HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG)
E-Bulletin, October 2015

Our vision: ***Patient and citizen perspectives improve HTA***

Welcome to this month's E-Bulletin

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HTAi 2016 – Informing Health Care Decisions with Values and Evidence

This Annual Meeting will take place May 10-14, 2016 in Tokyo, Japan

Abstract Submissions
Panel & Workshops: November 8, 2015 **(extended)**
Poster & Oral Presentations: November 30, 2016
Registration
Early Bird Deadline: March 4, 2016
Annual Meeting
Pre-Conference Workshops: May 10-11, 2016
Annual Meeting: May 12-14, 2016

Travel Grants – for patient organisations and patients, carers or citizens with an interest in health policy and health technology assessment – now open
Application Deadline: January 8, 2016
http://meeting.htai.org/events/tokyo2016/custom-115-4023afce0ec04ab387500e87f0a6a42d.aspx

Plenary topics:
Unlocking the Value Potential of New Technologies in Health Care - Are Evidence-based Decisions Possible?
Waste in Science - How Does this Affect the Perceived Value of a Health Intervention? New Ways of Measuring Value
Global Experiences in Universal Health Coverage - Potential Barriers and Enablers for the New Era of Valued HTA in Asia

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Neil Bertelsen to represent the Patient and Citizen Involvement in HTA Interest Group on new HTAi committee

Sean Tunis is Chair of the Interest Group Steering Committee. The committee's mandate is to make recommendations to the Board of Directors concerning issues related to IG governance and funding; and to act as a liaison between Interest Groups and the Board.

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PCIG/Patient Involvement and Education Working Group (PIE) meeting in Ottawa, Canada 18 to 20 October 2015

Present: Janet Wale, Neil Bertelson, Jen Dickson, Heidi Livingston, Ann Single, Ken Bond, Sarah Berglas, Tamara Rader, Laura Weeks, Carole McMahon, Elaine MacPhail, Deb Maskens, Deirdre DeJean, Maureen Smith (Monday morning), Yvonne Bombard (Tuesday)
Monday: Karen Facey, Sophie Werko, Sophie Staniszewska by teleconference

This is a brief narrative report for information and discussion.

Sunday 18 October 2015

Topic: Governance

1. We discussed the composition of the Steering Committee (SC) and the need for balance of its members with regard to geographical location, different working backgrounds/perspective in HTA, PCIG Working Group membership. The size of the SC is limited by the fact that meetings are held mainly by teleconference.
The present composition is well balanced. We ask for expressions of interest to become a member of the SC, or an invitation to join may be at an individual level to address 'balance'. These are voluntary positions, knowledge about HTA is not widespread, and so approaching individuals is still a method that is used.
2. Proposed creation of a permanent vice-chair position
This proposal was to mitigate risk around having a person working in industry in the chair position. It would also enable a spread of the work load. The person taking up this position will have a different working background to the Chair, though the enthusiasm of individuals is a key factor.
Another option is to have a Chair, Chair elect, past Chair.
3. Formation of a 'Patient Panel'
This group would interact directly with the Steering Committee (SC). It would provide advice to the SC as well as the Working Groups through clearly defined communication channels
4. Orientation Pack – for new Steering Committee members and patient advocates
Two main types of information are required. The first is on the structure of the PCIG, its tools and how it fits within HTAi. The second is on access to new technologies and what is meant by HTA.

Topic: Defining Process – for PIE as a Working Group of the Steering Committee

The considerations for any piece of work are: the purpose; the team; support needed, scoping questions; clear description of what and why, objective, for whom; consultation processes; getting sign off; implementation and communication.

Topic: A Roadmap of patient involvement in HTA

Many organisations are developing roadmaps for patient involvement in the lifecycle of technologies. HTA is just one part of this continuum. A roadmap for HTA would need to include the steps immediately before and after HTA as boundaries are becoming blurred and these stages have a large influence on what patients can contribute during and following the HTA stage (eg outcomes measured in clinical trials; clinical trial design; managed entry; postmarket determination of safety/co-payments by patients).

