Efficient methods of collecting phenotype and exposure data
and
Research in clinical care systems or small clinical practices

Efficient methods of collecting phenotype and exposure data

- Centralized databases and standard data structure
- Developing ontologies and consistent methods for capturing phenotypes—Gene and Environment Initiative
  - OBO / NCBO phenotype effort
  - SNoMed/Disease Ontology discussions
  - Lifestyle ontology??
- increasing implementation of electronic health records
- opportunity for feedback to EHRs to improve quality and consistency of data capture

Efficient methods of collecting phenotype and exposure data

- social economic status
  - Privacy issue
- environmental exposures
  - Air Quality System (http://www.epa.gov/ttn/airs/airsaqs/index.htm)
  - Data still limited
- Geographic Information Systems (GIS)
  - EPA Environmental Geospatial Access Project (http://www.epa.gov/enviro/geo_data.html)

Research in clinical care systems or small clinical practices

- Traditional Epidemiological Cohorts vs. Clinical Care Systems
  - completeness limited data vs incomplete broad data
  - enrollment bias
  - efficiency
- Clinic-hospital based cohorts
  - Clinical and Translational Science Award network
- Network of EMR-linked Biobanks
  - Mayo, Vanderbilt, Marshfield Clinic, Group Health Seattle, Northwestern U.

Research in clinical care systems or small clinical practices

- Practice Based Research Networks
  - improvement of primary care
  - expanding into quality assessment
  - applications for genomics research
  - Agency for Healthcare Research and Quality (AHRQ)
    - http://www.ahrq.gov/research/pbrn/pbrnfact.htm
    - http://www.aafp.org/online/en/home/clinical/research/fpbrn.html
    - http://jama.ama-assn.org/cgi/content/full/297/4/403
    - http://www.ajhp.org/cgi/content/abstract/64/19/2044

Goals for the Future

- Should we maximize use of Electronic Health Records for phenotype development and how?

- How to support ontology/vocabulary development for phenotypes and software and data mining tools for electronic medical records?

- Should we develop “best practices” repository for phenotype datasets?

- How do we integrate with CTSA network to maximize data harmonization?

Goals for the Future

- How do we support integration of phenotypes with environmental data from EPA and other databases such as Census track data?

- Should we maximize use of practice based research networks for cohort development, and if so how?

- How can we develop and test methods for sample collection and management across PBRNs?