

NAACCR Method to Estimate Completeness

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Who's on the Webinar?

- If epi or statistics – raise your hand
- If registry operations – raise your hand
- Only handle data going in to the registry– raise your hand
- Only handle data coming out of the registry – raise your hand

The logo for NAACCR (North American Association of Central Cancer Registries) is located in the bottom right corner. It features the acronym "NAACCR" in a bold, blue, serif font. A red swoosh underline is positioned beneath the letters "A", "A", and "C".

NAACCR Evolution of High Quality Incidence Data

- 1987-1994: Membership criteria
- 1992-3: Inclusion in Cancer in the USA (estimate of 95% complete)
- 1994: Inclusion in NAACCR Combined rates (combo metrics)
- 1996: NAACCR estimate of completeness
- 1997-98: other metrics added
- 1999: Registry Certification criteria met for each year of data
- 2000-01: Tweaked algorithm
- 2006: Another tweak



Estimating Completeness

Background: Before 1994

- Use age-specific cancer rates from SEER as *expected* age-specific rates.
- Apply the expected age-specific cancer rates to the age groups in the population.
- Compute the estimated number of cases for the whole population.
- Compare with the observed number of cases.
- $O/E * 100 = \text{Percent Complete}$

Problems with Age-specific Method

- Assumes age-specific cancer rates are the same everywhere.
- This model does not accommodate true differences in cancer incidence rates.
- Regional differences in screening, tobacco use, in other exposures and cancer profiles are known and they affect the magnitude of age-specific rates.

Important Definition: IMRR

- I = Incidence
- M = Mortality
- RR = Rate Ratio
- Rate = case count per 100,000 population at risk
- Thus, the relationship of the incidence rate to the mortality rate, that is age adjusted.
- Age-adjusted – removing the effect of age on the resulting rate to facilitate comparisons after removing impact of age differences.

Example IMRR

- Age-adj. Incidence Rate = 138.4
- AA Mortality Rate = 29.0
- $IMRR = 138.4/29.0$
- $IMRR = 4.77$
- Looking at these numbers can you guess the cancer site?

Breast cancer

White females in New Jersey
during 1999-2003

* In white males, the IMRR is
 $1.4/0.5 = 2.8$

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Example 2 IMRR

- Age-adj. Incidence Rate = 7.7
- AA Mortality Rate = 5.5
- $IMRR = 7.7/5.5$
- $IMRR = 1.4$
- Looking at these numbers can you guess the cancer site?

Liver cancer

White males in New York, 1999-2003

* In white females, IMRR is
 $2.5/1.9=1.3$

What does the IMRR measure?

- The case fatality, case fatality rate
- The number or rate of persons with a disease that die from the same disease (incidence/mortality; case/death)
- An indicator of survival – how long does one live after being diagnosed with a disease?

NAACCR Method to Estimate Completeness

- 1993-1995 development period
- Based the estimate on the mortality
- Assumes stable I/M rate ratios
 - ◆ A stable case fatality
- Specific sites are included and weighted
- Stratified by gender
- Omits screening-sensitive sites: unstable case fatality (breast and prostate)
- Based on white population



Rationale for Choices in the Algorithm

- Accounts for:
 - ◆ true variation in cancer burden (mortality differences),
 - ◆ differences in males and females,
 - ◆ differences in the magnitude of different cancers in the population.
- Using white population only minimized race misclassification & Census undercounting errors

Go to Worksheet 1

- Compute the IMRR for WM and WF for oral, esophagus, stomach, and colon-rectum
- Take five minutes and write down your answers

.....

- Review answers

Choose a standard

- Need to choose a standard IMRR
- If we really knew expected incidence, we wouldn't have to go through all this estimating
- In early 1990s – SEER incidence was gold standard for complete data

- Also need a stable – reliable IMRR
- SEER mortality rates highly variable from year to year

Assumptions in NAACCR Model

- The standard IMRR is stable
 - ◆ 5-year-average annual SEER incidence : 5-year-average annual US mortality in white population
- Case fatality is the same everywhere
 - ◆ Ratios of SEER incidence rate to US mortality rate are similar to those found in all white populations in No. America

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Exercise 2: Computing Expected Incidence

$$IR_{SEER}/MR_{US} = IR_{state}/MR_{state}$$

$$[IR_{SEER}/MR_{US}] * MR_{state} = IR_{state}$$

Get Standard IMRR

- If 50.52 is the SEER AAIR in WM;
- 20.13 is US mortality rate in WM
- IMRR standard is $50.52/20.13 = 2.51$

Getting Expected Incidence ...

