RESEARCH USING A STATE DOH-BASED CENTRAL CANCER REGISTRY – THE NEW JERSEY EXPERIENCE

North American Association of Central Cancer Registries Class on Registry Survival: Bears, Bugs, and Bioterrorists, June 11, 2004

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The New Jersey State Cancer Registry

- population-based cancer registry
- since October 1, 1978
- in the New Jersey Department of Health & Senior Services
- part of the NCI SEER Program and the CDC National Program of Cancer Registries
- NAACCR Gold Medal for data quality for each year of 1995-2001 data
- current through 2002
Why Important to Use Cancer Registries for Research

- Cancer a very important public health problem
- Many facets to cancer that need research
- Cancer registries among the best disease registries – a goldmine of information
- Justifies the existence & resources for cancer registries
- Brings in additional resources and partners
- Improves quality of data, e.g. follow-up
NJSCR Use for Cancer Research

Types of Studies:
- descriptive and etiologic epidemiology
  - case-control
  - linkage with cohorts
  - ecological studies (environmental hazards), e.g. EMFs from rail lines, radium in drinking water
- prevention and control, e.g. screening efficacy
- treatment, e.g. NCI’s Patterns of Care
- survivors, e.g. quality of life
NJSCR Use for Cancer Research (continued)

Role of NJSCR varies:

- provide data
- match another database with NJSCR
- ascertain and consent cases
- fully collaborate – study design, grant preparation, ascertain and consent cases, interview cases, analyze data, publish
- conduct study ourselves
NJSCR Research History

1976-1984 - sole source contract from National Cancer Institute:

- case-control studies - bladder cancer, liver cancer, lung cancer
- descriptive epidemiology - cancer mortality rates
- some collaborative with other SEER areas, others just New Jersey
1984-2003 – collaborative studies:

- NCI case control studies - esophageal & gastric cardia, breast cancer in young women, cancers among blacks, renal pelvis & ureter, male breast, brain, oral & pharyngeal, second primaries (testis, ovary)
- NIEHS & NJ Legislature – lung cancer & residential radon
- NIOSH – comparison of occupational information from different sources
- NAACCR CAIR Subcommittee – gastric cancer
NJSCR Research History (continued)

1984-2003 – (continued):

- ATSDR – case-control study of childhood cancer in Dover Township
- MSKCC – case-control study of melanoma
- ACS – cross-sectional & longitudinal studies of cancer survivors (SCS-I, SCS-II)
- CDC – Use of a Geographical Information System to Assess Late-stage Prostate Cancer Incidence
NJSCR Research History (continued)

Current Studies:

- MSKCC – case-control study of endometrial cancer
- ATSDR – case study of mesothelioma related to asbestos in vermiculite ore from Libby, MT
- CINJ – case-control study of ovarian cancer
- UMDNJ SPH – racial disparity in breast cancer treatment
- NAACCR CINA Deluxe Beta file tests - thyroid cancer, infant neuroblastoma
Research History (continued)

Linkage Studies:

Past:
- NCI National AIDS/Cancer Match Registry – 2 times (arranging for the 3rd)
- occupational cohorts – firefighters, Gulf War veterans
- health insurance and breast cancer outcome

Current/Future:
- SEER-NLMS Record Linkage Study
- CMS Medicare Health Outcomes Survey Linkage
- NCI Radiologic Technologists Study Linkage
Environmental Health Studies using NJSCR:
- osteosarcoma and radium in ground water
- childhood cancer & volatile organics in drinking water
- mesothelioma incidence in Manville, NJ

NJSCR studies:
- GIS & distant stage breast cancer
- case-control study of pediatric leukemia, susceptibility genes, and drinking water contamination
NJSCR Researcher’s Data Base

- data from 1991-1998 with 352,690 cases
- includes ID number, sequence number, county, 5-year age group, gender, race, year of diagnosis, primary site, histology, type of cancer, stage, behavior, laterality, grade, diagnostic confirmation
- available in ASCII and ACCESS formats with documentation, information on the website
- researcher must sign a Public Use Agreement
- available since 10/2001, so far 10 requests
- survey of 9 users in 9/2003 – only 1 responder who did not use it
- rethinking its utility
A Research Strategy

- What do we need?
- What do we have?
- How do we get what we need?
What the NJSCR Has For Research

Data:

- cancer incidence
  - since 1979
  - 45,000 new cases a year, over a million cases
  - high quality
  - racial and ethnic diversity
  - geocoded address at diagnosis
- stage at diagnosis
- survival (vital status follow-up)
What the NJSCR Has For Research (continued)

