4-3-2013

Publishing in eGEMs: Learning How to Learn from New Data in HSR

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Publishing in *eGEMs*: Learning How to Learn from New Data in HSR

Erin Holve, PhD, MPH, MPP, AcademyHealth
Beth Johnson, MPH, AcademyHealth
Adam B. Wilcox, PhD, Columbia University
Paul Wallace, MD, The Lewin Group, Inc.

April 3, 2013

Follow the conversation on Twitter!
#eGEMs @edm_ah @academyhealth
Welcome

→ Erin Holve, Ph.D., M.P.H., M.P.P.
  – Senior Director of Research & Education, AcademyHealth
  – Principal Investigator of the EDM Forum
  – eGEMs Editor-in-Chief

Follow the conversation on Twitter!
#eGEMs @edm_ah @academyhealth
AcademyHealth: Improving Health & Health Care

AcademyHealth is a leading national organization serving the fields of health services and policy research and the professionals who produce and use this important work.

Together with our members, we offer programs and services that support the development and use of rigorous, relevant and timely evidence to:

1. Increase the quality, accessibility and value of health care,
2. Reduce disparities, and
3. Improve health.

A trusted broker of information, AcademyHealth brings stakeholders together to address the current and future needs of an evolving health system, inform health policy, and translate evidence into action.
EDM Forum Updates

→ 2013 June Symposium Call for Abstracts
   **Deadline: April 5 (this Friday!)**
→ Data Quality Collaborative
   – **NEW** Request for input: Submit your feedback on the draft white paper and draft dimensions table
→ Coming Soon:
   – Upcoming webinars:
     User Experience and Research Computing
     May 16, 1:00 – 2:30 p.m. EST
     Faculty: Philip Payne, PhD, The Ohio State University

Innovative methods for analysis of observational data from EHRs
May 21, 2:00 – 3:30 p.m. EST
Faculty: Michael Stoto, PhD, Georgetown University (moderator) and Charles Bailey MD, PhD, UPenn (presenter)
EDM Forum Updates

→ New articles
  – “Development and Implementation of an Electronic Decision Support to Manage the Health of a High-Risk Population: The enhanced Electronic Medical Record Aging Brain Care Software (eMR-ABC)”
  – “Security Approaches in Using Tablet Computers for Primary Data Collection in Clinical Research”

→ Call for Manuscripts – Special Issues
  – *Ways Decision Makers Can Use Evidence to Improve Patient Outcomes in Learning Health Systems*
    **Deadline: May 1**
  – *Methods for CER, PCOR, and QI Using Electronic Clinical Data in a Learning Health System*
    **Deadline: June 1**
Connecting the Audio

- The audio will be delivered through your computer speakers. Speakers or headphones are required to hear the audio portion of the webinar.

- If you do not hear any audio now, check your computer’s speaker settings and volume.

- If you need an alternate method of accessing audio, please submit a question through the Q&A pod.
Technical Assistance

➔ Live technical assistance:
  – Call Adobe Connect at (800) 422-3623

➔ Refer to the ‘Technical Assistance’ box in the bottom left corner for tips to resolve common technical difficulties.
Questions may be submitted at any time during the presentation.

To submit a question:

1. Click in the Q&A box on the left side of your screen.
2. Type your question into the dialog box and click the Send button.
Learning Objectives

➔ Describe *eGEMs* and discuss the peer-reviewed process
➔ Provide an overview of current papers and ways to get involved in this new rapid learning community
➔ Discuss strategies and tips to maximize the likelihood of successful publication in *eGEMs*
Today’s Faculty

Erin Holve, MPH, PhD
AcademyHealth

Beth Johnson, MPH
AcademyHealth
Today’s Faculty

Adam Wilcox, PhD
Columbia University

Paul Wallace, MD
The Lewin Group, Inc.
Publishing in eGEMs: Learning How to Learn from New Data in HSR

