

Evidence-based Guidelines Affecting Policy, Practice and Stakeholders (E-GAPPS) III
Instructions for Choosing Your Sessions

ARE CLINICAL GUIDELINES IMPROVING HEALTHCARE QUALITY?

Congratulations for planning to take part in the 2017 E-GAPPS III Conference!! We are designing it as a unique opportunity to learn, interact, and most importantly to ENGAGE with individuals reflecting the many perspectives, roles and activities that determine what, if any, impact clinical guidelines have on healthcare.

OUR ROLE: We have developed a uniquely participative framework comprising plenary sessions, interactive breakout sessions, workshops and networking opportunities, culminating in a final ‘open space’ segment. During the latter, all conference attendees will meet as equals in a semi-structured forum in which themes, concepts, controversies and concerns voiced and registered prior to the event and during the earlier conference segments are freely discussed.

YOUR ROLE: We need you to BRING YOUR PASSION and a commitment to actively shape the content of the proceedings, starting as soon as you complete registration. The goal of E-GAPPS III is to foster new engagement and collaborative relationships across the diverse range of stakeholder groups and constituencies expected to attend. The development of these relationships will be tracked and tallied as part of the E-GAPPS program over the following 8 months.

FIRST PICK YOUR THREE BREAKOUT SESSIONS:

Breakout sessions for the first 3 segments of the conference are organized into tracks. They will be interactive sessions focused on specific challenges and skills pertinent to the tracks. All conference attendees, including keynote and plenary speakers, will be encouraged to take part in these sessions. You need not confine your choices to a single track. Rather, choose the sessions of most interest to you in the individual segments. However, you need to make your choices now; the ability to change them subsequently will be limited as some sessions may close early.

The three tracks of E-GAPPS III are:

Track 1 Impact & Implementation

This Track addresses issues related to guideline impact, beginning with a need to craft clear and actionable recommendations that address gaps in care relevant to diverse stakeholders, especially patients. With the demise of the sustainable growth rate (SGR) as the primary cost control lever by the Centers for Medicare and Medicaid Services (CMS), in the United States, new levers based on measuring performance and appropriateness are becoming the norm. Similar levers drive Canada’s publicly funded healthcare system. The role of guideline-based performance measures, which often focus on process not outcome, may be challenged by limited availability or by measures derived directly from clinical data registries, electronic health records, or other Big Data repositories. Moreover, it is time to question whether existing methodological expectations, which are often based on weak or indirect evidence, may result in guideline recommendations that are not worth adopting. The ultimate impact of these processes requires multi-stakeholder development, effective dissemination strategies, and validated measures of implementation outcomes.

Track 2 Multi Stakeholder Engagement

We have moved from “why” engage patients/consumers and other stakeholders including clinicians to “how” to most effectively tap their ideas and perspectives. Moreover, guideline developers are finding it challenging to identify the “right” stakeholders, particularly when it comes to consumers and patients, who can offer an informed, balanced, perspective as a guideline group member. There is also ongoing debate about who is the best person to represent the public’s views: patients, consumers, advocates, etc. The need to incorporate patients with multi-morbidities into guideline recommendations is also driving multi-stakeholder engagement. Specialists alone cannot adequately address the needs of patients with comorbidities that are managed by primary care clinicians and others. Furthermore, clinicians may need preparation and orientation to be able to contribute their perspectives to guideline efforts in an effective manner. This track will explore these issues.

Track 3 Challenges to Guideline Trustworthiness: Beyond Conflicts of Interest

Guideline development continues to challenge organizations striving to meet the 2011 Institute of Medicine standards. Developers are struggling with a) finding adequately trained and qualified individuals to serve on their guideline panels, b) incorporating all necessary perspectives in the guideline without creating an unmanageable number of panel members, c) executing the public comment period for draft guidelines, d) defining, creating, and executing effective engagement strategies in training and fully incorporating patients, family members, and/or caregivers into the development panel, and e) meeting the minimum standards set by the National Guidelines Clearinghouse to post their guideline for public consumption.

Menu of Breakout Sessions

Please review the descriptions below and select one (and only one) breakout session for EACH of the first 3 conference segments. The selection menu is to be found on the E-GAPPS conference registration page.

Monday AM (10:30 am – 12:00 pm)

TRACK 1: "Knowing what works: How do we best measure implementation outcomes?"