Purpose:

As an internal document to clarify our work; a visual for inclusion in the Orientation Pack explaining where HTA fits in the lifecycle of a healthcare intervention; to identify where patients can play a role;

define where we can assess 'Value' of patient involvement, recognising that the earlier continued involvement of patients begins the more engaged they are likely to be.
Audience:
'New' patient groups/advocates to HTA; Researchers
Discussion:
We discussed the concept of determining 'value' rather than 'impact', which can be measured for a range of stakeholders (whereas 'impact' is more 'one-way') in situations where patient involvement depends on many factors including opportunity, information provided, experience etc
The amount of guidance attached to each stage on the roadmap would clearly identify 'our priorities'
Reference: Gauvin F-P framework

Topic: Sharing experiences of patient involvement in HTA – What the different participating agencies are doing
CADTH: The Board of Directors has been developing the Strategic Plan for the next 3 years during 2015 – enhancing and deepening the patient involvement work.
The patient submission is provided before the systematic review (and so can inform the systematic review). It provides 'anecdotal evidence' on the use and effectiveness of disease treatments for a disease. CADTH is concerned about what it can do with this type of evidence; and the association of patient groups with industry. It also recognises that smaller patient groups are often working more closely with patients and can provide very good submissions. CADTH does not send out any personal invitations to make submissions. Individual patients can now provide submissions where there is an absence of patient groups. Submissions are placed on the website together with the clinical report to help others: who provided input; methodologies used; key outcomes including what CADTH heard when tracking the discussions. The summaries are also explicit about where there was patient input
Feedback letters are sent to patient groups with useful points; what public member said, clinical report said; helpful suggestions etc to add value to future submissions. They have prepared over 100 over the last 18 months. Tamara (researcher/systematic reviewer) is pulling out the main themes ie doing qualitative research; and evaluating the submissions before and after the feedback (for usefulness/uptake of that feedback ie having impact as adding value. She is also looking at practical issues, expectations, quality around the use of the templates; methods to collect information and whether they are providing current, specific, relevant, Canadian information; and use of quotes.
Tamara goes back to the patient groups to clarify points for the public members of CDEC, and so is developing relationships with them.
This work was presented in Oslo and has been prepared for publication.
The CADTH Patient Group Liaison committee of patient umbrella groups plus CADTH has been operational for 18 months – its purpose is to look for common priorities, share information, and identify what was found to be valuable.
Devices (Laura): Pilot of two projects using qualitative systematic reviews of patient preferences and impact on health (90 and 8 studies) supplemented with information from individual patients, nurse, Stroke Foundation etc. They get quotes eg that the monitor feels like an octopus on the chest.
CADTH Symposium
CADTH provides travel grants – over 20 patient groups attended this year and were involved in posters, panel and plenary sessions. A patient advocate is involved in planning for 2016.

NICE: Heidi talked about 'plans for the future' with regard to patient and public involvement in HTA. She set the question: what are the opportunities provided with 'in person' input (NICE has patient experts) compared with relying on patient submissions? They are measuring the impact of patient group submissions – and which bits of the submissions are the most useful.

Heidi also explained how NICE involves patient groups by involving them to comment on the initial scoping for guidance development and then in a face to face workshop for scoping the protocol. Each patient group is asked to bring 2 people to get actual patients there.
They are looking to more internet based training; bringing in more videos in their support materials
NICE is looking to set up an advisory panel of patient groups.
Its PPI team has different people for the different types of work eg HTA, so patient groups are dealing with different people in NICE for different things. They are looking at changing to different disease areas.

