NCDB Survival Reports

Introduction: The NCDB Survival Reports are provided to allow CoC-accredited cancer programs access to AJCC stage-stratified five-year observed survival rates for all cancer sites. Computed results are available for cases diagnosed between 1994-1997 (AJCC 4th ed.), 1998-2002 (AJCC 5th ed.), or 2003-2009 (AJCC 6th ed.) and output displays can be controlled to show overall rates and 95 percent confidence intervals. To facilitate local use and distribution, users are able to download reports to their computer in any one of the following file formats: Adobe Acrobat PDF, Microsoft PowerPoint, Excel, and Word.

In the documentation that follows, a general outline of how to navigate the reporting tool, specify the survival analysis of interest, and interpret the generated results is provided.

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Case Selection Criteria: All cases were reported to the NCDB for the diagnosis years 1994-2009. The diagnosis year 2009 is the last year available to the NCDB with reported five-year follow-up information, which includes the date of last contact or date of death and the vital status of the patient on the recorded date. Cases are limited to adult (over the age of 18) male and female patients with their first or only cancer diagnosis (sequence 00, 01) that received all or part of their first course of therapy at the reporting cancer program (class of case=10-14 or 20-22). Cases reported from hospitals that do not have cancer programs currently accredited by the Commission on Cancer are excluded. Department of Defense and Veterans Affairs facilities are also excluded. Cases are only included if the elapsed time between diagnosis and the date a case is (re)reported to the NCDB is greater than or equal to five years.

Primary Site: Sixty-one disease sites are available for the user. Cases are assigned to a disease site depending upon the ICD-O-2/3 topography code and histology code reported for each case using the NCI-SEER site-recode rules, a standard mechanism used in cancer surveillance to classify cases for analytic tasks (http://seer.cancer.gov/).

AJCC Stage: These survival reports include cases diagnosed between 1994 and 2009. Cases are bundled across diagnosis years by time periods covered by the 4th, 5th, and 6th editions of the AJCC Cancer Staging Manuals – 4th edition: 1994-1997; 5th edition: 1998-2002; 6th edition: 2003-2009. A combined AJCC Stage Group is used to categorize cases for computational and display purposes which uses pathological (pAJCC) stage group where documented, augmented by the clinical (cAJCC) stage group where pathological stage is not recorded. This combination of clinical and pathological stage groupings minimizes the number of cases under analysis without AJCC stage and also avoids the exclusion of non-surgical cases from review. The stage groupings displayed are sensitive to the disease site and staging edition selected by the user. If an organ site does not have a recognized AJCC staging schema, survival results are displayed for all cases combined, without employing further stratification.

Reference Date: Users can choose to view survival for all cases, or only cases diagnosed after the reference date. Every CoC-accredited facility has a reference date, from which they are accountable for the completeness of the data for cases diagnosed in that year through the present. Since a facility may request to move their reference date forward, there are some
instances where a case’s diagnosis year falls before the facility’s reference date. Reports for cases whose diagnosis date is prior to the reference date cannot be changed or updated by the facility.

Age: The application allows users to select from three age groups: All adults (age 18-90+), ages 18-64, or ages 65 and older.

Sex: Users may select to view cases stratified by sex.

Sequence Number: Users may select to view cases that have had only one primary in their lifetimes (sequence 00), cases diagnosed with the first of two or more primaries (sequence 01), or both sequence 00 and 01.

Charlson-Deyo Comorbidity Index: Users may select to view cases that have a Charlson-Deyo comorbidity score of 0, 1, or 2 or more. The score is the sum of weighted scores assigned to selected comorbid conditions. For more information, see Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with ICD-9-CM administrative databases. J Clin Epidemiol 1992;45:613–19.

Observed Survival Rates: The NCDB Survival Reports provide users with unadjusted five-year observed survival rates. Rates are computed by the actuarial method, compounding survival in one-month intervals from the date of diagnosis, with death from any cause as the endpoint. Survival rates are not displayed when fewer than 30 cases are available, as survival rates calculated from small numbers of cases can yield misleading results and may have very wide confidence intervals. The survival graph that is generated will also display confidence intervals for 1, 2, 3, 4, and 5 year survival in a pop-up window by pointing your mouse to the specific year and group on the graph.

For more information regarding calculation methodologies for observed survival rates, standard errors, and confidence intervals, please refer to the AJCC Cancer Staging Manual, 7th edition, American Joint Committee on Cancer, Chapter 2 (pp. 15-20).

Displayed Results: Displayed results are controlled by the user and may include stage-stratified rates, overall rates, or the two combined on the same display. Stage-stratified rates displayed are specific to the organ site and staging edition selected. Users may also select to stratify on stage and sex, stage and comorbid condition, and stage and age group. Comorbid condition is defined as 0, 1, or 2+ Charlson/Deyo conditions, and is only available for AJCC 6th edition data. However, you may want to limit the number of stratification groups in each survival request, since the graphical display may be difficult to read when there are several different groups plotted on each graph.

Survival rates are not displayed when fewer than 30 cases are available within a stage group as rates calculated from small numbers of cases can yield potentially misleading results, with very wide confidence intervals. When small numbers of cases are encountered, a stage-specific curve will not be displayed, but the number of cases will be displayed in the accompanying table even though survival rates are not computed. If selected by the user, the overall rate shown in these reports is based on the total number of cases from all stage groups, including those with a small numbers of cases. The 95 percent confidence interval (CI) is displayed for computed survival rate at each year interval. The CI is calculated as +/- 1.96 standard deviations from the calculated year-specific survival rate. Users have the option to generate cancer program-specific survival rates. Users are cautioned that their program may not have encountered and reported a sufficient number of cases to the NCDB to facilitate the generation of survival rates that can be adequately generalized. A review of the confidence intervals provided as part of these reports is an important component of any interpretation of cancer program-specific rates.
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Comparing Survival Rates: Calculated survival rates are not case-mix or risk adjusted, and can affect interpretation as some hospitals may care for sicker or older patients. Some facilities have asked to publicly report their five year survival rates derived from the NCDB online survival tool or CQIP. The Commission on Cancer’s formal policy is to not permit public reporting of survival rates from CQIP or from the NCDB survival tools. Survival rates can differ from one facility to another for a variety of reasons, including differences in age distribution, comorbidities and other clinical and biologic factors. Our internal assessment of survival revealed that most facilities unadjusted survival rates are not significantly different from the survival rates for all CoC. Even fewer were statistically different after risk adjustment. Publishing unadjusted survival rates or risk-adjusted survival rates with or without confidence intervals and statistical interpretation can lead to erroneous conclusions. CoC believes in complete transparency and there are too many reasons comparative survival rates currently can be misleading.

- The Commission on Cancer policy does NOT permit public reporting of survival for a given facility, as well as all other cases reported to the NCDB from CoC-accredited cancer programs, even if the 95% confidence intervals are included in the presentation.

- If the confidence intervals overlap, there is no statistical difference between the 5th-year survival rate at your facility with that of all other CoC-accredited cancer programs.

The survival reports are intended for internal quality improvement purposes. Major findings from these reports should be reviewed at your facility’s Cancer Committee meetings and any interventions for improvement in quality of care should be recommended.

Sharing Results: Users can select from five separate formats to download the computed and displayed results. These including Adobe Acrobat (pdf); Microsoft Excel (xls), Word (rtf), PowerPoint (ppt), and PNG Image. These are to be used for internal distribution only at your facility.