- Because case fatality is stable, apply the standard IMRR (e.g., 2.51) to the mortality in the state/province for the 5-yr. period.

E.g., state mortality rate in WM is 22.3.

- So multiply standard IMRR (2.51) by the mortality rate of 22.3
- $22.3 * 2.51 = 55.97$ expected incidence rate for WM

Go to Worksheet 2: Computing Expected Incidence

- Calculation is site-specific
- Site-specific percents can be computed
- This is only an intermediate step – not the final answer
- Model never tested for site-specific estimation accuracy
- Robustness for total estimate only

Worksheet 2

- Compute expected incidence for oral, esophagus, stomach, and colon and rectum
- Take 5 minutes

- Review Answers

Identify cancer sites

- Within each sex, identify common cancer sites to be included
- IMRR for that site must also be stable
- Impact of screening variation will impact IMRR and resulting estimate of completeness
- Early – avoid prostate and breast
 - ◆ 15 sites in males
 - ◆ 18 sites in females

Expected Total Incidence

- Repeat computations for each cancer site for both white males and white females.
- Sum across all sites and both sexes to get an expected rate for the registry.

Observed Incidence rates ...

- For the same time period, insert the observed incidence rate for each site in the algorithm for both white males and white females.
- Sum all the observed rates.
- Finally compare the observed rate with the expected rate & multiple by 100 (to get % complete)

Thus

- Total expected IR in WM = 258.48
- Total observed IR in WM = 248.95
- Divide Observed by Expected, then multiple by 100 = Percent complete
- $O/E * 100 = \% \text{Complete}$

$$248.95/258.48 = .9631$$

$$.9631 * 100 = 96.31\%$$



Go to Worksheet 3

Computing Completeness

1. Add Expected Incidence for sum of WM
2. Add observed incidence for sum of WF
3. Add male and female totals for AW
4. Compute $(O/E * 100)$ for each row to get the site specific completeness estimate

Obtain Weighted Expected

- Compute each site-specific expected incidence rate
 - ◆ Weighted by site frequency
- Sum within sex-race groups
- Weight by gender distribution

From CINA* Inclusion to Registry Certification

- Evaluating one year of data, not five
- Use the standard I/M rate ratio (IMRR) based on five-years of data, BUT
- Apply the standard to the two most recent years of mortality (current year and the one previous)
- When the population is <500,000, apply standard to three years of mortality



*Cancer in North America

CINA* Combined Criteria

- Must meet GOLD registry certification criteria for each year in the five-year interval.
- Criteria will be used for CINA, CINA+ Online, and CINA Deluxe.
- Inclusion criteria later relaxed to require Silver certification only.

*CINA= Cancer in North America



But what if

- More white people in your area die because they don't get diagnosed until later stage than what occurs in the SEER area?
- Or fewer white people in your area die because for some reason they are more likely than SEER to get early Dx and state-of-the-art Rx.
- If either true, case fatality is affected; thus expected incidence affected and the estimate of completeness

Ex. of differing case fatality ...

- In your registry, you see that 40% of WM colorectal cases are diagnosed in late stage. In SEER it is 33%.
- Case fatality will be higher in your area than in SEER.
- This will give you a higher estimate for expected incidence, and ...
- a lower estimate of completeness.

Case Fatality Assumption Violated

- From 1998-2000, it appeared that the completeness estimates were inflating.
- Was declining national cancer mortality causing error in completeness estimating algorithm?
- And if so, did it differ by region?

