The FCDS/NCHS Data Linkage Project

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Outline

• The National Center for Health Statistics (NCHS) Health Surveys
• Description of the Proposed Pilot Linkage
• GO-Grant submission
• The Future

National Center for Health Statistics (NCHS)

• Responsible for conducting health surveys representative of the US population
  – Data are used to monitor health status and health trends of the (civilian) US population
• Branch of the Centers for Disease Control and Prevention (CDC)
  – NCHS modest operational budget $116 million/yr
NCHS Surveys:
National Health Interview Survey (NHIS)

- Annual Household Survey conducted since 1957
  - Collects information on a broad range of health topics, health risk & health protective behaviors, and health care utilization & access
  - Each year information collected on ~ 90,000 household members

NCHS Surveys:
The National Health and Nutrition Examination Survey (NHANES)

- Annual survey includes a household interview, physical examination & nutritional assessment
  - Biological information (i.e., blood and urine) collected in addition to examination data
  - Each year information collected on ~ 5,000 household members

Both NCHS Surveys Linked to the National Death Index

- Allows researchers to identify factors related to an increased or decreased risk of mortality
NCHS Surveys & Cancer Registries

• 2007 FCDS Christmas potluck sugar-induced “high” leads to the generation of a “brilliant” idea:
  – Same data collected for NDI linkage could be used to perform registry linkages!!!

**TABLE 1**

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**NCHS Surveys & Cancer Registries**

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**Why is this “COOL”?**

Can Study Two Distinct Nationally Representative Groups:

1. Cancer Dx NHIS/NHANES Participant
   -- i.e., Cancer Survivor Study
2. Participant Cancer Dx
   -- i.e., Cancer Incidence Study
Why is this “COOL”????

Combined Information Enhances the Value of the Registry and NCHS data:
- Risk factors (smoking, occupation, etc)
- Cancer Dx/Rx & Cancer screening behaviors
- Other illnesses, insurance, demographics
- Medical examination, genetic information

Be Careful What You Wish For

- Planning with colleagues at the NCHS began in earnest in early 2008 but challenges only grew:
  - Need for interagency agreements between registries and NCHS
  - Data access issues
  - IRB issues
  - $$ for pilot

The “Proof of Concept” Plan
A Stimulating Opportunity

• NCI issues a call for Grand Opportunity (GO) grants in Spring 2009
  – Plan to support 3-5 large projects with budgets of $2-4 million over a 24-month period
  – 2.5 weeks to put together!!!

A Stimulating Opportunity

• Go-Grant Program supports large-scale research projects that accelerate critical breakthroughs, early and applied research on cutting-edge technologies, and new approaches to improve the synergy and interactions among multi and interdisciplinary research teams.

Cancer Registry Linkage Consortium Project
Plans B and C

• Pilot linkage IRB is in place
• Partial funding secured to begin Florida pilot NHIS-FCDS linkage
• Bankhead-Coley Cancer Research Program Competition for Cancer Grants
  – Special Call for Applications for Florida RC1 Grants
    • Eligible?

Questions?