



# **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:

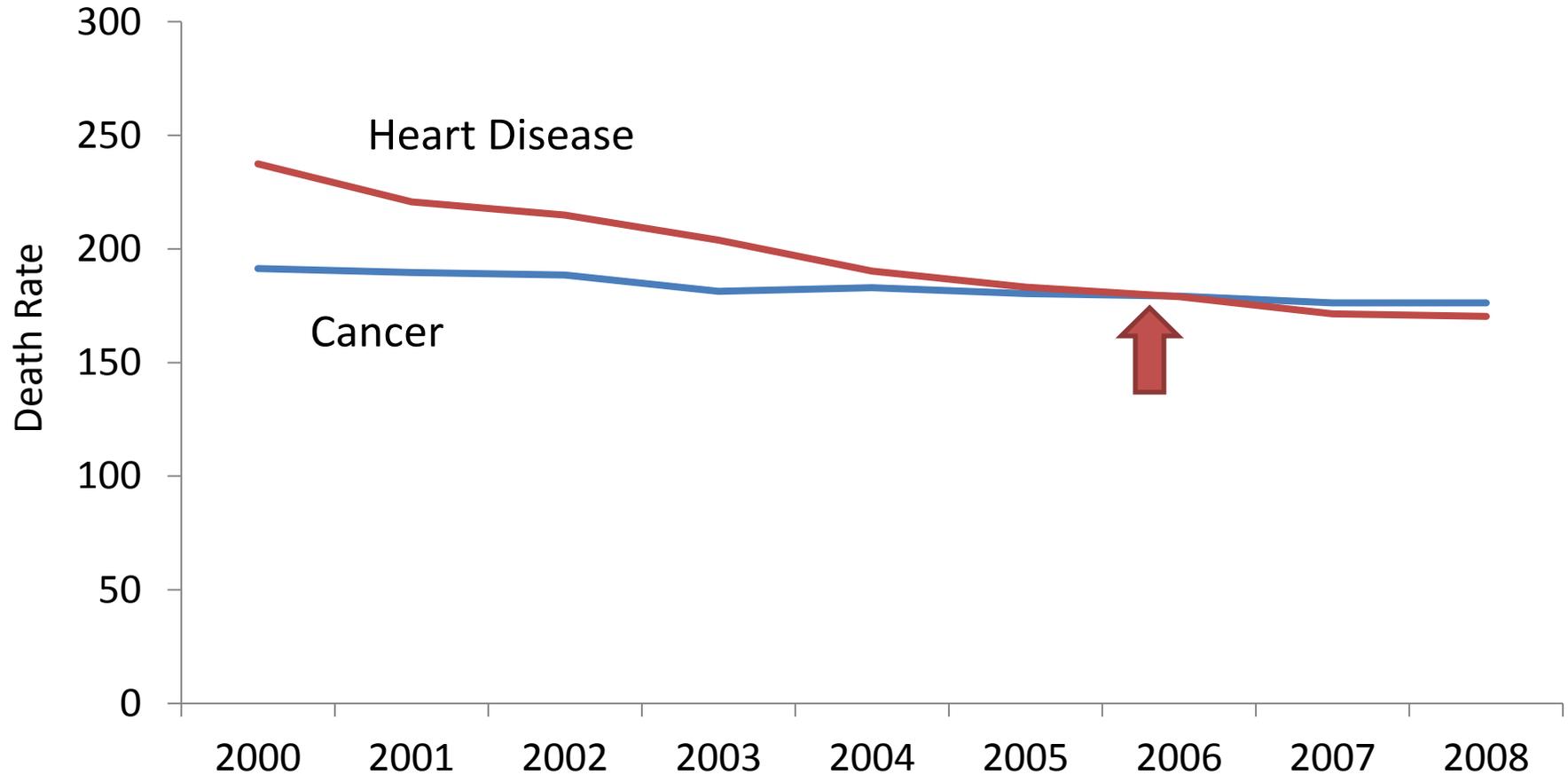
**“Are we on the right track?”**



- Most relevant source for improving public health is population-based data.
- Obligated by state and national public health agencies to record and report.

