U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

CISNET: Looking Towards the Future

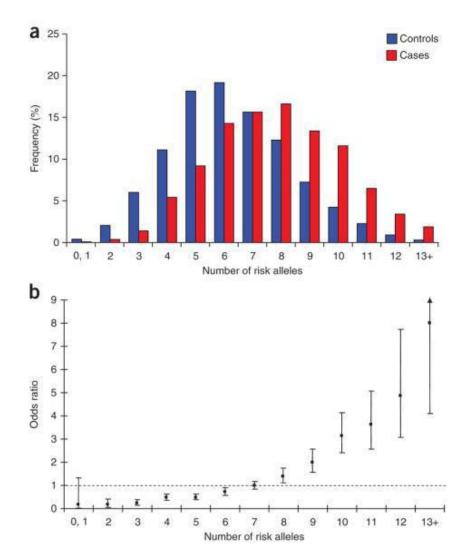
Possible Future Priorities

Presented for Discussion at the Spring 2013 CISNET Meetings

Possible Priority I: Polygenic Risk and Family History

- Polygenic risk traits where the genetic component is determined by many genes with individually small effects
 - Stratifies across the risk spectrum – potential to identify both high and low risk strategies (unlike family history)
 - Currently level of risk discrimination is not great for common cancers, but has potential to improve in the next 5 years
- Should polygenic risk be the first or last factor considered?
- How do we best integrate genetic and nongenetic factors?

Cumulative impact of 10 variants on chronic lymphocytic leukemia risk. Crowther-Swanepoel et al. Common variants at 2q37.3, 8q24.21, 15q21.3 and 16q24.1 influence chronic lymphocytic leukemia risk. Nature Genetics 42, 132–136 (2010)







What is the impact of SNPs on the natural history of disease?

- Can common variants identified by GWAS and other approaches go beyond characterizing just cancer vs. control to more specific characterization of cancer (aggressive/non-aggressive disease, adenomas, size/type of adenomas, etc)?
- Using Results from The Cancer Genome Atlas (TCGA) and Other Data Sources
 - Genomic characterization of disease (e.g. triple negative breast cancer and beyond)
 - Genomic risk stratification for treatment

Possible Priority II: Understanding How Screening Works in Real-World Settings and Determining the Best Routes to Optimize the Process



Partnerships between CISNET and those who collect cancer screening process data in community settings

> Example:

- PROSPR (Population-based Research Optimizing Screening through Personalized Regimens -<u>http://appliedresearch.cancer.gov/networks/prospr/</u>)
 - PROSPR recognizes that screening is not a singular event, but rather a process (recruitment, screening, positive screen evaluation, diagnosis, referral for treatment), and that all parts of the process must be working to effectively
 - PROSPR collects data on all phases of the process in various health care settings (for breast, colorectal & cervical cancers)
 - Modeling can determine how far from the efficiency frontier current screening is, and the most important leverage points in the screening process to get closer
 - PROSPR includes modelers, but does not necessarily facilitate comparative modeling, which could be facilitated by CISNET

Possible Priority II: Understanding How Screening Works in Real-World Settings and Determining the Best Routes to Optimize the Process



- Other examples
 - Breast Cancer Surveillance Consortium
 - <u>http://breastscreening.cancer.gov/</u>
 - Cancer Research Network
 - <u>http://crn.cancer.gov/</u>

Possible Priority III: Supporting the Development of Decision Aids



- Modeling results can provide a key element for input into Decision Aids
- Decision Aids
 - Tools to Allow Individuals to Elucidate Harms and Benefits and to Weigh Potential Choices Given their Personal Preferences
 - Tools to Allow Health Care Professionals to Guide Shared Decision Making
 - Evaluation of the Benefits versus Costs (esp. time) of Shared Decision Making
- Decision Support Tools
 - Tools that aid physicians in making decisions –e.g. tools to help radiologists make decision about call backs
- What types of additional expertise would need to be brought in (e.g. behavioral economics)

Possible Priority IV: State and Local Cancer Control Planning



- CISNET Models can Inform State and Local Cancer Control Planning
 - CISNET supplements funded by CDC
 - CRC screening in South Carolina
 - Tobacco control and lung cancer screening in NE Pennsylvania
 - CRC screening in NE Pennsylvania
 - Tobacco control and lung cancer screening in Detroit and across Michigan
 - Supplements were selected for funding not just based on their applicability to the specific area, but as an exemplar for other similar areas around the country
 - Extensions to other areas is of interest, and should become easier as the modeling community learns how to extend a model previously applied on the national level

Possible Priority V: International Cancer Control Planning



International Cancer Control Planning

- Cancer control planning in middle income countries (e.g. South America, Caribbean, Far East, Middle East, Eastern Europe) is an opportunity for CISNET to make an impact
- International Cancer Control planning brings up many unique issues (e.g. different health care systems, cultural barriers, access to health care, data infrastructure to support modeling)





- As the affordable care act is implemented across the country (in some cases differently in different places), there will be opportunities to explore the differential impact on health care outcomes
- Modeling is an ideal way to explore these relationships, and allows for control of confounding factors, time lags between policy changes and their impact, and statistical variation
 - An example of using modeling to explore a natural experiment
 - Shaw et al. An ecologic study of prostate-specific antigen screening and prostate cancer mortality in nine geographic areas of the United States. Am J Epidemiol. 2004 Dec 1;160(11):1059-69.

Affordable Care Act (continued)



- Phase in for ACA (2010-2015)
- > Opportunities for modeling, e.g.,
 - Declines in health disparities
 - BRCA counseling about genetic testing for women at higher risk
 - Elimination of cost sharing for mammography, colonoscopy
- Surveys will be enhanced to support research on the impact of ACA
 - BRFSS, NHIS, National Ambulatory Care Survey, MEPS

Possible Priority VII: Value of Information (VOI) Analyses



Value of Information (VOI)

- The amount a decision maker would be willing to pay for information prior to making a decision
- VOI is gaining more interest around NIH
 Example may be valuable before initiating an expensive prevention trial