Summary Stage:
Data Effects of the Changes in 2000

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INTRODUCTION

SSS1977 to SSS2000

The SEER Summary Stage Guidelines were developed by the Surveillance, Epidemiology and End Results (SEER) Program as an indirectly derived summary indicator of SEER's extent of disease (EOD) measures. Summary stage has been used historically for comparative analyses of stage of disease at diagnosis among different populations and locations and to monitor changes over time. The 1977 Guidelines were developed to assist in interpreting SEER Summary Stage values (referred to as SSS1977 in this report). The code category definitions are presented in Table 1.

Table 1. 1977 Summary Stage Guidelines code category definitions

Code	Definition
0	In situ
1	Localized only
2	Regional by direct extension only
3	Regional lymph nodes involved only
4	Regional by BOTH direct extension AND lymph node involvement
5	Regional, NOS (Not Otherwise Specified)
7	Distant site(s)/node(s) involved
9	Unknown if extension or metastasis (unstaged, unknown, or unspecified)

Since 1977, incremental changes were made to the EOD that resulted in changes in the computed SEER Summary Stage. These were not reflected in SSS1977. The changes included precise distinctions in measures that were assigned to specific Summary Stage values, the timing during which staging could take place, and the sites (and histologies) subject to specific staging regulations. Introduction of the *International Classification of Diseases for Oncology, Second Edition* (ICD-O-2) and, subsequently, ICD-O-3, required additional adaptations to the EOD.

During the same period, many central registries not in the SEER Program began to adopt SSS1977 as their required measure of disease spread at diagnosis. Unlike SEER, however, these states used SSS1977 as a directly coded measure based on the Guidelines. The American College of Surgeons also required direct coding of SSS1977 for cases for which the American Joint Committee on Cancer (AJCC) did not assign a Tumor, Node, Metastases (TNM) based stage.

SEER developed SEER Summary Stage 2000 (SSS2000) to address issues related to directly coded summary stage and discrepancies in summary stage classification being identified between direct and indirect coding procedures. All of the changes to EOD that occurred between 1977 and 2000 were incorporated into the modified SSS2000. The new *Summary Stage 2000 Manual* was written for registries that coded SSS2000 directly. The accumulated changes were not amenable to conversion between SSS1977 and SSS2000, but the new manual documented the numerous changes in stage assignment. The code assignment, timing rule, and instruction changes are summarized in Appendix A.

Formation of the SEER Summary Stage Comparability Project and the Advisory Group

By the time SSS2000 was published, several central registries had used a direct-coded Summary Stage variable for many, even as long as 10 or more, years and this raised questions about the effect of the changes on interpretation of their longitudinal data. The National Program of Cancer Registries (NPCR) awarded monies to the North American Association of Central Cancer Registries (NAACCR) to conduct an assessment of the impact of SSS2000 on the interpretation of historical time trends and research uses in public health.

The project was designed to investigate the effect of changing from SSS1977 to SSS2000 on the use and interpretation of Summary Stage codes. An Advisory Group was formed to develop a study protocol for the project. Participants in the Advisory Group were recruited from all NAACCR members through an open invitation of interested persons to join the Advisory Group.

METHODS

Development of the Study Design

The Advisory Group determined the extent of the SSS2000 changes and identified where the changes might have the greatest effect on data uses. First, as documented in the *SEER Summary Stage Manual 2000,* the changes were extensive, in that almost every SSS2000 site schema had at least one change from the earlier version (see Table 2). These changes were the basis of most concerns.

Table 2. SSS2000 schema that involved changes from SSS1977

Lip	Rectosigmoid junction	Vulva
Tongue	Anus	Vagina
Soft palate	Liver	Cervix uteri
Cheek	Gallbladder	Uterus
Parotid gland	Extrahepatic bile duct	Fallopian tube
Other major salivary glands	Ampulla of Vater	Prostate
Oropharynx	Pancreas	Kidney
Nasopharynx	Larynx	Ureter
Esophagus	Lung	Bladder
Stomach	Skin	Brain
Small intestine	Breast	Thyroid

More than 75 percent of all cancer cases originate in a site that had at least one change made in its staging schema. Advisory Group members with access to central registry data tabulated the distribution of their cases by SSS1977 to determine the maximum proportion of cases that might be affected by stage classification. The proportion of cases that were in stage categories affected by changes varied by primary site. The percent of cases in site-specific stage categories that changed, for major cancers (invasive cancers only) were: female breast (52%; local – 48%, distant – 4%); lung (66%; local – 20%, distant – 46%); melanoma of skin (33%; local – 33%); prostate (93%; local – 33%, regional – 57%, distant – 3%); and colon (0%).

