One central cancer registry's use of National Death Index (NDI) linkage to become a survival registry

Chester Schmaltz, PhD

Dept. of Health Management & Informatics, School of Medicine
Missouri Cancer Registry and Research Center (MCR-ARC)
University of Missouri – Columbia

Presenter Disclosure

Chester Schmaltz, PhD

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

Coauthors

❖ Saba Yemane, BS

  ❖ Database Administrator, MCR-ARC

❖ Awatef Ben Ramadan, MPH

  ❖ Graduate Research Assistant, HMI

❖ Jeannette Jackson-Thompson, MSPH, PhD

  ❖ Director, MCR-ARC

  ❖ Research Associate Professor, HMI

Special Thanks

❖ Nancy Cole, CTR

   ❖ MCR-ARC's former Operations Manager

Background

❖ The Missouri Cancer Registry and Research Center (MCR-ARC) collects population-based data from healthcare providers about Missouri residents diagnosed with reportable tumors.

❖ The data includes:

   ❖ Patient information

   ❖ Tumor characteristics

   ❖ Summary 1st course treatment

Background

❖Timely, complete, & accurate cancer data are needed for

 ❖Public health surveillance

 ❖Research

Background

❖ The Missouri Cancer Registry and Research Center (MCR-ARC) is an *incidence-only* registry since it lacked complete follow-up (survival) information.

❖ Vital status

❖ Date of last contact / death

❖ Cause of death

Background

❖ Tracking survivorship is important for fully assessing the burden of cancer and for comparing treatment outcomes and survivorship by age group, place of residence, race/ethnicity, *etc*.

Background

❖In order to measure the impact of public health and other programs aimed at improving population health, MCR-ARC needs to become a *survival registry*—one with complete survival information.

Background

❖ Active follow-up

  ❖ Contacting someone to provide more up-to-date information

    ❖ Patient, provider, family member, or other informant

  ❖ Expensive

  ❖ Perhaps unnecessary

Background

❖ Passive follow-up

  ❖ Database linkage

    ❖ State Death Certificate (DC) file
    ❖ Social Security Death Index (SSDI)
    ❖ National Center for Health Statistics' (NCHS') **National Death Index (NDI)**

  ❖ May be sufficient for complete ascertainment of survival information

Background

❖ MCR annually performs death clearance and follow-back with Missouri's state death certificate file.

❖ Unfortunately it appears many individuals become lost to follow-up via this linkage alone.

Background

❖MCR has recently embarked on the first step to become a survival registry by focusing on patients with breast and cervical tumors via passive linkage utilizing the NDI.

Methods

❖ Annual death clearance and follow-back for all cancer cases diagnosed in 2011

❖ SSDI linkage on breast and cervical cancer cases diagnosed 1996 through 2011

　❖ Reduce the number of cases with unknown vital status or Social Security number

Methods

❖ SSDI linkage was also used to create alias records.

❖ If a match with SSDI was uncertain due to discrepancies, then both the MCR & the SSDI information would be sent to NDI.

  ❖ The results from NDI would then be used to resolve the discrepancy.

Methods

❖ A set of checks were run using CDC NCPR's GenEDIT Plus program with an NDI-specific checks.

  ❖ Performs single-field and inter-field checks to identify issues that may adversely impact the NDI linkage.

Methods

❖ Subset of breast & cervical cancer cases were sent to NCHS for linkage to NDI.

❖ Only those who are either:

❖ Alive, or

❖ Dead with unknown cause.

Methods

❖ Processing the results from NDI was greatly eased by 2 tools produced by the CDC's National Program of Cancer Registries.

  ❖ A SAS program

  ❖ Access DB

❖ The SAS program was used to separate definite matches from those needing manual review.

Methods

❖ Staff reviewed linkage results to identify matches.

❖ Utilized the Access DB produced by NPCR

  ❖ Slightly modified by MCR-ARC

Methods

Methods

❖ Manual review sometimes involved going to other sources to resolve discrepancies and verify questionable matches.

