Emerging Data Resources, Tools, and Publications from the ARRA-CER Infrastructure Awards

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The EDM Forum is supported by the Agency for Healthcare Research and Quality (AHRQ) through the American Recovery & Reinvestment Act of 2009, Grant U13 HS19564-01.
Advancing the National Dialogue on Use of HIT for Research & Quality Improvement

- Electronic Data Methods (EDM) Forum
  - Working with the community to identify cross-cutting
    - Challenges
    - Opportunities
    - Research priorities
  - Providing opportunities for collaborative learning
  - Accelerating widespread promotion and adoption of promising tools, techniques, and findings

~25 million patients touched by the PROSPECT, DRN, and Enhanced Registry Projects

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ARRA Investments Provide Infrastructure Needed for CER

→ Electronic data infrastructure enhances the ability to conduct CER, PCOR, and QI
  – CER requires linking large data sources held by different institutions

→ Infrastructure and methods development is a top priority for the FCCCER and PCORI
  – Generating and aligning the evidence supported by data infrastructure can support improvement and innovation in a learning health system (IOM)
¼ of the ARRA-CER Investment Supports Building Electronic Data Infrastructure

<table>
<thead>
<tr>
<th>Total ARRA-CER Funding</th>
<th>$1.1 billion</th>
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<tbody>
<tr>
<td>Evidence development and synthesis</td>
<td>Translation and dissemination</td>
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<tr>
<th>Infrastructure &amp; Methods Development</th>
<th>$417.2 million</th>
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<tr>
<td>Governance</td>
<td>Data</td>
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<table>
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<tr>
<th>Electronic Clinical Data Infrastructure</th>
<th>$276 million</th>
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<tr>
<td>Clinical and claims databases, electronic health records, and data warehouses</td>
<td>Patient Registries</td>
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</table>

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<tr>
<th>AHRQ Awards to Build Infrastructure Using Electronic Clinical Data for CER, PCOR, and QI</th>
<th>$100 million</th>
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<tr>
<td>PROSPECT</td>
<td>Enhanced Registries</td>
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Landscape of Electronic Health Data Initiatives for Research, 2013

Convening Bodies:
- EDM Forum
- BEIN
- CTSA KFCs
- HIT Taskforce (ONC)
- RoPR

Implementation & Application
- QI PILOTS
  - Enhanced Registry
- Beacon Communities
  - Query Health (ONC)
- Clinical Looking Glass
- eMerge

State HIEs
- Clinical & Community Care
  - SHARPn (ONC)
  - HITIDE (VA)
  - Multiple Chronic Conditions Research Networks (AHRQ)

High Value Healthcare Collaborative

INFRASTRUCTURE BUILDING
- Enhanced Registry – DRN – PROSPECT
- PHIS+

CER PILOTS
- Enhanced Registry – DRN – PROSPECT
- i2b2
- VINCI (VA)
- Sentinel Network (FDA)

Research
- HMORN
- DARTNET
- PECARN
- MPCD

CoNNECT
- REDCap
- TRIAD

CYCORE
- PACES & JANUS (FDA)
- DEcIDE (AHRQ)
- OMOP (FNIH)

jDASH
- caBIG
- NIH Challenge Grants

Source: Electronic Data Methods Forum, 2013
Methods Phase I*: Identifying & Classifying the ARRA-CER Awards

- Document review of the 2009 ARRA-CER award programs
  - AHRQ Factsheets on Data Infrastructure Awards
  - Federal Business Opportunities Website
  - NIH RePORTER
  - GAO Report on ARRA and PPACA funds

- Award programs were identified by:
  - reviewing the executive summaries
  - Conducting a key word search of terms related to electronic clinical data infrastructure

Keywords:
- Electronic health record(s), electronic medical record(s)
- Data, database(s), warehouse
- Distributed data network(s)
- Link(s), linking, linkage(s)
- Collect, collection
- Claim(s)
- Exchange(s)
- Informatic(s), bioinformatic(s)
- (Health information) technology
- Repository, repositories
- Registry, registries

Methods Phase II: Identifying Products & Tools

→ Queried RFA #s for grant programs in NIH RePORTER to identify individual awards and extracted grant record information
→ Searched grant IDs using the grant # MeSH tag [gr] in PubMed to identify manuscripts
→ Conducted website searches of project titles and other identifying grant information

→ Collected information for 66 of the 86 awards
  – Leveraged info previously collected for 13 projects in the EDM Forum community
  – Contacted PIs for 53 projects
    • Invited to submit a project snapshot (n=12 submitted)
    • Review identified papers and products (n=24 responses)
Productivity of ARRA-CER Infrastructure Awards is High
## Growing Data Analytic Resources (>100)

<table>
<thead>
<tr>
<th>Tools/Products (&gt;100)</th>
<th>#</th>
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<tbody>
<tr>
<td>Research Infrastructure (e.g., data warehouses with integrated analytic tools)</td>
<td>26</td>
</tr>
<tr>
<td>Data Linkage, Distributed Research Network, or Registry</td>
<td>24</td>
</tr>
<tr>
<td>Databases, Repositories, and Datasets</td>
<td>23</td>
</tr>
<tr>
<td>Measures, Algorithms, and other Methods Development</td>
<td>21</td>
</tr>
<tr>
<td>mHealth Technology and PRO tools</td>
<td>7</td>
</tr>
<tr>
<td>EHR Extensions or Clinical Decision Support Tools</td>
<td>7</td>
</tr>
<tr>
<td>Natural Language Processing or Abstraction</td>
<td>3</td>
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<tr>
<td>Data Collection Tool</td>
<td>3</td>
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Emerging Publications (n>400)

- PubMed Search of Grant IDs and Feedback from PIs Identified >400 Articles
- 213 (~50%) are relevant to CER
  - Research Findings: 76 (~30%)
  - Infrastructure Development: 137 (~70%)
    - Informatics systems and processes;
    - Analytic methods and validation of measures;
    - Stakeholder Engagement;
    - The science and conduct of CER, etc.
- “Comparative Effectiveness Research” or the MeSH tag were found in 70 of the articles
ARRA-CER Papers are Published in a Range of Journals (n = 120)

- Medical Care: 32 articles
- Journal of the National Cancer Institute: 20 articles
- Radiology: 18 articles
- Fertility and Sterility: 16 articles
- Cancer Epidemiology, Biomarkers & Prevention: 15 articles
- Annals of Internal Medicine: 12 articles
- American Journal of Roentgenology: 10 articles
- JAMIA: 9 articles
- Experimental and Clinical Psychopharmacology: 8 articles
- JAMA: 7 articles
- Breast Cancer Research and Treatment: 7 articles
Conclusion

- Demonstrated productivity in the ARRA funds
  - In order to enhance transparency and support sustainability, early dissemination is key
  - Convening projects early for shared learning and collaboration
- Where future publications live and are focused on in the short-term and in the long-term
- Limitations: Identifying projects and related publications was a “needle in a haystack” problem
  - Identification of individual awards and information
  - Grant ID required manual translation to query in PubMed
Discussion

→ How do we measure productivity of these projects?
  – What are the scientific contributions that may not be reflected in the literature, but demonstrate this new capacity to conduct more research and answer new questions?
  – How can we measure how much more research was enabled because of the new infrastructure?

→ Future plans/Next Steps
  – Re-run the PubMed queries and conduct additional outreach for projects to submit snapshots
  – *eGEMs* can be a useful dissemination vehicle for the products and lessons learned that may not be captured in the traditional peer-reviewed literature

[repository.academyhealth.org/egems]
Thank you!

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