SMC: Jen and her team have initiated an advisory panel together with the lay members of SMC and patient/carer group representatives, no industry (Public Involvement Network Advisory Group). The advisory group provides advice to SMC with a view to developing a partnership approach with patient/carer groups. This group has already had significant impact after only a couple of meetings with tangible actions.
The previous advisory group (Patient and Public Involvement Group) included patient partners and industry body representative – no patient groups. It did not have terms of reference or objectives.
SMC has worked on the overlap of presentations from the public partners (from patient group submissions) and from PACE at SMC meetings. Impact is being looked at.
Jen and the support team meet new groups one-on-one and provide email support. They are also running training. They worked with patient groups to develop a new submission form, from 1 April. This is shorter; the guidance is separate; and conflict of interest information is collected annually. Patient groups want to feel like they are partners with demonstrated value – so now they can register as a patient group partner. Overall there is a new style of decision making in SMC. It invests in the liaison team to help patient groups make their submissions. Patient groups want examples of good submissions re useability and meeting requirements of the template.
SMC has formed a short-term working group with their User Forum (industry including EFPIA) to 'walk the tight rope' on interpretation of the Code of Conduct for providing drug information to patient groups, for example trial data and other relevant information.

Topic: Sharing experiences in HTA – Patient/public members and patient group(s)
Maureen Smith (Ontario Committee to Evaluate Drugs) was present and described her experience on this committee. The patient member has to have a chronic disease. Maureen has a rare disease and is very conscientious about her role on this committee. It was a steep learning curve at the beginning and the committee and secretariat provided her with many enabling opportunities. She has had many conversations about conflicts of interest so that she does not have to stop being a patient advocate on this committee – the same way as doctors do not stop being doctors when they are on a committee.
Maureen gets all the documentation and writes a summary of the patient input, with only some training to do this. The committee takes individual submissions as well as group submissions. It may be that the patient input differs from the clinical evidence, especially where there is uncertainty (where the patient input can have more impact), where there are differences between the CADTH and Ontario decisions (because different criteria may be applied or regional differences exist etc.).
She provides feedback to patient groups about their submissions and where they were good, questions that were asked in the committee, and what had an impact.

Carole McMahon (pan-Canadian Oncology Drug Review (pCODR) Expert Review Committee (pERC)
Carole receives the papers early – so she can reach out to the patient groups before a meeting to clarify points. The patient members deliver a report and provide a presentation. Carole tries to generate questions. She has gained enough experience (over 4 years on the committee) working with the

evidence presented to the committee and applying patient values (she is a breast cancer survivor but not a member of a patient group). Patient group information may differ from the clinical information eg on long-term effects where quality of life data from a 12-week trial only.
The initial pERC report is circulated and states what pERC noted from the patient input and how the input was used so that the patient groups can respond. The value to the patient group may include exposure of their submission to other members of the HTA committee to provoke thought etc (eg clinical specialists, economists); submissions include outcomes that are not in the studies; unmet needs that are not addressed

Deb Maskens very ably provided the patient group perspective (Canadian and international). She interprets this as being a patient expert who can communicate patients' issues.

HTAi PCIG Projects
Values and Quality Standards: these are our overarching principles for HTA agencies.

Values and Standards – Charter for Patient Groups
The general consensus was that the present draft charter is not what we want

Guidance
Based on the pCODR guidance (October 2013). The generic guidance document has been updated and the new version is on the web pages.
A short version was suggested but people can pick and choose what they want from the existing guidance.

Ethics guidance
Deb raised a question around the ethics of patient groups collecting 'low level' evidence for their submissions, which has limited credibility as evidence. Patient groups do not want to 'harm' anyone when collecting this information and they need to be respected
Jen stated that their patient groups clearly stated that they 'want a voice' in the HTA decision making. She and Heidi cannot go direct to a patient to ask them about their experiences of a disease and its treatment.

Meeting with Canadian Drug Expert Committee (CDEC) members – Dr Lindsay Nicolle, Chair; Dr Jim Silvius, Vice-Chair; Frank Gavin and Allen Lefebvre, public members
A patient input report is prepared from the patient submissions by the CADTH team – this is communicated in the public member report, which is after the clinician report. The public members can ask for points of clarification, through Tamara. They also report back on how the information was used during the meeting. Patient groups want more and more information on how the information was used. It is hard to say how each member sees the patient information. Frank and Allen comment on the value of the input, and state if they 'believe' the information (if pharma funded, straight from their website etc; richness is not in 'numbers' eg per cent of patients). There is need to improve how patient input is incorporated into the process, by developing tools. The materials from the companies that are important or relevant to patients are not included in the patient group report and they are not seen by the patient groups.
The public members consider they have a much broader perspective than patients. They are valued members of the committee.
The CADTH person who manages CDEC would like to simplify patient involvement; and define the purpose, what the involvement is trying to achieve.

