



AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



# **National Guideline Dissemination - Funding, Logistics, D&I Challenges: the AHRQ Guideline Clearinghouse Story**

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**Design for Implementation (DFI): The Future of Trauma Research and Clinical Guidance**

COI: None

# The Storyline

- **Beginning and Middle**

- ▶ Pain point
- ▶ Solution
- ▶ Successes
- ▶ Challenges



- **Foreseeable Future**

- ▶ How do we advance guideline dissemination and implementation at the same time?

# AHRQ's National Guideline Clearinghouse: Beginning

- **Pain Points:**

- ▶ AHRQ no longer developing EB-CPGs
- ▶ How will AHRQ CPG users know what other guidelines 'out there' and which are evidence-based to AHRQ's scientific standard?
- ▶ How can AHRQ be sure the clinical and payer communities will trust AHRQ's solution?



**OUCH!**

# AHRQ's National Guideline Clearinghouse: Beginning con't



- **Solution:** Concept born in mid-1990's, as internet coming on the scene
  - ▶ Since AHRQ no longer developing CPGs, let's support the book-ends of the process: systematic evidence reviews and dissemination of published guidance
  - ▶ Since the internet is the future, let's create an online repository of evidence-based CPGs driven by a database that facilitates discovery and use of guidelines meeting specific criteria by the masses
  - ▶ To get the clinical and payer communities to buy-in, let's invite them to join AHRQ in a public-private partnership
- [www.guideline.gov](http://www.guideline.gov) was launched in Dec 1998, with full launch in Jan 1999, by AHRQ, AMA, and AAHP (now AHIP).

# What NGC did, didn't do

- **DID – from inception (except where noted)**

- ▶ Respected IP of guideline developers
- ▶ Inclusion criteria
- ▶ Created/posted detailed abstract of each accepted CPG
  - Educated guideline developers on how to meet criteria
- ▶ Indexed those abstracts using NLM metadata vocabularies
- ▶ Posted content each week
- ▶ Public access, including for those needing accommodations
- ▶ Supported online guideline comparison
- ▶ Created/posted guideline syntheses
- ▶ Grew the database/online presence/dissemination of thousands of CPGs
- ▶ Added assessments of extent adherence to trustworthy guideline standards (2015)

- **DIDN'T**

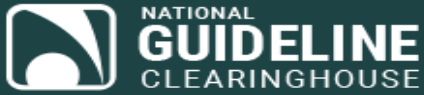
- ▶ Charge fees
- ▶ Advertise
- ▶ Require personally-identifiable information to access
- ▶ Endorse CPGs

# NGC Successes (ups)

- **User Base** – hundreds of thousands visits a month
  - ▶ GREW!
  - ▶ Repeat users
- **Design** - evolved to incorporate latest in website design
- **Governance** – started with AHRQ/AMA/AAHP Policy Board, evolved to AHRQ and NGC Editorial Board
- **Improved outputs of guideline developers** – guidelines not included at first, included later after changes in sci method by developer
- **Trust** – by guideline developers, clinicians, others

# NGC: Challenges (downs)

- .gov websites must meet specific **federal regulations**
  - ▶ Added time, complexity, and cost
- Robust process to respect editorial controls and IP created **slowdowns in production** – took approx. 4-6 months to post a ‘new’ guideline
  - ▶ Too long! Not ‘current’. Won’t support “living guidelines”
- Guideline developer organizations’ **lawyers** don’t support release of NGC data/metadata to support clinical implementation, research, and/or AI possibilities
- **Funding** always dependent on **congress**, every year
  - ▶ \$1M-\$3M per year (higher cost years included technology upgrades and/or website redesigns)



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## TAKE NOTICE: This Web site, AHRQ's National Guideline Clearinghouse, will not be available after July 16, 2018.

Federal funding through AHRQ will no longer be available to support the NGC as of that date. For additional information, read our full announcement.

We will continue to post summaries of new and updated evidence-based clinical practice guidelines until July 2, 2018. For any questions, please contact Mary Nix, [mary.nix@ahrq.hhs.gov](mailto:mary.nix@ahrq.hhs.gov).