Only specific tissues and/or lymph nodes were involved in changed definitions. For lung cancer, there was no mention of “acteletesis/obstructive pneumonitis” or “lymphadenopathy” in

SSS1977, so these would have been coded *local*; they are *regional* in SSS2000. There was no mention of "pleural effusion" in SSS1977; it was coded as *distant* in SSS2000. The following tissues were considered *local* for SSS1977 and *regional* for SSS2000: (1) multiple masses/ separate tumor nodule(s) in the SAME lobe, and (2) tumor of main stem bronchus greater than 2.0 cm from carina. Separate tumor nodule(s) in different lobe(s) was considered *local* for SSS1977 and *distant* for SSS2000. Lastly, the following tissues were considered *distant* for SSS1977 and *regional* for SSS2000: (1) aorta, (2) brachial plexus from superior sulcus, (3) chest (thoracic) wall, (4) diaphragm, (5) pancoast tumor (superior sulcus syndrome), and (6) parietal (mediastinal) pleura.

For breast cancer, adherence, attachment, fixation, induration, and thickening (skin changes) conditions were ignored in SSS1977 and, consequently, would have been coded as *local*. They are defined as *regional* in SSS2000. Additionally, infraclavicular (subclavicular) nodes were considered *distant* in SSS1977 and *regional* in SSS2000.

The 1977 Guidelines did not address timing. The SEER EOD timing instructions changed prior to the study period for prostate only from 2 to 4 months, but the change was not to be applied to direct coding of Summary Stage. The timing rule for SSS2000 is 4 months for all sites or to completion of first-course treatment (whichever is longer) in the absence of disease progression.

Registry Use of Summary Stage

Many registries routinely report stage distribution of all (or nearly all) site groups, but no longitudinal information is provided for most sites. The states represented on the Advisory Group used SSS1977 as a dependent variable in determining cancer screening or early detection needs or in tracking prevention and early detection program effectiveness. They also tracked effectiveness of cancer control interventions by changes in the distribution of Summary Stage (using SSS1977) over time. None of the Advisory Group members used SSS1977 for case selection for any type of study (whether longitudinal or not), and no examples to the contrary were found for any central registries.

The Advisory Group determined that the study should focus on a small number of primary sites subject to cancer control that have a substantial number of cases in SSS1977 stage categories that were subject to changes in SSS2000.

Study Design

Sites. As noted above, Summary Stage is a useful indicator for historical surveillance of trends in stage of disease at diagnosis and for use in public health cancer control activities, both in identifying high-risk populations and in evaluating impact of programs. Five common cancers are amenable to early detection and prevention programs: cancers of the breast, prostate, lung, and colon, and melanoma of skin. Selection of cancer sites to include in the study was based on (1) changes between SSS1977 and SSS2000 (colon cancer had none and thus was excluded; (2) completeness of staging information (melanoma was excluded due to expected high frequency of missing data from records of diagnosis and treatment occurring outside the registry's reporting infrastucture); and (3) absence of other external factors that might affect time trends (prostate

cancer was excluded based on regional variation in screening affecting the stage trends). As a result, the Advisory Group selected invasive carcinomas of the lung and female breast for the study

Registries. The Advisory Group selected three central registries, to reabstract 200 lung and 200 female breast cancer cases each, or 600 total cases for each site. Interested central registries were solicited and considered for the study if they met the following criteria: (1) NAACCR Gold or Silver Certification for diagnosis year 1999, (2) collection of text information supporting stage at diagnosis for year 2000 cases, and (3) at least 500 incident cases on file for breast and lung carcinomas.

