one was developed in close liaison with HTAi.
- [18 EUPATI National Platforms](#) have been established, 6 more than anticipated.

And of course all these figures don't tell us about the people whose lives have been changed by the knowledge and networking that EUPATI has supported. In our community we are grateful for the work of Marleen Kaatee on the patient panel and for her energy in all our work. But that's not the end of EUPATI, their sustainability plan is in place and they are transforming from an IMI project into a permanent EPF-led EUPATI Programme.

Karen Facey will continue to be the official link between HTAi and EUPATI.

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### The IMI PREFER (patient preferences project)

This now has a website up and running with information accumulating on the project: <http://www.imi-prefer.eu/>

Nigel Cook

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### Patient perspectives in the medicines lifecycle - a new Innovative Medicines Initiative topic, led by EFPIA

This is open for public partner applications. The private consortia of 17 EFPIA members represents unique work in the EU as the deliverables are expected to be co-created by industry, Patients, HTAs, HCPs and Academia. The deadline for (public partner) applications will be on 28 March. Listen to and watch the public offering and recording here [Watch Recording](#).

Neil Bertelsen

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### Wellcome Public Engagement Fund

This funding is for anyone with a great idea for engaging the public in conversations about health-related science and research. UK, Republic of Ireland, Some low- and middle-income countries.

You may also be interested in the Engagement Fellowships scheme, designed to support and develop the careers of emerging leaders in public engagement. The deadline for this scheme is 10 February 2016.

[Find out more and apply](#)

JoAnne Zaborowski

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### Highlights from the European Patients' Forum (EPF)

- On 17 and 18 January 2017, the Adapt Smart consortium held its Annual General Assembly at the European Medicines Agency, in London. The two-day event gathered representatives from regulatory bodies, pharmaceutical industry, HTA agencies and patient organisations

[READ MORE »](#)

- EPF has officially launched their one-year campaign on Access to Healthcare – see the dedicated pages on their [website](#). They are also organising a meeting on the 27th of February in the European Parliament, where they will describe the five areas for policy action and reflect with participants on the measures needed to really achieve 'Universal Health Coverage for All' by 2030. A major milestone of our recent campaign on Patient Empowerment has just been published.
- The Roadmap for Action proposes concrete actions policymakers, healthcare professionals, and other stakeholders across the EU can take to drive positive change.

[READ MORE »](#)

[READ MORE »](#)

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### European Reference Networks (ERNs) approved!

All 23 applications for the establishment of European Reference Networks have been approved by the Board of Member States in the European Commission. It is hoped that the ERNs will revolutionise rare disease patient access to care by connecting patients, experts and hospitals. This will help break the isolation of patients, tackle the silos that experts work in, and help to reduce inequality in the delivery of care for people with rare diseases in different EU countries. [Go here for more.](#)

IPPOSI Newsletter

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### Benefit-Risk Assessments at the US Food and Drug Administration - Finding the Balance

Robert M Califf, US Food and Drug Administration

<http://jamanetwork.com/journals/jama/fullarticle/2599251>

JAMA. Published online January 20, 2017. doi:10.1001/jama.2017.0410

The US Food and Drug Administration's (FDA's) independent evaluation of medical products for safety and effectiveness prior to granting approval for marketing or new labeled indications is fundamental to assuring the public and clinicians that marketed products have a positive balance of benefit to risk when used according to labeling. Ever since this foundational protection was established in 1962, a body of evidence has supported the use of a flexible but consistent standard when making decisions about marketing approval: Do the benefits of a product outweigh the risks when used as intended and labeled? This seemingly simple question is among the most difficult encountered at the agency. To answer it, FDA product review teams must weigh scientific and clinical evidence and consider conflicting stakeholder and societal perspectives about the value of benefits and the tolerability of risks. They must consider the existence and effectiveness of alternative treatments, disease severity, risk tolerance of affected patients, and potential for additional insight from postmarket data. Such decisions require seeking the appropriate balance between high-quality evidence and early access, between benefit and risk, between protecting the US public and encouraging innovation that may improve health outcomes. Given the importance of these tasks, it is essential for FDA to adopt a harmonized framework for medical product approval that consistently accomplishes 3 key goals: (1) applying a core set of scientific, medical, and public health principles; (2) articulating a clear approach for addressing uncertainty and patient viewpoints; and (3) providing a predictable pathway for therapeutic development.