- **Expertise (flexible, as needed):**
  - epidemiologic – study design and implementation, data analysis, preparation of grant proposals
  - computer – draw samples, match cohorts, set-up databases, data entry and quality control
  - field – rapid case ascertainment, obtain consent, interview over phone or in home
  - administrative support – clerical, IRB approval
Research Infrastructure

- **enabling legislation** - Cancer Registry Statute
- **commitment** to use of the registry for research
- **staff** - epidemiologists, statistician, data analysts, field staff
- **administrative support** - clerical, budget, personnel, legal provided by CES, NJDHSS
- **financial base** – epidemiologists, statistician, computer programmers state or other stable funding, rest funded by research grants
- **computer** – hardware, software, support
- **space** – appropriate, e.g. interview rooms
What Would Strengthen the NJSCR for Research?

- **Staff:**
  - GIS expertise

- **Data items:**
  - Insurance coverage - yes/no if not type
  - Better occupation and industry
  - Information on health habits – smoking, alcohol use
  - Measures of socio-economic status (SES) – income, education
  - Better current address data for follow-back
  - Access to DNA material

- **Computer:**
  - Computerized interviewing systems, e.g. Teleform automated data entry software
Research Budget Considerations

Need to know scope of work & length of time to do it, then can calculate:

- **staff** - grant supported, also usually need in-kind
- **fringe benefits** - set by state, union contract
- **indirect** - usually a negotiated % of salaries, fringe
- **consultants or subcontracts** - may not be allowed
- **travel**: in-state - car buying, car rental, mileage; out of state - to required meetings, for training
- **training** - computer, analytic, may not be allowed
- **equipment** - computers, furniture, may not be allowed
- **supplies** - office, computer
- **other** – phone, computer network & support
Research Challenges

- tension between collecting complete high quality data and using it – when are data good enough?
- judging viable research projects – when to say no or refer elsewhere
- ensuring confidentiality – staff assurances, computer files, hardcopy information
- time – may be short time frame to apply for research funding
Research Challenges (cont.)

- funding requests – enough to do the job well, but not prohibitively expensive
- juggling funding and staff – core permanent experienced staff and temporary/part-time staff
- various funders have different expectations, administrative procedures, budgetary rules
Promotion of Registry for Research

Develop collaborations:

- within health department – vital statistics, birth defects registry, HIV/AIDS registry, environmental health, occupational health, cancer control & prevention, breast & cervical cancer screening program
- with other state departments, government agencies – DEP, NCI, CDC
- with academia – schools of public health, medical schools
- with cancer institutes
- with cancer organizations – NAACCR, ACS
Promotion of Registry for Research (continued)

Be Informed of:
- research interests – researchers, officials
- past/current research

Conduct own research:
- with new tools, e.g. GIS
- of general interest in public health, e.g. disparities
- of specific interest in your state, e.g. radon
- replicate other studies
Promotion of Registry for Research (continued)

Market the registry:

- **assign** knowledgeable staff - to work with interested researchers
- **visit** - potential collaborators
- **mentor students** – part-time/summer jobs, fieldwork projects
- **promote use** of registry
- **promote awareness** among public officials
Promotion of Registry for Research (continued)

- **publish** – data reports, articles in MMWR, peer-reviewed journals
- **presentations/posters** – national professional meetings, local meetings, classes
- **informational materials** – about the registry, bibliography of publications, report on research, data use policy and forms
- **use the web** – put lots of information on your website, especially the above
Abbreviations

ACS – American Cancer Society
ATSDR – Agency for Toxic Substances and Disease Registry
CAIR – Comparative Analysis of Incidence Rates (a subcommittee of NAACCR)
CDC – Centers for Disease Control and Prevention
CINJ – Cancer Institute of New Jersey
CMS – Centers for Medicare and Medicaid Services
DEP – Department of Environmental Protection
GIS – Geographical Information System
MSKCC – Memorial Sloan Kettering Cancer Center
NAACCR – North American Association of Central Cancer Registries
Abbreviations (continued)

NCI – National Cancer Institute
NIEHS – National Institute for Environmental Health Services
NIOSH – National Institute for Occupational Safety and Health
NJDHSS – New Jersey Department of Health & Senior Services
NJSCR – New Jersey State Cancer Registry
NLMS – National Longitudinal Mortality Study
SEER – Surveillance, Epidemiology and End Results
SPH – School of Public Health
UMDNJ – University of Medicine & Dentistry, New Jersey
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