Six registries expressed interest, and they were further asked to identify how long the registry had collected SSS1977, whether they trained registrars specifically in coding SSS1977, and how they used Summary Stage data in the registry. The Advisory Group ranked the registries that had collected SSS1977 for at least 5 years; could demonstrate widespread use of SSS1977 in research studies; and whether the variable, class of case, was collected. Three central registries were selected for participation in the study: the New Jersey State Cancer Registry, the Wisconsin Cancer Reporting System, and the Minnesota Cancer Surveillance System. The Advisory Group stipulated that all reabstracting must be performed by Certified Tumor Registrars (CTRs) and all of the selected registries provided CTRs from their staff for this purpose.

Cases. Cases were selected using a random sample. Each registry was asked to identify all lung and female invasive breast carcinomas (specified as ICD-O-2 histologies 8010-8580 with behavior 3) diagnosed in 2000 and reported to their registry by an in-state hospital that had provided at least part of first-course treatment (Class of Case 1 or 2 for the hospital). If more than one hospital provided first-course treatment for the same eligible case, the report from the lower numbered hospital (using the state's own numbering system) was chosen. The state assigned a code to each eligible case, which subsequently was used to identify the case to be abstracted. A file consisting only of the code numbers and the primary site was sent to the analyst, who drew the final random sample. The results then were returned to the submitting state. A copy of the data preparation instructions is included as Appendix B.

The study was designed to detect an absolute difference of 10% in cases coded to regional or 5% in cases coded to distant stage for either breast or lung cancer with an alpha of 0.05 and a beta of 0.20.

Items measured. Participants created two files: one for importing into the abstracting software (this file included confidential data identifiers) and a second was sent to the analyst (no confidential identifiers). The items considered confidential were birth date; reporting hospital; medical record number; and first, middle, and last name. Six other registry items were used for case identification in the field and were submitted for analysis: identifier key, date of diagnosis, primary site, laterality, ICD-O-2 histology, and ICD-O-2 behavior. The following 13 registry items were provided for analysis, but were not available to abstractors in the field: SSS1977, Text-DX Pro-PE, Text-DX Proc-X-ray/scan, Text-DX Proc-Scopes, Text-DX Proc-Lab Tests, Text-DX Proc-OP, Text-DX Proc-Path, Text-Staging, RX Text-Surgery, RX Text-Radiation (Beam), RX Text-Radiation Other, RX Text-Chemo, and RX Text-Hormone.

The selection of text fields collected was based on the Advisory Group's observation that text fields often reflect content that might be expected in other fields. The Advisory Group requested that registries sanitize the text fields before submitting data. Field abstracting included reabstracting all items also collected from registry data, except for the six confidential items, the identifier key, SSS2000, and the date of surgery.

Data collection instrument. Programming staff at CDC modified Abstract Plus, a publicly available software package, to serve the data collection needs of this study. Applicable single- and inter-item edits for items coded in the field were used. A notable exception was the necessary omission of the edit that requires use of SSS2000 for post-2000 cases only. A separate extraction application selected only the non-confidential items requested for the study for submission to the analyst.

Timeframe

The Advisory Group began its deliberations at the end of November 2001. The project was announced at the annual NAACCR meeting in Toronto the following June, and responses were received in July 2002. A few months were required for all states to sign contractual agreements.

The original intent was to have a single face-to-face training meeting with all abstractors, the contact from each state, and trainers with respect to Summary Stage, Abstract Plus, and the data manipulations. After it became apparent that it was not possible to meet with all three registries at once, the Advisory Group Co-Chairs provided the training for each participating registry individually in late September and early October 2002.

The training highlighted a few changes needed in the modified Abstract Plus software. The final version of the customized Abstract Plus data collection tool was available in mid-December 2002. Two states submitted their eligible cases and received their sample cases in December 2002, and the third state did so the following February. Two states provided their files in April and the third submitted their data in September 2003 (a delay was caused by computer failure, loss of all work, and the need to re-reabstract all cases).

Training

Training for participating central registries involved three components: (1) the purpose of the study, (2) use of Abstract Plus, and (3) abstracting lung and female breast cancer cases according to SSS1977 and SSS2000. Training was provided separately for each registry in 1-day sessions. The central registry Project Manager, all project abstractors, and any programmers were asked to participate. The division of labor was different at each registry, so the actual format of the presentations differed, but the content was kept as similar as possible, and the handout materials were the same for all three registries.

