Using National Death Index linkage to improve data on female breast cancer survival

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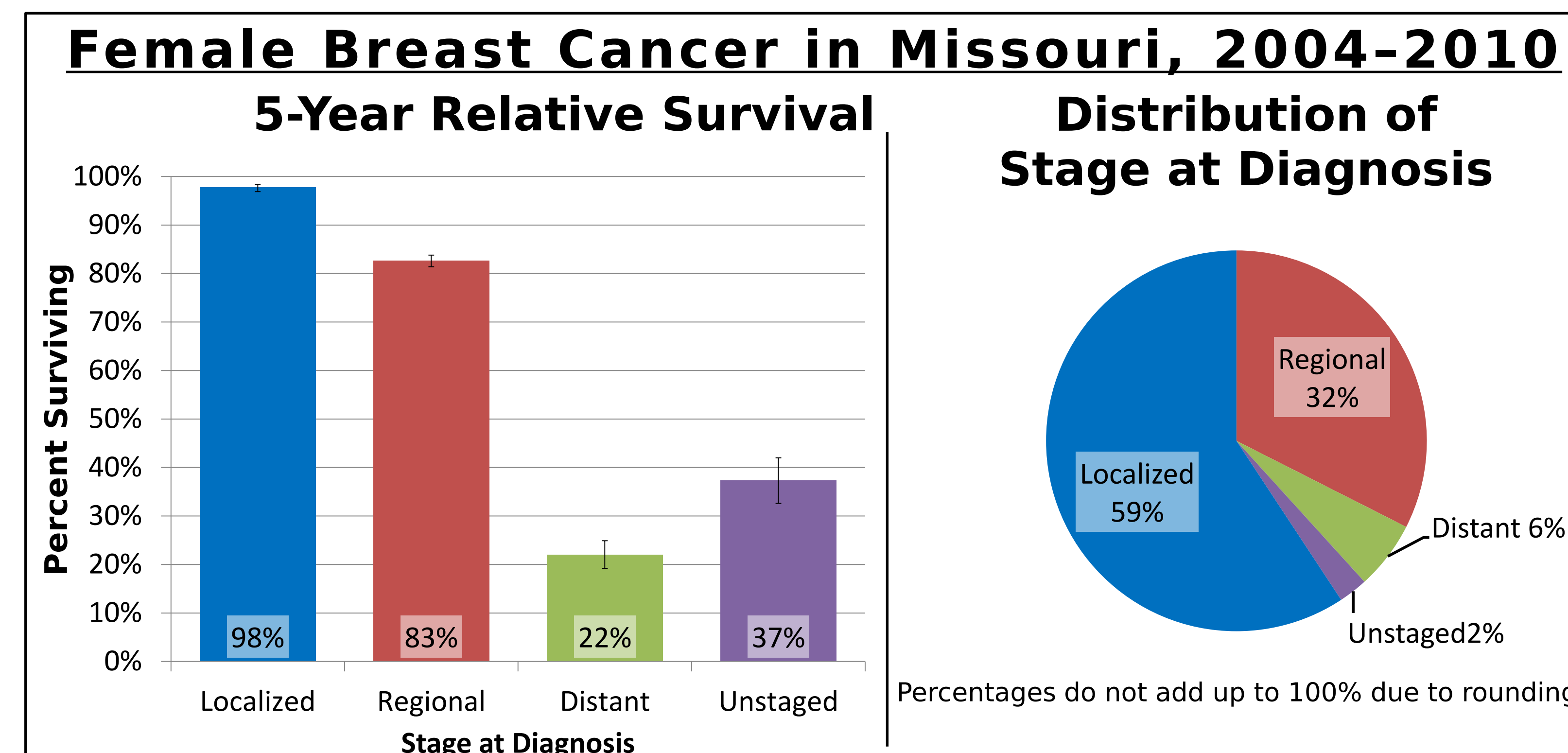
1. Background