Erin Holve, PhD, MPH, MPP
Beth H. Johnson, MPH
AcademyHealth, April 3, 2013
Advancing the National Dialogue on Use of HIT for Research & Quality Improvement

→ Electronic Data Methods (EDM) Forum Goals
  – Work with the community to **identify cross-cutting**
    • Challenges
    • Opportunities
    • Research priorities
  – Provide opportunities for **collaborative learning**
  – Ensure **widespread promotion of tools, techniques, and findings**

Join the Discussion
Sign up at  edmforum@academyhealth.org
Challenges to Disseminating Research & QI Innovations

Where and how to share the ‘journey’ of research

- Limited venues exist to share new methods and practical lessons
- Need to tell stories about ‘learning how to learn from EHR data’ differently

Responding to and informing policy

- Few mechanisms exist to disseminate innovations in a timely and credible way
- Difficult to manage the accumulation of new knowledge flexibly

Reaching authors and audiences beyond HSR

- Few platforms for acknowledging scientific contributions of multi-disciplinary collaborators in a variety of formats
- Access to articles varies across traditional journals
eGEMs
A New Publication for ‘Generating Evidence & Methods to Improve Patient Outcomes’
eGEMs: Generating Evidence and Methods to improve patient outcomes

→ Peer-reviewed, open access epublication

→ Submissions must:
  – Address use of ECD for research and QI
  – Highlight generalizable ‘lessons learned’
  – Contribute to improving patient outcomes
eGEMs: Generating Evidence and Methods to improve patient outcomes

- Four thematic domains
- Submissions may include:
  - Papers
  - Visualizations
  - Other media (audio/video)
Why Publish in eGEMs?

Unique Content

→ Tell compelling stories about learning how to learn from EHR data
  - Highlight innovation
  - Provide “news you can use”

→ Share approaches to developing infrastructure and tools, and preliminary findings to inform health science

→ Novel formats include visualizations, presentations, and other media

Innovative Process

→ Manuscripts reviewed by a true committee of peers

→ Free; open access

→ Condensed timeline for review and publication

→ Papers optimized for online searches in Google, etc.
  - Durable links

→ Ongoing promotion to reach diverse audiences

→ Monthly readership reports
## Submission Types

<table>
<thead>
<tr>
<th>Papers</th>
<th>Visualizations</th>
<th>Other Media</th>
</tr>
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<tr>
<td>Commentary</td>
<td>Data visualization</td>
<td>Tutorial</td>
</tr>
<tr>
<td>Framework</td>
<td>Infographic</td>
<td>Training video</td>
</tr>
<tr>
<td>Case Study</td>
<td>(interactive PDFs of processes; interactions)</td>
<td>Didactic learning seminar</td>
</tr>
<tr>
<td>Empirical Study</td>
<td></td>
<td></td>
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<tr>
<td>Study Protocol</td>
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CRAFTING A SUBMISSION FOR SUCCESSFUL PUBLICATION

Recent Publications
Commentary: Meeting an Expressed Need to Disseminate Approaches and Methods for Using ECD

→ Identifies 3 areas in which the field of HSR can deliver relevant, timely evidence on how to achieve better care and cut costs
  – Asking and addressing the right questions by engaging users
  – Improving methods and capabilities to navigate new amounts and types of data in research, like ECD
  – Timely translation and dissemination of findings

Case Study: Evaluating Progress Towards Using EHRs as the Backbone of LHS

- Identifies requirements of LHS
- Grades progress of ImproveCareNow IBD registry toward requirements
  - Data collection (Qualified Pass)
  - Data transmission (Needs Improvement)
  - Data processing (Pass)
  - Analysis (Needs Substantial Improvement)

Marsolo, Keith. In Search of a Data-in-Once, Electronic Health Record-Linked, Multicenter Registry—How Far We Have Come and How Far We Still Have to Go.
Case Study: Creating an Electronic Decision Support System to Manage a High-Risk Population