During the training, registries were provided with the framework of the study, including a general summary of the history provided in the Introduction of this report, instructions for file preparation, and coding exercises for SSS1977 and SSS2000. Abstractors were guided through

the installation and use of Abstract Plus, and central registry information technology representatives providing support for the study were given instructions.

The background information emphasized the importance of following the specifications in SSS1977 and SSS2000 precisely because the differences in those two publications were of greatest interest. Abstractors practiced loading the registry data into Abstract Plus and entering codes and text, setting password protection, and exporting the data file. Programming support staff were given instruction for installing Abstract Plus and loading registry data. Both registrars and programmers were given instructions for data preparation. Abstractors used Abstract Plus to code practice cases, with ample opportunity to explore both the operation of Abstract Plus and coding specifications (see Appendices C-N for training materials).

Statistical Analysis

A chi-square test was used to compare the characteristics of the samples drawn from the three registries. The Kappa statistic was used to compare the agreement between the original abstract and the re-abstracted codes; the original abstract and the SSS2000 codes; and the re-abstracted 1977 values with the SSS2000 codes. A Kappa statistic that falls below 0.40 is considered poor agreement beyond chance; from 0.40 - 0.74, fair to good agreement beyond chance; and higher than 0.75 excellent agreement beyond chance. The results were considered statistically significant when the p value was 0.05 or less. All Summary Stage values pertaining to a regional EOD (values 2 through 5) were collapsed into one regional category for the purposes of statistical testing.

RESULTS

The Sample

A total of 200 cases were randomly drawn from the eligible cases for each site in each state. The states did not differ significantly in their numbers of male and female lung cancer patients or in their distribution of age for either primary site as shown in Table 3.

Sixty-seven (5%) of the original 1,200 cases were omitted from the analysis. Twenty-two were determined in field reabstracting to have been ineligible due to coding errors for site, histology, behavior, or date of diagnosis. Nineteen cases were ineligible because one central registry selected cases with histologies outside of the range specified by the study protocol. Finally, 26 eligible cases were not reabstracted due to the inaccessibility of the patient records. After these exclusions, 575 breast cancer cases and 558 lung cancer cases were evaluated.

Table 3. Descriptive characteristics of the study subjects by registry

	Registry A				Registry B				Registry C				Total			
	Lung		F Breast		Lung		F Breast		Lung		F Breast		Lung		F Breast	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
# Eligible Cases	2,214	--	3,334	--	2,780	--	4,406	--	2,425	--	3,292	--	7,419	--	11,032	--
# Cases selected	190	--	197	--	184	--	187	--	184	--	191	--	558	--	575	--
Gender																
Male	116	61	0	--	100	54	0	--	105	57	0	--	321	58	0	--
Female	74	39	197	100	84	46	187	100	79	43	191	100	237	42	575	100
Age																
< 45	2	1	28	14	9	5	14	8	4	2	28	15	15	3	70	12
45-54	19	10	49	25	20	11	47	25	22	12	39	20	61	11	135	24
55-64	37	20	46	23	46	26	45	24	26	14	35	18	109	20	126	22
65-74	69	36	42	21	59	32	34	18	69	38	38	20	197	35	114	20
75 +	63	33	32	16	50	27	47	26	63	34	51	27	176	32	130	23
SSS1977																
Local	38	20	110	56	40	22	110	59	38	21	139	73	116	21	359	62
Reg-extension	14	7	1	0.5	13	7	6	3	11	6	3	2	38	7	10	2
Regional Nodes	23	12	64	32	16	9	51	27	22	12	31	16	61	11	146	25
Regional extension & nodes	20	10	9	5	18	10	8	4	24	13	3	2	62	11	20	4
Regional NOS	2	1	0	0	3	2	2	1	1	0.5	0	0	6	1	2	0.3
Distant	85	5	45	2	89	48	9	5	74	40	6	3	248	44	20	4
Unknown	8	4	8	4	5	3	1	0.5	14	8	9	5	27	5	18	3

The three samples were similar with regard to the distribution of subjects by age and sex (lung only). The distributions of central registry SSS1977 (including unknown stage) differed among the three states (chi square based on SSS1977 values < .05). The states did not differ significantly in their distribution of unknown versus known SSS1977 for breast cancer cases (chi square for known versus unknown cases $p > .05$), but they did for lung cancer cases ($p < .05$). When SSS1977 was grouped as local (code 1), regional (codes 2-5), and distant (code 7), the states differed significantly in their ordinal distribution of breast SSS1977 for known stages ($p < .001$), but not for lung.