❖ Breast cancer is the leading reportable cancer diagnosed among females in Missouri and a major cause of cancer deaths.
❖ 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*.
  ❖ 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.
  ❖ MCR has recently embarked on the first step to become a survival registry by focusing on patients with breast and cervical tumors.
❖ National Death Index (NDI) linkage provides a cost-effect method of obtaining information needed by public health and other researchers.
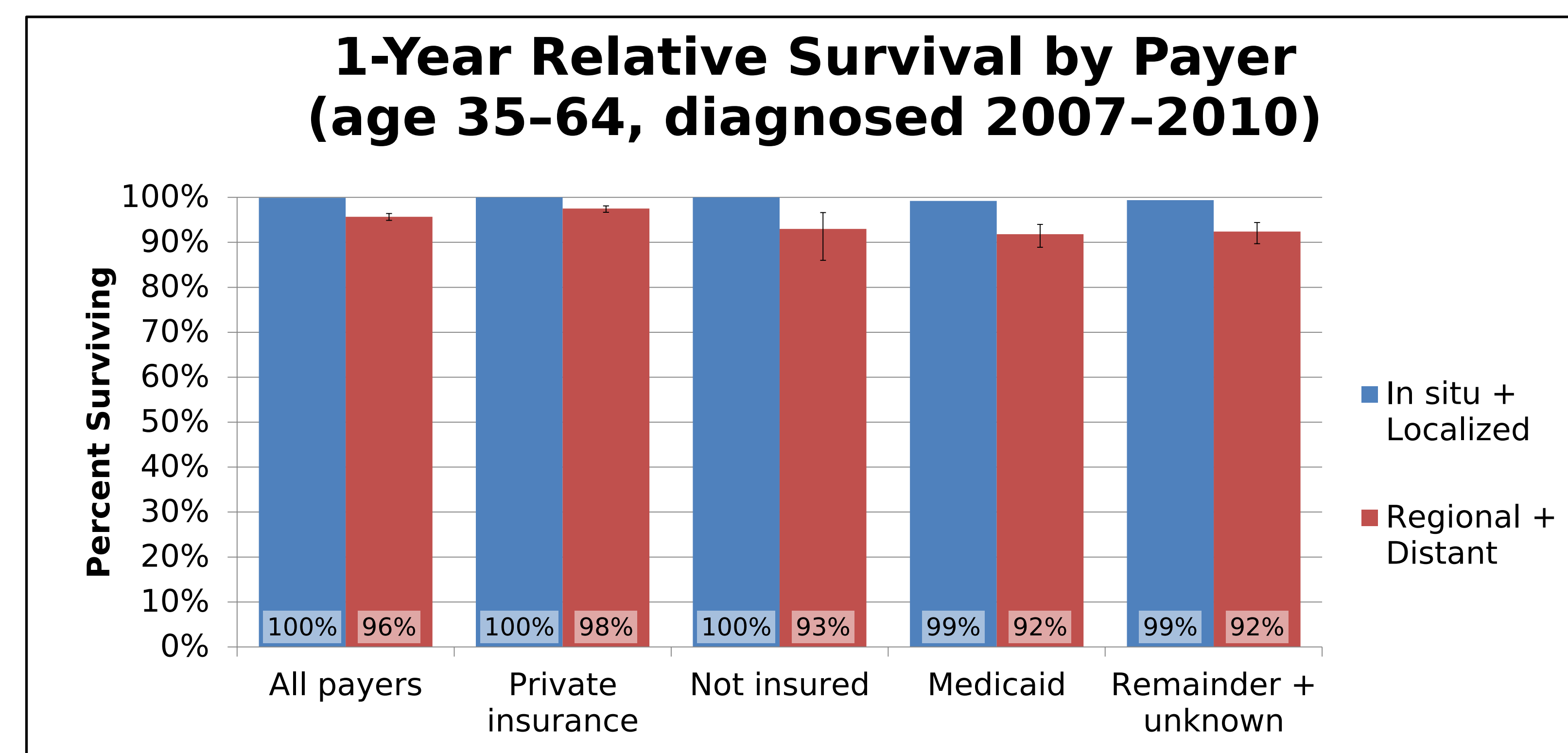
2. Methods