Methods

❖ Helpful sources:
  - ❖ Find A Grave, http://www.findagrave.com/
    - ❖ Cemetery listings,
    - ❖ Tombstones often verify spouse,
    - ❖ Many times has link to obituary.
  - ❖ Legacy, http://www.legacy.com/
    - ❖ Newspaper obituaries & death notices.
  - ❖ Spokeo, http://www.spokeo.com/
    - ❖ People searcher with some demographics & family information.

Methods

❖ Other resources occasionally helpful:

❖ SSDI

❖ CaseNet

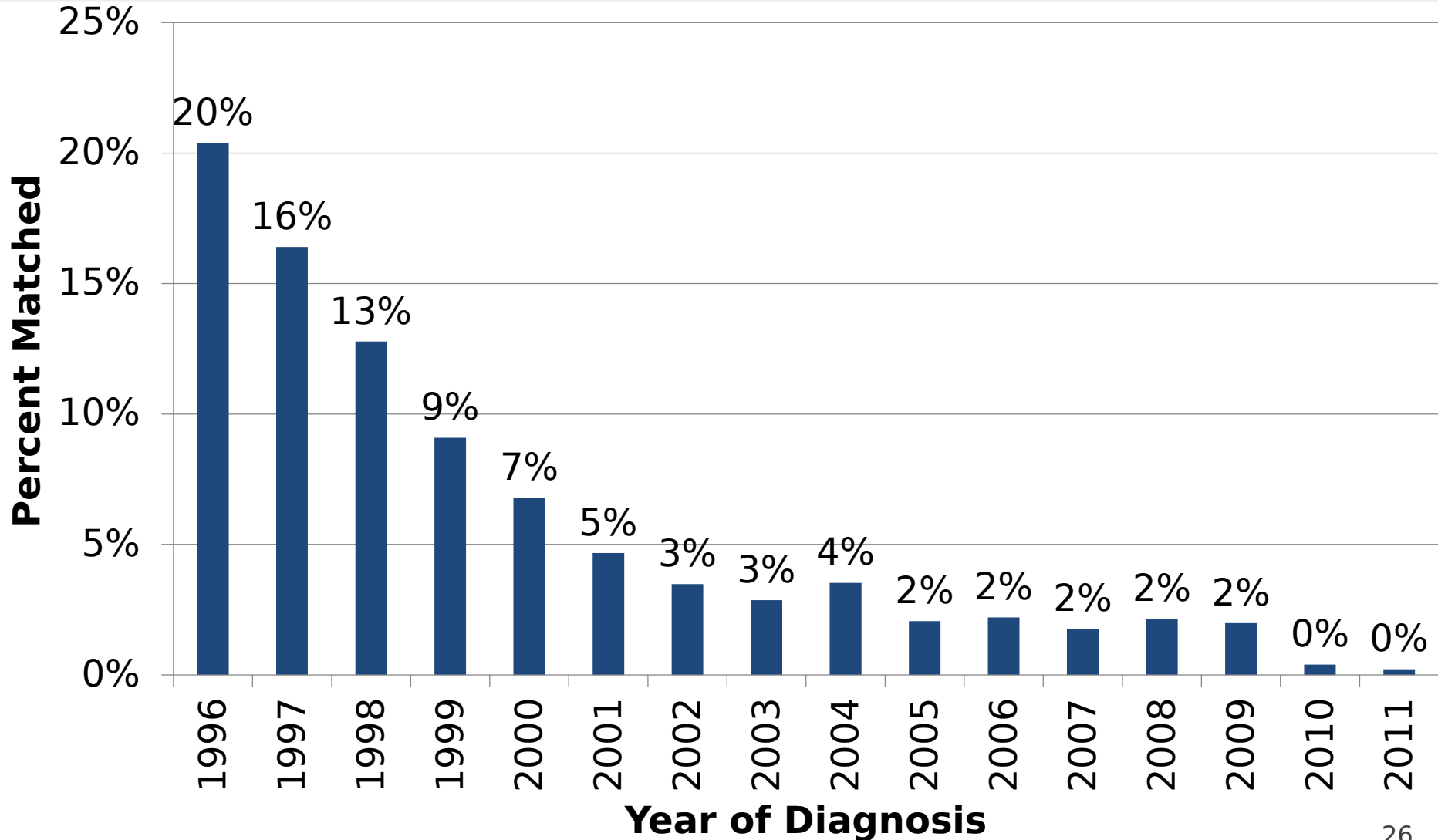❖ https://www.courts.mo.gov/casenet/

❖ Online Missouri court records.