Reabstracting SSS1977 Values

Approximately 70 reabstracted records from each registry had different reabstracted values for SSS1977. Table 4 compares the SSS1977 values assigned by the registries and abstractors by site for cases that were reabstracted. Percentages highlighted in bold indicate the percent of cases in each registry stage category that were reabstracted to the same code. For lung cancer cases, the Kappa statistic was 0.71 ($p < .001$), indicating good statistical agreement beyond chance. For breast cancer cases, the Kappa statistic was 0.83 ($p < .001$), suggesting excellent agreement beyond chance.

Table 4. Percentage distribution of reabstracted SSS1977 by registry SSS1977

Original SS1977	***Reabstracted***				
Lung					
Percents	**Local**	**Regional**	**Distant**	**Unk**	**Total**
Local	**79.3**	13.8	3.4	3.4	100
Regional	2.4	**75.4**	19.8	2.4	100
Distant	0.8	6.0	**91.1**	2.0	100
Unknown	11.1	18.5	44.4	**25.9**	100
Total	18.1	29.0	49.3	**3.6**	100
Counts					
Local	**92**	16	4	4	116
Regional	4	**126**	33	4	167
Distant	2	15	**226**	5	248
Unknown	3	5	12	**7**	27
Total	101	162	275	20	558
Female Breast					
Percents					
Local	**96.4**	2.5	0.3	0.8	100
Regional	6.2	**90.4**	0.6	2.8	100
Distant	0.0	10.0	**85.0**	5.0	100
Unknown	66.7	16.7	0.0	**16.7**	100
Total	64.2	30.4	3.3	2.1	100
Counts					
Local	**346**	9	1	3	359
Regional	11	**161**	1	5	178
Distant	0	2	**17**	1	20
Unknown	12	3	0	**3**	18
Total	369	175	19	12	575

Although the selection criteria were limited to cases from hospitals that provided any first-course treatment, the SSS1977 codes submitted by the registry were consolidated codes, and thus discrepancies between the reabstracted SSS1977 values and the registry SSS1977 values may be related to differential information available to the hospital registries or to conflicting information submitted by multiple hospitals. Therefore, participating central registries were requested to determine, for each case in which the two values were not the same, whether there were multiple first-course reports in central registry files and, if so, any other SSS1977 values that were reported to the central registry. Only one central registry was able to complete this review for inclusion in this report. For that registry, 13 percent of the discrepant cases had other reports that agreed with the reabstracted value. Seventy-five percent of the discrepant cases had either one report in registry files or additional report(s) that were present but unstaged. Small numbers of cases had other records on file with SSS1977 values other than the reabstracted values recorded.

Comparison of Original SSS1977 and SSS2000 Values

Table 5 compares the SSS1977 values assigned by the registries and the abstractors codes for SSS2000 by site. Percentages highlighted in bold indicate the percent of cases in each stage category that were in agreement. For lung cancer cases, the Kappa statistic was 0.89 ($p < .001$), indicating excellent agreement beyond chance. For breast cancer cases, the Kappa statistic was 0.99 ($p < .001$), also suggesting excellent agreement beyond chance.