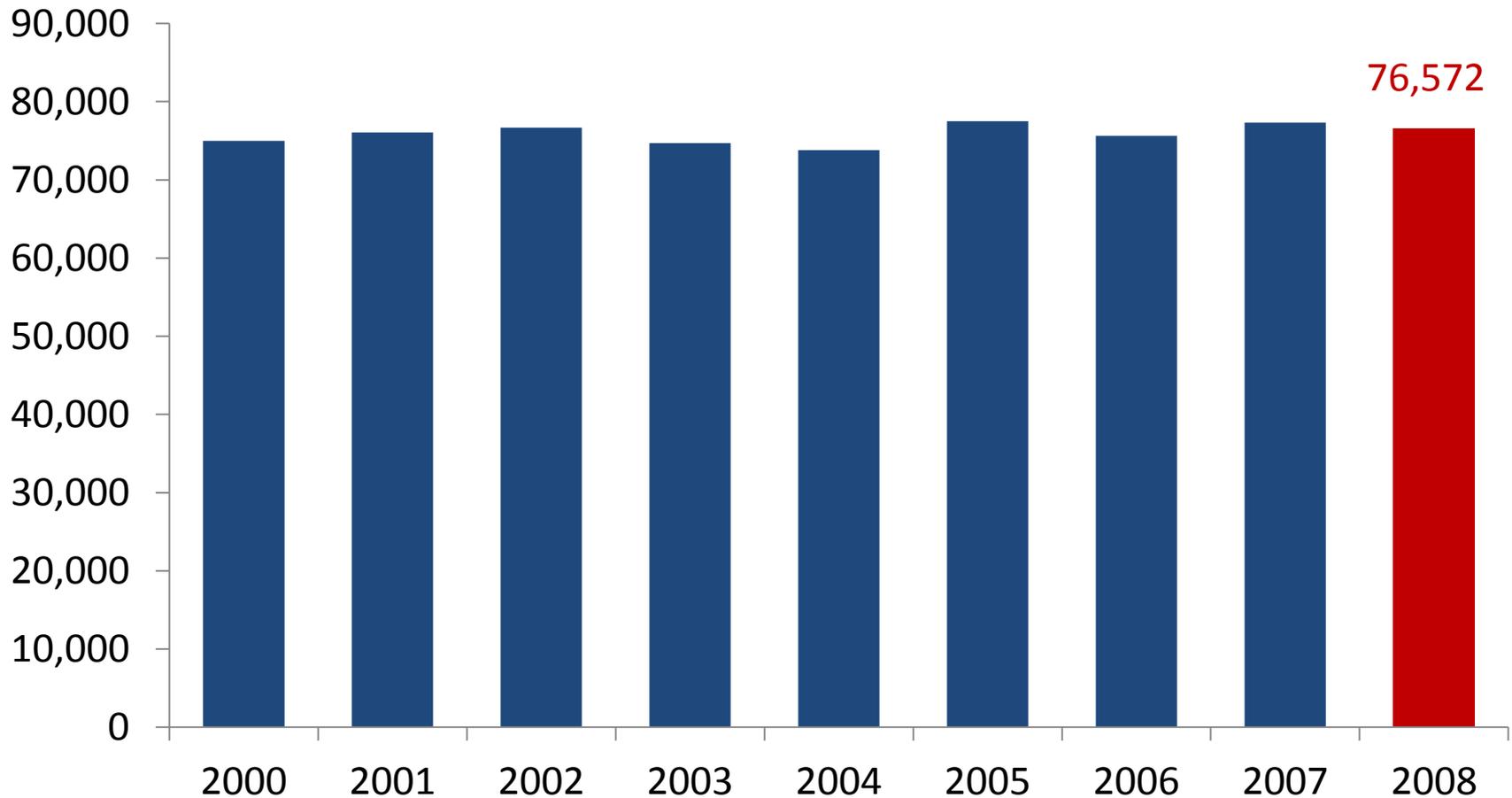


# Age-adjusted mortality



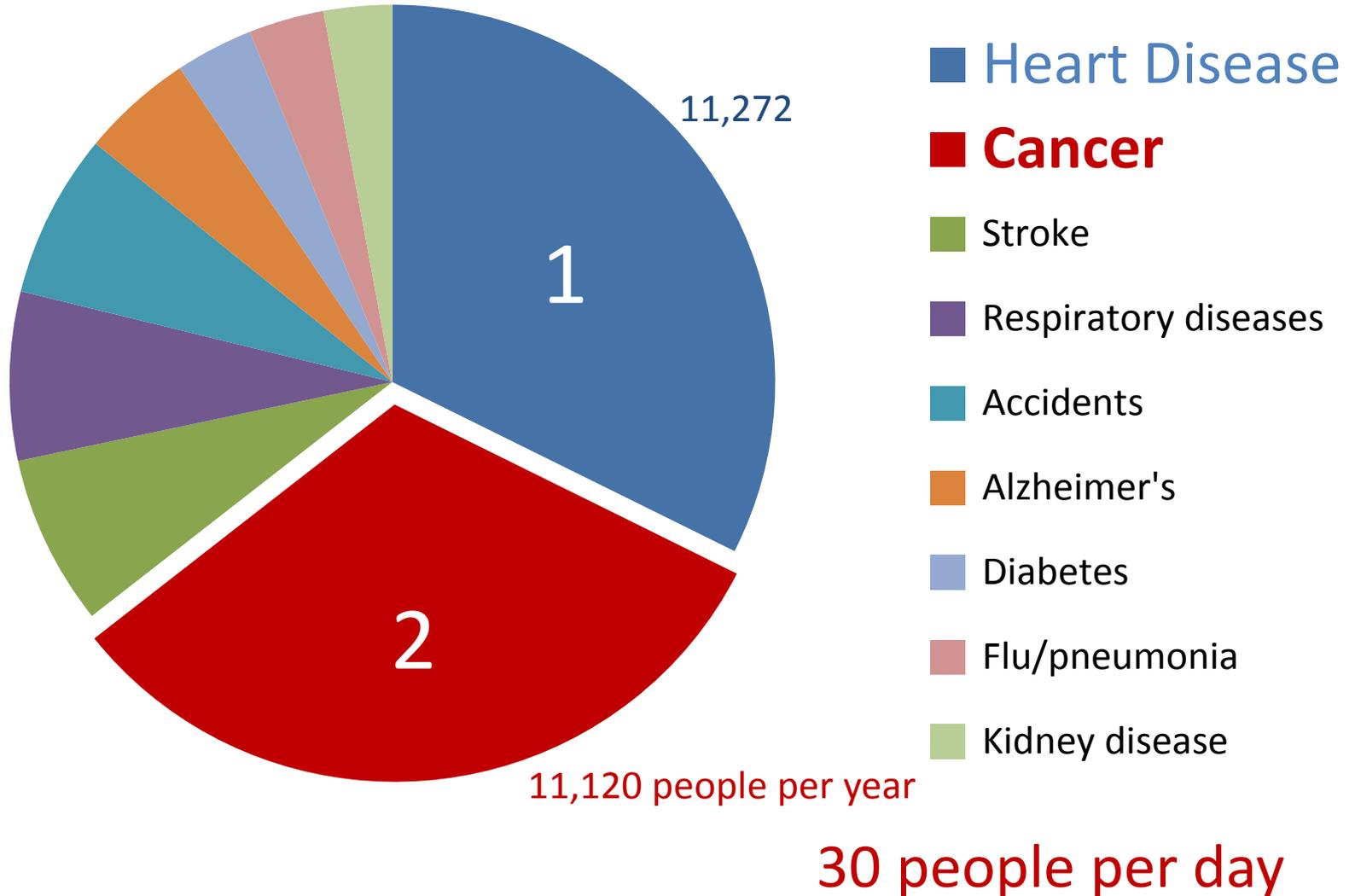


# Years of Potential Life Lost



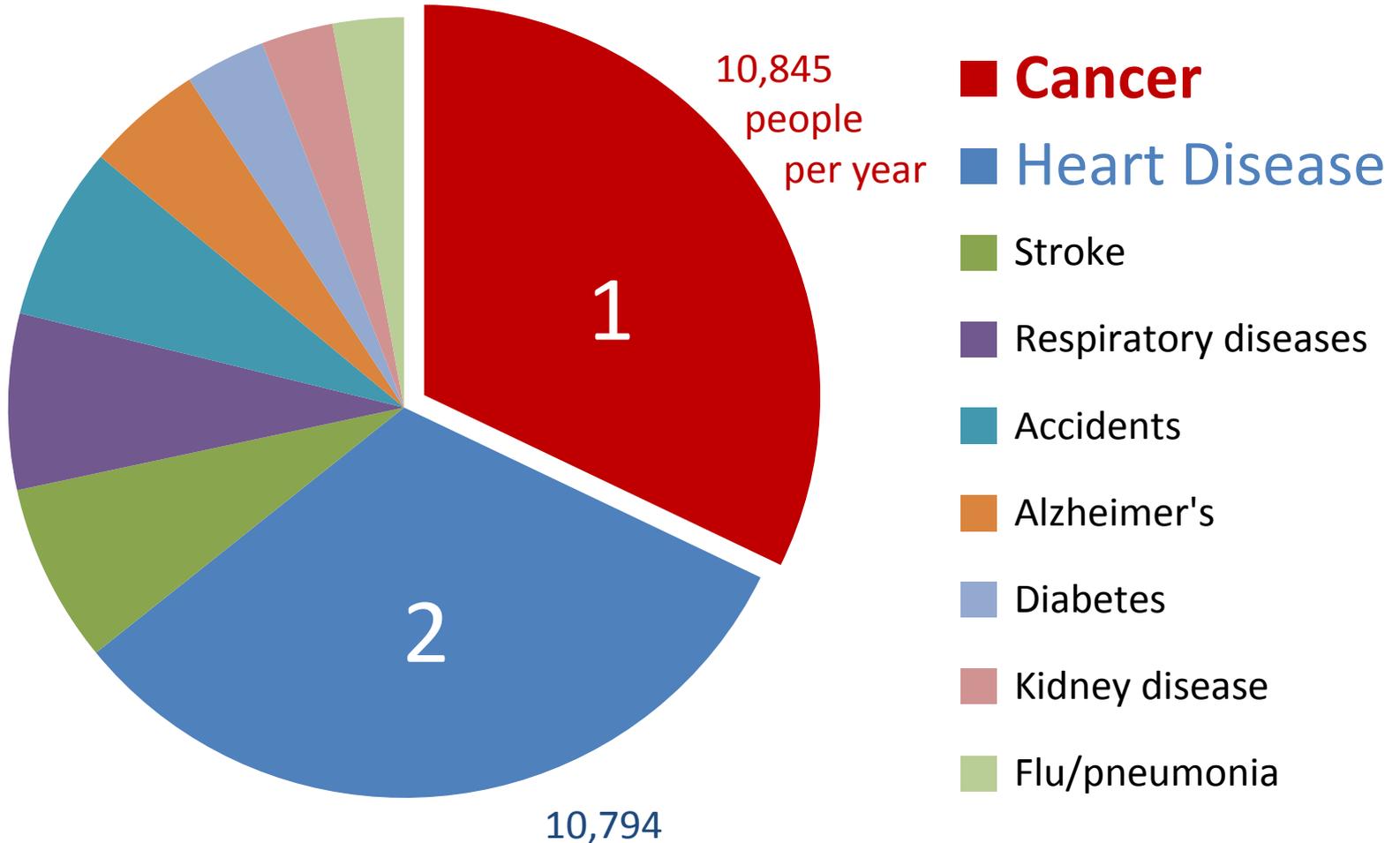


# Leading Causes of Death, 2008





# Leading Causes of Death, 2009



30 people per day

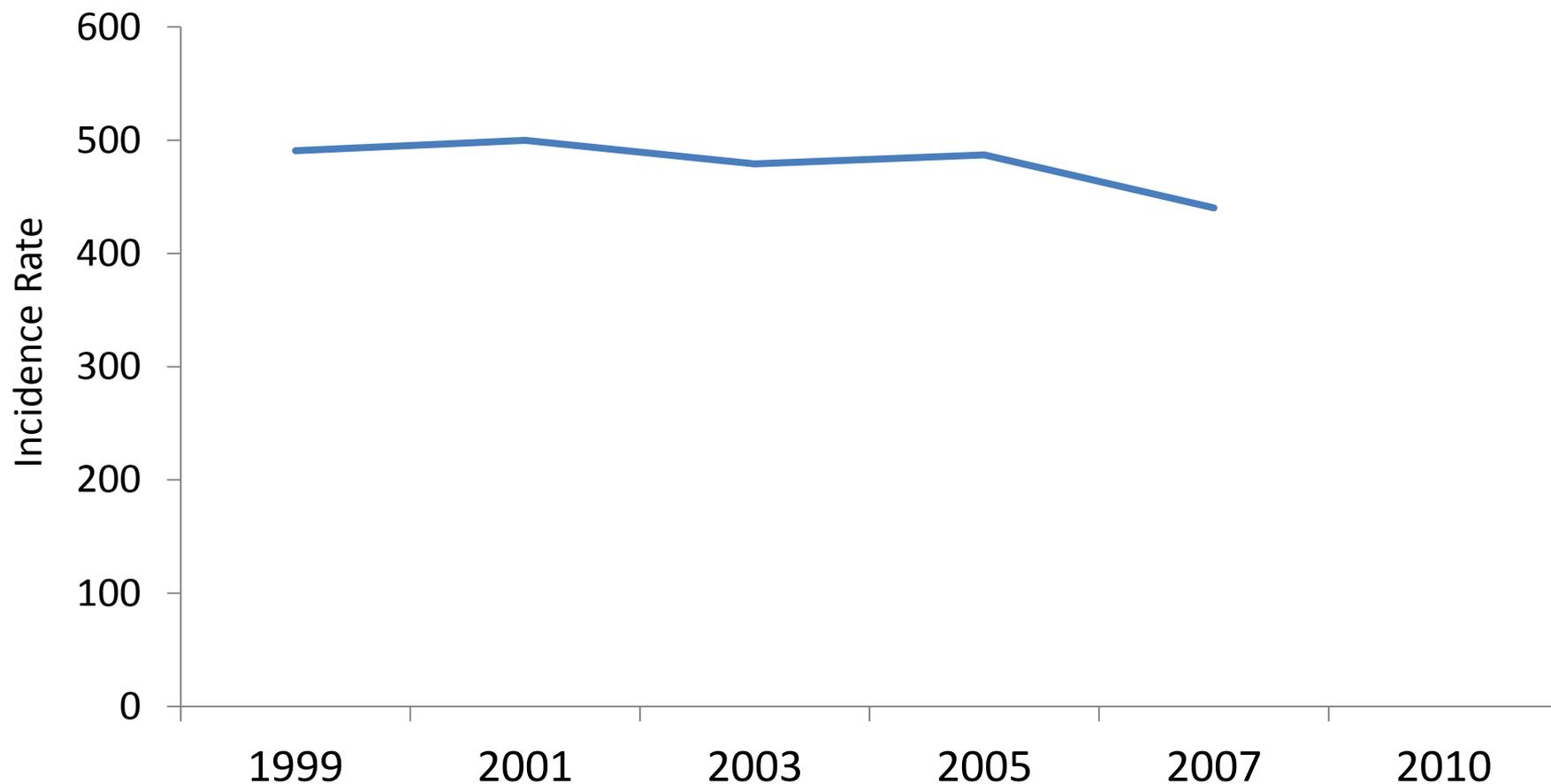


# HD vs Cancer Difference in 2009

51 deaths

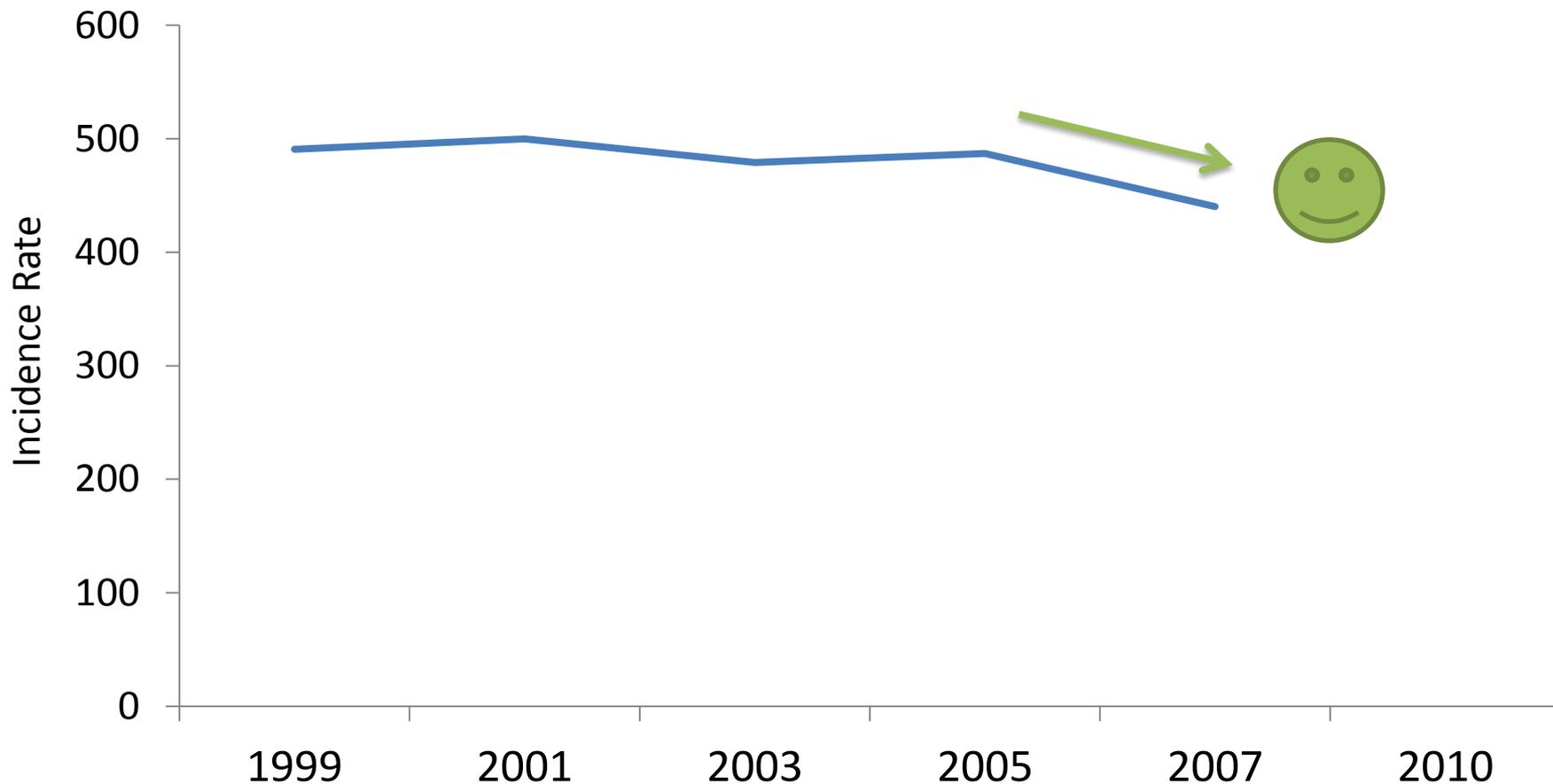


# New cases of cancer





# New cases of cancer





# 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



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Motivation

Examples

Worries

Illustrations

Summary

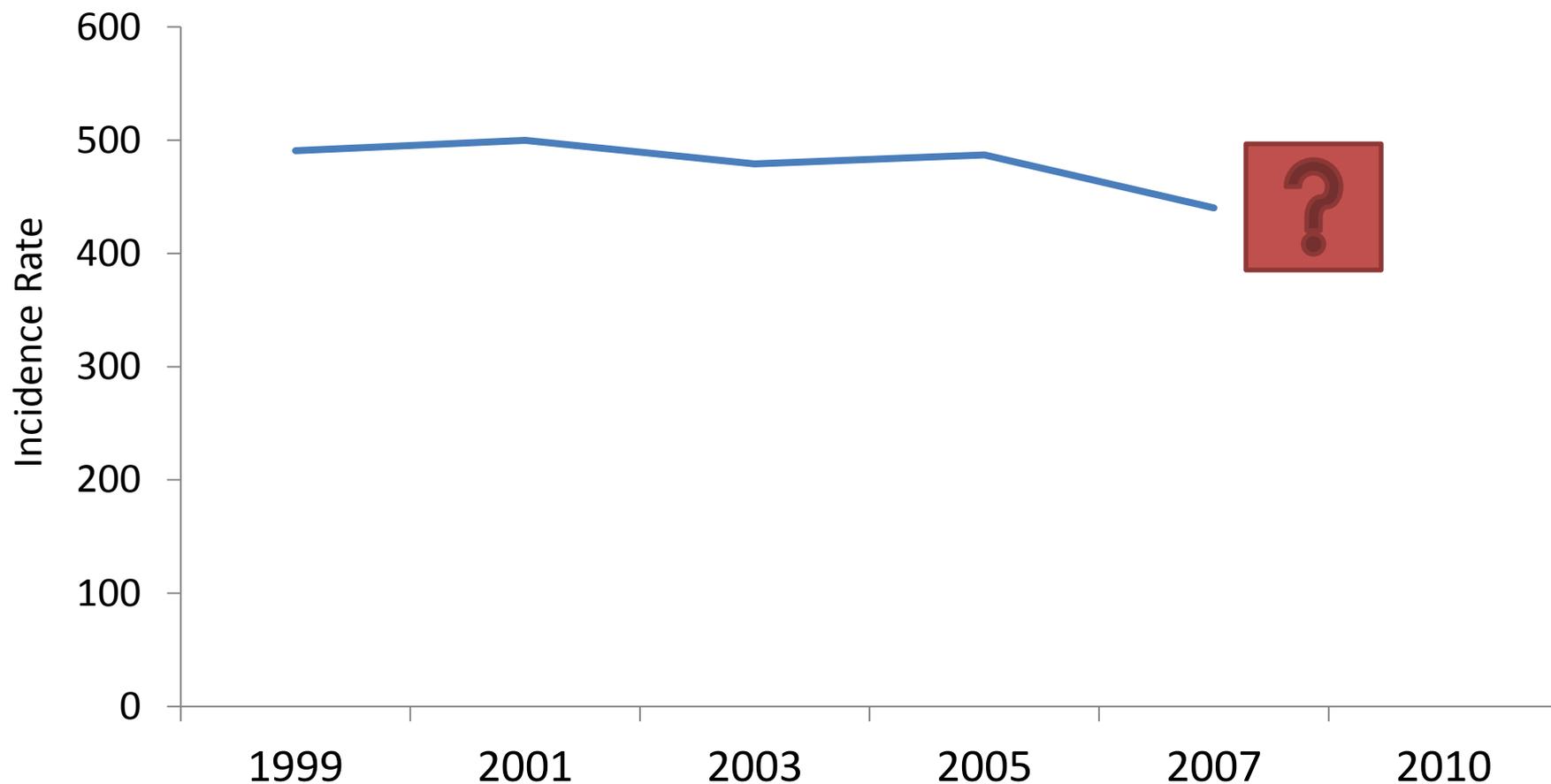
Questions



# New cases of cancer

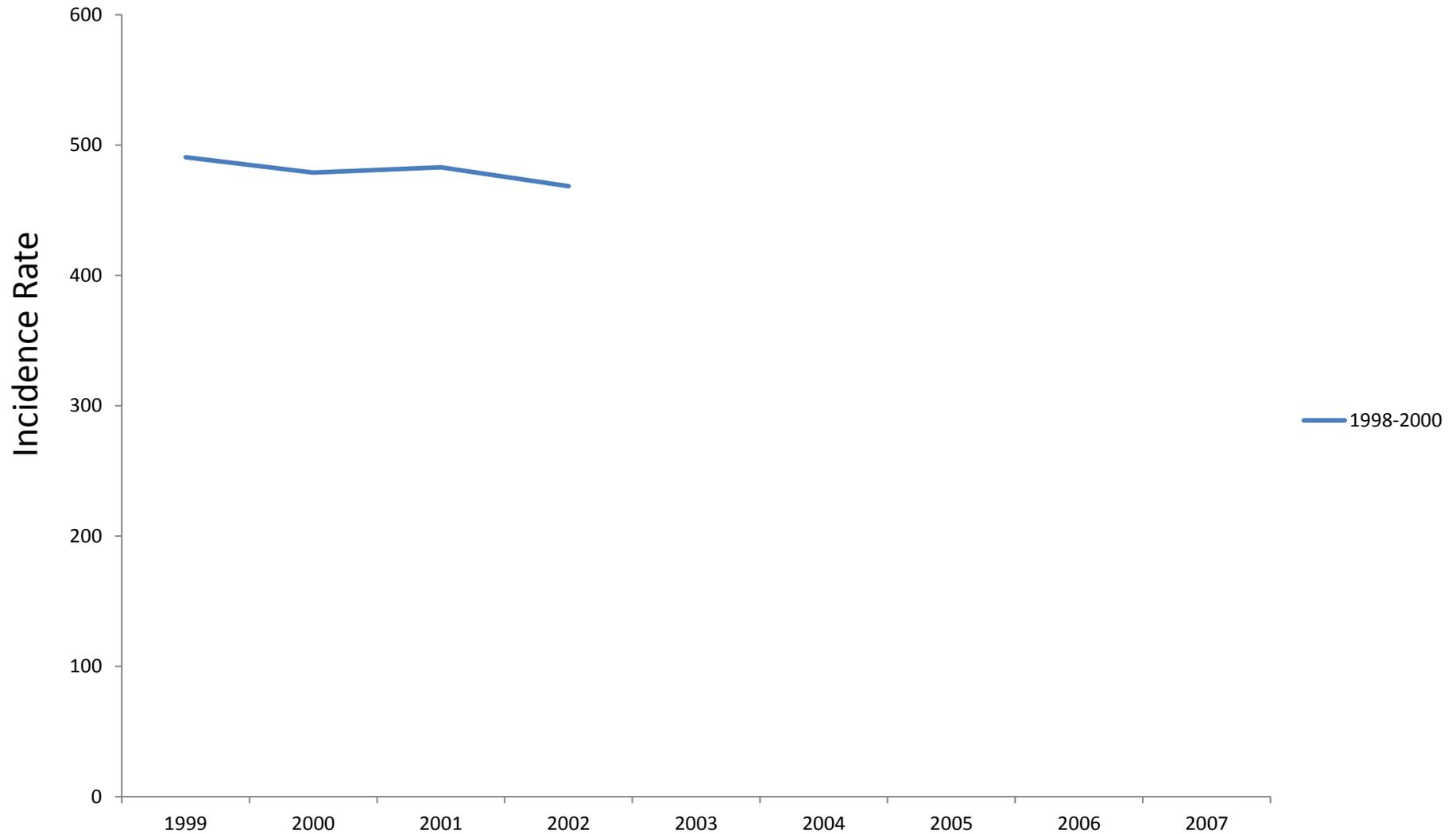


# New cases of cancer





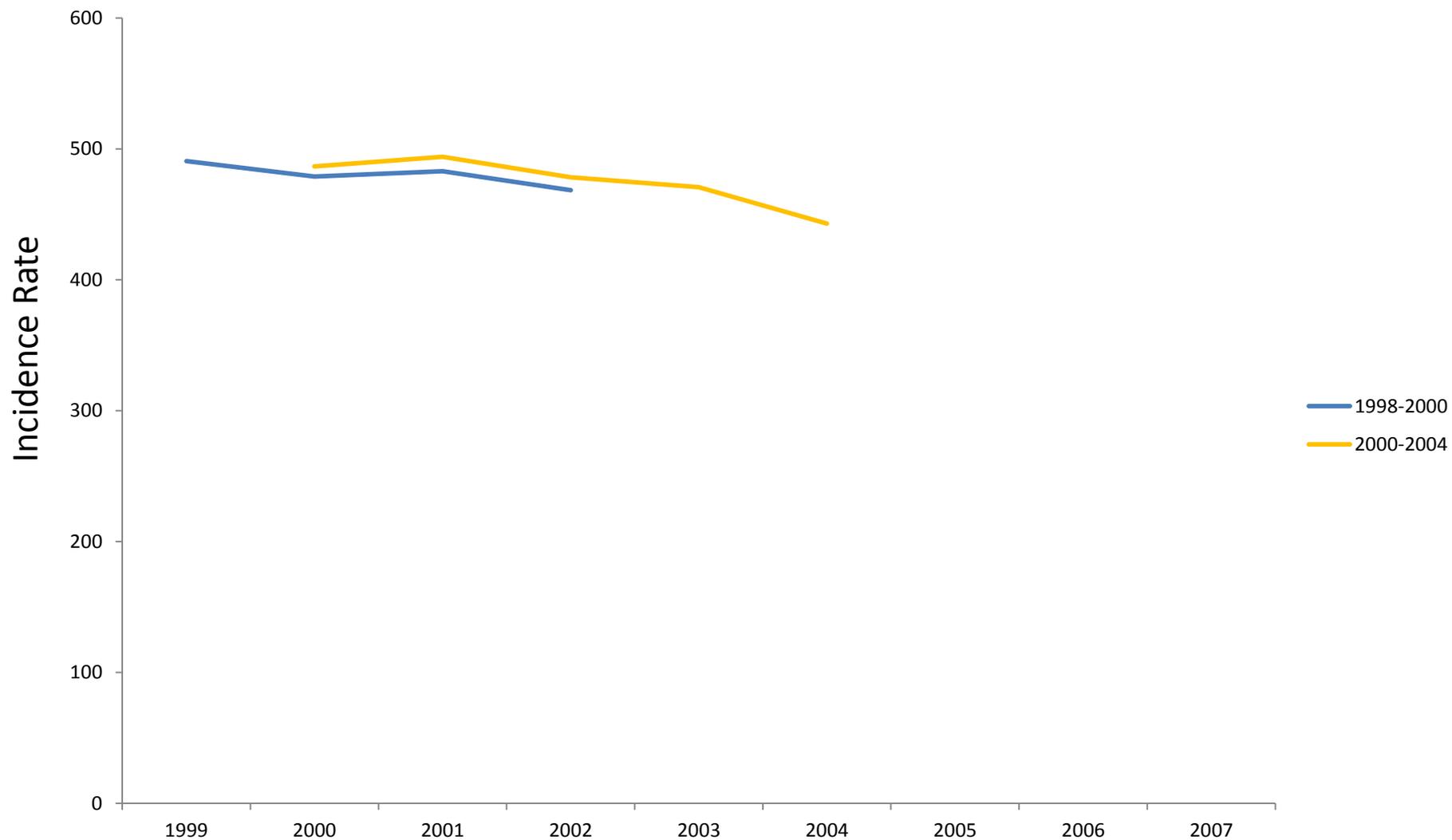
## Incidence rates by data source



Source: Wisconsin Cancer Facts and Figures publications and CDC WONDER