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### New head and neck cancer book - Swallows Charity, UK patient support group

<https://www.yumpu.com/xx/embed/view/JeadszUChigSILmQ>

You can download the book as a PDF, plus we have 10,000 copies ready for distribution

Chris Curtis, Chairman & World Patient Ambassador

Swallows Charity UK. [www.theswallows.org.uk](http://www.theswallows.org.uk)

*As a support group we would like to advise you that we are a patient-led self-funding charity. Our sole aim is to help people, and we offer advice based on our experiences in dealing with Head & Neck Cancer. 'We are here to support patients, carers and their families who have concerns relating to the cancer 'Journey'.*

Submitted by Heidi Livingstone

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### Patient peer review at *The BMJ*

<http://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers>

If you're a patient living with disease or have experienced a significant illness or medical condition, a carer of a patient, a patient advocate acting on behalf of a patient group, or you play a leading part in advocating for patient participation and partnership in healthcare we'd like to invite you to take part in a unique initiative. The BMJ has committed to improving the relevance and patient centredness of its research, education, analysis, and editorial articles by asking patients to comment on them. We need your help to make these changes.

If you already review for *The BMJ* as a researcher or clinician, but you are also interested in reviewing as a patient, carer, or patient advocate, you can do this too.

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### OECD health ministers back new global league table of patient outcomes

Éanna Kelly, published: 17 JANUARY 2017

<http://sciencebusiness.net/health/news/2017/oecd-health-ministers-back-new-global-league-table-of-patient-outcomes/>

#### International comparisons of patient-reported experience of medical care will enable health systems to pinpoint what works and what does not, cutting waste and adding value

Health ministers from the world's major industrial powers gave their backing to a new international patient outcomes league table at a meeting in Paris on Tuesday.

The [patient reported indicator survey](#) (PARIS), in development by the OECD, will collect a new generation of health statistics on patients' own experience of medical care and health care outcomes.

"It will involve the actual rolling out of a set of commonly accepted indicators to track quality, access and value for money of health policies and inputs," said OECD secretary-general José Ángel Gurría. "We will no longer just measure health inputs, but also whether medical care leads to people being in less pain, more mobile and in better health."

The data collection will start small, covering representative samples of patients who have had strokes, heart attacks, cancer, hip and knee surgery, and mental illness. The Commonwealth Fund and the International Consortium for Health Outcomes Measurement (ICHOM) will help design survey questions and indicators.

"We want to hear patients' experiences," said Francesca Colombo, head of health at the OECD, noting that her group already records some aspects of patient experience in 19 countries. "What is their pain like? How is their functionality? Can they live a normal life now? These kinds of questions."

Knowing more about patient experiences is essential for lowering the cost of healthcare, said influential Harvard economist Michael Porter, who co-founded ICHOM in 2012 to promote value-based healthcare by defining outcome measurements that are clinically relevant and really matter to patients.

"We measure a lot of stuff [but] we have to measure the most important thing. Outcomes are the things patients want to know the most about. When we think about cost reduction, we need outcomes," Porter told the meeting....

The EU already works with the OECD on research into European health systems and will support the development of the outcomes league table, both politically and financially, Prats Monné said.

OECD health statistics have driven policy change in the past. For example, [South Korea put a huge amount of effort into improvements](#) after it saw its lowly ranking against other OECD members in 30-day mortality after admission to hospital for a heart attack.

Submitted by Nigel Cook

Note: Karen Facey is moderating a panel session at HTAi 2017 about outcomes and value that includes a speaker from ICHOM

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### Patient advocacy organizations, industry funding, and conflicts of interest

Rose SL, Highland J, Karafa MT, Joffe S. *JAMA Internal Medicine* January 2017

With accompanying invited commentary by Ray Moynihan and Lisa Bero: Toward a healthier patient voice. More independence, less industry funding - but without any helpful suggestions on how.