Discussion
The meeting with CDEC members was thought provoking. Many of the issues were the same as we have been talking about, which helps to validate our discussions
Process does matter; and a minimum standard is needed as a safety net until patient involvement is ingrained ie value for money spent doing patient engagement
Diseases shape our identity as patients – compared with the work of scientists, who are reductionist
Public members say they are giving the public health perspective but only epidemiology can do that; also they are using patient experience data. This is a total mismatch. The usual practice is to match the methods to the goals
Role of industry – there is conceptual conflict; with uncomfortableness of HTA agencies and EMA around involving patients in early development
Carole clearly has a public perspective as well as a patient perspective. She likes numbers, and the average patient has co-morbidities
Most corporate organisations do not 'hear' the patient voice
Where is the value of public input and social values compared with patient input (on our road map)?
A code of conduct for patient groups(including how patient groups interact with industry) is the 'third leg of the Values and Quality Standards tripod'.

Topic: Quality Criteria for good patient evidence/ fit for purpose patient evidence

- To develop a menu of criteria, for submissions based on individual experience to submissions involving surveys, validating the literature etc.

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Recent Progress of HTA in Taiwan
Professor Yen-Huei (Tony) Tarn
Executive Board, TaSPOR (Taiwan Chapter of ISPOR); Board of Directors, ISPOR; Chair, ISPOR Asia Consortium Executive Committee

Taiwan National Health Insurance Administration (NHIA) started using HTA for new drug reimbursement decision making in 2008. In 2013 it was written down in the second generation NHI regulation, and now is to gradually expand to assessing medical device and diagnostics. Taiwan HTA Guidelines were published in March 2014 by the HTA division of the Center for Drug Evaluation, Taiwan, and put on the PE Guidelines around the World section of ISPOR website in April 2015. This HTA guideline contains methodology guides on systematic review, cost-effectiveness study and budget impact analysis. The HTA division also published the quality assessment tool for critical appraisal of the quality of the pharmacoeconomic report submitted by the manufacturers when applying for new drug reimbursement.

Taiwan NHIA announced the mechanism of collecting patient voices for HTA decision making in April, 2015. Although not an ideal method, it indicated that for new drug reimbursement decision making process, patient evidence may play a role in the future. More education to patient groups and communication with NHIA to improve the mechanism are the interest of the TaSPOR (Taiwan chapter of ISPOR) and pharmaceutical industry in Taiwan.
More transparent mechanisms for the HTA process were developed in 2014: (1) the full HTA report is put on the NHIA website, (2) request for feedback from industry ends 7 days before the appraisal meeting, (3) the actual appraisal meeting agenda, appendix, meeting minutes and voice record are put on the website.

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ISPOR 18th Annual European Congress Milan, Italy, 7 to 11 November

The theme of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) conference is "Impacting Health Decision Making with Outcomes Research: Closing the Gap," and it will be centred on the use of outcomes assessment in decision making.

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EUPATI and practical examples of how patients can be involved in HTA

Karen Facey was invited to contribute to the EUPATI webinar on strengthening patient involvement in HTA last month. She was speaking alongside Nick Meade of Genetic Alliance UK. Nick gave some great, practical examples of how patients can be involved in HTA. If you missed the webinar you can access the presentations and the full recording – including the interesting discussion section at the end.
http://www.patientsacademy.eu/index.php/en/8-news/539-webinar-strengthening-patient-involvement-in-health-technology-assessment-hta

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Next EUPATI Webinar

On 16 November EUPATI will host a webinar for its European network on the "Interaction between patients and other stakeholders in the medicine development process". You must be a registered network member to attend
http://www.patientsacademy.eu/index.php/en/component/comprofiler/registers