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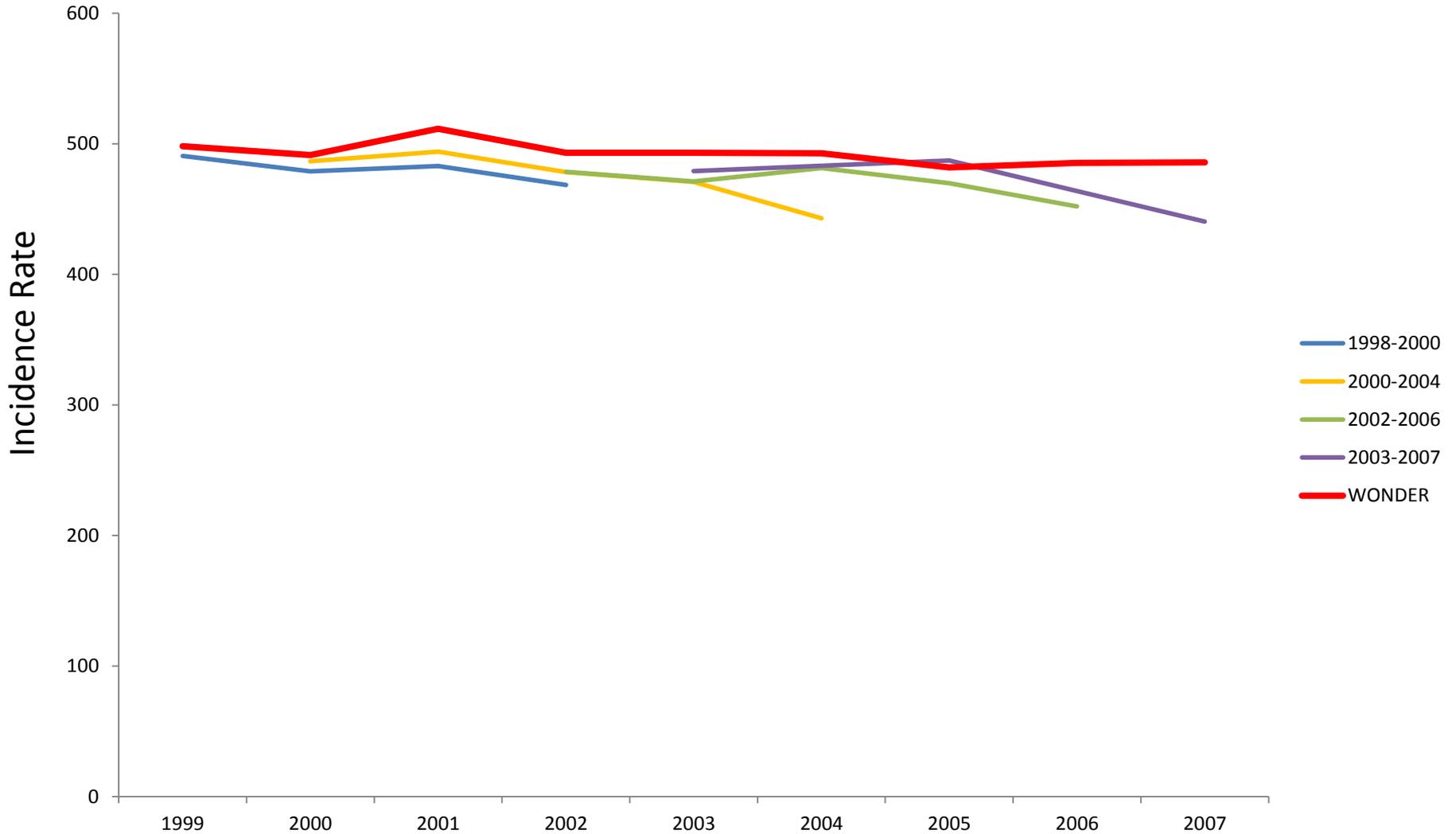
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Department of Health and Human Services  
 Centers for Disease Control and Prevention

## Cancer Prevention and Control

[Cancer](#)

### Options

- > [State Cancer Facts Home](#)
- > [Glossary](#)
- > [Return to Cancer Prevention and Control](#)

### Contact Info

Centers for Disease  
 Control and Prevention  
 Division of Cancer  
 Prevention and Control  
 4770 Buford Hwy, NE  
 MS K-64  
 Atlanta, GA 30341-3717

**Call:** 1 (800) CDC-INFO  
**TTY:** 1 (888) 232-6348  
**FAX:** (770) 488-4760

## 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,<sup>\*</sup> including 26,703 in Wisconsin.
- 562,867 cancer deaths occurred in the United States<sup>\*</sup>, including 10,963 in Wisconsin.