Submitted by Anna Scott and Sally Wortley

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### An Analysis paper on: Cancer drugs, survival, and ethics

PH Wise PH, *BMJ* 2016;355:i5792 questions just how much of the improved cancer survival can be attributed to drugs

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### Bulletin du Labo du partenariat / Partnership Lab Bulletin Janvier/January 2017

Engagement en recherche / Engagement in research

[Improving how patients and the public can help develop NICE guidance and standards](#) (Accès libre/Open access)  
NICE (2016)

[Patient involvement in the development of patient-reported outcome measures: A scoping review](#) (Accès libre/Open access)

Wiering et al. (2017) *Health Expectations*

[Framework for enhancing clinical practice guidelines through continuous patient engagement](#) (Accès libre/Open access)

Armstrong et al. (2017) *Health Expectations*

[Involving members of vulnerable populations in the development of patient decision aids: a mixed methods sequential explanatory study](#) (Accès libre/Open access)

Dugas et al. (2017) *BMC Medical Informatics and Decision-Making*

[Engaging patients as partners in research: Factors associated with awareness, interest, and engagement as research partners](#) (Accès libre/Open access)

Hearld et al. (2017) *SAGE Open Medicine*

[Development and testing of a medline search filter for identifying patient and public involvement in health research](#) (Accès libre/Open access)

Rogers et al. (2016) *Health Information & Libraries Journal*

[Strengthening international patient advocacy perspectives on patient involvement in HTA within the HTAi Patient and Citizen Involvement Interest Group – Commentary](#) (Accès libre/Open access)

Wale et al. (2017) *Research Involvement and Engagement*

[Patient advocate perspectives on involvement in HTA: An international snapshot](#) (Accès libre/Open access)

Scott & Wale (2017) *Research Involvement and Engagement*

[Learning to work together—lessons from a reflective analysis of a research project on public involvement](#) (Accès libre/Open access)

Howe et al. (2017) *Research Involvement and Engagement*

[A systematic scoping review of the evidence for consumer involvement in organisations undertaking systematic reviews: focus on Cochrane](#) (Accès libre/Open access)

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

[What is the role of culture, diversity, and community engagement in transdisciplinary translational science?](#) (Accès libre/Open access)

Graham et al. (2016) *Translational Behavioral Medicine*

[Every participant is a PI : Citizen science and participatory governance in population studies](#) (Accès libre/Open access)

Buyx et al. (2017) *International Journal of Epidemiology*

[Effective public involvement in the HoST-D Programme for dementia home care support: From proposal and design to methods of data collection \(innovative practice\)](#) (Accès libre/Open access)

Giebel et al. (2017) *Dementia*

[Patient and public involvement \(PPI\) report for proposed study: Listen and learn](#) (Accès libre/Open access)

Cox et al. (2016) *Manchester Metropolitan University*

[Seeing is engaging: Vlogs as a tool for patient engagement](#)

Lee et al. (2017) *The Patient: Patient-Centered Outcomes Research*

[Moving from patient advocacy to partnership: A long and bumpy road](#)

Wong-Rieger (2017) *The Patient: Patient-Centered Outcomes Research*

[Engaging patient advocates and other stakeholders to design measures of patient-centered communication in cancer care](#) Treiman et al. (2017) *The Patient: Patient-Centered Outcomes Research*

[Patient engagement in research: Are we really worse than orthopaedics?](#)

Noble (2016) *Thrombosis Research*

[Continuous patient engagement in cardiovascular disease clinical comparative effectiveness research](#)

Vandigo et al. (2016) *Expert Review of Pharmacoeconomics & Outcomes Research*

### [Incorporating the patient's perspective in outcomes research](#)

Hsiao et al. (2017) *Current Opinion in Rheumatology*

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

New book >> [Patient Engagement: Catalyzing Improvement and Innovation in Healthcare](#) (Accès libre/Open access)