### Guideline Summaries

Guidelines are organized by clinical specialty.

- [Cardiology](#)
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### Guideline Syntheses

Systematic comparisons of areas of agreement and disagreement among selected guidelines addressing similar topics. [View All >](#)

### Expert Commentaries

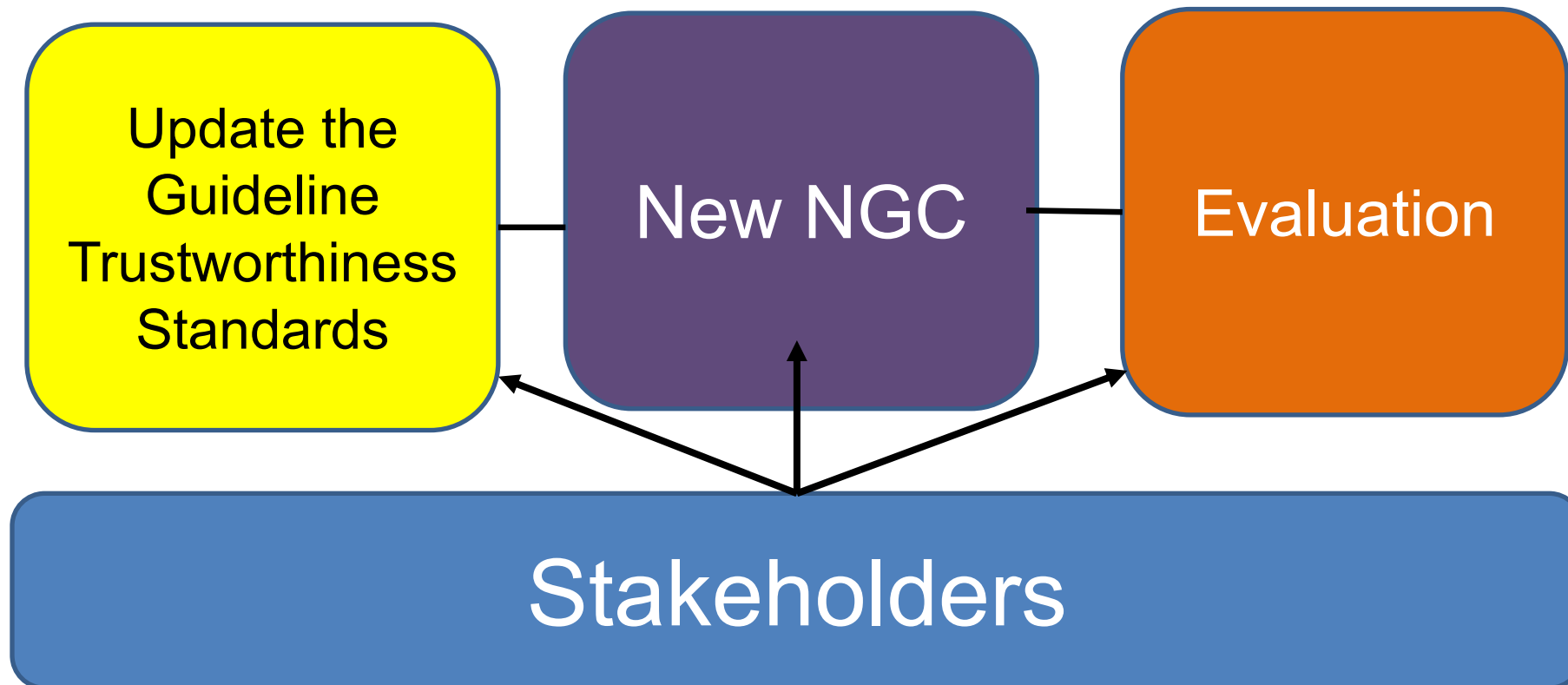


# NGC: 2018 to Now (ups and downs)

- Taken offline July 2018
- Commissioned study to determine path to sustainability without funding -> transfer NGC to an external entity
- Can't take path recommended: AHRQ doesn't have authority as an agency to give its data to any entity – will always own it.
- Further exploration into bringing NGC back online via zero-dollar contract
- Vendor feedback on draft contractor: thumbs down
- Pursue funding again.....but so much has changed, esp technology!