#### New Cancer Case (Incidence) Rates<sup>†</sup>

Area	Rate
Wisconsin	440.2
United States	465.1

#### Death Rates<sup>†</sup>

Area	Rate
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](#)



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### New Cancer Case (Incidence) Rates<sup>†</sup> **484!**

Area	Rate
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United States	465.1

For every 100,000 men and women in Wisconsin, on average, approximately

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#### New Cancer Case (Incidence) Rates<sup>‡</sup>

**484!**

5-year avg

**480!**

Area	Rate
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United States	465.1

For every 100,000 men and women in Wisconsin, on average, approximately

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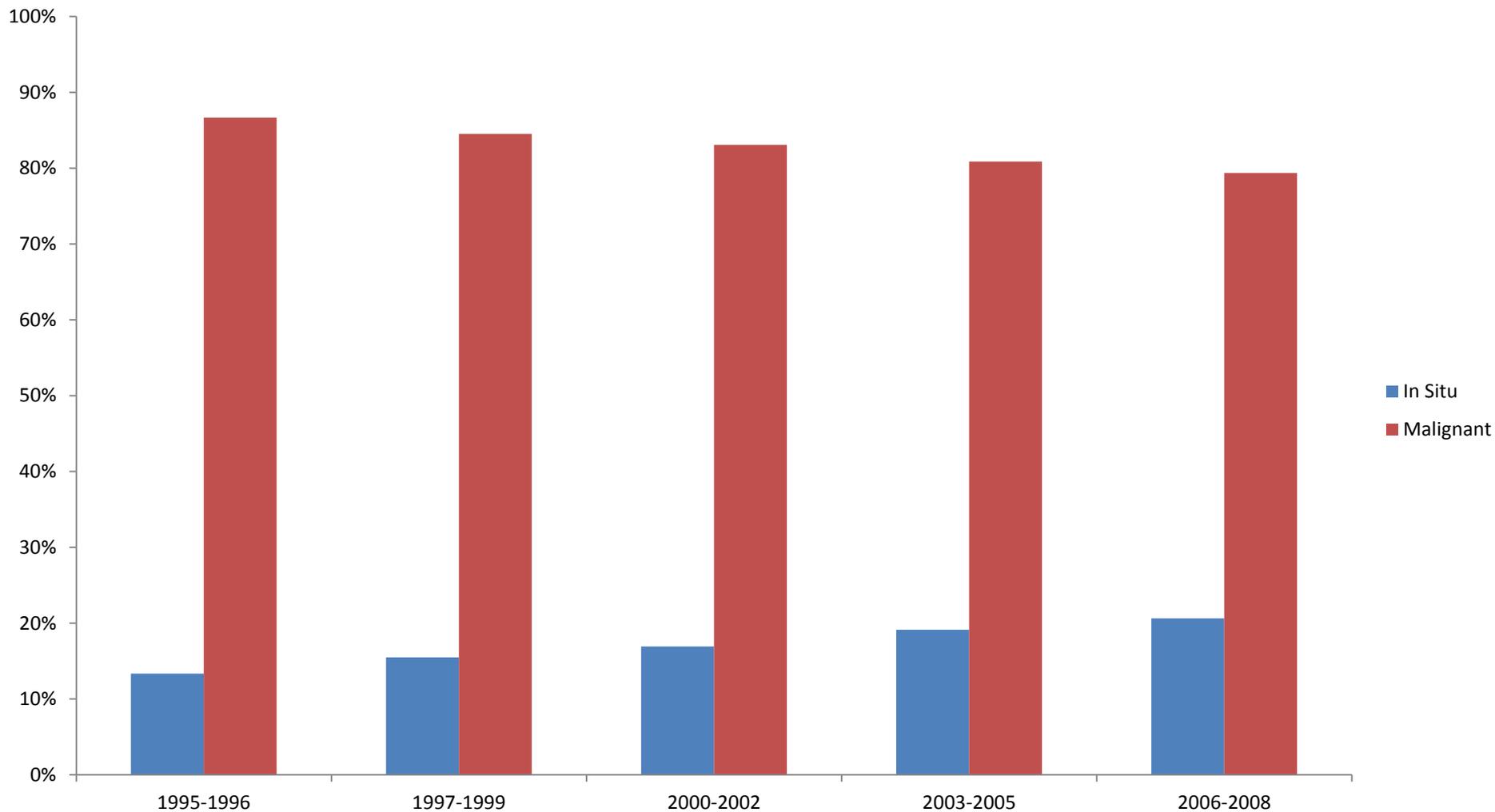


# How big could the impact be?

- Delayed reporting
- **Unstaged tumors**
- Missing race identifiers

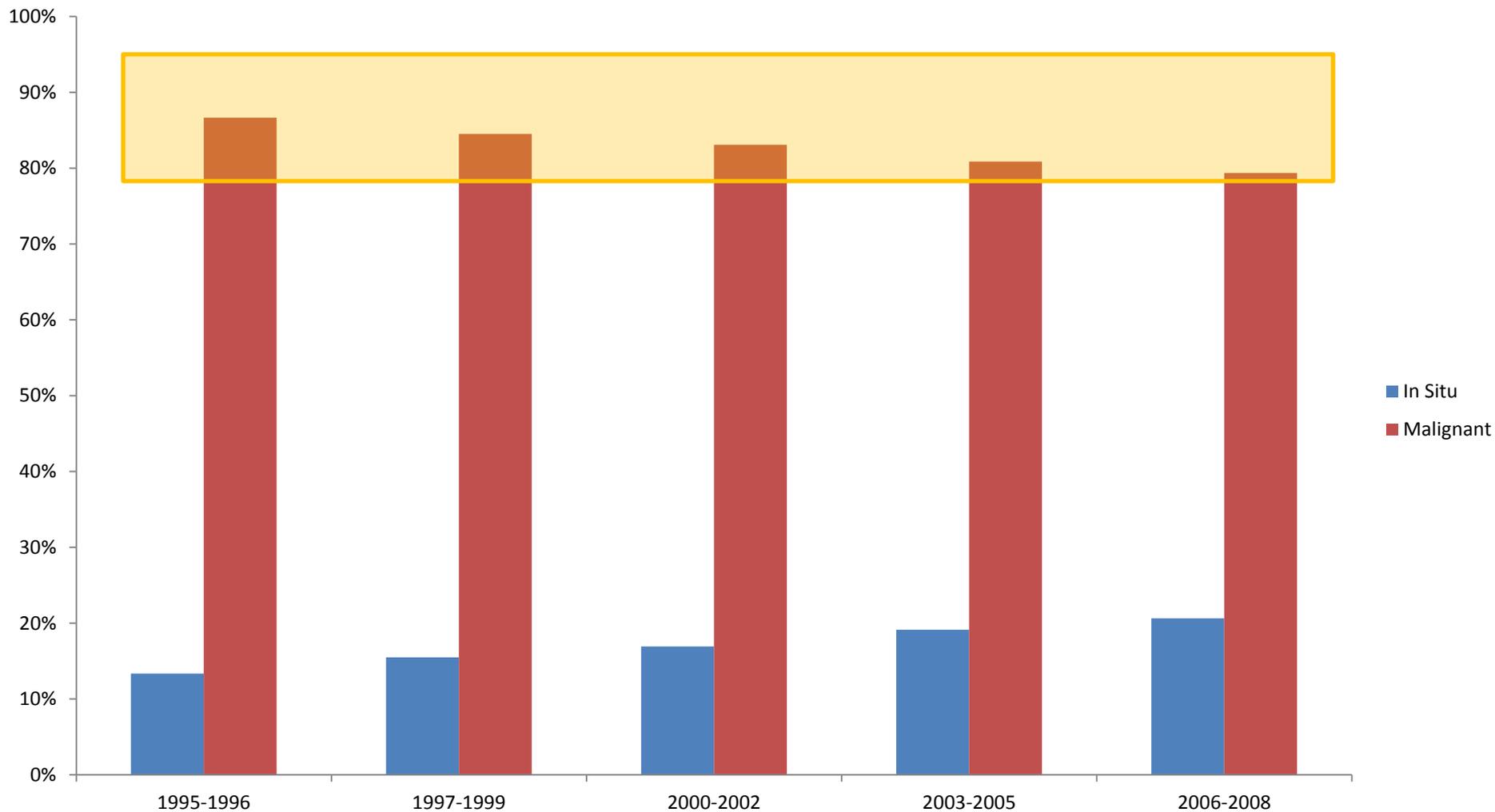


## Malignant and in situ trends, 1995-2008



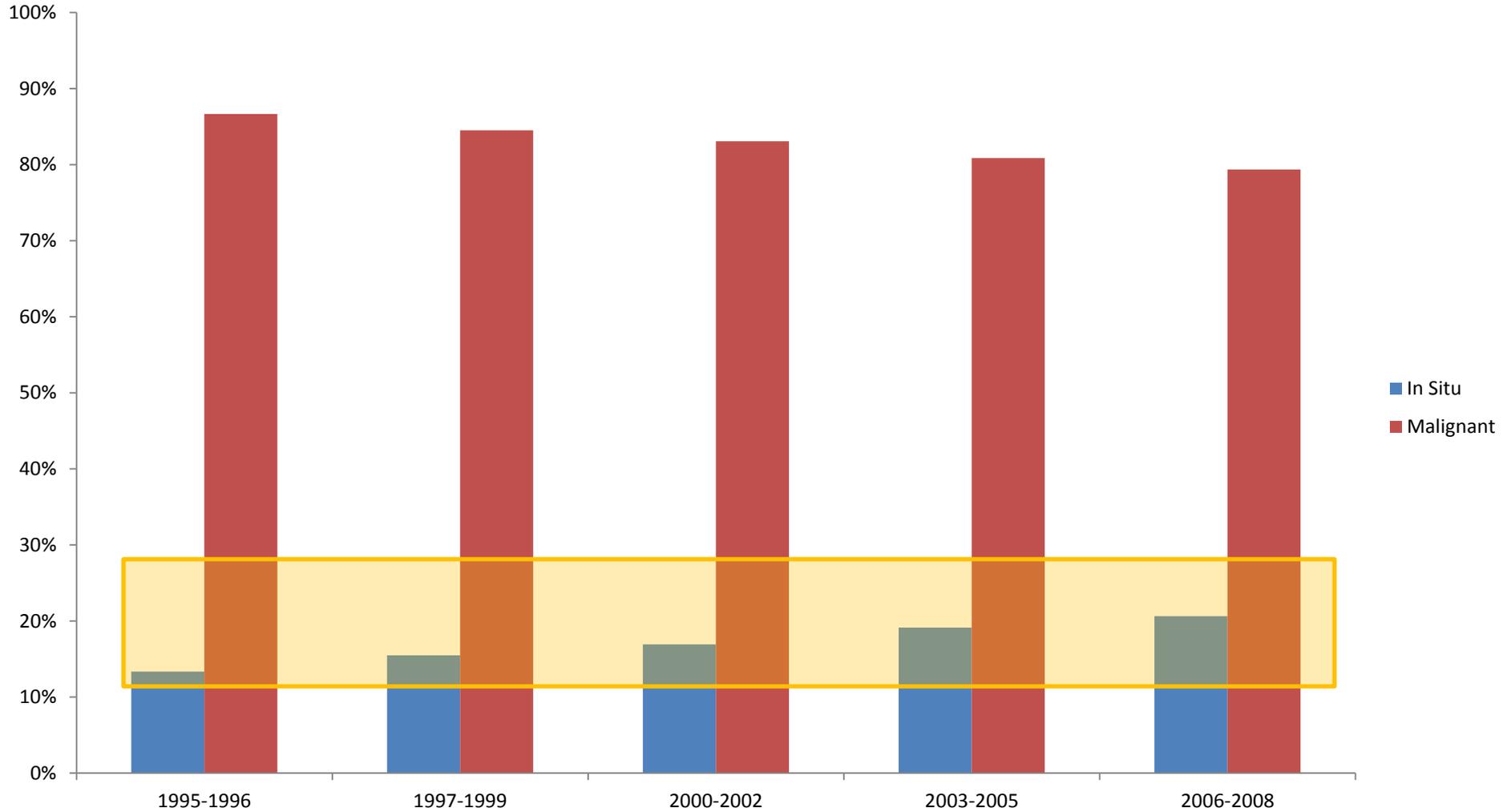


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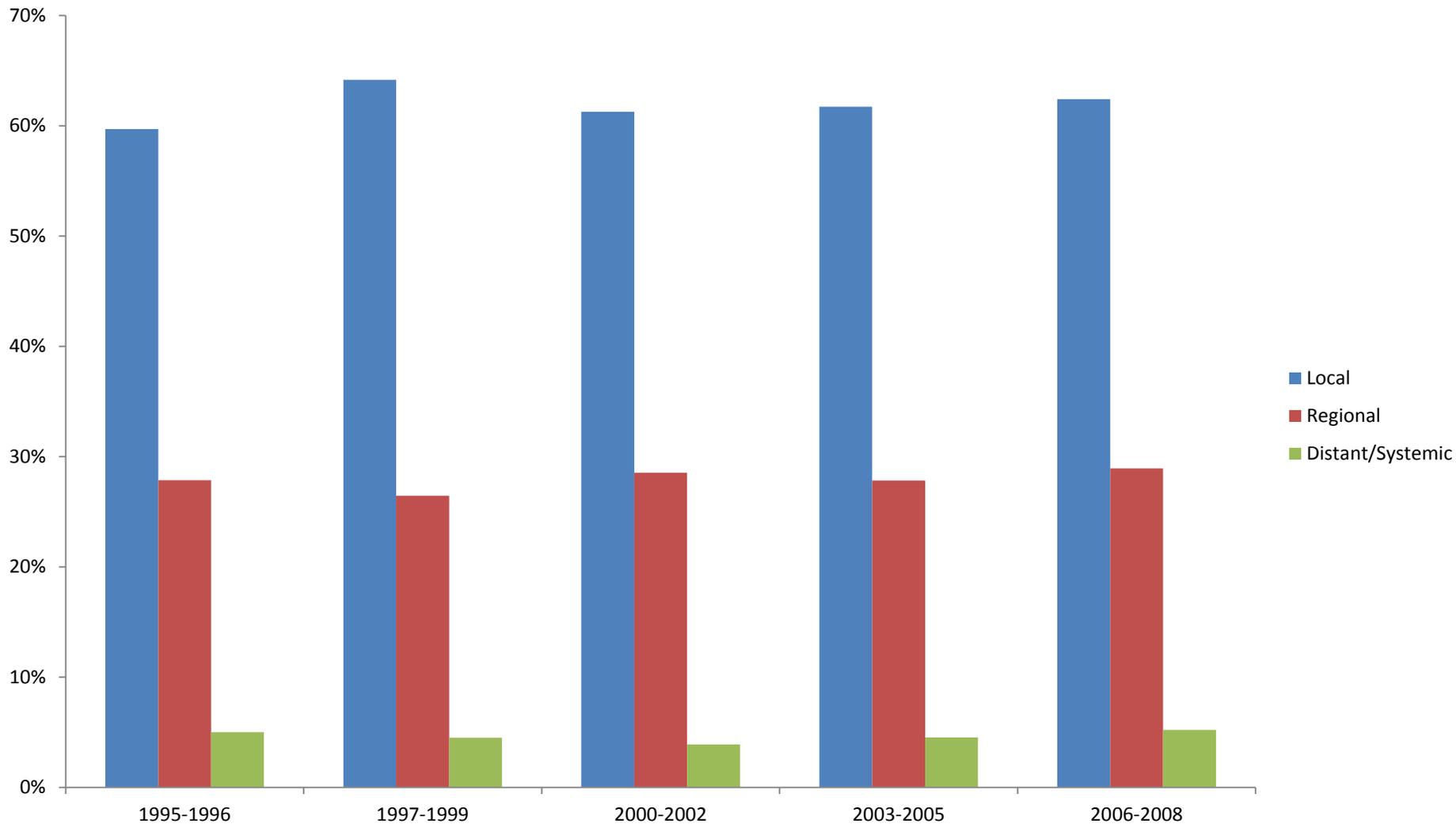