1. We conducted:
   a. Annual death clearance and follow-back for all cancer cases diagnosed in 2011;
   b. SSDI linkage on breast and cervical cancer cases diagnosed 1996 through 2011
      ❖ This reduces the number of cases with unknown vital status or SSN.
   c. NDI linkage for all the remaining breast and cervical cancer cases marked alive or dead with unknown cause.
2. Staff reviewed linkage results to identify matches, then updated the database to include the date and cause of death.
   ❖ Tools produced by the CDC's National Program of Cancer Registries greatly reduced the burden of manual review.
3. We then computed survival statistics (relative survival, cause-specific survival, crude probability of death) using SEER*Stat.
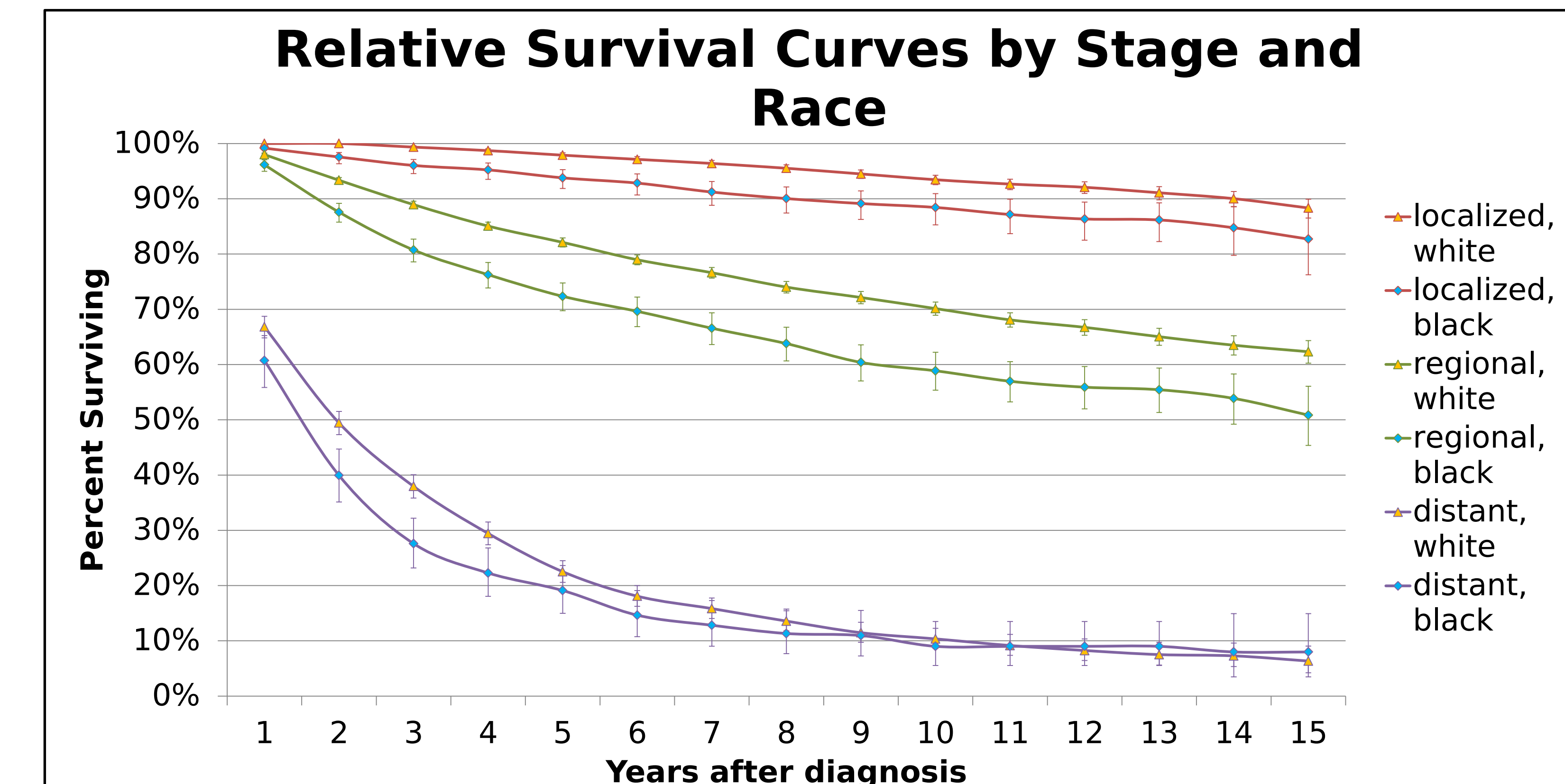
3. Results

❖ Stage at diagnosis had a very large effect on survival, reinforcing the need for early detection.
   ❖ *In situ* cases (not graphed) had relative survival of ~100% while localized was 98%.
   ❖ Survival dropped to 83% for regional stage.
   ❖ It dropped dramatically for distant stage (22%); fortunately, these cases comprised a small percentage (6%) of diagnosed cases.

Female Breast Cancer in Missouri, 2004–2010

5-Year Relative Survival — 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 up to 100% due to rounding.

❖ Patients without private insurance as the primary payer had a slightly lower survival for later stage breast cancer than those who had private insurance.
   ❖ Significantly lower for those with Medicaid as the primary payer.
   ❖ Percentage of cases diagnosed at regional & distant stage was higher as well.

1-Year Relative Survival by Payer (age 35–64, diagnosed 2007–2010)

	In situ + Localized	Regional + Distant
All payers	100%	96%
Private insurance	100%	98%
Not insured	100%	93%
Medicaid	99%	92%
Remainder + unknown	99%	92%

❖ Survival rates were fairly stable from 1996 to 2010.
❖ Black females fairly consistently had worse survival outcomes than white females.

Relative Survival Curves by Stage and Race

Legend: localized, white; localized, black; regional, white; regional, black; distant, white; distant, black

4. Conclusion/Discussion

❖ NDI linkage provides a cost-effective method of obtaining information needed to assess survivorship.
   ❖ Passive (database linkage) follow-up cheaper than traditional, active follow-up.
❖ By having more complete survival data, Missouri's breast and cervical cancer control program staff can better evaluate their program/implement changes.
❖ Improvements are needed:
   ❖ Eliminate disparity between black and white females and those with and without private insurance.
   ❖ Improve survival rates over time.

5. Contact

For more information about this linkage project or about the Breast & Cervical Survival Report, contact:

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