Baker et al. (2016) *Longwoods*

### [Patient engagement: WHO technical series on safer primary care](#) (Accès libre/Open access)

Valderas Martinez & Ricci-Cabello (2016) *World Health Organization*

### [Patient engagement in the process of planning and designing outpatient care improvements at the Veterans](#)

[Administration Health-care System: Findings from an online expert panel](#) (Accès libre/Open access)

Khodyakov et al. (2017) *Health Expectations*

### [Engaging patients in primary care practice transformation: Theory, evidence and practice](#) (Accès libre/Open access)

Sharma & Grumbach (2016) *Family Practice*

### [Users' involvement in mental health services: Programme logic model of an innovative initiative in integrated care](#) (Accès libre/Open access)

Tremblay et al. (2017) *International Journal of Mental Health Systems*

### [Experience as evidence: The dialogic construction of health professional knowledge through patient involvement](#) (Accès libre/Open access)

Renedo et al. (2017) *Sociology*

### [Democratization of health care](#)

Tang & Smith (2016) *JAMA*

### [Families experiences of involvement in care planning in mental health services: An integrative literature review](#)

Doody et al (2017) *Journal of Psychiatric and Mental Health Nursing*

### ["The new patient": The emergence of a political persona](#)

Pedersen et al. (2017) *International Journal of Public Sector Management*

### Engagement en santé des communauté / Engagement in community health

[Engaging stakeholders and target groups in prioritising a public health intervention: The Creating Active School Environments \(CASE\) online Delphi study](#) (Accès libre/Open access)

Morton et al. (2017) *BMJ Open*

### Engagement en enseignement / Engagement in teaching

["My way of giving something back": Patient and carer experiences of involvement in medical education](#) (Accès libre/Open access)

Fielden & O'Rourke (2016) *MedEdPublish*

[Le savoir des malades à travers un référentiel de compétences «patient» utilisé en éducation médicale](#) (Accès libre/Open access)

Flora (2016) *La recherche en éducation*

[Patient participation in general practice-based undergraduate teaching: developing information and resources for patients](#)

Park et al. (2017) *British Journal of General Practice*

### **François-Pierre Gauvin, PhD**

Associé de recherche, Centre d'excellence sur le partenariat avec les patients et le public

Courriel: [fpgauvin@ceppp.ca](mailto:fpgauvin@ceppp.ca)

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[And finally, a series of articles by Health News Review in the US: Conflicts of interest in medicine: pervasive, worrisome, and detrimental to healthcare](#)

Michael Joyce

<http://www.healthnewsreview.org/2017/01/123967/>

[Guideline writers didn't adhere to Institute of Medicine standards](#)

Researchers wanted to know if the doctors involved in writing guidelines for the management of cholesterol and hepatitis C had any conflicts of interest. In 2011, the Institute of Medicine (IOM) published standards for what they believed constituted conflict of interest (COI). The IOM standards call for no commercial COI among guideline committee chairs and co-chairs. Commercial COI should exist in less than 50% of regular committee members. [This study](#) found that both groups — the chairs and co-chairs, as well as the regular committee members — not only had conflicts of interest that they disclosed, but also conflicts of interest they did not disclose (but were revealed in other publications).

Chair & co-Chair group: about one-third of the doctors involved with the cholesterol guidelines disclosed COI, and a review of publications found more COI that was not reported. In the hepatitis C group two-thirds of the doctors disclosed COI and, again, more COI was found in outside sources. (again, according to IOM standards, none should have COI).

Regular committee group: 44 percent of the members involved with the cholesterol guidelines disclosed COI, but other conflicts of interest were identified that were not disclosed. In the hepatitis C group almost 3 out of 4 members disclosed COI but further conflicts of interest were identified in other publications. (again, according to IOM standards, no more than half of the regular committee members should have COI).

Other conflicts of interest that were most typical included industry-sponsored research, consultancy fees, and honoraria. Therefore, neither group met the IOM standards for commercial conflict of interest. Furthermore, there was often a discrepancy between self-reporting by doctors and conflicts of interest discovered in contemporaneous articles.