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Successful launch of the revised GIN public toolkit with its HTA chapter:

Beyond guidelines - tools to support patient involvement in Health Technology Assessment
Karen Facey and Tania Stafinski wrote the chapter on behalf of the PCIG.
The toolkit is freely available at: http://www.g-i-n.net/working-groups/gin-public/toolkit

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Patient perspective in HTA at European Cancer Congress/European Cancer Organisation (ECCO) 2015, Vienna, Austria, September 2015

Presented by Kathi Apostolidis, European Cancer Patient Coalition

Among the ECCO2015 trending topics were HTA, pricing and reimbursement of new medicines and Immunotherapies in oncology. Cancer Drug Development Forum (CDDF) together with ECCO organized a special session on European Regulation and Health Technology Assessments in Immunotherapy. The purpose of the session was to discuss the new challenges that immunotherapy presents for regulators given the very different nature of the efficacy and side effect profiles compared to traditional medicines used for cancer. The focus was on science aspects in developing immunotherapies, assessment and how patients can access these new medicines.
The 3 speakers presented three different aspects: the challenges of combining different immunotherapies; the huge challenge presented to HTAs in deciding what is meant by value in a comparative sense; the complex area of the roles the general public have in influencing the very difficult decisions that have to be made by HTA

My presentation was on **How effective is the public in influencing HTA decisions?**

The key points I raised were: the fragmentation of HTA processes in Europe, the lack of harmonization, the paradox of availability of innovative and effective drugs but not for all patients in Europe, the unacceptable delays in reimbursement of new drugs. HTA can respond to the challenge by inviting patients to participate, harmonising HTA in Europe to reach EU-wide HTA reference evaluations, and to institutionalise the patients' roles with HTA agencies. I concluded with the mantra that the best drug that does not reach the patient on time and at a reasonable price is of no benefit to patients. The other speakers were Francesco Pignatti of the /EMA and Bruno Flamion of the University of Namur, Belgium who gave excellent and well-argued presentations. The CDDF will soon publish a report.

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Forum HAS: Health Technology Assessment sans frontiers, Paris, France, 30 October

This conference was organised by the French National Authority for Health (HAS) and the European Commission, and was dedicated to Health Technology Assessment (HTA) and the benefits of European cooperation in this field.

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Papers of interest

Kim C, Prasad V. Cancer Drugs Approved on the Basis of a Surrogate End Point and Subsequent Overall Survival: An Analysis of 5 Years of US Food and Drug Administration Approvals. JAMA Intern Med. **2015** Oct 19:1-2. doi: 10.1001/jamainternmed.**2015**.5868. [Epub ahead of print]

This is a Research Letter showing that:

"Surrogate endpoints were used as the basis for FDA approval for 36 out of 54 cancer drugs from 2008 through 2012, and after an average of 4 years of follow-up, 31 of all of these cancer drugs still had unknown effects on overall survival (OS) or failed to show gains in survival"

http://www.medpagetoday.com/PublicHealthPolicy/FDAGeneral/54174

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Single AN, Scott AM, Wale J. Developing Guidance on Ethics for Patient Groups Collecting and Reporting Patient Information for Health Technology Assessments. Patient. 2015 Oct 17. [Epub ahead of print] PMID: 26476960

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Lynch R, Cohn S. In the loop: Practices of self-monitoring from accounts by trial participants. Health (London). 2015 Oct 13. pii: 1363459315611939. [Epub ahead of print]

Self-monitoring, by which individuals record and appraise ongoing information about the status of their body in order to improve their health, has been a key element in the personal management of conditions such as diabetes, but it is now also increasingly used in relation to health-associated behaviours. This article explores how participants in a particular trial ('Get Moving') experienced the process and nature of feedback. Although the trial aimed to compare the potential efficacy of three different monitoring activities designed to encourage greater physical activity, participants did not present distinctly different accounts of each intervention and the specifics of the feedback provided. Instead, their accounts took the form of much more extended and personal narratives that included other people and features of the environment. We conclude that self-monitoring is neither solely about 'self' nor is it exclusively about 'monitoring'. We suggest that a more expansive social and material understanding of feedback can give insight into the ways information is made active and meaningful for individuals in their everyday contexts.