Table 5. Percentage distributions of stage for registry SSS1977 and SSS2000 by primary site

SSS2000	**Original SS1977**				
Lung					
Percents	**Local**	**Regional**	**Distant**	**Unk**	**Total**
Local	**100.0**	0.0	0.0	0.0	100
Regional	4.3	**88.3**	7.4	0.0	100
Distant	0.4	6.7	**92.9**	0.0	100
Unknown	0	0	0	**100.0**	100
Total	18.1	29.0	49.3	3.6	100
Counts					
Local	**93**	0	0	0	93
Regional	7	**143**	12	0	162
Distant	1	19	**263**	0	283
Unknown	0	0	0	**20**	20
Total	101	162	275	20	558
Female Breast					
Percents					
Local	**100**	0	0	0	100
Regional	2.2	**97.8**	0	0	100
Distant	0	0	**100**	0	100
Unknown	0	0	0	**100**	100
Total	64.2	30.4	3.3	2.1	100
Counts					
Local	**365**	0	0	0	365
Regional	4	**175**	0	0	179
Distant	0	0	**19**	0	19
Unknown	0	0	0	**12**	12
Total	369	175	19	12	575

Comparison of Reabstracted SSS1977 and SSS2000 Values

Table 6 compares the re-abstracted codes with the abstractors SSS2000 codes by site. Again, the percentages highlighted in bold indicate the percent of cases in each stage category that were in agreement on both measures. For lung cancer cases, the Kappa statistic was 0.68 ($p < .001$), indicating good statistical agreement beyond chance. For breast cancer cases, the Kappa statistic was 0.84 ($p < .001$), suggesting excellent agreement beyond chance.

As was noted in Table 4 comparisons, the selection criteria limited cases to those reported from hospitals that provided any first-course treatment. The SSS1977 codes submitted by the registry were consolidated codes, and thus discrepancies between the reabstracted SSS1977 values and the SSS2000 values reported in Table 6 (and the resulting lower kappa statistics) may be related to differential information available to the hospital registries or to conflicting information submitted by multiple hospitals.

Table 6. Percentage distributions of stage for reabstracted SSS1977 and SSS2000 by primary site

SSS2000	Original SS1977				
Lung					
Percents	**Local**	**Regional**	**Distant**	**Unk**	**Total**
Local	**73.3**	20.7	2.6	3.4	100
Regional	1.8	**73.7**	22.2	2.4	100
Distant	0.8	5.2	**91.9**	2.0	100
Unknown	11.1	7.4	55.6	**25.9**	100
Total	16.7	29.0	50.7	3.6	100
Counts					
Local	**85**	24	3	4	116
Regional	3	**123**	37	4	167
Distant	2	13	**228**	5	248
Unknown	3	2	15	**7**	27
Total	93	162	283	20	558
Female Breast					
Percents					
Local	**96.1**	2.8	0.3	0.8	100
Regional	4.5	**92.1**	0.6	2.8	100
Distant	0	10.0	**85.0**	5.0	100
Unknown	66.7	16.7	0	**16.7**	100
Total	63.5	31.1	3.3	2.1	100
Counts					
Local	**345**	10	1	3	359
Regional	8	**164**	1	5	178
Distant	0	2	**17**	1	20
Unknown	12	3	0	**3**	18
Total	365	179	19	12	575

Tissue Involvement Contributing to Code Changes

One lung cancer case was upgraded from local in SSS1977 to distant in SSS2000 had nodules in two lobes. Two lung cancer cases were local according to SSS1977 based on information available within 2 months of diagnosis, but regional according to SSS2000 using subsequent information. One was upgraded due to involvement of the main stem bronchus and one due to multiple nodules in a single lobe. Three cases were upgraded from local to regional because of acteletesis or obstructive pneumonitis.

There are several tissues whose involvement downgrades lung stage from distant in SSS1977 to regional in SSS2000, and the cases in the study evidenced a variety of them in the absence of distant involvement as defined in SSS2000. Three had parietal pleura involvement only mentioned, two had involvement of the parietal pleura and chest wall, three had involvement in the chest wall only, one had chest wall and pancoast involvement, and two aortic involvement. One case had chest wall involvement plus positive regional lymph nodes, which down-staged the SSS2000 value from a code of 7 (distant) for SSS1977 to a code of 4 (regional, extension and nodes).

Many lung cancer cases staged regionally using SSS1977 with dissimilar SSS1977 and SSS2000 values had nodal involvement. Two cases were affected by the difference in the timing rule. Twenty cases were staged 3 (nodes only) for SSS1977 that were 4 (nodes plus extension) due to reassignment of extension of particular tissues from local to regional, and one shifted from 4 to 3. The terms “lymphadenopathy” (evidence of regional nodes for lung cancers in SSS2000) and

"pleural effusion" (distant in SSS2000) were not mentioned in SSS1977. For strict adherence to the printed staging documents, abstractors were asked not to use those references for coding. One stage assignment was affected by reference to lymphadenopathy, and 15 were affected by reference to pleural effusion.

