

*Linking Existing Databases -  
Poisoned Chalice or Holy Grail?*

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Participants:

Robert LoCasale – Senior Epidemiologist, Merck,  
United States

Ron Herings – Director, PHARMO Institute,  
The Netherlands

Dan Huse – Vice President, Thomson Reuters,  
United States

Alison Bourke – Managing Director, CSD MR UK  
(THIN), United Kingdom

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*Linking Existing Databases -  
Is it Worth the Pain?*

Robert J. LoCasale, PhD MS  
Pharmacoepidemiology and Database Research Unit, Merck  
Sharp & Dohme Corp., North Wales, PA

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Conflict of Interest

- Employee of Merck Sharp & Dohme Corp.  
and own stock

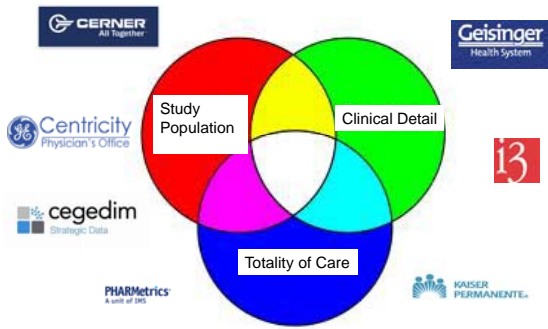
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Agenda

- Points to consider when selecting a  
database
- Where are we now?
- Where do we need to go?

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## Selecting a database: Where does the database fall?



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## Selecting a Database

- Points to consider
  - Sliding scale for each of the 3 metrics depending on the database
  - What's the question? (general descriptive epidemiology, drug utilization, comparative safety or effectiveness)
    - Trade-offs (e.g. limitation section) are made to best answer the question
- The world of proxies<sup>1</sup>
  - Concerns of internal validity
    - Depending on the database, proxies could be needed for the study population, exposure, outcome and covariates (confounders, risk factors)
  - Supports the need for linkages. Strive to get the real thing!

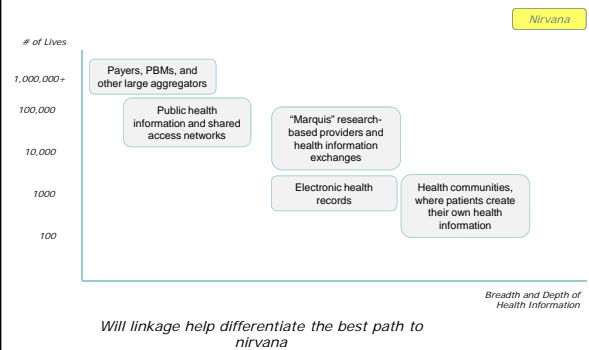
<sup>1</sup>Schneeweiss S. Understanding secondary databases: a commentary on "Sources of bias for health state characteristics in secondary databases." J Clin Epidemiol. 2007;60:648-650.

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## Where are we now?

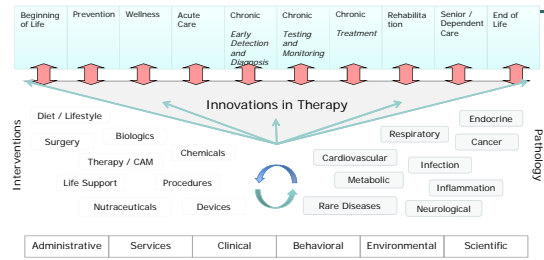
Theme	<ul style="list-style-type: none"> <li>• Public health information and shared access networks</li> <li>• VIREC, DARTNet, OGD and more</li> </ul>	Distance from Patient 
Theme	<ul style="list-style-type: none"> <li>• Payers, PBMs, and other large aggregators</li> <li>• Medco, United Health Group, ...</li> </ul>	Distance from Patient 
Theme	<ul style="list-style-type: none"> <li>• Electronic health records</li> <li>• HANYS (PACeR), Aurora Health Care, and more</li> </ul>	Distance from Patient 
Theme	<ul style="list-style-type: none"> <li>• "Marquis" research-based providers and health information exchanges</li> <li>• Partners/Deloitte, Regenstrief/Indiana, Vanderbilt/Tennessee</li> </ul>	Distance from Patient 
Theme	<ul style="list-style-type: none"> <li>• Health communities, where patients create their own health information</li> <li>• PatientsLikeMe, CureTogether, Inspire</li> </ul>	Distance from Patient 

## Where do we need to go? Best Path to Nirvana?



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## Focus on the patient's well-being: The emerging healthcare ecosystem



- Where does Johnny or Janie go for...
  - Where does John, Jane, Grandpa John and Grandma Jane go for...
  - Where does Juan or Juana go for...

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## "Wish List" from a Convenient Sample

- In the mean time, please work on the following short list ..... 😊
  - Improved access to US data for >65 years of age;
  - Improved mother-baby links;
  - Biomarker data;
  - Data in emerging markets (Brazil, China, India);
  - Link to anonymized charts for validation of outcomes of interest;
  - Link to survey data for patients in the database;
  - Link to national death data;
  - Data on family history, behaviors, imaging, vital signs, microbiology;
  - Data on inpatient drug use (drug, biologics), medication samples and over-the-counter;
  - Data on doctor decision making (e.g. why they prescribe a certain medication);
  - Data on actual medication adherence and persistence (e.g. did the patient follow the dosing instructions);
  - Ability to randomize patients within a system and then follow them for outcomes;
  - Improve outpatient lab capture;
  - Ability to include a PRO into the EMR for specific studies

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*Thank You!*

Robert\_locasale@merck.com

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