



Enjoy the end of the year AND Very best wishes for



HTAi Patient and Citizen Involvement in HTA Interest Sub-Group (PCISG) E-Bulletin, December 2014

Our vision: Patient and citizen perspectives improve HTA

What we have been doing in 2014:

Developing resource documents (which we are happy for people to adapt, and also translate – for example we have some adaptations in Mandarin):

- ✚ Values and Standards for patient involvement in HTA (<http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html>)
- ✚ Patient Group Submission templates – for medicines (<http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement/patient-group-submissions-to-hta.html>) and now non-medicines (available in January)
 - Both projects undertaken by Karen Facey with wide international consultation, funded by Eli Lilly
- ✚ Guidance for Patient Organisations on Completing the Medicines Template (draft for comment on Resources page at www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html)
 - Have you looked at it yet; and do you have any feedback to send us?
- ✚ Continuing to build on HTA Agency examples of best practice (also available on the link above)

Collaborating with the:

- ✚ Information Resources Interest Sub-Group, in particular Patrice Chalon, to develop the Citizen and Patient Involvement Library of published papers on the HTAi Vortal (from our Resources page at www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html; or <http://vortal.htai.org/?q=cpil>)
- ✚ Ethical Issues in HTA Interest Sub-Group for patient organisation guidance on gathering patient experiences to complete the templates and retain the soul of the information obtained.

Developing workplans: two Working Groups have updated theirs (soon available on our webpages). Evolving interests are on patient organisation involvement in clinical trial design and reported outcomes; and managed entry schemes.

The Methods and Impact Group has consulted widely among our membership on the EUnetHTA core model. They commented on the update of the Guidelines International (GIN) Public Toolkit. Work continues on 'defining' the role of qualitative research to capture patient experience.

Building partnerships: we are striving to strengthen our partnerships (identified as a priority at the October face to face meeting in 2013). A number attended our October face to face meeting.

Networking: members have been involved in numerous talks and training sessions related to the work of the PCISG.

We had a strong presence in HTAi 2014 (Washington) to promote the patient-centred theme with Chair participation in a Plenary Session and Policy Forum panel. Training was given to EUnetHTA and IAPO; eMEET was launched; and Karen Facey collaborated with ISPOR to support their Patient Roundtable

A revamp of our webpages is currently in process and we now have a twitter account.

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Ready for comment on:

Completing a patient group submission template: Guidance for patient organisations for Health Technology assessment and appraisal of medicines

(draft on Resources page at www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html)

The HTAi PCISG has developed this guide by working with Mona Sabharwal (pCODR) to adapt the pCODR guide as a way of supporting the use of the HTAi Patient Group Submission Template.

Please feel free to use Track Changes in this document and send them back to us. It would be good if you could have immediate comments back to us by mid-January 2015. We recognise that this document will constantly change over time, that people will use it as a basis for their own documents and for translation at least in part.

If you are interested in translating this document, in part or its entirety, please let us know.

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New journal now accepting submissions: *Research Involvement and Engagement* <http://www.researchinvolvement.com>

The journal aims to develop the evidence-base underpinning patient and public involvement and engagement in health research. The Editorial Board includes academics, patients, carers and policy-makers, working together. *Research Involvement and Engagement* is published by [BioMed Central](http://www.biomedcentral.com), the leading open access publisher. It is part of the Medical Evidence portfolio, and can benefit from its close relationship with journals such as [Trials](http://www.tandfonline.com/journals/trials), [Systematic Reviews](http://www.tandfonline.com/journals/syrev) and [Journal of Negative Results in BioMedicine](http://www.tandfonline.com/journals/jnrm).

Authors who genuinely cannot afford to pay the article-processing charge are able to request a discretionary waiver, to allow patients, carers and those without institutional funding to submit.

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Additional reading:

France EF, Ring R, Thomas R, Noyes J, Maxwell M, Jepson R. A methodological systematic review of what's wrong with meta-ethnography reporting. [BMC Med Res Methodol](http://dx.doi.org/10.1186/1471-2288-14-119). 2014 Nov 19;14(1):119. doi: 10.1186/1471-2288-14-119.

A methodological systematic review of health-related meta-ethnography journal papers published from 2012–2013.

Meta-ethnography was applied in diverse ways, sometimes inappropriately. In 13% of papers the approach did not suit the research aim. In 66% of papers reviewers did not follow the principles of meta-ethnography. The analytical and synthesis processes were poorly reported overall. In only 31% of papers reviewers clearly described how they analysed conceptual data from primary studies (phase 5, 'translation' of studies) and in only one paper (3%) reviewers explicitly described how they conducted the analytic synthesis process (phase 6). In 38% of papers we could not ascertain if reviewers had achieved any new interpretation of primary studies. In over 30% of papers seminal methodological texts which could have informed methods were not cited.

Tailored meta-ethnography experience requires reporting that clearly conveys the methodology, analysis and findings. Tailored meta-ethnography reporting guidelines, developed through expert consensus, could improve reporting.

