Linking Existing Databases – Poisoned Chalice or Holy Grail?

Participants:

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Linking Existing Databases – Is it Worth the Pain?

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Conflict of Interest

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

Agenda

- Points to consider when selecting a database
- Where are we now?
- Where do we need to go?
Selecting a database: Where does the database fall?

- Study Population
- Clinical Detail
- Totality of Care
- Geisinger
- Centricity Professional Office
- McKesson
- cegedim
- HANYS (PACeR), Aurora Health Care, and more
- "Marquis" research-based providers and health information exchanges
- Partners/Emory, Regenstrief/Indiana, Vanderbilt/Tennessee
- Health communities, where patients create their own health information
- PatientsLikeMe, CureTogether, Inspire

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
  - 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!

Trade-offs (e.g., limitation section) are made to best answer the question


Where are we now?

- Public health information and shared access networks
  - VITAL, QDARTNet, OGDE and more
- Payers, PBMs, and other large aggregators
  - Medco, United Health Group, …
- Electronic health records
  - "Marquis" research-based providers and health information exchanges
  - PatientsLikeMe, CureTogether, Inspire
- Health communities, where patients create their own health information

Distance from Patient

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

- # of Lives
  - 0,000
  - 1,000
  - 10,000
  - 100,000
  - 1,000,000+

- Health communities, where patients create their own health information

Will linkage help differentiate the best path to nirvana?
Focus on the patient’s well-being: The emerging healthcare ecosystem

Innovations in Therapy
- Prevention
- Prevention
- Prevention
- Prevention
- Prevention
- Prevention

End of Life
- Senior / Dependent Care
- Rehabilitation
- Chronic Treatment
- Chronic Testing and Monitoring
- Chronic Early Detection and Diagnosis

Beginning of Life
- Acute Care
- Acute Care
- Acute Care
- Acute Care
- Acute Care

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…

“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;
- 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

Thank You!

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