Methods

❖ Survival statistics were then computed using SEER*Stat.

 ❖ Relative survival,

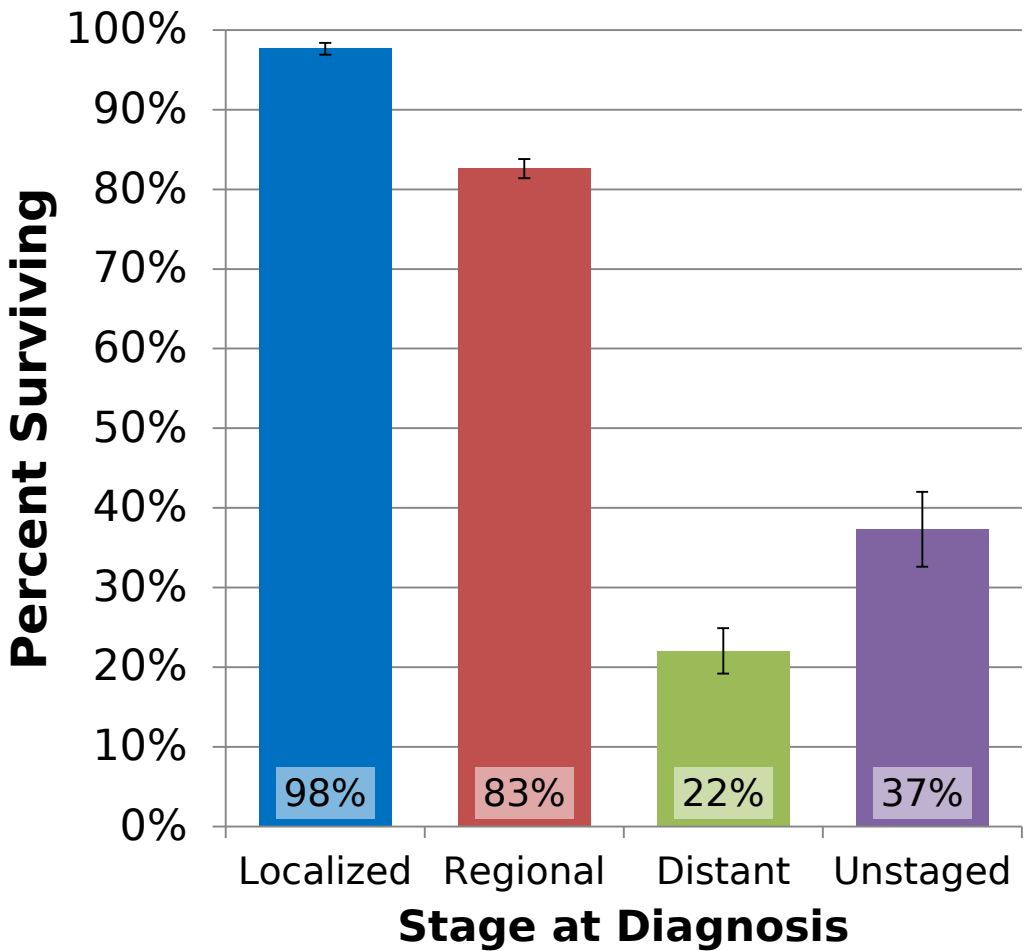 ❖ Cause-specific survival,

 ❖ Crude probability of death

Results

❖ We obtained death data for patients who were Missouri residents at the time of their diagnosis and had incomplete survival information.