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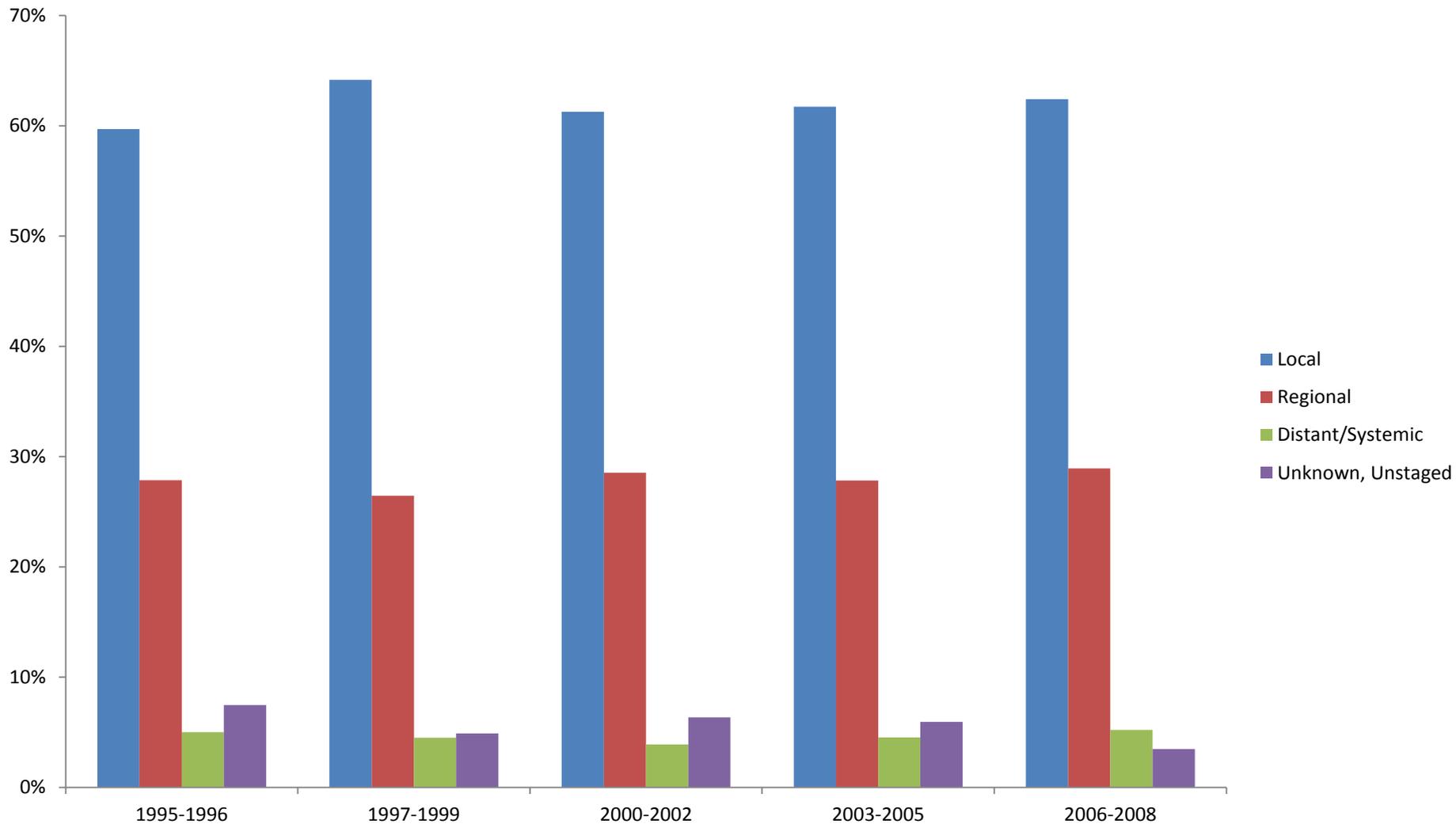


## Female breast, by stage



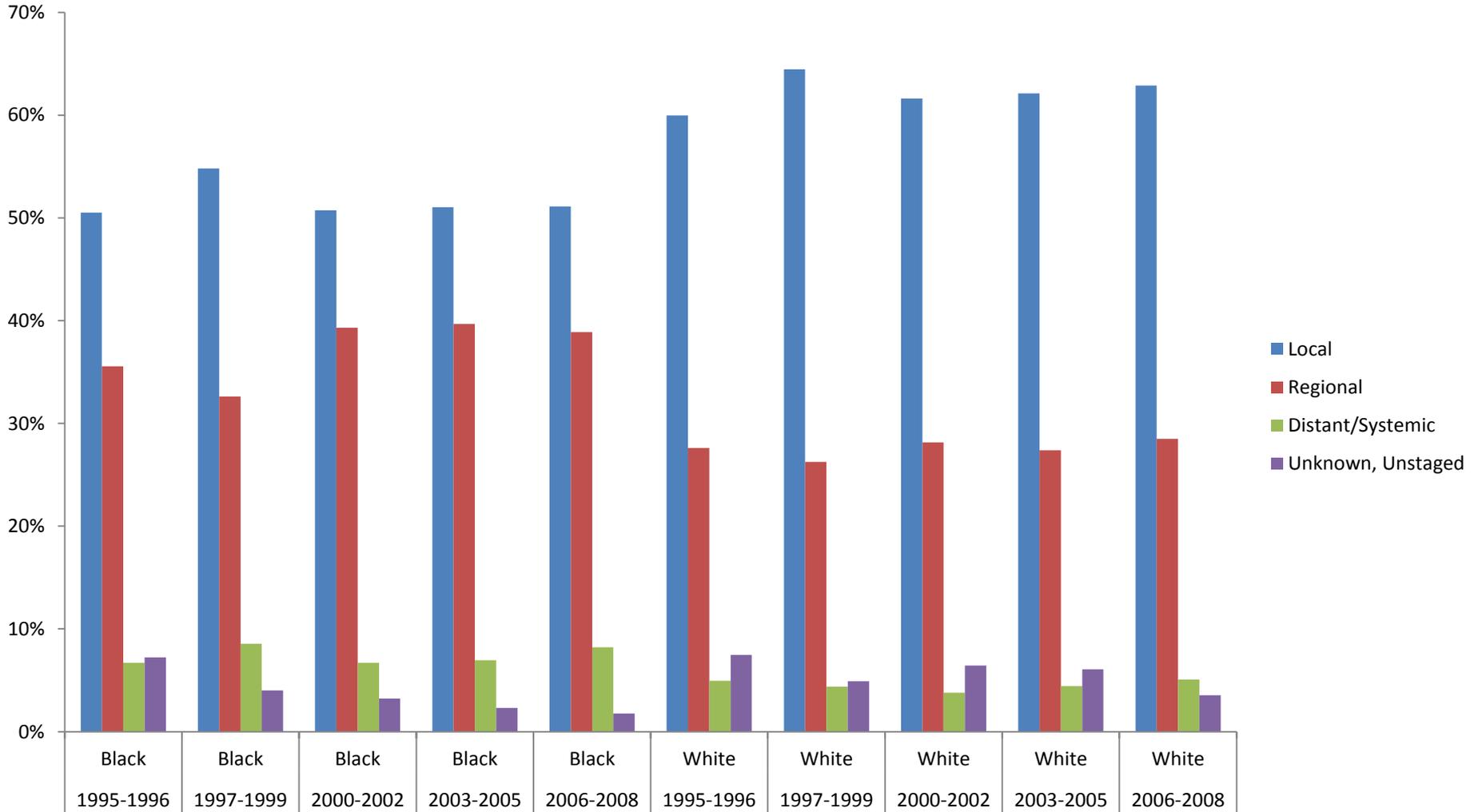


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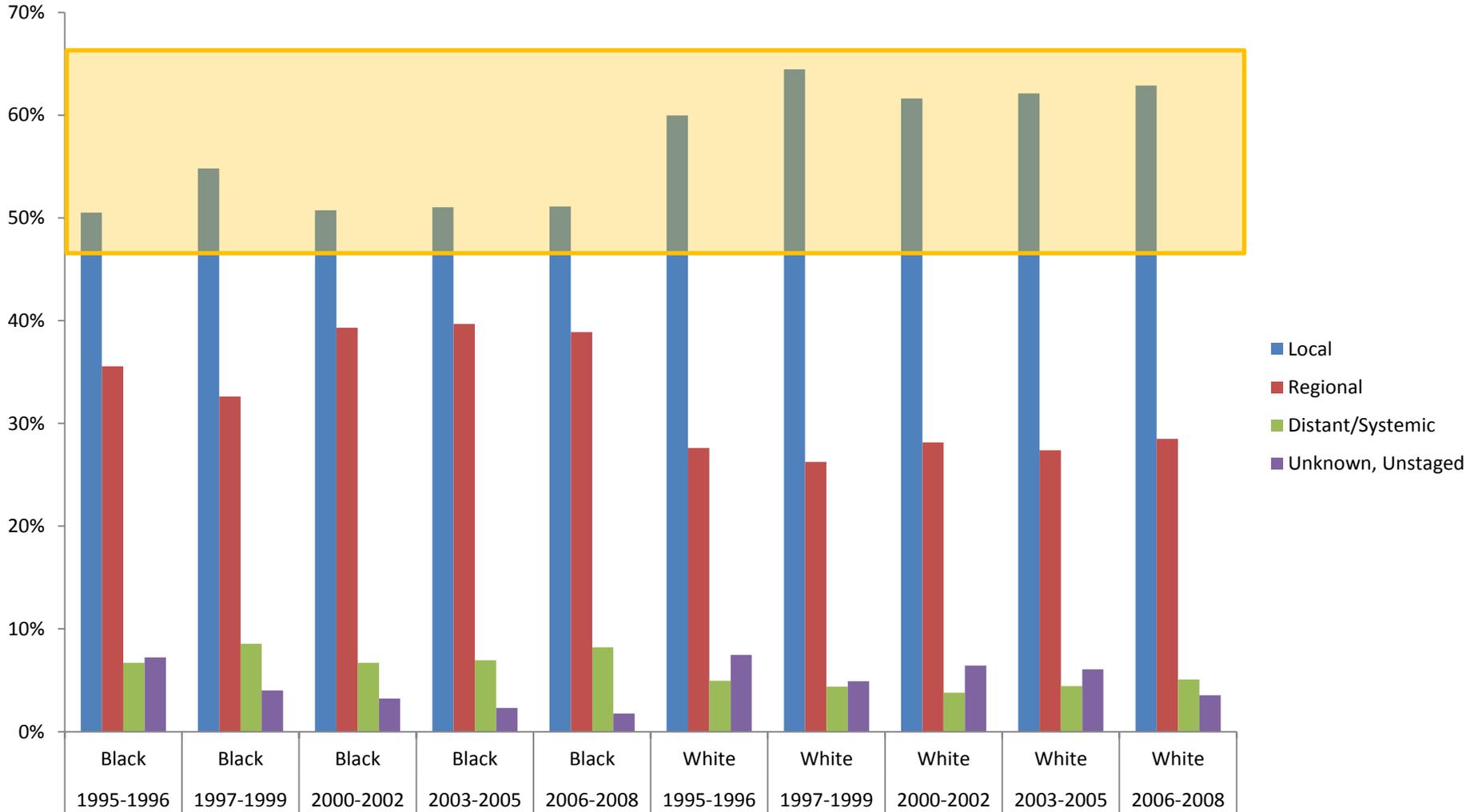


