Downstream from the Registry
A User’s Perspective

Nathan R. Jones, PhD
UW Carbone Cancer Center
Desire to reduce the burden of cancer

- Registry allows us to answer the question: “Are we on the right track?”

- Most relevant source for improving public health is population-based data.

- Obligated by state and national public health agencies to record and report.
Age-adjusted mortality

Source: Wisconsin Interactive Statistics on Health (WISH)
Years of Potential Life Lost

Source: WISH
Leading Causes of Death, 2008

Heart Disease: 11,272 people per year
Cancer: 11,120 people per year

Other causes:
- Stroke
- Respiratory diseases
- Accidents
- Alzheimer's
- Diabetes
- Flu/pneumonia
- Kidney disease

Source: Wisconsin Interactive Statistics on Health (WISH)
Leading Causes of Death, 2009

- **Cancer**: 10,845 people per year
- **Heart Disease**: 10,794 people per year
- **Other Causes**:
  - Stroke
  - Respiratory diseases
  - Accidents
  - Alzheimer's
  - Diabetes
  - Kidney disease
  - Flu/pneumonia

Source: Wisconsin Interactive Statistics on Health (WISH)

30 people per day
HD vs Cancer Difference in 2009

51 deaths
New cases of cancer

Source: Wisconsin Cancer Facts and Figures (2011) and Wisconsin Cancer Reporting System
New cases of cancer

Source: Wisconsin Cancer Facts and Figures (2011) and Wisconsin Cancer Reporting System
Who is using WCRS data?

• Wisconsin Comprehensive Cancer Plan 2010-2015 uses registry data to track progress.

• DCIS – Trentham-Dietz (UW-Madison)

• WICaRE WI Cancer Registry Evaluation – Wilson (MCW)

• PLCO Cancer Screening Trial – Greenlee (Marshfield)

• ACS, Komen, other organizations
A demographer worries...

• What could go wrong?
  – Completeness of information
  – Timeliness of reports
  – Non-random variation in data quality
How big could the impact be?

- Delayed reporting
- Unstaged tumors
- Missing race identifiers
How big could the impact be?

- Delayed reporting
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New cases of cancer
New cases of cancer

Source: Wisconsin Cancer Facts and Figures (2011) and Wisconsin Cancer Reporting System
Incidence rates by data source

Source: Wisconsin Cancer Facts and Figures publications and CDC WONDER
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State Cancer Facts

Wisconsin

In 2007, according to the United States Cancer Statistics:

- 1,455,611 new cancer cases were diagnosed in the United States, including 26,703 in Wisconsin.
- 562,867 cancer deaths occurred in the United States, including 10,963 in Wisconsin.

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For every 100,000 men and women in Wisconsin, on average, approximately 440 were diagnosed with cancer and approximately 178 died from it.

For more information about top 10 cancers in Wisconsin

- [New cancer cases by gender](#)
- [Cancer deaths by gender](#)
State Cancer Facts

Wisconsin

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Motivation

Examples

Worries

Illustrations

Summary

Questions

State Cancer Facts

Wisconsin

In 2007, according to the United States Cancer Statistics:

- 1,455,611 new cancer cases were diagnosed in the United States,† including 26,703 in Wisconsin.
- 562,867 cancer deaths occurred in the United States,‡, including 10,963 in Wisconsin.

New Cancer Case (Incidence) Rates†

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Cancer Prevention and Control

State Cancer Facts

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| Death Rates‡ | Area         | Rate |
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| Wisconsin    | 178.2        |
| United States| 178.1        |

For every 100,000 men and women in Wisconsin, on average, approximately 440 were diagnosed with cancer and approximately 178 died from it.

For more information about top 10 cancers in Wisconsin
- New cancer cases by gender
- Cancer deaths by gender
State Cancer Facts

Wisconsin

In 2007, according to the United States Cancer Statistics:

- 1,455,611 new cancer cases were diagnosed in the United States;
- 562,867 cancer deaths occurred in the United States*, including Wisconsin.

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For every 100,000 men and women in Wisconsin, on average, approximately 440.2 new cancer cases were diagnosed, compared to 465.1 in the United States.

For more information about top 10 cancers in Wisconsin:
- [New cancer cases by gender](#)
State Cancer Facts

Wisconsin

In 2007, according to the United States Cancer Statistics:

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For every 100,000 men and women in Wisconsin, on average, approximately 448.2 new cancer cases were diagnosed.

For more information about top 10 cancers in Wisconsin:
- [New cancer cases by gender](#)
State Cancer Facts

Wisconsin

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For every 100,000 men and women in Wisconsin, on average, approximately 484 new cancer cases were diagnosed in 2007.

For more information about top 10 cancers in Wisconsin, see:
- New cancer cases by gender
How big could the impact be?

- Delayed reporting
- **Unstaged tumors**
- Missing race identifiers
Malignant and in situ trends, 1995-2008

Source: WCRS
Malignant and in situ trends, 1995-2008

Source: WCRS
Female breast, by stage

- **Local**
- **Regional**
- **Distant/Systemic**
- **Unknown, Unstaged**

Source: WCRS
Female breast, by stage and race

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Female breast, by stage and race

-15 -24 -45 -48 -47

Source: WCRS
Female breast, by stage and race

Source: WCRS
How big could the impact be?

- Delayed reporting
- Unstaged tumors
- **Missing race identifiers**
Unreported race as a proportion of all cases

Source: WCRS
Unreported race as a proportion of all cases

Source: WCRS
Non-white race as a proportion of all cases

3.7% → 5.4%

Source: WCRS
Unknown race ratio to non-white cases

19.8% → 47.3%

Source: WCRS
How big could the impact be?

- Unknown cases ratio to American Indian cases
  - 2:1 in 1999
  - 4:1 in 2007
  - Same for Asian/OPI
Setting health priorities

• Data quality is essential to setting appropriate health goals and measuring progress towards meeting them.

• Even small data problems can be problematic, especially for sub-populations.

• Late reporting can lead to difficulties determining trends.
Setting health priorities

- How many cases *over 5 year period* does it take to flip a county from over or under the state average incidence rate?
Cancer incidence, 2004-2008
Cancer incidence, 2004-2008
<50 cases over 5 years would flip the county!
Take home

- **THANK YOU** for all your hard work
- Every **CASE** matters
- Every **PART** of every case matters
- Demographers **love** to count and worry
Questions?

Contact information

Nathan R. Jones, PhD
Wisconsin Comprehensive Cancer Control Program

nrjones@uwcarbone.wisc.edu
608-265-8780