❖ After completing review of matches and potential matches, the database was updated.

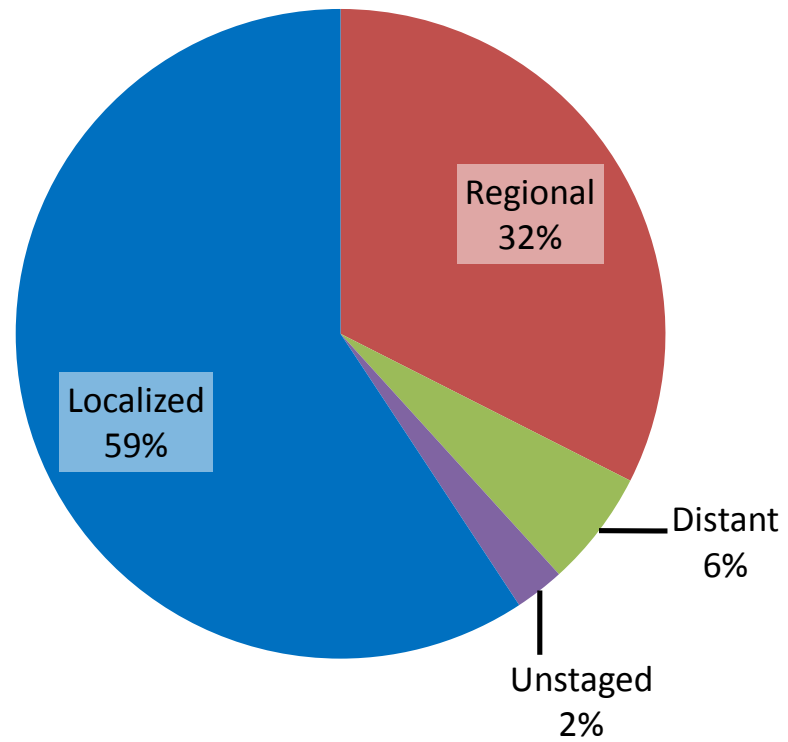# Percent of Malignant Female Breast Cases Matched by NDI