### Female breast, by stage and race



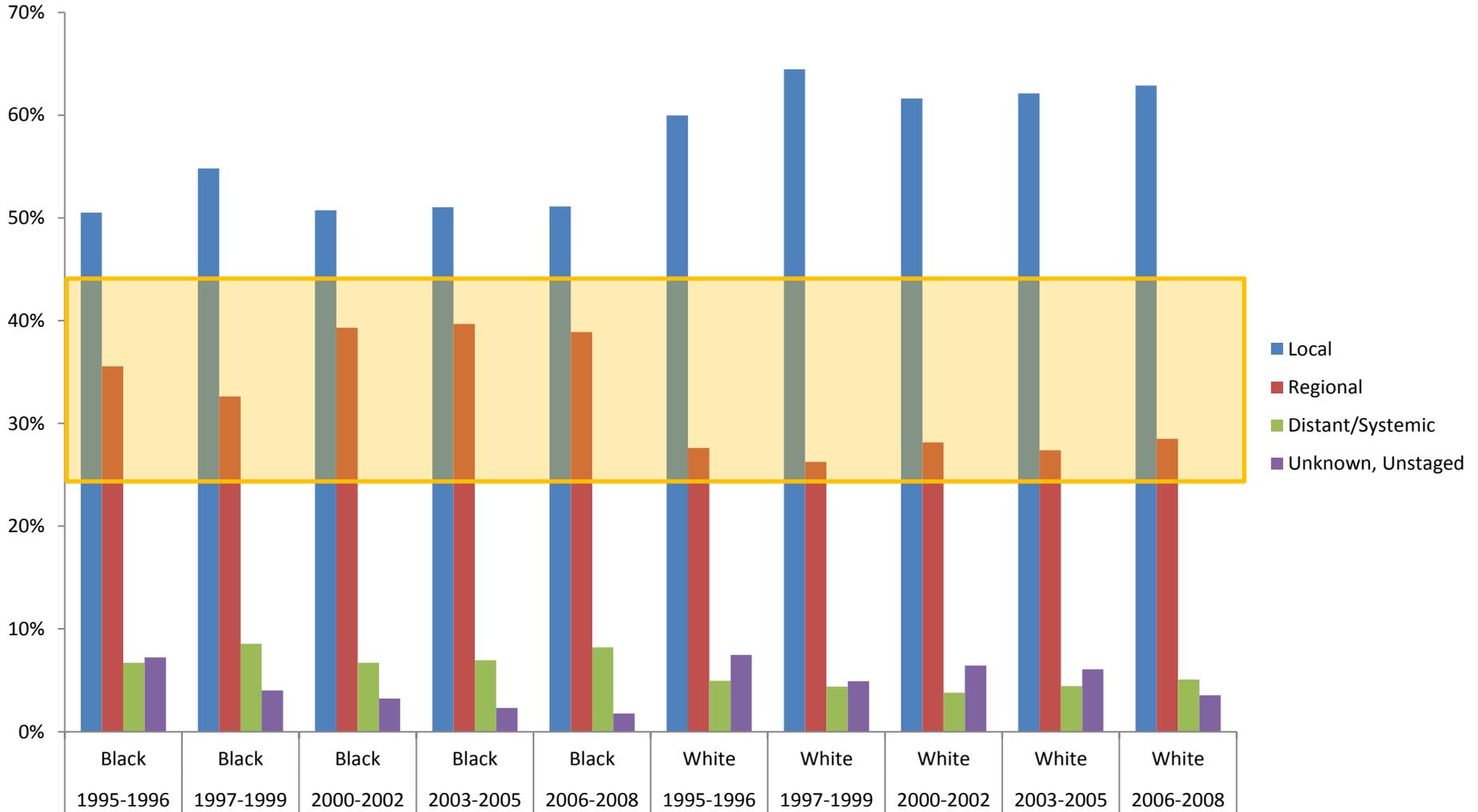


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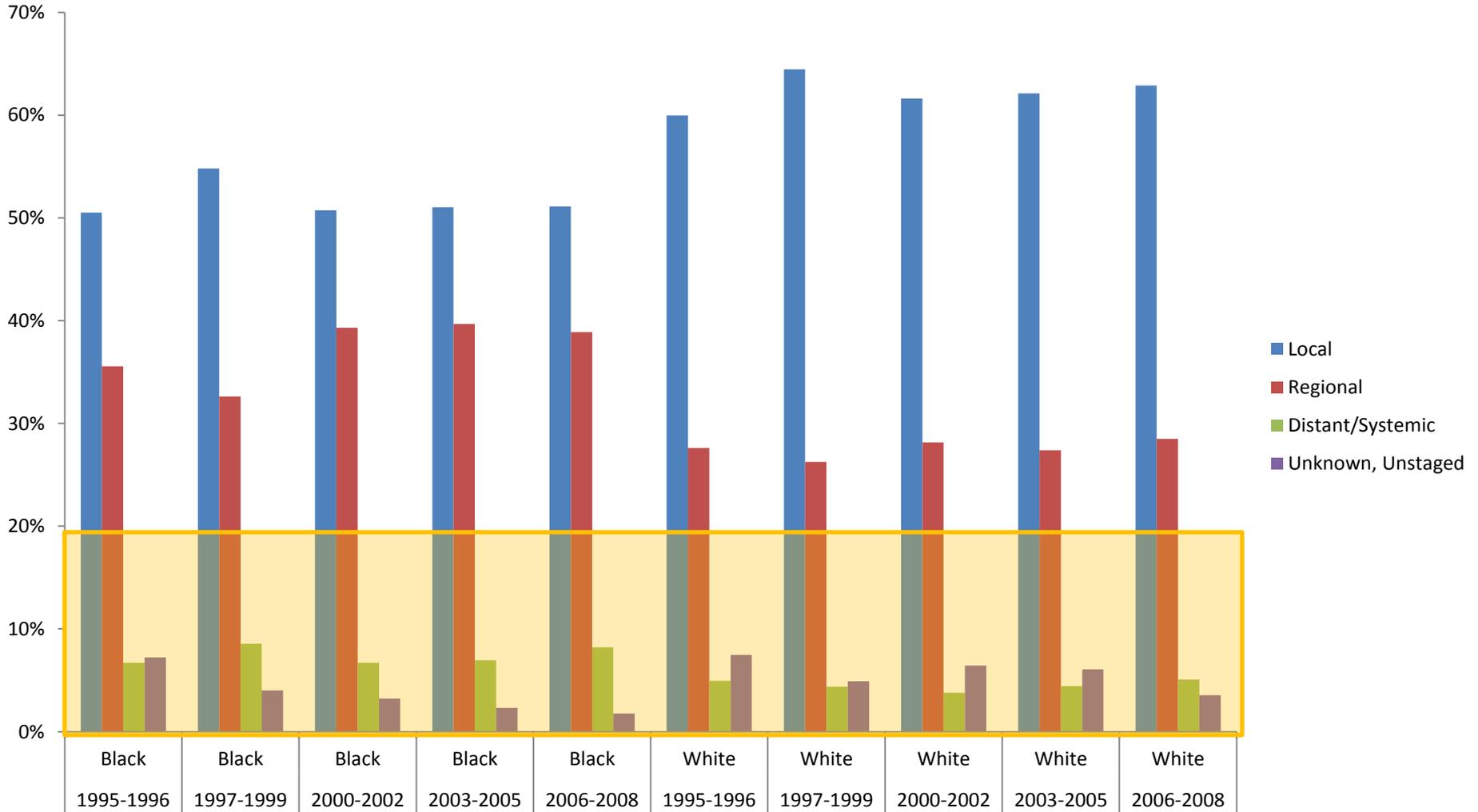


### Female breast, by stage and race



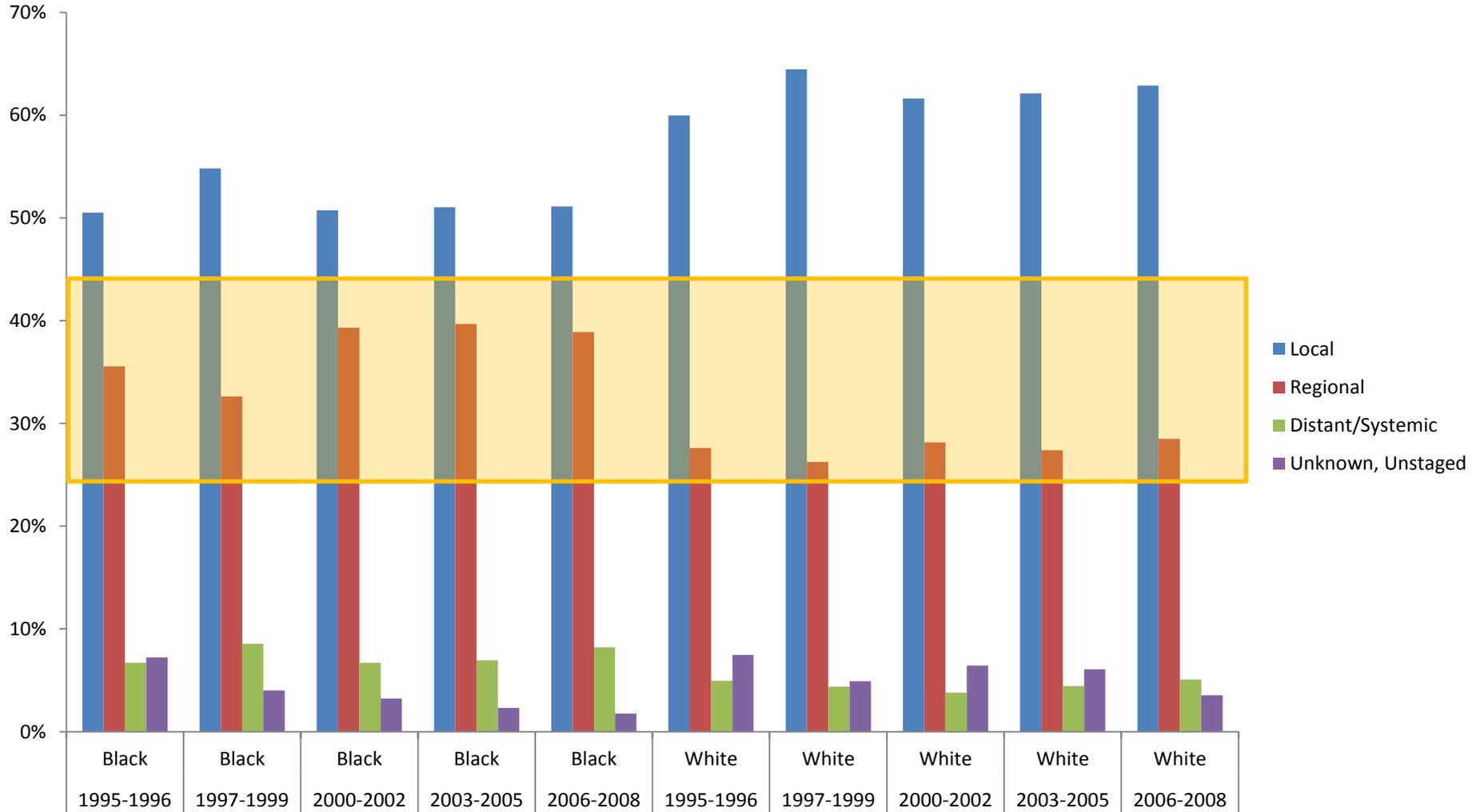


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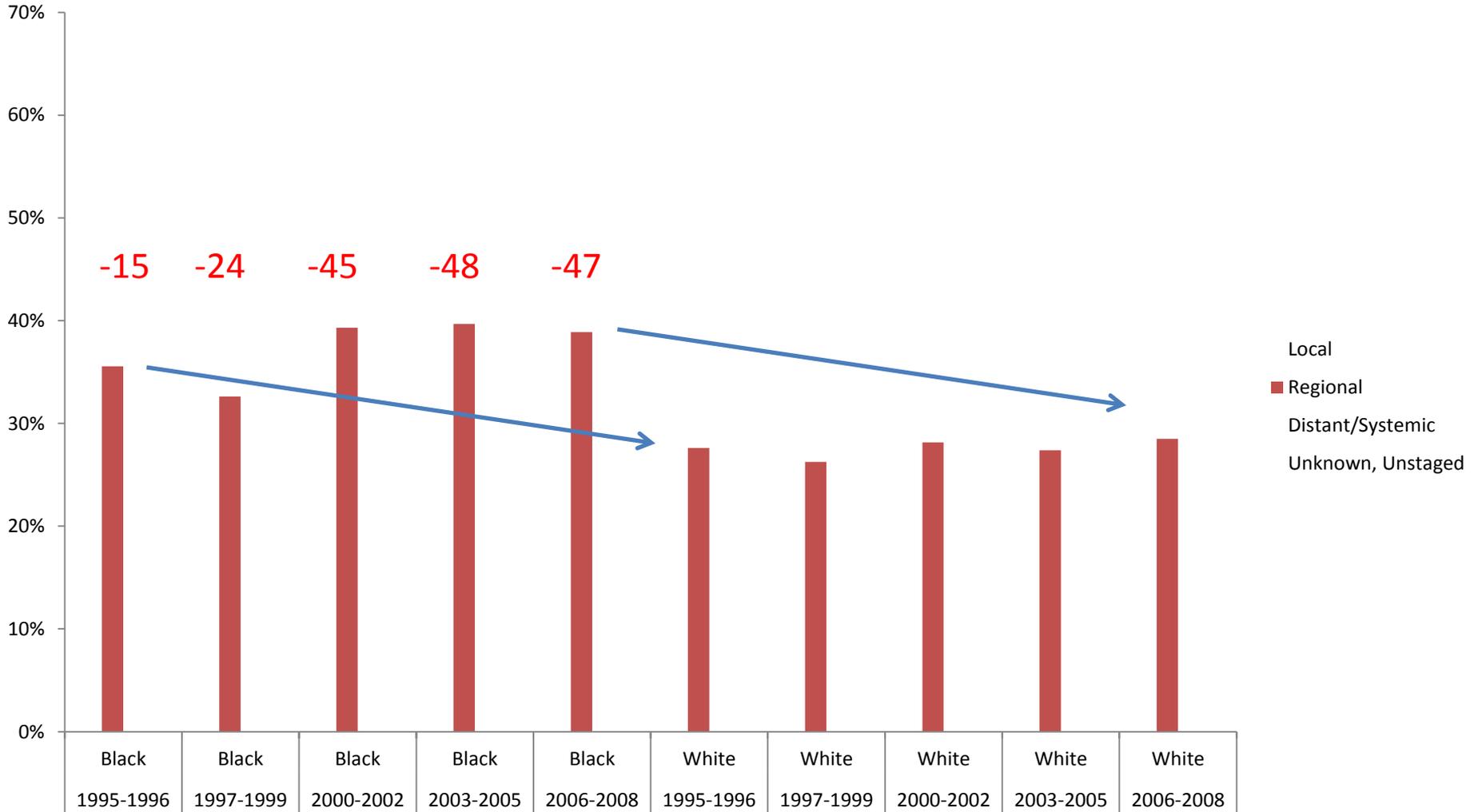