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Onwujekwe O et al. Health Research Policy and Systems (2015) 13:46. Role and use of evidence in policymaking: an analysis of case studies from the health sector in Nigeria
This paper examines the role of different types of evidence in health policy development in Nigeria using three case studies representing different health policies, namely the (1) integrated maternal neonatal and child health strategy (IMNCH); (2) oral health (OH) policy; and (3) human resources for health (HRH) policy. The data was collected using document reviews and 31 in-depth interviews with key policy actors. The value of different evidence types, combined with structures for generating and using evidence, are recognised.

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Recent articles published in Research Involvement and Engagement
Andy Gibson, Kate Boddy, Kath Maguire, Nicky Britten. Exploring the impact of providing evidence-based medicine training to service users.
Abstract | Full Text | PDF

Review
Kristina Staley. 'Is it worth doing?' Measuring the impact of patient and public involvement in research. A review.
Abstract | Full Text | PDF

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McMaster Health Forum
Summary of a Citizen Panel on the challenges of sharing health information with older adults through online resources:
Gauvin FP, Moat K, Lavis JN. Sharing Online Health Information with Older Adults. 22 November 2014.
https://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/citizen-panel-summaries/online-resources-for-older-adults-in-canada_cps.pdf?sfvrsn=2

Participants reflected on three options (among many) for sharing health information with older adults through online resources in Canada: 1) developing an online one-stop shop for older adults and their informal/family caregivers that provides timely access to the best available health information; 2) developing and implementing community outreach programs that aim to improve older adults' (and their informal/family caregivers') e-health and digital literacy; and 3) developing and implementing healthcare provider training programs that ensure providers are equipped with the knowledge and skills to be able to support their patients' use of online resources. Several values-related themes emerged throughout the discussion about these options, including user-friendliness and simplicity, personalization, contextualization, credibility, transparency, accessibility, consistency, accountability, standardization, quality and efficiency.

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UK Accelerated Access Review of innovative medicines and medical technologies - interim report
https://www.gov.uk/government/publications/accelerated-access-review-interim-report

The authors have distilled five key propositions and a number of provisional, high-level conclusions associated with each proposition.

- Putting the patient centre stage: Patients should be given a stronger voice at every stage of the innovation pathway.

- Getting ahead of the curve: A radically new approach is required to accelerate and manage entry into our health system for the emerging products that promise the most significant, potentially transformative impact in terms of patient benefit and overall value.
- Supporting all innovators: In addition to accelerating access to a select number of the most promising new products, our end-to-end innovation pathway can, and should, also be more responsive to the wider, irrepressible surge of innovation presented at all levels of the system, particularly where its introduction will contribute to better outcomes for patients and more productive and efficient ways of delivering care.
- Galvanising the NHS: The NHS must be an active partner in promoting innovation, and must be incentivised to adopt new products and systems quickly and effectively.
- Delivering change: Building on existing health system structures, a new system architecture is required at local and national level to accelerate access to the best new products and related models of care on a sustainable basis, within a framework of collective agreement to ambitions and goals.

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UK Charity petitions pharmaceutical company to reduce its process

In the UK, a petition from charity Breast Cancer Now has urged Roche to cut the price of its secondary breast cancer drug Kadcyla (trastuzumab). The petition has over 42,000 signatures.
The drug costs more than £90,000 per patient at its full list price, which caused NICE to reject the treatment for routine funding. It is due to be removed from the Cancer Drugs Fund

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IMI2 ADAPT-SMART Launch

http://adaptsmart.eu/press-release-innovative-medicines-initiative-launches-adapt-smart-an-adaptive-pathways-project-with-32-international-participants/
ADAPT SMART, a European public-private collaboration bringing together 32 international participants, was launched on the 4th of September at a meeting hosted by the project coordinator, the European Medicines Agency (EMA).
The project will establish a platform that enables the coordination of Medicines Adaptive Pathways to Patients (MAPPs) related activities within the Innovative Medicines Initiative (IMI) and engages in dialogue with all relevant stakeholders. MAPPs seek to foster access to beneficial treatments for the right patient groups at the earliest appropriate time in the product life-span in a sustainable fashion. The outcomes of the ADAPT SMART consortium will help inform future research agendas and discuss approaches for the implementation of MAPPs.