- Discusses using the Complex Adaptive System and the Reflective Adaptive Process to develop the eMR-ABC software
- Details experiences of Regenstrief Institute to assemble an interdisciplinary team to build eMR-ABC
- Highlights process of engaging and meeting the needs of care coordinators

Frame, Amie; et. al. Development and Implementation of an Electronic Decision Support to Manage the Health of a High-Risk Population: The enhanced Electronic Medical Record Aging Brain Care Software (eMR-ABC).
Visualization: Identifying Four Pillars of Sustainability for Research and QI

- Addresses infrastructure investments for initiating and maintaining multi-institutional research and quality improvement projects using ECD
- Discusses four “pillars” of sustainability as a conceptual framework based on experiences of EDM Forum grantees and other research and QI networks.

Launch: January 17, 2013

- General Themes
- Decision Makers
- Methods

8 published manuscripts

3,312 downloads (as of 3/31/13)

>150 topics identified
CRAFTING A SUBMISSION FOR SUCCESSFUL PUBLICATION

The Submission Process
Editorial Structure and Review Criteria

EDITORIAL BOARD

Editorial Staff
Erin Holve, Editor-in-Chief
Beth Johnson, Managing Editor
Eric Schultz, Editorial Assistant

Senior Editors

Reviewers

REVIEW CRITERIA

Clear statement of what the submission is (e.g. case study, process framework)

Relevance to using electronic health data to conduct CER, PCOR, QI

Detailed account of best practices, challenges and lessons learned to inform the community (if appropriate)

Usefulness

Innovation

Credibility
Senior Editors

→ Wade Aubry, MD, University of California, San Francisco
→ Suzanne Bakken DNSc, RN, FAAN, FACMI, Columbia University
→ Beth Devine, PhD, PharmD, MBA, University of Washington
→ John Holmes, PhD, University of Pennsylvania School of Medicine
→ Clete Kushida, MD, PhD, Stanford University
→ Hal Luft, PhD, Palo Alto Medical Foundation
→ Jonathan Nebeker, MD, MS, University of Utah School of Medicine
→ Brian Sauer, PhD, VA Salt Lake City Healthcare System
→ Lucy Savitz, PhD, MBA, Intermountain Healthcare
→ Lisa Schilling, MD, MSPH, University of Colorado, Denver
→ John Steiner, MD, MPH, Kaiser Permanente Institute for Health Research
→ Mike Stoto, PhD, Georgetown University
→ Adam Wilcox, PhD, Columbia University/Intermountain Healthcare
Submission Process

Submission not relevant to scope

Initial Decision: Rejected

Decision based on three review criteria:
- Informative and Useful
- Credible
- Innovative

Will be sent back to the author for revision and re-reviewed prior to publication.

Decision: Accepted

Decision: Conditional Acceptance (Needs Revision)

Published in eGEMs
Quick Turnaround from Submission to Publication

Minimum 3-4 weeks (depending on length of submission)
Instructions for Authors

→ [http://repository.academyhealth.org/egems/policies.html](http://repository.academyhealth.org/egems/policies.html)

→ More specifics on
  – Format
  – Style guidelines
  – Technical information (e.g. supported file types)
FINDING AND SHARING YOUR PUBLICATION

Searching and Sharing
Finding eGEMs

Permanent link to article available on eGEMs website: [http://repository.academyhealth.org/egems](http://repository.academyhealth.org/egems)

Platform optimized for indexing in Google, Google Scholar, and Bing

Publications promoted via
- EDM Forum website
- AcademyHealth
- Affiliate Organizations
- Social Media
Participate in eGEMs – the 4 S’s:

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  – Via the eGEMs website

→ Subscribe
  – Via email, RSS, or follow on Twitter: @edm_ah

→ Share
  – Link to your or colleagues’ publications

→ Support
  – Interested in reviewing? Contact beth.johnson@academyhealth.org
Submit Today!