Cara Lewis *Chair (Associate Investigator, Group Health Research Institute)*

Jean Slutsky *(Chief Engagement and Dissemination Officer PCORI)*

Flora Lum *(VP of Quality and Data Science, American Academy of Ophthalmology)*

Description: High quality measurement is critical to advancing knowledge, yet new fields, such as implementation science, are often beset with measure gaps and poor quality instruments. Core implementation outcomes include acceptability, adoption, appropriateness, cost, fidelity, penetration, and sustainability. For example, acceptability is the perception that a given intervention (treatment, service, practice, or innovation) is agreeable, palatable. Adoption, in contrast, is the intention, initial decision, or action to try or employ an innovation or evidence-based practice. Unfortunately, most implementation outcome measures are underdeveloped and lack psychometric strength. Using mental and behavioral health as an example, this session will highlight the current state of science, and knowledge gaps, in measuring implementation outcomes.

TRACK 2: "Should there be guidelines for stakeholder involvement"

John Santa *(Retired-Former health editor Consumer Reports)*

Wally Smith *(Division of Quality of Care, Center for Health Disparities)*

Tracy Wasylak *(Senior Program Officer, Strategic Clinical Networks with Alberta Health Services and Patient and Community Engagement Research, Alberta, CA)*

Description: Josh Sharfstein recently wondered aloud about whether the term "stakeholder" should be banished. His objections to the term included an undesirable association with mercenary considerations. In fact, the term "stakeholder" encompasses multiple perspectives which is exactly its appeal. However, engagement may be handled poorly. For example, disproportionate representation of some stakeholders, such as pharmaceutical firms, may serve to dilute the input of others such as consumers and patients. This panel will consider the definition of a stakeholder, the role of stakeholders in guidelines development, the key groups that should be engaged in guidelines development, the expectations for engagement of the public versus other stakeholders, and the role of healthcare cost in guidelines development. Breakout session leaders include an active healthcare provider, a former consumer advocate and physician, and a community engagement officer who will provide their perspectives and stories of experience.

TRACK 3: "Public comment: Inviting a select few or opening the floodgates"

Thomas Getchius, *Chair (American Academy of Neurology)*

Amy Miller *(American College of Radiology)*

Cynthia Sitkov *(Consumer Panelist, American Academy of Neurology)*

Description: The IOM report for guidelines states that the document should be available for public comment and doesn't give specific context or parameters. Several medical specialty societies have updated their process manuals, methodologists have published proposed checklists and frameworks, and some companies have developed technology solutions to assist with the process for managing public comment. Developers vary on how tightly or loosely the draft guideline should be vetted prior to publication and vary in how they define "public". In this session you'll have the opportunity to engage with the panel as they share their experiences with the process for making their guidelines available for public comment.

Monday PM (3:00pm-4:30pm)

TRACK 1: "Disseminating guideline recommendations through sharable decision support and registry-enabled quality measures: creating linked end products"

Vivian Coates, Chair (ECRI Institute)

Jeremy Michel (ECRI Institute and Children's Hospital of Philadelphia)

Nitu Kashyap (Yale School of Medicine)

Jan Losby (Centers for Disease Control)

Description: Guideline-based care seeks to improve patient outcomes and healthcare efficiency. But standard dissemination strategies are no longer sufficient for our rapidly adapting healthcare systems. Clinical decision support (CDS) and quality measures (QM) can promote guideline adoption. However, traditionally, CDS has not been sharable and QM have relied upon administrative data, which limits applicability. In this session, drawing from the experience of recent projects, we will describe a systematic process for translating guidelines into CDS and QMs. Examples will include efforts to implement opioid prescribing guidelines in various settings.

TRACK 2: "Education vs indoctrination: Preparing stakeholders for the process of guideline development"

Rich Rosenfeld, Chair (American Academy of Otolaryngology – Head & Neck Surgery Foundation)

Ngina Lythcott (Black Women's Health Imperative)

Walter "Buzz" Stewart (Vice President and Chief Research & Development Officer, Sutter Health)

Astrid Jimenez, Esq. (Executive Director, Nueva Vida)

Description: Patient or consumer stakeholders are expected to contribute an independent perspective from those of providers and policymakers, which is why they are included in guidelines panels. Yet, "traditional" guideline panelists can be annoyed at the issues patients/consumers raise and fear extra time demands as well as the need to focus on what might be viewed as an outlier perspective. They may also question the importance of consumer groups' focus on special populations such as minorities or women. As a result, efforts to acculturate patients, consumers and other stakeholders into the clinical guideline process may contribute to loss of the special perspective that patients/consumers are asked to bring to the table. The session will address these challenges and offer approaches to surmounting them based on panelists' experience.

