Making Evidence Synthesis Data Open and Shareable

Ian Saldanha, MBBS, MPH, PhD

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Where would **YOU** go to find the evidence behind interventions for improving your health?
What is evidence-based healthcare?

“The integration of best research evidence with clinical expertise and patient values.”

Sackett D et al, 2000
Evidence-based healthcare paradigm

Evidence Generation (e.g., Clinical Trials) → Evidence Synthesis (e.g., Systematic Reviews) → Clinical Practice Guidelines → Evidence-based Healthcare
National Institutes of Health Budget, 1998-2017
budget authority in billions of constant FY 2016 dollars

In billions

https://www.aaas.org/sites/default/files/NIHBudget.jpg
One problem with this paradigm

Evidence Generation
(e.g., Clinical Trials)

Evidence Synthesis
(e.g., Systematic Reviews)

Clinical Practice Guidelines

Evidence-based Healthcare
One problem with this paradigm

Evidence Generation
(e.g., Clinical Trials)

Evidence Synthesis
(e.g., Systematic Reviews)

Clinical Practice Guidelines

Evidence-based Healthcare
Multiple sources of evidence, i.e., data

Public data sources
- Short report (e.g., letter, conference abstract)
- Journal article
- Trial registration
- Results on trial registry
- Information from regulators

Non-public data sources
- Unpublished manuscript
- Individual participant data (IPD)
- Grant proposal
- Study protocol
- Case report form
- Memos and emails

Mayo-Wilson, 2015. DOI: 10.1186/s13643-015-0134-z OA
Multiple data sources

Doshi, 2013. DOI: 10.1136/bmj.f2865
Our team

**CENTER FOR EVIDENCE SYNTHESIS IN HEALTH**

**Ian Saldanha, MBBS, MPH, PhD**
Director and Principal Investigator:
Brown University

**Joseph Lau, MD**
Founder and former Director:
Brown University

**Ethan Balk, MD, MPH**
Co-Investigator:
Brown University

**Bryant Smith, MPH, CPH**
Administrator:
Brown University

**Birol Senturk, BA**
Assistant Programmer:
Brown University

**Jens Jap, BS**
Lead Programmer:
Brown University
Our vision

Center for Evidence Synthesis in Health

Free, open access to evidence synthesis data
• Re-use during updates of the systematic review
• Sharing for various purposes
  • Transparency
  • Reducing redundancy and research waste
  • Secondary analyses
  • Methodologic and other kinds of research

A global, community resource

From the Unite for Sight “About US” website...

Cutting-Edge Research

Our programs are designed to continually enhance global health delivery, both with our eye clinic partners and on a global scale. We review cutting-edge literature about global health delivery and share information gleaned from this research with our eye clinic partners so they can apply new practices in the field. We also develop our own research studies by recruiting volunteers to serve as Global Impact Fellows. We work with the Fellows to design, implement, and study critical elements of improving quality of health care delivery. For example...
Systematic Review Data Repository (SRDR)

- Free, open-source
- Web-based, collaborative workspace for conducting systematic reviews (e.g., screening, data extraction)
Data sharing through SRDR

https://srdr.ahrq.gov/projects/published

- Free, open-access
- Web-based repository
- Each project has its own Digital Object Identifier (DOI)
- Published data
  - 132 projects
  - Median=69 studies per project
- 2/3 projects contain structured data
Projects with publicly available data in SRDR

Saldanha et al. (manuscript submitted)
Foci of the 132 projects

<table>
<thead>
<tr>
<th>Primary focus of the review</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interventions (therapeutic or preventive)</td>
<td>102</td>
<td>(77)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>15</td>
<td>(11)</td>
</tr>
<tr>
<td>Epidemiology – exposure-outcome association</td>
<td>10</td>
<td>(8)</td>
</tr>
<tr>
<td>Epidemiology – incidence or prevalence</td>
<td>3</td>
<td>(3)</td>
</tr>
<tr>
<td>Methodology</td>
<td>2</td>
<td>(2)</td>
</tr>
</tbody>
</table>
# Topic areas of the 132 projects

