NAACCR Data Use and Research

Holly L. Howe, PhD

Presented at

Registry Survival: Bugs, Bears, and Bioterrorists

June 11, 2004

Salt Lake City, Utah



Introduction

- NAACCR has an annual call for data.
- Data are evaluated for quality in producing accurate incidence rates.
- They are compiled into analytic files to produce:
 - an annual statistical monograph of cancer incidence (CINA/ CIUSHL);
 - an online query system (CINA+ Online);
 - ◆ a data file for cancer surveillance research (CINA Deluxe).

Cancer Incidence in North America (CINA)

- Released annually in April
- Case counts and rates are produced for individual NAACCR member registries.
- Data from registries meeting NAACCR high quality standards are aggregated to produce NAACCR Combined Incidence rates for the United States and Canada.
- Released in three volumes: incidence, mortality, and the combined (including pediatric) rates.
- In 2005 4th Volume: Latinos

CINA+ Online

- Provides incidence counts and rates for high quality NAACCR member registries.
- Accessible by the general public.
- Flexible data formats are available as defined by user.
- Results available in tables, graphs, or maps.
- The system is available on the NAACCR web site at

http://www.naaccr.org/cinap/index.htm

CINA Deluxe

- Data on the file are cumulative with 1995 as a base year;
 - although registries may be included with at least 3 consecutive years meeting NAACCR quality.
- Each registry's data must meet NAACCR high quality data standards for incidence at the time of submission to be included in the file.
- Registries must give consent before data are included in the data set.
- Released only under signed confidentiality assurances and agreements to NAAGCR members

Registry Consenting

- Registries provide consent for each project
- This ensures registries are aware of and maintain control over who will access and use their data & for what purpose.
- Consenting process by email; started as biannual process; now ad hoc as projects approved by NAACCR IRB.

A Word about Consenting

- Not all registries consent, but most do.
- Registries can withdraw their consent any time up to publication submission.
- Registries cannot ADD their consent after initial consenting request/process.
- Issue: requires lots of staff time to follow-up with non-responders in consenting process.

Sad, but True

- Registries did not agree to have data on the analytic file, but later want to be included in specific projects.
- Registries have said "No" when they don't understand project; make false assumptions; and don't ask questions of staff.
- When they learn more about a project, they want their data in it, but it is too late.

Advantages: NAACCR Uses

- Increases use of registry data without additional funding or staff to registry.
- Projects can be added to local lists of data uses and publications.
- Data Improves Through Use (ITU).
- Rich resource to learn about rare events due to large number of cases.
- Meets our mission: Provide more good information to decrease cancer burden.

Examples

- CIUSHL regional variation in incidence among US Latino populations
- Inflammatory breast cancer
- Breast non-carcinomas
- Pediatric ovarian tumors
- Multiple primaries of the ovary
- Urban-rural variation in site-specific incidence
- Race-ethnic variation in ovarian cancer
- Age-specific rates for specific cancer sites for the US

Privacy Use



Balance

- Registry NAACCR: Informed and consent to specific Uses;
- NAACCR → Investigator: Detailed process to access data; limited access; assurances; agreements
- Investigator Registry: Consent; assurance; NAACCR agreement
- NAACCR IRB
- NAACCR Scientific Editorial Board (SEB)

Researcher Access

- Prepare a description of the proposed study
- Obtain approval of the proposal by the appropriate NAACCR committees
- Sign the NAACCR Researcher Agreement Form which defines all parameters for use of the data and adherence and protections for data confidentiality

Researcher Access (2)

- Sign an Assurance Form stipulating agreement to adhere to all rules and provisions regarding the data and their confidentiality
- Submit the proposal to the NAACCR Institutional Review Board (IRB) for approval
- Obtain approval from the NAACCR Scientific Editorial Board for all presentations and manuscripts resulting from the use of the data

NAACCR IRB

- Established in 2002
- Fully compliant with all federal regulations in the protection of human subjects
- Guidelines are extensive and detailed for both the review process and IRB operations
- All materials (applications; guidelines, membership) are available to the public on the NAACCR website

Security

- All the data are transmitted through a secured Internet medium to IMS
- Annually, IMS completes the NAACCR Data Security Inventory which assures us of adequate protections of the data in the physical and electronic IMS environment and that IMS staff are adequately trained and follow secure processes in accessing and using the data.
- All data files remain at IMS and are accessed through a secure Internet clientserver environment.

Security (Cont'd)

- If data need to be exported for analysis in external statistical software, registries are informed and must provide their consent before a researcher takes this step.
- Evaluating tailoring of CINA Deluxe files so researchers will not see data from non-consenting registries (a nonhonor system)

Future Initiatives

- Evaluate data for research uses
- ?Extend research access to non-NAACCR members
- ?Research broker for multi-registry investigator studies
- ?Streamline consenting process
- Special calls for data for various purposes: linkages using identified records; expanding the data set for particular studies
- Generally, facilitating use of cancer registry data by researchers.

Conclusions

- Data are used and uses are increasing.
- Consenting has been less than what we would hope.
- Informed consent and privacy/security processes are well-developed.
- Must continue to meet investigator needs by expansion, process modification, increased data availability.