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From the [McMaster Health Forum Evidence Service](#)

[You can register for [Health Systems Evidence](#) to receive a monthly alert of new documents related to health systems topics, themes and domains that you select as being of interest (e.g., consumer & stakeholder involvement).]

Grajales FJ3rd, Sheps S, Ho K, Novak-Lauscher H, Eysenbach G. Social media: A review and tutorial of applications in medicine and health care. *Journal of Medical Internet Research*. 2014;16(2):e13.

"We conducted a narrative review with the aim to present case studies that illustrate how, where, and why social media are being used in the medical and health care sectors.

Using a critical-interpretivist framework, we used qualitative methods to synthesize the impact and illustrate, explain, and provide contextual knowledge of the applications and potential implementations of social media in medicine and health care...

We reviewed, evaluated, and synthesized 76 articles, 44 websites, and 11 policies/reports. Four recommendations are provided and explained for stakeholders wishing to engage with social media while attenuating risk: (1) maintain professionalism at all times, (2) be authentic, have fun, and do not be afraid, (3) ask for help, and (4) focus, grab attention, and engage....

The role of social media in the medical and health care sectors is far reaching, and many questions in terms of governance, ethics, professionalism, privacy, confidentiality, and information quality remain unanswered. By following the guidelines presented, professionals have a starting point to engage with social media in a safe and ethical manner. Future research will be required to understand the synergies between social media and evidence-based practice, as well as develop institutional policies that benefit patients, clinicians, public health practitioners, and industry alike."

Brandon PR, Fukunaga LL. The state of the empirical research literature on stakeholder involvement in program evaluation. *American Journal of Evaluation*. 2014;35(1):26-44.

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A brief recap

The [World Health Organization in May 2014](#) approved a resolution on health intervention and technology assessment in support of universal health coverage: to set up evidence-based policy with defined roles and responsibilities in health research, strengthening of information systems, sustainable health financing structures and universal coverage.

Where health care may be going:

We are "on the eve of a revolution in health policy": in February 2014, P-G Forest of John Hopkins University, Institute for Health and Social Policy, wrote an editorial 'A new synthesis' (*Int J Health Policy Manag* 2014;2:55-7).

In the 1970s health administration or policy emerged, aiming to align health services with the population's needs. Needs, resources, and services were key themes.

Over time it was apparent that health care was "marred by waste, error, and in matters related to patient rights and well-being, a good dose of paternalism". Quality and safety became key themes. As were patient wants informed by evidence, patient-centred care, and integration of care (informed by the patient's capabilities, "from social and cultural skills to actual health status and prognostic, and guided by well-honed tools for shared decision-making"). The allocation of resources is still based on immediate health needs.

In the era of genomics and technological advances we now acknowledge:

- "biological pathways through which social conditions can alter individuals' physical and mental health";
- the psychology and economics of how people (including the patient-doctor) make choices;
- policy instruments;
- second-order system effects as demonstrated by A Gawande's classic article on "across-the-board overuse of medicine" entitled 'The Cost Conundrum: What a Texas Town Can Teach Us About Health Care' (www.newyorker.com/reporting/2009/06/01/090601fa_fact_gawande); and
- the powers of big data to address some of our questions with "nearly complete data sets of real world, real time situations". Utilisation statistics can inform resource allocation. The question will then be who should be answering these questions, is it citizens?

A couple of months earlier in: Predictive, preventive, personalised and participatory medicine (L Hood, C Auffray. Genome Medicine 2013;5(12):110 . Participatory medicine: a driving force for revolutionizing healthcare) – "the coming revolution in medicine is with us already" and "we see patient (consumer)-activated social networks as one of the principle driving forces – the challenge is how to generate effective patient-activated social networks centred on the requirements and opportunities" of this type of medicine.

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Accepting Oral/Poster Abstract Submissions for HTAi Oslo 2015

Global Efforts in Knowledge Transfer: HTA to Health Policy and Practice

The theme of this year's annual meeting is focused on the latest and best thinking regarding the dissemination of HTA reports, uptake of HTA findings and implementation of decisions informed by HTA.

The meeting is organized by the Norwegian Knowledge Centre for the Health Services in collaboration with the HTA agencies from Sweden, Denmark and Finland.

Key Meeting Sub-themes/Plenary Topics Producing HTA

- Knowledge in the 21st century—What, when and how?
- Using the knowledge: Needs of decision makers, clinicians and patients
- International collaboration in knowledge synthesis and transfer: Is it worth the effort?

[Submission Guidelines](#) **Apply Now**

Oral/Poster Abstracts

Abstract Submissions Open: Nov. 4/14

Abstract Submissions Close: Jan. 25/15

Notification of Abstract Acceptance: Feb. 23/15

Registration



Registration Open: Jan. 27/15
Early Bird Deadline: Apr. 1/15

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I am happy to address any questions you may have as a result of this e-Bulletin.

To unsubscribe from this group and stop receiving emails from it, send an email to isg-patientinvolvement+unsubscribe@htai.org