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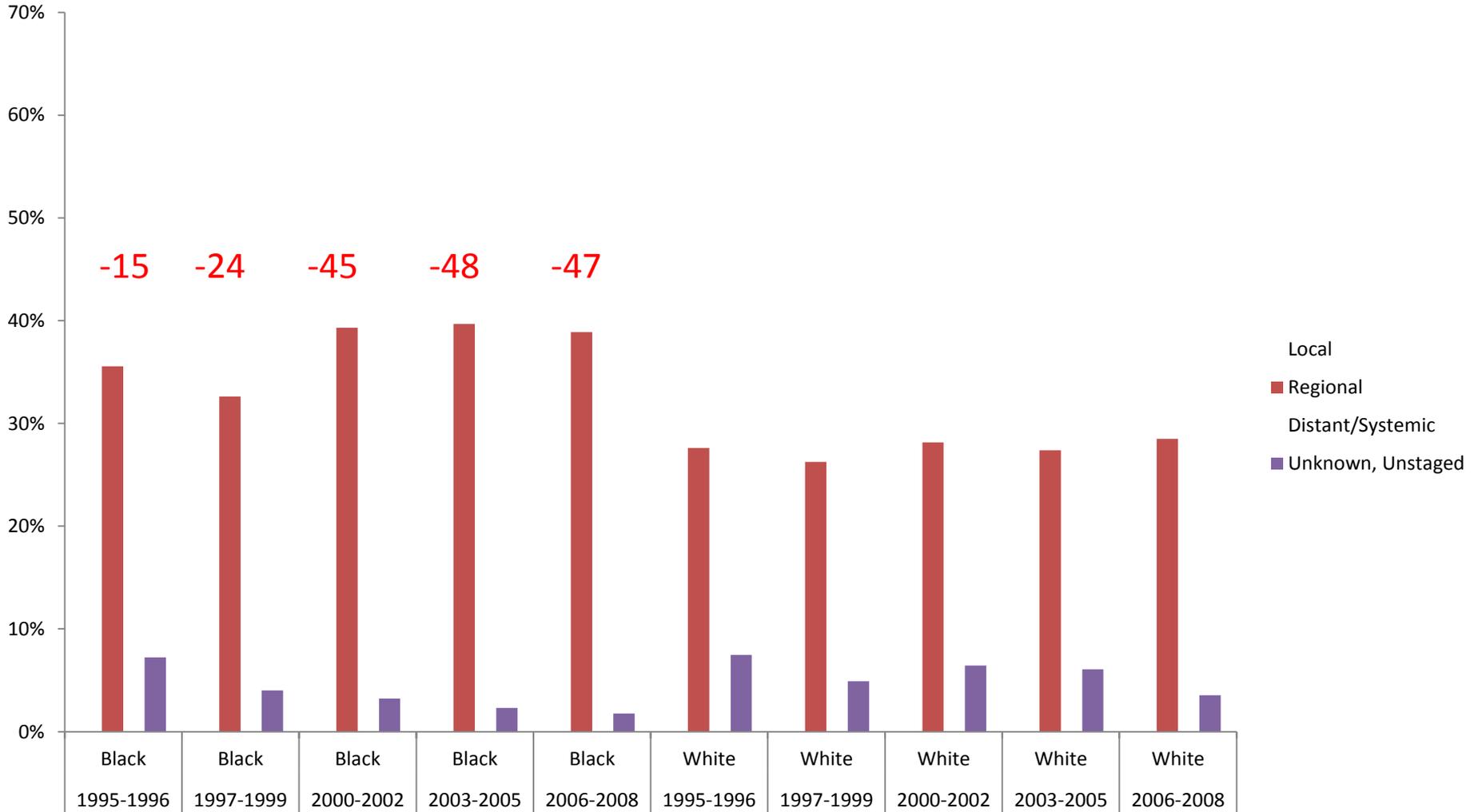
### Female breast, by stage and race



Source: WCRS



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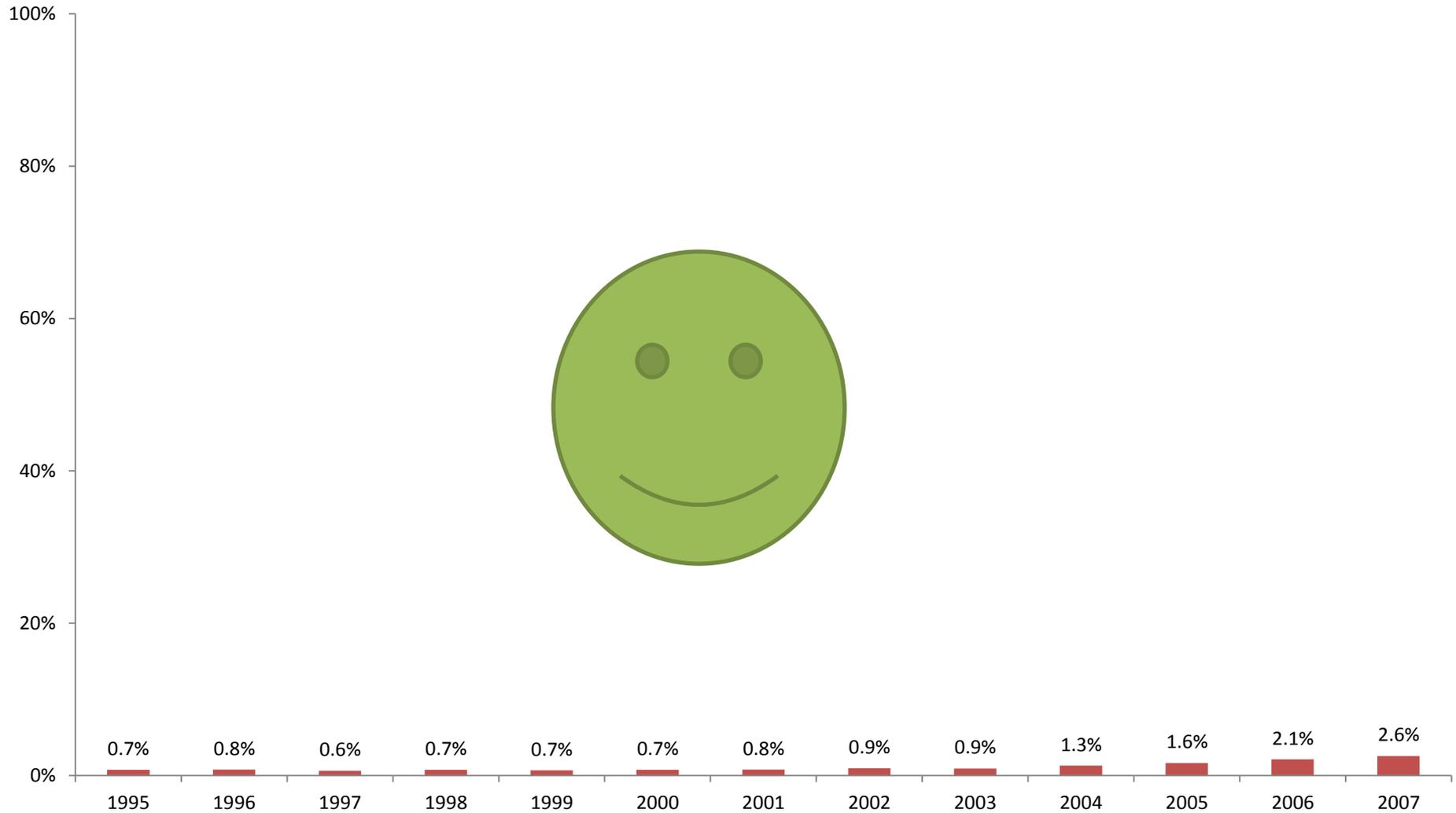


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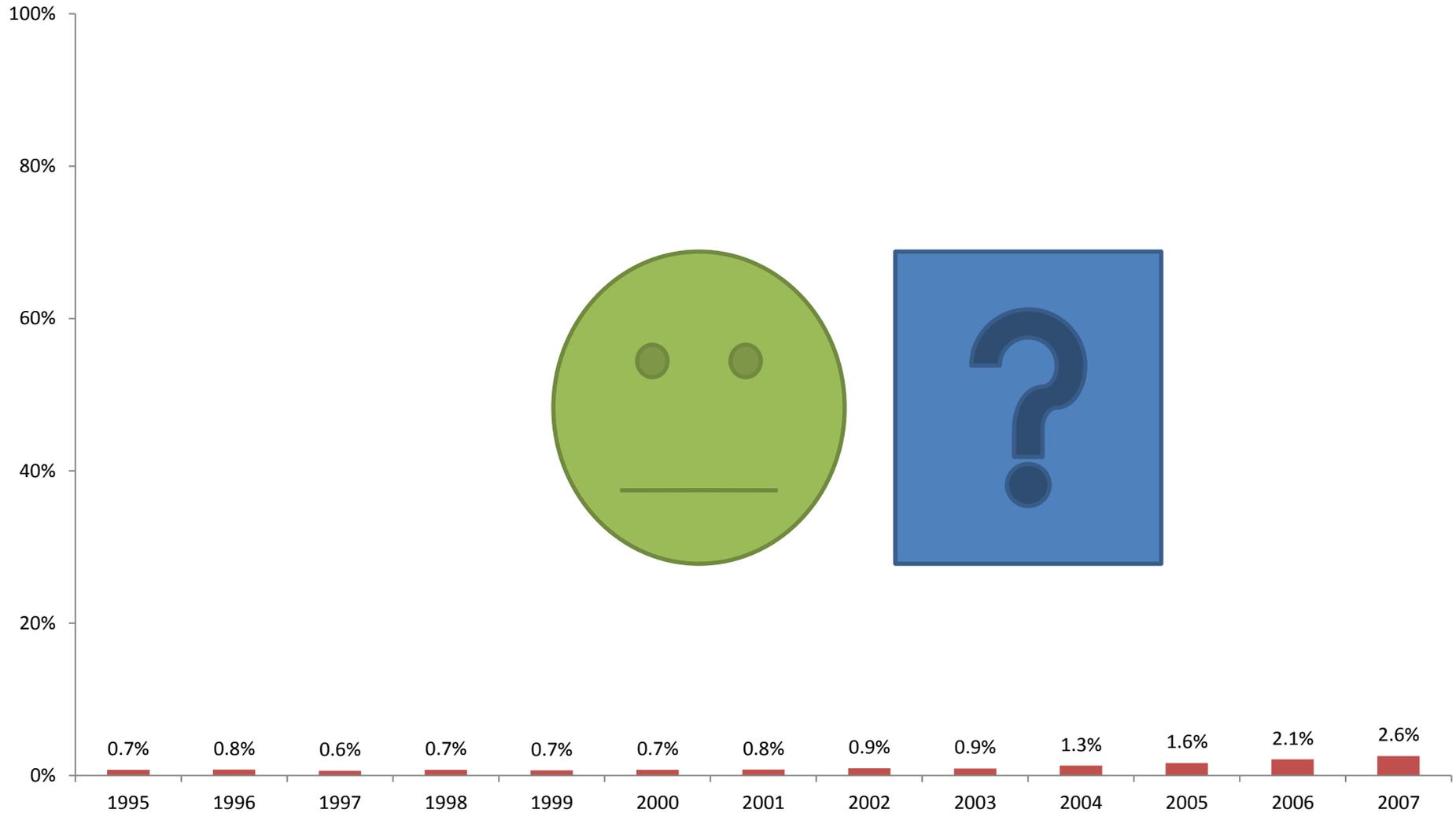
## Unreported race as a proportion of all cases