# NGC Story: Next chapters

- Proposal for 4 NGC projects approved



# The Future: Disseminating Guidelines to Advance Implementation



- For guideline repository: **only include evidence-based CPGs that meet criteria for being implementable?**
  - ▶ Shero, S.T., Ammary-Risch, N.J., Lomotan, E.A. *et al.* Creating implementable clinical practice guidelines: the 2020 Focused Updates to the National Heart, Lung, and Blood Institute’s Asthma Management Guidelines. *Implement Sci Commun* 4, 36 (2023).
  - ▶ CPGs in digital, computable format
  - ▶ CPGs with implementation tools: clinical decision support artifacts, translation products (e.g., decision guides – for clinicians, practices, payers, patients/families), more!
  - ▶ CPGs that address available resources of an implementer (e.g., lower-resourced practices get guideline derived tools more relevant to their situation)
  - ▶ WHAT ABOUT TRUSTWORTHINESS? Can an implementable CPG be trusted?
  - ▶ WHAT ABOUT IP? Who owns the IP of a computable guideline or guideline-derived tool? Who is liable if a computable/executable guideline/recommendation causes harm?

# Implementable Guidelines: knowledge from research



- Kastner M et al. *Guideline uptake is influenced by six implementability domains for creating and communicating guidelines: a realist review*. J Clin Epidemiol. 2015 May;68(5):498-509. <https://pubmed.ncbi.nlm.nih.gov/25684154/>
  - ▶ Creation: 1. stakeholder involvement, 2. evidence synthesis, 3. considered judgment in formulating recommendations, 4. feasibility
  - ▶ Communication: 5. the message, 6. its format
- Shiffman RN et al. *The GuideLine Implementability Appraisal (GLIA): development of an instrument to identify obstacles to guideline implementation*. BMC Med Inform Decis Mak. 2005 Jul 27;5:23. <https://pubmed.ncbi.nlm.nih.gov/16048653/>
  - ▶ GLIA: a tool for CPG developers to ID, correct deficiencies; implementers to select implementable recs
- Gupta S et al. *The Guideline Language and Format Instrument (GLAFI): development process and international needs assessment survey*. Implementation Sci **17**, 47 (2022). <https://implementationscience.biomedcentral.com/articles/10.1186/s13012-022-01219-2>
  - ▶ a tool that could be used by guideline developers to optimize language and format during development

# The Future: Disseminating Guidelines to Advance Implementation (con't)



- Reimagined repository, like a New NGC, will leverage:
  - ▶ Experience curating evidence-based, trustworthy CPGs
  - ▶ Adult education principles to teach guideline developers
  - ▶ **Stakeholder input**
  - ▶ **Digital, computable, interoperable, standards-based, reusable**
  - ▶ **Findings from implementation – research and quality improvement**
  - ▶ **Expanded guideline implementation support tools/document/resources**
  - ▶ **Resources to address guideline developer fear of liability**
  - ▶ **Opportunities to connect guidelines to payment/policy**
  - ▶ **Feedback loops (implementers<->guideline developers)**

# The Future: Disseminating Guidelines to Advance Implementation (con't)



- Reimagined repository, like a New NGC, will leverage (con't):
  - ▶ Technology, informatics, publishing tactics to **showcase and promote implementable guidelines**
    - FHIR
    - FAIR
    - Computable recommendations, Clinical decision support, e-measures, more!
  - ▶ **The now and future of implementation:**
    - What makes a guideline implementable?
    - Is there a place for an “implementability index” per guideline?

# Next Steps and Thank you



- AHRQ will engage with stakeholders on a New NGC starting Fall 2024
- AHRQ is exploring an update to the IOM/NAM “*Clinical Practice Guidelines We Can Trust*” standards for guideline trustworthiness
  - ▶ Digital
  - ▶ Equity
  - ▶ Shared decision making
  - ▶ Derivative/related guideline outputs supporting implementation
- AHRQ will evaluate a New NGC
- [mary.nix@ahrq.hhs.gov](mailto:mary.nix@ahrq.hhs.gov)
- THANK YOU!!