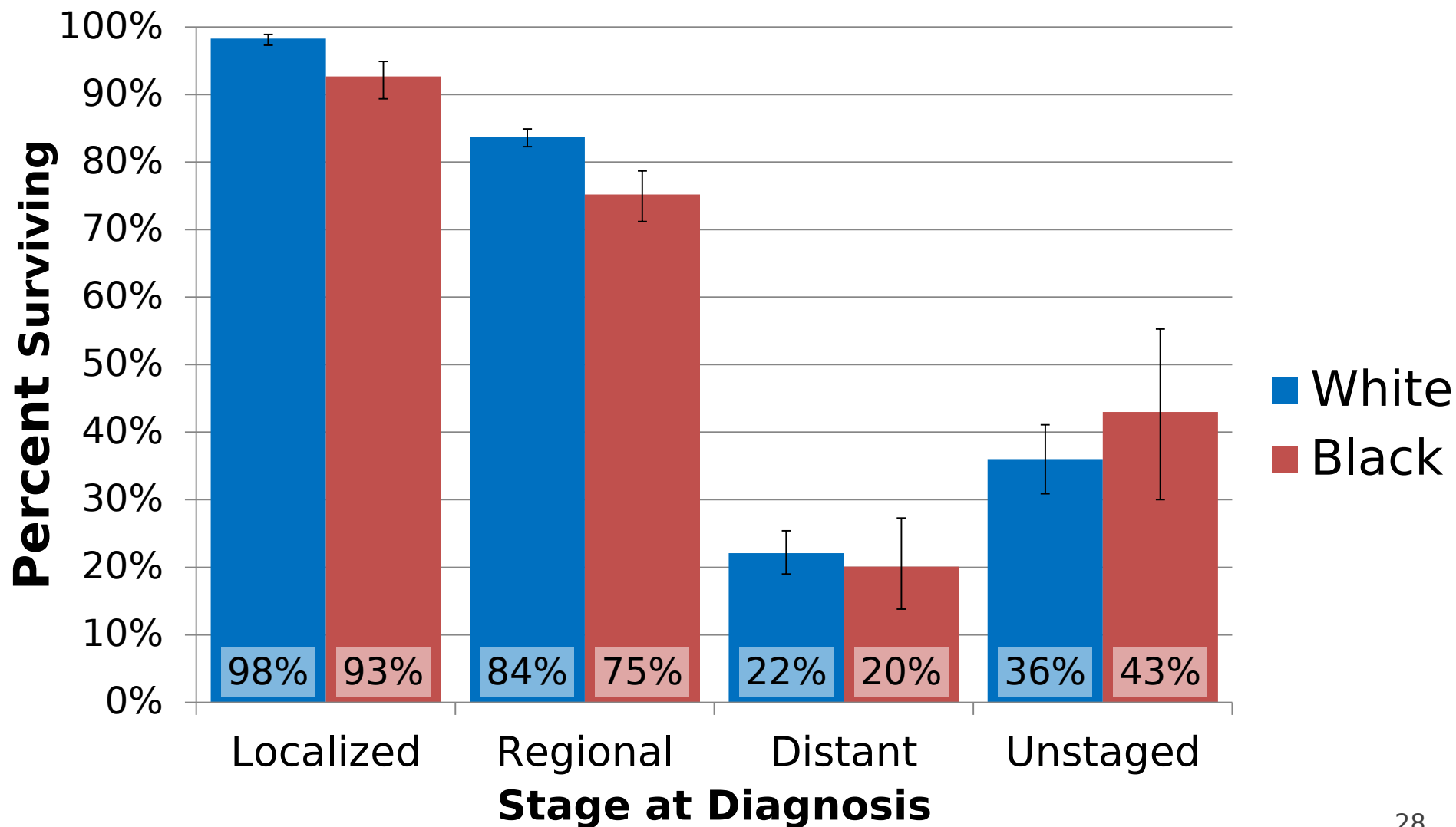# Female Breast Cancer Survival in Missouri, 2004-2010

5-Year Relative Survival

Percent Surviving by Stage at Diagnosis:
- Localized: 98%
- Regional: 83%
- Distant: 22%
- Unstaged: 37%