Source: WCRS



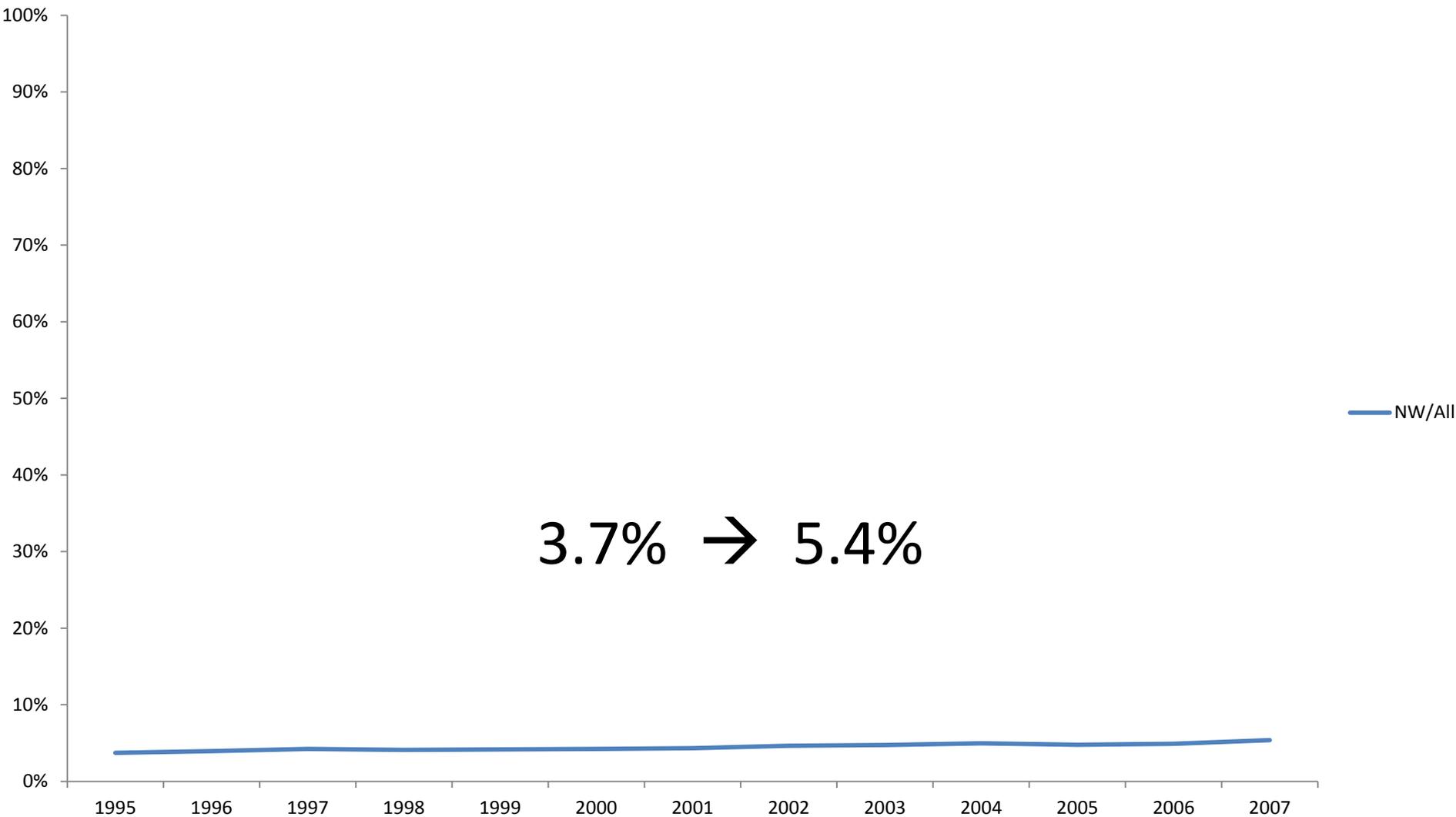
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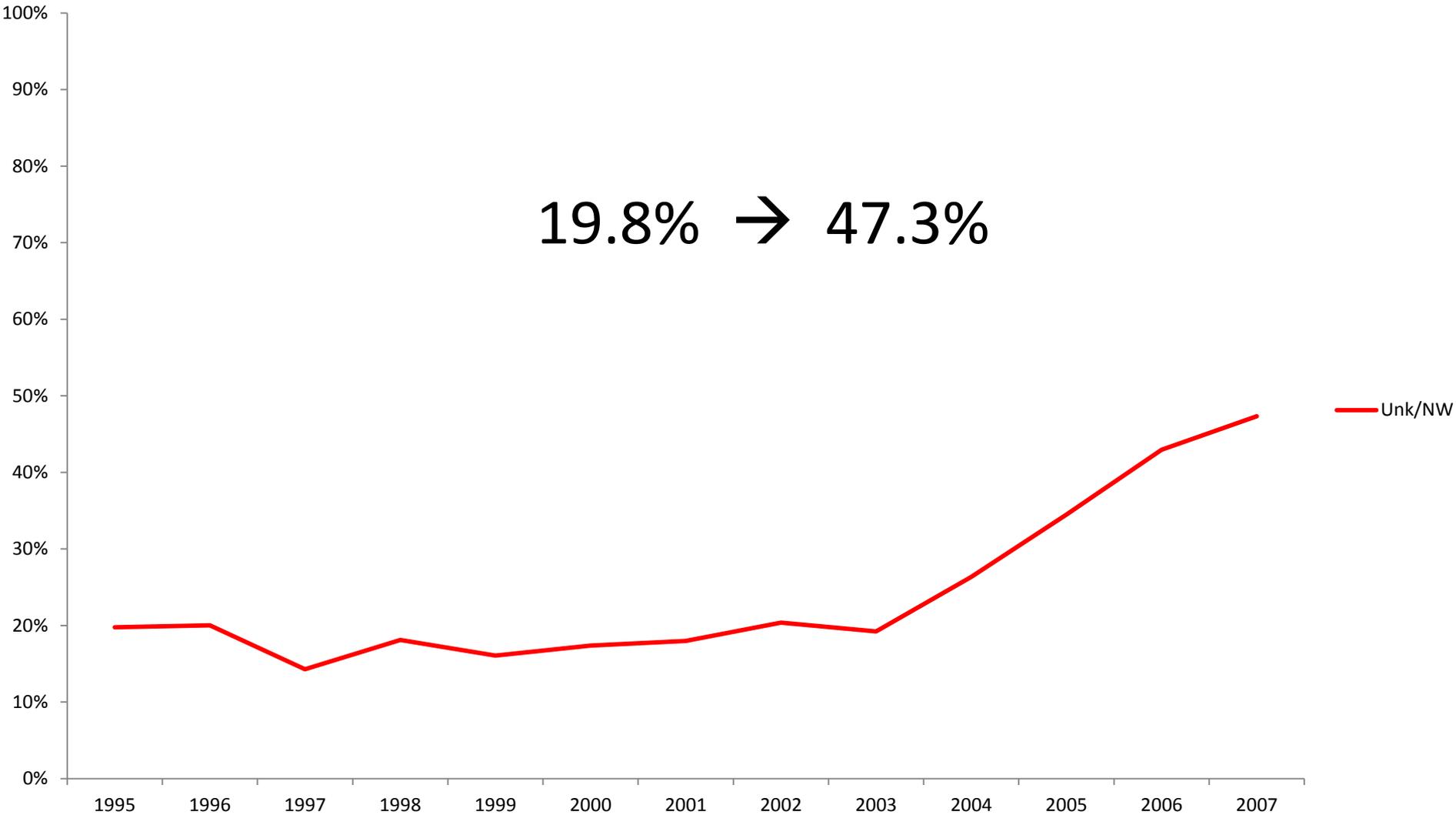
## Non-white race as a proportion of all cases





## Unknown race ratio to non-white cases

19.8% → 47.3%





# 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.

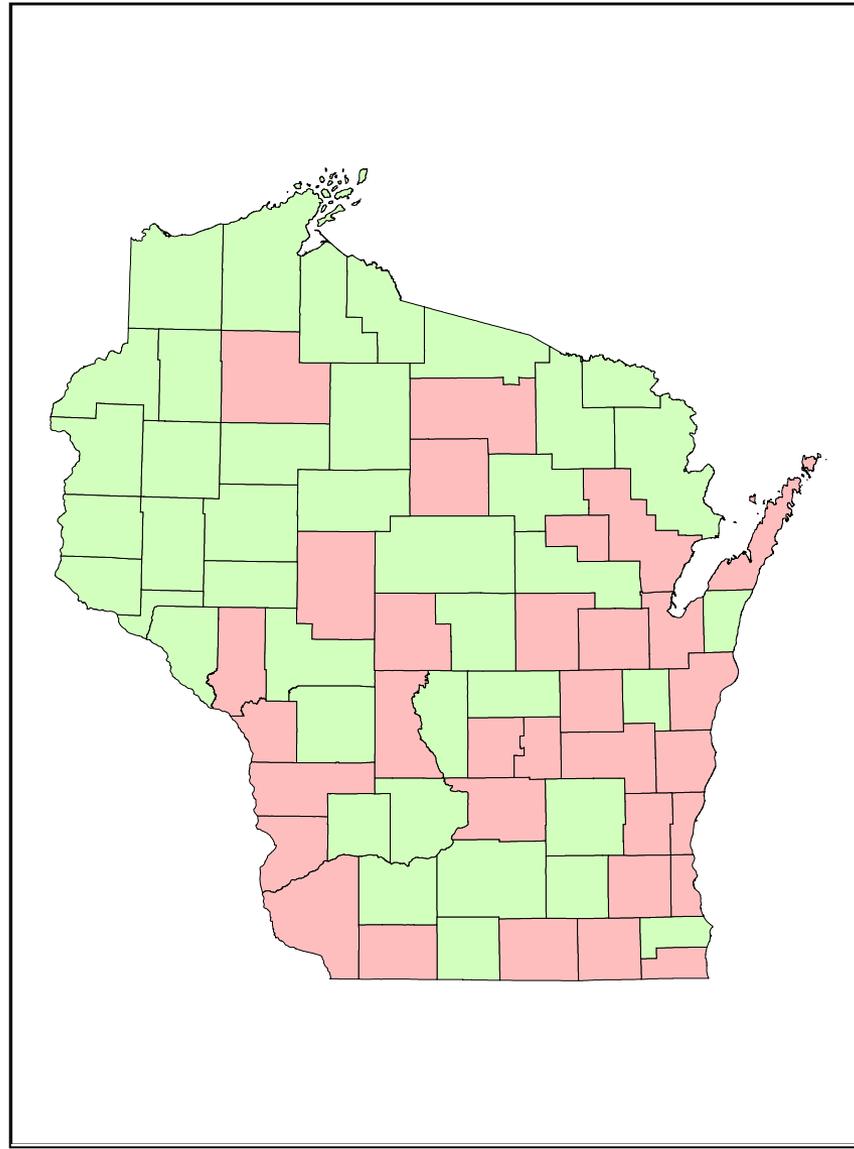
# Setting health priorities



- How many cases **over 5 year period** does it take to flip a county from over or under the state average incidence rate?

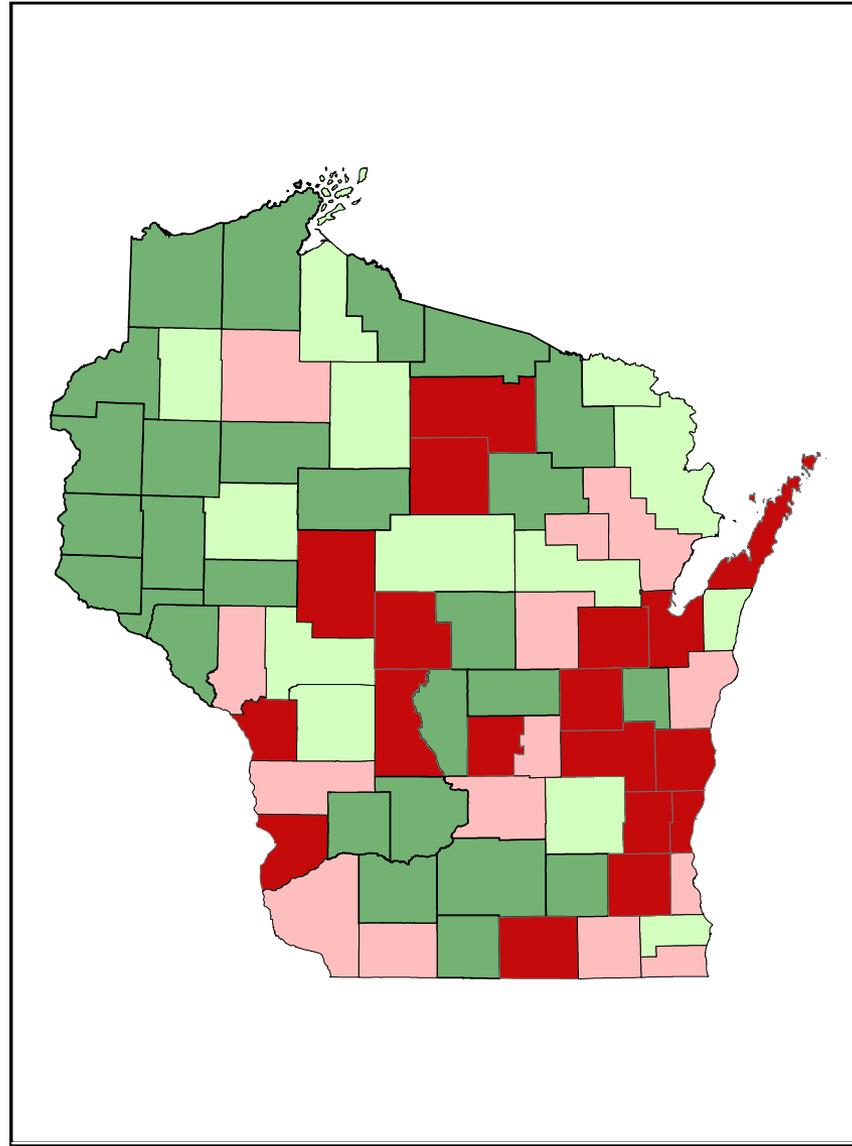


# Cancer incidence, 2004-2008



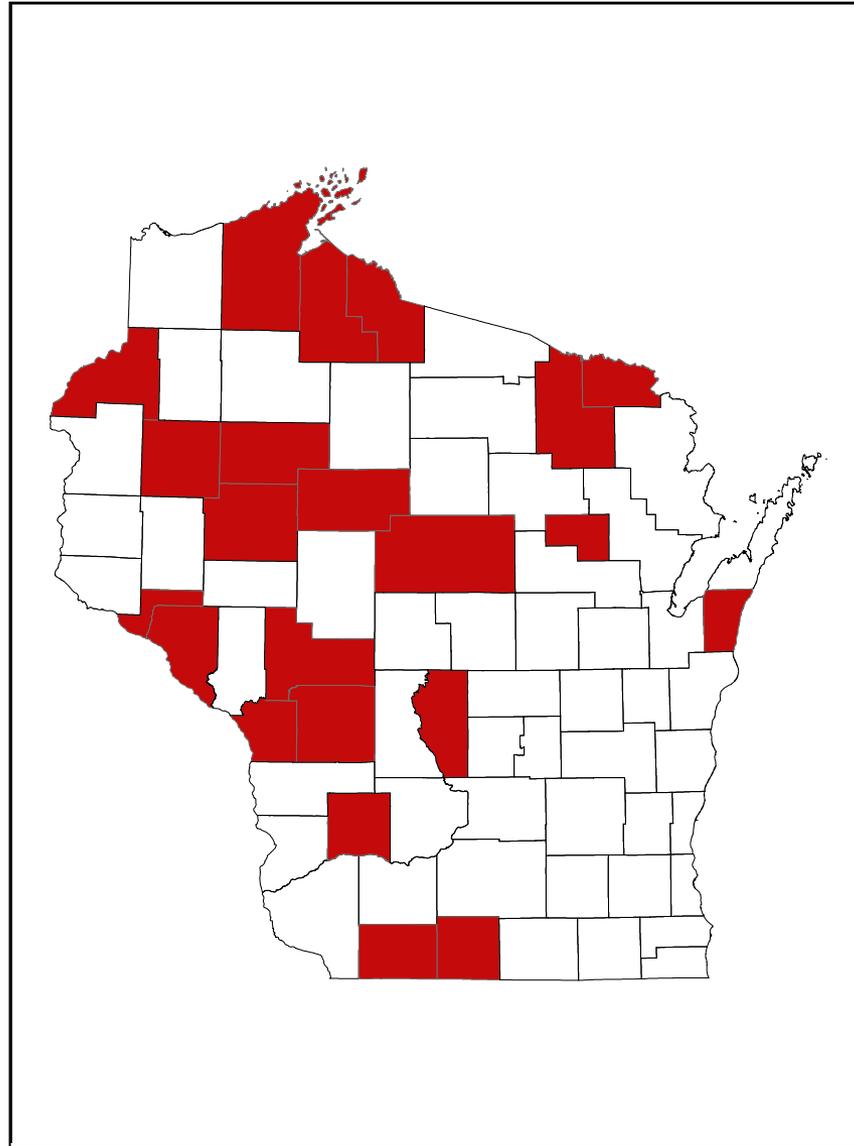


## Cancer incidence, 2004-2008





<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](mailto:nrjones@uwcarbone.wisc.edu)

608-265-8780