- General Themes (rolling submission)
- Special Issues – Call for Papers!
  - *Ways Decision Makers Can Use Evidence to Improve Patient Outcomes in Learning Health Systems*
    Submission Deadline: May 1
    Guest Editor: Wade Aubry, MD
  - *Methods for CER, PCOR, and QI Using EHR Data in a Learning Health System*
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BONUS SLIDES
## Impact of Comparator Journals

<table>
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<th>Journal</th>
<th>Impact Factor (2011)</th>
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<tbody>
<tr>
<td>Health Affairs</td>
<td>4.313</td>
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<tr>
<td>HSR</td>
<td>2.157</td>
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<tr>
<td>Implementation Science</td>
<td>3.100</td>
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<tr>
<td>JAMIA</td>
<td>3.609</td>
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<tr>
<td>JCER</td>
<td>N/A</td>
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<tr>
<td>Medical Care</td>
<td>3.411</td>
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<tr>
<td>PLoS</td>
<td>4.092</td>
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<tr>
<td>PLoS Medicine</td>
<td>16.269</td>
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<tr>
<td>NEJM</td>
<td>53.298</td>
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<tr>
<td>JAMA</td>
<td>30.000</td>
</tr>
<tr>
<td>Journal of Internet Research</td>
<td>4.663 (2010)</td>
</tr>
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Security Approaches in Using Tablet Computers for Primary Data Collection in Clinical Research

Adam Wilcox, PhD
Associate Professor, Columbia University
Primary Data Collection is ...

- necessary;
  - Most research studies still collect some data directly from or about subjects.

- expensive;
  - One of the most expensive components of a clinical trial

- awkward;
  - Either paper-based (requiring later transcription) or forces the subject within the electronic workflow

- changing?
  - New devices have the potential to change how primary data collection is done
Many studies about the use of computers (usually tablets) in primary data collection

Studies demonstrated benefits
  ◦ Easier to use
  ◦ More accurate

Still, people preferred paper-based
  ◦ Simplicity of implementation
  ◦ Training
And then,
Tablets ...

- are cheaper
  - Than previous-generation tablets
  - Than PCs

- are more mobile
  - Average weight of a MacBook Air or Ultrabook: 3lbs
  - iPad weight: 1.5lbs
  - Nexus 7 weight: ¾ lbs

- are more common
  - 47% of consumers are expected to own by end of 2013

- use “apps”
  - Cheaper and easier application distribution model

- use “cloud-based” storage
Cloud-based storage and Protected Health Information (PHI)

- Cloud data are stored on servers owned by software
  - Outside direct control of a research institution

- PHI requires a business associates agreement to be stored outside an institution’s control
  - Software companies are reluctant to assume the full risks of PHI
Data Security and Tablets

Local Data Storage

Data Transmission

Server Data Storage
Web-based Data Collection with External Hosting

- Tablet computer
- External web server
- External data storage (cloud-based)
Web-based Data Collection with Internal Hosting

Tablet computer

Research institution firewall

Internal web server and storage
Tablet App–based Data Collection

1. Tablet computer
2. Research institution firewall
3. Internal data server
4. External data storage (cloud-based)
Tablet App–based Data Collection, Internally–hosted App Server

- Tablet computer
- Research institution firewall
- Internal data server and storage
## Comparison of Methods

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Experience with Tablets

AHRQ R01HS019853 (Suzanne Bakken)
WICER Project (2010– )

- Across care institutions
  - Hospital, ambulatory care, home care, long-term care
  - Longitudinal
- Outside the care setting
  - Vital statistics
  - Demographics and social information
  - Patient assessments
Survey Populations

~8,000 surveys

- Household Surveys
- Ambulatory Clinics
- Community Outreach Center
# Comparison of Methods

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Both methods were approved by the CUMC IRB.
Conclusions

- Significant improvements in using tablets for primary data collection
- Security is a critical issue for tablet survey software
- Workflow is a consideration when using web-based approaches
- Data transcription costs are significant
eGEMs: An Opportunity for Better Science

Paul Wallace MD
SVP and Director, Center for CER, The Lewin Group
Board of Directors, AcademyHealth
April 3, 2013
Context

➤ eGEMs seeks to
  – accelerate the pace for dissemination of scholarly knowledge
  – expand audiences

➤ eGEMs also can support better science

➤ What are the editorial implications?
In pursuit of desired outcomes...