TRACK 3: "Collaborative efforts to engage multiple institutions for CPGs development and implementation-the Mexican experience "

Jesús Ojino Sosa (Mexican Institute of Clinical Excellence)

Jorge Guadarrama (Mexican Society of Oncology)

José Luis Mayorga (National Institute of Pediatrics, Mexican Society of Otolaryngology)

Description: Incorporation of research into clinical policy is an ongoing challenge in developing countries such as Mexico. Institutions lack resources to address all of the needs. Collaborative efforts between government agencies, medical societies, public institutions, researchers and stakeholders have emerged as a compelling option to improve guideline development and implementation strategies. Internationally, challenges posed by collaboration are considered insurmountable by some leaders of the clinical guideline movement. Challenges include coherence of stakeholder groups, agreement on methodology, standards for management conflict of interest, timing of release of recommendations for comment and review and the responsibility for updates. However, other leaders report positive collaborative experiences. This session will draw upon recent Mexican experience in forming synergistic relationships traversing government agencies, public and private sector institutions in developing trustworthy clinical guidelines with a high likelihood of successful implementation and adoption. Participation of developers and stakeholders attending the E-GAPPS conference can make it into a unique opportunity to explore the challenges and rewards facing collaborative efforts across different settings and contexts.

Tuesday AM (10:30 am – 12:00 pm)

TRACK 1: "Facilitating implementation with guideline-based measures: strategies for success"

Rich Rosenfeld, Chair (American Academy of Otolaryngology – Head & Neck Surgery Foundation)

Stephanie Jones (American Academy of Otolaryngology-Head and Neck Surgery)

Martin Burton (Joint Coordinating Editor Cochrane Ear, Nose & Throat Disorders Group)

Sandy Walsh (American Academy of Otolaryngology-Head and Neck Surgery)

Description: Guideline recommendations that are clear and actionable promote uptake by clinicians and lay the foundation for corresponding guideline-based performance measures suitable for clinical decision support and registry implementation. This interactive workshop describes practical strategies for developing actionable guideline statements and related performance measures based on multi-stakeholder engagement, including consumers. Our speakers will offer insights based on their diverse backgrounds in government, clinical care, evidence-based medicine, and a specialty medical society. Attendees will have the opportunity to critique published guideline recommendations, improve upon the wording, and decide how to best measure clinician performance for the recommended actions.

TRACK 2: "How the multi-stakeholder movement can lead to a better world of healthcare"

Bill Vaughan, Chair (National Committee to Preserve Social Security and Medicare-Retired)

Sandra Zelman Lewis (Doctor Evidence)

Daniel Mullins (University of Maryland School of Pharmacy)

Description: In a March 2016 JAMA article, Don Berwick outlined "Era 3" for medicine and healthcare, driven by transparency and improvement science and featuring less inspection, and more civility. The Era 3 vision entails reduction in the use of quality measures and complex incentives for individual clinicians, and also on the emphasis on revenue. At the same time, it calls for more attention paid to the clinical team, transparency, civility and attention to the voice of the public. Panelists will bring a variety of perspectives to the session, which will focus on strategies for more productive engagement in the process of healthcare, ways of finding out what is important to the patient/consumer, and of attending to the needs of the poor, the disadvantaged, and the marginalized.

TRACK 3: "So you *NEED* a consumer on your panel? Do more than check the box!"

Reva Datar, Chair (Consumers United for Evidence-Based Healthcare)

Shannon Merillat (Guideline Development Program Manager, American Academy of Neurology)

Description: It's all well and good to have a consumer/patient representative on the author panel but you can engage them in more activities beyond question development and recommendation phrasing. Attend this session to learn how Consumers United for Evidence collaborates with guideline developers to match trained consumers in their network with organizations that are developing guidelines. You'll also hear from and engage with the American Academy of Neurology staff on the evolution of the process employed by AAN to interview and appoint consumers and patient representatives on AAN guideline panels and on dissemination panels to raise awareness about recently published AAN guidelines.

NOTE: Following completion of registration you will receive an invitation to take part in available social media channels which will allow you to begin to interact with other conference attendees and to voice your ideas and concerns as we move towards the conference.