Thirty-three Years of Rapid Case Ascertainment: Lessons Learned

Dennis Deapen, DrPH
Los Angeles Cancer Surveillance Program

NAACCR Annual Meeting
Cambridge, MA
June 8, 2005
RAPID CASE ASCERTAINMENT (RCA)

- Purpose
- Methods
- Costs/challenges
- Potential additional benefits
- Future directions
RCA ENHANCES RESEARCH

Identification of people newly diagnosed with cancer
- For invitation to participate in epidemiologic and clinical research
RCA ENHANCES RESEARCH

Benefits

- Maximizes participation in population-based research

- Rapidly fatal or debilitating diseases: lung, ovary, pancreas

- Highly mobile populations: younger, oldest, immigrants
RCA ENHANCES RESEARCH

Benefits
- Enhance study quality
- Minimizes recall loss and bias
- Permits prospective research
- Treatment decision-making
- Understanding barriers to treatment
- Quality of life
- Some funding streams require RCA
METHODS

Two-stage reporting
  – Initial report, typically based on pathology report
    ✨ Site
    ✨ Histology
    ✨ Patient identifiers
    ✨ Patient contact information
    ✨ Physician contact information
  – Subsequent report – full abstract
METHODS

Two-stage reporting
- Initial report
  Days or weeks after diagnosis
- Subsequent report – full abstract
  Four to six months after diagnosis, or longer
METHODS

Los Angeles Cancer Surveillance Program

- RCA since 1972
- Four to twelve simultaneous researcher-initiated RCA-based studies
- 100% pathology screening at all hospitals by central registry staff
- Eligibility criteria are screened for all studies simultaneously
METHODS

Los Angeles Cancer Surveillance Program

- All pathology reports for reportable cases are photocopied
- Pathology reports contain little patient identifier and contact information
- For RCA study-eligible reports, patient identifiers and contact information are collected from electronic hospital admission record and written on report
METHODS

Los Angeles Cancer Surveillance Program

– Every hospital screened at least monthly
– Pathology reports hand-delivered to central registry at least weekly
– Staff enters diagnosis and patient data into RCA database, assigns unique identifier barcode
– Copies of RCA study-eligible pathology reports hand or overnight delivered to investigator
METHODS

Los Angeles Cancer Surveillance Program
- Timeliness monitoring
  - Review weekly report
    - Overall
    - By study
    - By steps in the process
    - More detailed reports available by
      - Hospital
      - Field abstractor
METHODS

Los Angeles Cancer Surveillance Program
– Typical results (days):
  - Path date to ascertainment by field technician: 20
  - Ascertainment to delivery to central registry: 4
  - Delivery to central registry to delivery to investigator: 4
  - Overall: 28
COSTS

- About $22 per delivered pathology report
- Average 1.5 pathology reports per diagnosis
- Cost covered in investigators research funding
In Los Angeles, cases not found in hospital pathology files are not included due to:
- Other hospital databases not screened
- Lack of patient contact information
- Free-standing pathology laboratories
- Late in casefinding process
- Physician-only
- Out of catchment area
- DC only
CHALLENGES

- Difficult to staff and manage, if not continuous
- Difficult to understand reasons for ~15% invalid addresses
CHALLENGES

- Too rapid?
  - Prior to notification of diagnosis to patient?
- 28 day average from pathologic diagnosis to delivery to investigator
- Investigator must contact physician and either
  - Receive permission
  - Wait two weeks
- California policy: Investigator must wait six weeks from pathology date before contacting patient
BENEFITS

Los Angeles performs 100% pathology screening

Continuous casefinding audit enhances:
  – Completeness of routine reporting
  – Timeliness of routine reporting
BENEFITS

- Expands public health value of the registry
- Provides desirable research potential for local investigators
- Provides revenue streams for registry
- Provides justification for registry funding
BENEFITS

Extremely popular among cancer patients

- Thousands are contacted annually in Los Angeles
- Opportunity to “fight back” or, at least, benefit others
- Low refusal rate
FUTURE DIRECTIONS

Epath

- Relatively expensive initially
- Less costly than manual casefinding, especially including travel time
- Offers very fast and efficient RCA capability
- Can assist hospital registrars in casefinding
- Protects confidentiality and enhances HIPAA compliance
SEE OUR POSTER!

Donna Morrell can answer questions

P-39