Distribution of Stage at Diagnosis

- Localized 59%
- Regional 32%
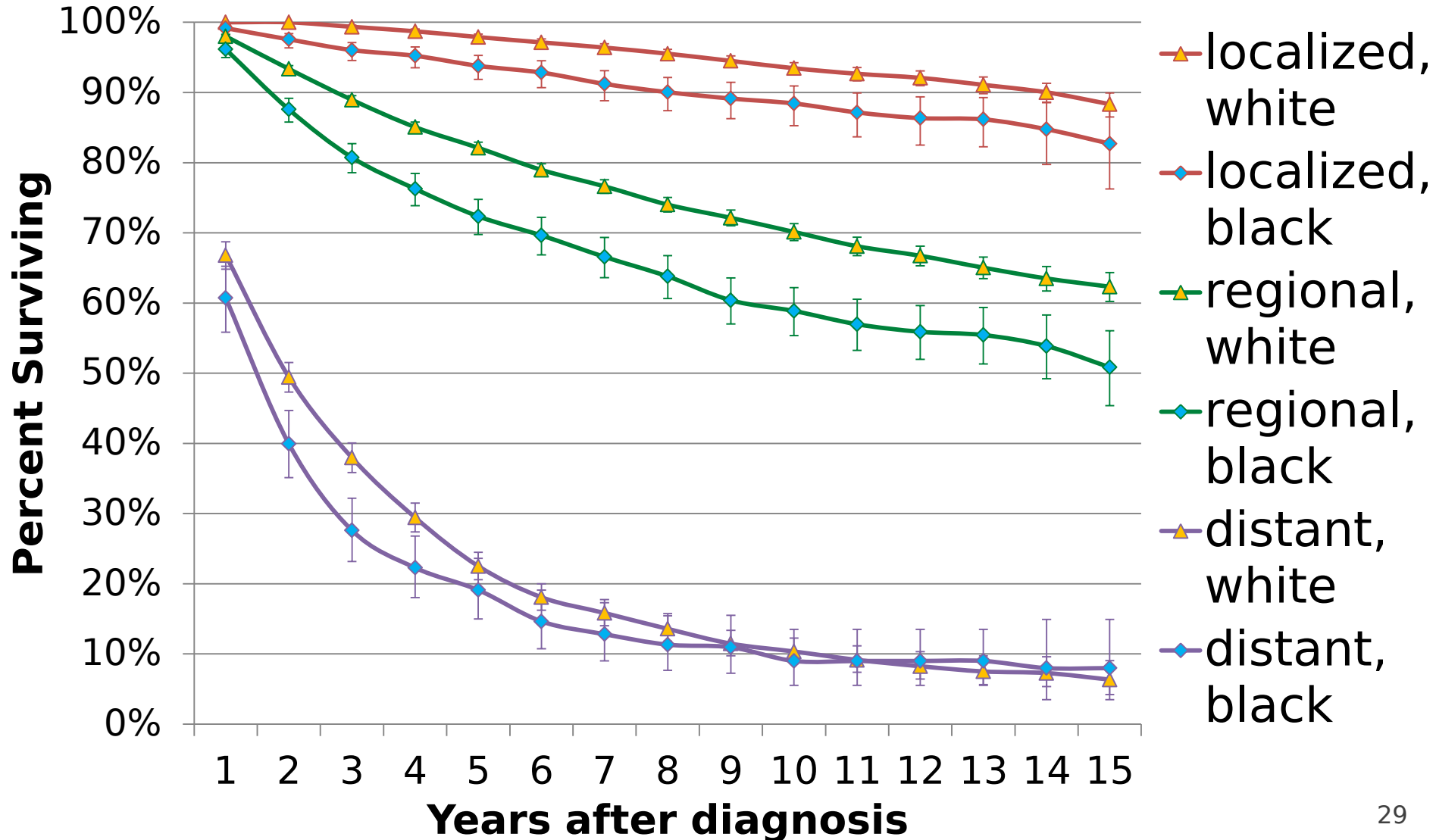- Distant 6%
- Unstaged 2%

Percentages do not add to 100% due to rounding

5-Year Relative Survival for Black & White Females, 2004–2010

Relative Survival Curves by Stage and Race

Chart: Relative Survival Curves by Stage and Race. X-axis: Years after diagnosis (1–15). Y-axis: Percent Surviving (0%–100%). Legend: localized, white; localized, black; regional, white; regional, black; distant, white; distant, black.

Breast & Cervical Cancer Survival in Missouri

❖ Release of this follow-up information to outside researchers:

  ❖ SSDI: Public information

    ❖ Fact & date of death, but cause is not in the SSDI

  ❖ NDI: Fact & date of death

  ❖ NDI: Cause of death (contingent)

    ❖ Cause of death is re-releasable to researchers for studies after formal review and approval

Breast & Cervical Cancer Survival in Missouri

❖The report on breast and cervical cancer survival among Missouri females is being prepared.

Conclusions

❖ The process for the NDI linkage differed significantly from the process that the registry uses for other linkages, but utilizing tools produced for the CDC's National Program of Cancer Registries, the burden was reduced substantially.

Conclusions

❖ NDI linkage provides a cost-effective method of obtaining information needed to assess survivorship.

❖ Passive (database linkage) follow-up is cheaper than traditional, active follow-up.

Acknowledgments

Questions?

Contact info:

Chester Schmaltz, PhD

Senior Statistician, Missouri Cancer Registry and Research Center

Health Management & Informatics

SchmaltzC@Missouri.edu

401 Clark Hall

University of Missouri, School of Medicine

Columbia MO 65211–4380

573–882–7775

http://mcr.umh.edu