Evaluation led to Changes

- SEER11 used for the standard incidence in the I/M rate ratio
- Added female breast cancer to the model
- Added data for black pop. to the model
- Introduced an allowance for variation in case fatality
- Weighted final estimate by sex

Considerations for Blacks

- Weight result for blacks and whites in direct proportion to population
- E.g., 85% white; 15% black then results get weighted by .85 for whites and .15 for blacks
- Same principle applied to sexes

Rationale for Adjustments

- Adjust for variation in case fatality
- Cancer mortality declining since 1992
- Rate of decline is NOT the same everywhere
- Thus case fatality assumption is violated
- Thus not all incidence estimate is directly related to mortality

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Case Fatality Adjustment Questions

- How much of the variation in mortality should reflect the variation in incidence?
- How much of the variation is due to other factors (like later stage of disease, inadequate treatment)?
- How much represents the true differences in incidence?

Case Fatality Adjustments pg 1

- Examine 5-yr US mortality rate.
- Compare this with the 5-yr state/province mortality rate.
- $\text{US mortality} / \text{State mortality} = ?$
 - ◆ < 1.0 if US mortality is higher
 - ◆ > 1.0 if state mortality is higher
 - ◆ 1.0 if both are the same

Case Fatality Adjustments pg 2

- If ratio = 1.0; no adjustment
- If ratio > 1.0; adjust difference by .20 (i.e., only 80% of the higher state mortality is attributable to true differences in incidence; 20% is higher case fatality).
- If ratio < 1.0; adjust difference by .20 (i.e., only 80% of the lower state mortality is attributable to true differences in incidence; 20% is lower case fatality).

Case Fatality Adjustments pg 3

- If not = 1.0, adjust 2-yr state mortality rate
- Ex. US-5yr-mortality = 3.65; state-5yr-mortality = 3.71; ratio is not 1.0
- $3.71 - 3.65 = 0.06$
- Adjust difference by 0.20 (= .012)
- 2-yr mortality is 3.85; adjusted mortality is $3.85 - 0.012 = 3.838$ adjusted 2-yr mortality

Case Fatality Adjustments pg 4

- Evaluate mortality ratios for each site within each sex-gender group using the method described above.
- Use the adjusted 2-year mortality to compute expected incidence

Go to Completeness Template

In Excel on Laptop

Open File:

case.completeness.1995-03.v22b.xls

Save as: [newname.xls]

“ _____03.xls”



Review of Completeness Template Worksheets

- Go to Worksheet Registry Info
- Insert year -- 2003
- Insert State name – check changes for populations
- Finally choose _____
- Insert duplicate rate -- .003 or 0.3%

Review of Template Sheets

- Go to “Completeness report”
- Note Registry information is carried forward.
- Still blanks where calculations will be carried over.
- This is the summary page that will give final estimate.

Template Worksheets

- Other tabs – worksheet for whites, blacks
- Instructions – when you are on your own
- Documentation of columns in the white and black worksheets
- Adjustment information – 0.20 – which can be changed and will automatically change the worksheet formula
- Population table by registry and year
- SEER incidence data for all periods

Go to Instructions Notes:

- 1 The spreadsheet has been loaded with information from the SEER Incidence and US Mortality cancer databases.
- 2 SEER and US Mortality rates may be suppressed due to publication schedules.
- 3 Cancer rates throughout the spreadsheet are per 100,000 and are age-adjusted to the 2000 U.S. population standard.
- 4 The cancer rates for Male Prostate (Whites and Blacks) and Melanomas of the Skin (Blacks) are not included in the completeness estimate computations.
- 5 The areas requiring information from the Registry are highlighted in yellow.
- 6 The Adjustment Terms have been set to .2 and .2.



Instructions:

To obtain an estimate of the completeness of case ascertainment for your registry, perform the following steps:

A: Preliminary Steps:

A1. Calculate the total number (count) of reportable cases for your registry for the reporting year. For ___ = _____

A2. Complete the NAACCR Duplicate Record Protocol on a sample of all reportable cases. For ___ = _____%



Go to Worksheet 4

Start with White Male

Oral cavity ...

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Go back to template
Make copy for your registry ...
Insert data that you brought

If you don't have data,
complete the _____
example with data
for WF, BM, & BF

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Template

- Updated annually
- Released in April (after embargo lifted on the Standard IMRRs)
- Before a call for data, you can estimate your new completeness using last year's STANDARD IMRR

2006 Modification

- Breast cancer has been dropped from the model again
- Declines in incidence are occurring
- Case fatality assumption is again violated for this site; declines are not the same everywhere.

Any questions?

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