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### *[Patient advocacy organizations \(PAO's\) receive extensive industry funding](#)*

From September 2013 through June 2014 researchers looked at a random sample of 439 PAO leaders, representing about six percent of the nearly 8,000 PAO's identified in the United States. They were asked about the nature of their activities, their financial relationships with industry, and the perceived effectiveness of their conflict of interest policies. Of the 439 surveys mailed to PAO leaders, two-thirds were returned with at least 80 percent of the questions answered. [The survey results](#) were:

- Two-thirds of those surveyed reported receiving industry funding, with just over 1-in-10 of this group receiving more than half of their funding from industry.
- The median amount received by those who got industry funding was \$50,000.
- Nearly half the industry support came from the pharmaceutical, device, and/or biotechnology sectors.
- Just over 80 percent of the respondents indicated that conflicts of interest are very or moderately relevant to PAOs. About half believed that their organizations' conflict of interest policies were very good.
- 8 percent of PAO leaders perceived pressure to conform their positions to the interests of corporate donors.

[Conflicts of interest with patient advocacy groups](#) are particularly disconcerting because of the potential to directly misguide patients. These groups now have — for better and for worse — an extended reach and influence on the Internet. They also can author and dictate guidelines, fundraise, sponsor research, influence and guide media coverage, and shape public policy and perception.

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### *[Critics of opioid guidelines more likely to be connected to industry money](#)*

When the 2016 opioid prescription guidelines were published by the CDC they received substantial criticism. Some claimed the guidelines were based on weak evidence, others found the process by which the guidelines were formed to be 'too secretive,' and there were those who found them overly strict or, at least, restrictive for doctors who wished to prescribe opioid pain medications.

In response, a one-month public comment period was opened and 158 organizations responded. Of those respondents 44 groups (28%) got money from opioid manufacturers, 15% had ties to other life science companies, and 40% had no funding from life science companies.

Of the 44 groups who did have ties to opioid manufacturers, none disclosed this to the CDC. However, the CDC did not prompt or require organizations to disclose their financial associations in their comments.

Approximately 80 percent of the respondents supported the CDC guidelines with or without recommendations; including many that received funding from opioid manufacturers.

[But the most disconcerting finding](#) was that opposition to the guidelines was more common from organizations who got money from opioid manufacturers (38%) when compared to those who did not (6%). Funding was defined as "receipt of grants, contracts, gifts, advertising revenue, exhibition fees, or other material support." Evidence for funding relationships came from "self-reports, public website disclosures, annual reports, and federal tax returns."

In their discussion the authors offer the following closing comment:

"US Senate committees and investigative journalists have scrutinized the financial associations of opioid manufacturers and patient advocacy and professional organizations. A major concern is that opposition to regulatory, payment, or clinical policies to reduce opioid use may originate from groups that stand to lose financially if sales of opioids decline. Our findings demonstrate that greater transparency is required about the financial relationships between opioid manufacturers and patient and professional groups."

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### *[Tweeting doctors who have financial conflicts of interest](#)*

The authors looked for potential conflicts of interest among 634 hematologist-oncologists who use Twitter. Using the [open payments website](#), they found that about 80 percent of these tweeting doctors had at least one documented financial conflict of interest.

Roughly half of the hematologist-oncologists were recipients of research funding. Nearly 3 out of 4 received personal payments (ie. checks made out personally to them and not tied to their employer). About 60 percent received more than \$100 in personal payments and about 45 percent got more than \$1000. Hematologist-oncologists on Twitter received a median of \$1,644 in personal payments and a median of \$11,064.21 in research payments...

"Our results raise the question of how FCOIs should be disclosed and managed in an age in which information, interpretation, and criticism associated with cancer products and practices are increasingly available on social media. As a minimum standard, physicians who are active on Twitter should disclose FCOIs in their 5-line profile biography, possibly with a link to a more complete disclosure. For tweets regarding specific products that cause an FCOI, we advise users to include the hashtag #FCOI. Policies beyond disclosure should also be considered."

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Janet Wale, HTAi PCIG

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