- If you want a different outcome, it’s prudent to examine the contributing structures and processes...

- Consider incorporation and encouragement of:
  - additional processes for generating credible and rigorous dissemination materials (Example: *The Health Care Grey Literature*)
  - alternative structures for systematic hypothesis generation and testing (Example: *Knowledge generation in the semiconductor industry*)
Example 1: The Health Care Grey Literature

- Definition: "That which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers."

- More than...
  - the scientific “minor leagues”
  - a vehicle to surface work that is not yet ready or below the standards of commercial academic publishing

The Health Care Grey Literature... examples

Evaluation of Phase I of the Medicare Health Support Pilot Program Under Traditional Fee-for-Service Medicare: 18-Month Interim Analysis

Report to Congress

GAO Report to Congressional Committees

Drug Pricing
Manufacturer Discounts in the 340B Program Offer Benefits, but Federal Oversight Needs Improvement

GAO 20 Years of Service

Analytic Methods and Options for Generating National Estimates of Patient Safety Events in Ambulatory Care Settings

Final Report: Task 5 Infrastructure, Tools and Data Needed to Measure Ambulatory Care Patient Safety Events

Prepared for: The Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services

Submitted by: The Lewin Group, Inc.

August 11, 2002
The Health Care Grey Literature… continued

→ Drivers:
  – specific sponsor needs: customization and stakeholder focus that are often not well served by academic publishers
  – timeliness
  – rigor via advisors, TEPs, and Public Comment

→ Formats:
  – White Papers and Reports
  – Blogs, Commentary, Tweets…
Example 2: The Semiconductor Industry

Moore’s Law

Requirements:
- Continuous innovation
- Reliable system capable of producing needed change on a predictable schedule
The Semiconductor Industry: Enablers

→ Highly integrated oversight and planning across multiple investigators
→ Frequent knowledge turns
→ Common goals and standardized endpoints
→ Experimentation occurs in a physical setting that anticipates eventual large scale production
The consistent achievement of Moore’s Law for over 40 years reflects:

- parallel testing of multiple hypotheses toward a shared goal
- a predictable rate of collective success despite expected failure of most initially promising ideas,
- coordinated redirection of resources to the most promising ideas at the moment, and
- an environment and processes that recognize and reward the timely demonstration of both positive and negative findings.
Implications: Editorial Considerations for eGEMs

→ Recruitment of diverse contributors –
  – Does eGEMs have a role in recognizing and disseminating selected grey literature that has achieved credible sponsor validation and approval?
  – Are there specific editorial review principles that should be developed for this complementary work?

→ Preference for approaches that explicitly anticipate the issues of dissemination and spread within the experimental design.
Editorial considerations for eGEMs…continued

→ Accelerated sharing of good ideas that, addressed with appropriate rigor, **have been shown to not work**.
  
  – Elevating a problem formulation at the earliest opportunity from “no evidence available” to “no evidence of effect” would be a huge service to other investigators and to advancing the field.

→ Pursuit of common and scalable metrics to guide collaborative and competing efforts
Thanks

Paul.Wallace@Lewin.com
Submitting Questions

To submit a question:

1. Click in the Q&A box on the left side of your screen
2. Type your question into the dialog box and click the Send button
Continue the Discussion!
www.edm-forum.org

- Medical Care supplement
- Issue Briefs
- CER Project Profiles
- Descriptions of eHealth data initiatives for research & QI
- Event archives
- Wiki glossary
- Webinars

Sign up at edmforum@academyhealth.org
Thank You

Please take a moment to fill out the brief evaluation which will appear in your browser.