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First ever HTA capacity building meeting held by the Uganda Alliance of Patients Organizations (UAPO), 13-14 October. The meeting was supported by HTA Canada with Dr Cliff Goodman as the facilitator

Civil Society Health Rights Manifesto: *In 2016, Ugandan Voters Must Elect Leaders who will defeat the leading causes of preventable death in Uganda*
Uganda Demands Life-Saving Health Services. Voters say #NoHealthNoVote in the 2016 elections

Political leaders in Uganda have treated the health of the people as a non-priority issue—neither for development nor politics. Health is treated as a 'consumptive' area of the budget—meaning that health is considered to be *subtracting* funds from the national budget without contributing to national security and development.

The Constitution of the Republic of Uganda provides for all people in Uganda to enjoy equal rights and opportunities, have access to health services, clean and safe water and education, among many other essential services. Investing in the promotion of people's health and nutrition ensures that they remain productive and contribute to national security and development. The government therefore is obliged to deliver the Uganda National Minimum Health Care Package (UNMHCP), increase resources for better health, and political and financial accountability to its citizens.

In order to guide candidates and political parties on how to respond to the national crisis of preventable death and disease, civil society organisations in Uganda have developed a platform. This election pledge, if implemented, will achieve ambitious progress in treating, preventing, and ultimately ending the major causes of preventable disease and death in Uganda. We call on all political parties and candidates to publicly adopt and support this Election Pledge and include these targets in their own party election manifestos:

STOP STARVING THE HEALTH SECTOR OF FUNDING: Our leaders must fully fund the most pressing priorities in the health sector. The government of Uganda currently invests only approximately USD 7 per person per year on health. This is a national disgrace. Uganda government must increase, as a matter of urgency, its domestic investments in the areas of the health sector that would immediately save lives, protect communities, improve livelihoods, and ultimately expand GDP. For decades, the government has refused to allocate funding for primary health care and local government in order to make the health system functional. This has resulted in impoverishment of families who face health crises but cannot use the public system—because services are not available. We demand: annual increases in funding for: a) recruitment, motivation and retention of health workers; b) primary health care funds for health facilities at the local government level; c)consistent procurement and distribution of essential commodities and equipment to all health facilities to eliminate stock outs and d)monitoring and supervision of health service delivery at all levels.

IMPROVE RECRUITMENT AND RETENTION OF HEALTH WORKERS*:* Uganda government must invest in increasing recruitment of new health workers, their wage and non-wage remuneration Uganda needs at minimum a 50% increase of health workers just to provide basic services. Nearly 70% of medical doctors and dentists, 80% of pharmacists and 40% of nurses and midwives, are in urban areas serving only 13% of the population. Absenteeism of health workers is on the rise—from 29.9% in 2010 to 45.6% in 2012. Candidates and political parties must commit to increasing the salaries of health workers by at least 120% to be at per with their counterparts in the region and other professions, deploying health workers where they are most needed, and dramatically improving their support supervision to ensure quality services are provided to all Ugandans. The coming government should motivate, supervise, and retain health workers to eliminate absenteeism**.** Leaders must revise the staffing norms to address the staffing gaps at all levels of service provision.