<table>
<thead>
<tr>
<th>Primary health area addressed (International Classification of Diseases [ICD]-10 chapter)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental and behavioral disorders</td>
<td>29</td>
<td>(22)</td>
</tr>
<tr>
<td>Diseases of the eye and adnexa</td>
<td>22</td>
<td>(17)</td>
</tr>
<tr>
<td>Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>12</td>
<td>(9 )</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>11</td>
<td>(8 )</td>
</tr>
<tr>
<td>Diseases of the musculoskeletal system and connective tissue</td>
<td>10</td>
<td>(8 )</td>
</tr>
<tr>
<td>Diseases of the circulatory system</td>
<td>9</td>
<td>(7 )</td>
</tr>
<tr>
<td>Diseases of the genitourinary system</td>
<td>9</td>
<td>(7 )</td>
</tr>
<tr>
<td>Diseases of the respiratory system</td>
<td>5</td>
<td>(4 )</td>
</tr>
<tr>
<td>Endocrine, nutritional, and metabolic diseases</td>
<td>4</td>
<td>(3 )</td>
</tr>
<tr>
<td>Pregnancy, childbirth, and the puerperium</td>
<td>4</td>
<td>(3 )</td>
</tr>
<tr>
<td>Factors influencing health status and contact with health services</td>
<td>4</td>
<td>(3 )</td>
</tr>
<tr>
<td>Certain infectious and parasitic diseases</td>
<td>3</td>
<td>(2 )</td>
</tr>
<tr>
<td>Diseases of the digestive system</td>
<td>2</td>
<td>(2 )</td>
</tr>
<tr>
<td>Injury, poisoning, and certain other consequences of external causes</td>
<td>2</td>
<td>(2 )</td>
</tr>
<tr>
<td>Congenital malformations, deformations, and chromosomal abnormalities</td>
<td>1</td>
<td>(1 )</td>
</tr>
<tr>
<td>Diseases of the ear and mastoid process</td>
<td>1</td>
<td>(1 )</td>
</tr>
<tr>
<td>Codes for special purposes</td>
<td>1</td>
<td>(1 )</td>
</tr>
<tr>
<td>Other – Methodology</td>
<td>2</td>
<td>(2 )</td>
</tr>
</tbody>
</table>
Making systematic review data publicly available

<table>
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<tr>
<th>Opportunities</th>
</tr>
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<tr>
<td>Advance open science</td>
</tr>
<tr>
<td>Minimize redundancy</td>
</tr>
<tr>
<td>Facilitate systematic review updates</td>
</tr>
<tr>
<td>Drive methodological research</td>
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Wolfenden et al. *Systematic Reviews* (2016)
Saldanha et al. (Submitted)
## Making systematic review data publicly available

<table>
<thead>
<tr>
<th>Opportunities</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance open science</td>
<td>Perpetuation of errors (if extracted data had errors)</td>
</tr>
<tr>
<td>Minimize redundancy</td>
<td>Intellectual property (IP) considerations</td>
</tr>
<tr>
<td>Facilitate systematic review updates</td>
<td>Revenue considerations</td>
</tr>
<tr>
<td>Drive methodological research</td>
<td></td>
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</tbody>
</table>
Some other platforms

- NIH U.S. National Library of Medicine
- ClinicalTrials.gov
- Vivli Center for Global Clinical Research Data
- figshare
- Open Science Framework
Why should **YOU** care?

1. **Economics**

2. **Transparency**

3. **Your health!**
   
   – **Relevant** to decision-makers – your doctor, you!
Where would **YOU** go to find the evidence behind interventions for improving health?

- **Evidence Generation** (e.g., Clinical Trials)
- **Evidence Synthesis** (e.g., Systematic Reviews)
- **Clinical Practice Guidelines**

Evidence-based Healthcare
Funding

• Since SRDR’s launch in 2012

• Disclaimer: No statement in my presentation should be construed as an official position of AHRQ or of the United States Department of Health and Human Services.
THANK YOU!

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