ADDRESS THE AIDS EPIDEMIC THROUGH EVIDENCE, UNIVERSAL TREATMENT, HUMAN RIGHTS, AND AN END TO STIGMA: Effective, evidence-based HIV prevention programs in Uganda should be available and accessible to all populations and should promote safer behaviours, reduce vulnerability to HIV transmission and provide commodities such as female and male condom and give accurate and adequate information. By 2021, all people with HIV should be on treatment, HIV transmission among newborns should have been eliminated, and rates of new infections among adults through sex should have been reduced by at least 90%. Candidates and political parties should commit to *doubling* the national budget for ARVs and for domestic direct support for treatment for at least 20% of adults and children.To reduce overdependence on foreign funding, the national AIDS trust fund should be operationalized, with a commitment to adequately and consistently fund HIV programs in addition to national budget allocations.

STOP VIOLENCE AGAINST WOMEN AND GIRLS AND PROMOTE ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS*:* In Uganda, women and girls confront unimaginable violence.

Rape, assault, abuse, and lack of control over reproductive health care generate not only trauma but also significant health and economic consequences, from HIV to teenage pregnancy to impoverishment. There is limited sexual and reproductive health rights information and services for young people—yet young people especially women are at high risk of pregnancy, sexual violence, HIV infection, and unsafe abortion. Candidates and political parties must support implementation of policies and programs that prioritize the sexual and reproductive health and rights of women and girls, includingcomprehensive reproductive health care services such as family planning.

END MALARIA, TUBERCULOSIS, AND EMERGING THREATS SUCH AS VIRAL HEPATITIS, Uganda is one of 22 high burden TB countries, and has one of the highest rates of malaria deaths in the world. Other infectious diseases, such as viral Hepatitis, lead to preventable death, disability, impoverishment, and lost economic productivity—yet prevention and treatment are available. Leaders must increase investment in high impact anti malaria, TB, and Viral Hepatitis prevention and treatment.

OPPOSE DISCRIMINATORY LAWS AND POLICIES THAT KEEP UGANDANS FROM LIFE SAVING HEALTH SERVICES*:* Discriminatory laws undermine effective health service delivery, in particular for stigmatized diseases such as HIV/AIDS and other sexually transmitted infections. These policies drive people away from lifesaving services. Uganda's health sector must defend and advance the health rights of all people, including excluded and criminalized minorities such as sex workers, and sexual minorities. Candidates should commit to working with Parliament to repeal the harmful laws and draconian provisions such as those in the HIV Prevention and Control Act.

ADDRESS THEFT OF PUBLIC RESOURCES IN THE HEALTH SECTOR.

According to the daily monitor of Sunday, June 21 2015 cancer drugs supplied by NMS to the Cancer Institute, were priced nearly five times higher than the cost of the same drugs from private suppliers. This implied that the government spent more public resources on procuring drugs from its own agency than from private suppliers. While the new vision of Aug 06, 2015 reported a commencement of withdrawal of rejected health equipment from 46 health facilities supplied by M/S Sino Africa Medicines and Health Ltd as part of the 130 million US$ world bank loan over their poor quality. Government through Leaders must ensure there is effective and efficient spending and engage citizens more actively in monitoring public spending, with particular focus on the areas most vulnerable to fraud—massive contracts and procurements at the central level.(Patrick to provide statistics on resources lost from auditors report).

TACKLE MATERNAL MORTALITY AS A NATIONAL CRISIS: More than 16 pregnant Ugandan women die every day from completely preventable causes. For every death, many more women suffer severe and sometimes disabling complications. In other countries in the region, maternal mortality trends have improved dramatically—but not in Uganda. We need leaders who will prioritize equipping health facilities, training health workers, empowering communities, improve referral, changing laws and policies, and adequately funding the health sector so that unsafe abortion, sepsis, hemorrhage, and obstructed labor stop killing Ugandan women.

HANDLE NON-COMMUNICABLE DISEASES SUCH AS SICKLE CELL ANEMIA, HYPERTENSION, DIABETES, AND CANCER: Non- communicable diseases are rampant in Uganda and have become health threats to children and adults. Some of these diseases are preventable to avoid death, disability, impoverishment, and lost economic productivity—information and must be availed to all Ugandans to eliminate the diseases. Leaders must increase investment in high impact prevention and treatment of NCD.

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I am happy to address any questions you may have as a result of this e-Bulletin, and to forward information

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