Only five breast cancer cases were coded differently using SSS2000 than SSS1977. All except one resulted from timing differences, with regional node involvement not being recognized until more than 2 months after diagnosis. The single exception was upgraded due to skin involvement. That case was an unusual one in that the patient previously had been treated for breast lymphoma, and developed ductal carcinoma in the scar tissue that affected the dermal lymphatics. No cases involved a more conventional spread to the skin.

DISCUSSION

Cancers of the female breast and lung differ considerably in staging issues and the role of cancer control. In particular, early detection (and a concomitant downshifting in the stage at diagnosis) is an important goal in breast cancer control. However, lung cancer control programs are more directed toward prevention. Another feature that distinguishes lung cancer from female breast cancer is treatment, especially as it relates to stage. Breast cancer can be treated by radiation only (especially early in its development), but it usually involves multi-modality treatments, the selection of which is dependent on stage of disease. Lung cancer treatment selection, on the other hand, is not necessarily determined by stage of disease.

Many of the training materials used by the Advisory Group to prepare central registries for participation in the project are included as Appendices. In addition to those handouts, all participants were given photocopies of the introductory material and all relevant site-specific coding instructions in SSS1977 and SSS2000. All participants were encouraged to contact the Advisory Group Co-Chairs with questions. The Advisory Group received questions related to case selection, implementation of Abstract Plus, data export and extraction procedures, and abstracting questions. One set of questions was of particular interest for the purposes of this project: after SSS1977 was published, some modifications and clarifications to SEER EOD were so broadly publicized that they are taken for granted by many registries, although they are not documented in SSS1977. It was decided that abstractors should adhere strictly to the specific wording in the document; however, to the extent that their registries and others adapted to the changing EOD standards, actual SSS1977 registry data may be more similar to the SSS2000 specifications than the data collected for this study might indicate.

The differential variability based on known versus unknown SSS1977 and on known SSS1977 reflects the roles of staging in cancer control efforts for the two primary sites. For lung cancer, cancer control programs focus on prevention, particularly on reduction of smoking activity. Lung cancer patients often are characterized by additional co-morbid conditions, relating both to the smoking-related etiology of lung cancer (which also is implicated in other chronic diseases) and to the advanced age of a large portion of the patients (a group also characterized by multiple health problems). Lung cancer itself is less amenable to treatment than breast cancer, and is more frequently diagnosed after distant spread. For all of these reasons, some physicians do not believe that careful staging of lung cancer is a worthwhile activity.

The Advisory Group extensively discussed the criterion that the hospital provide at least part of the first-course of treatment. There was a desire to select reports from sources that had some reason to be able to stage the case and had a probable need to have good staging. However, there also was a desire to examine "ordinary" reports and not bias the selection for "best case" scenarios. This procedure seemed to offer the best balance and set a criterion that was independent of possible differences in central registry consolidation procedures for Summary Stage. All three participating states adhered to the criterion. This may have biased the results toward the null hypothesis by not allowing us to pick the facility where the most information was likely to be available for coding stage.

The number of discrepant values associated with the percent distribution of reabstracted SSS1997 by registry SSS1977 surprised some study participants. One central registry noted the poor coding in the hospitals with its submission, suggesting that they would need to find a way to improve the coding. Another indicated that, during the months that intervened between drawing the sample and examining the results, some of the discrepant SSS1977 codes had been updated to equal the reabstracted values through routine registry processing, even though more than 2 years had passed since the cases were diagnosed.

CONCLUSIONS

The change from SSS1977 to SSS2000 is only one factor affecting longitudinal use of the two Summary Stage coding systems. There is ample reason to expect some inconsistency in SSS1977 codes currently in most registry files. The Guidelines were not developed to serve as instructions for coding, and it is likely that they were not consistently interpreted. Although the Kappa statistics showed good to excellent agreement beyond chance between the registry records and the reabstracted SSS1977, all three central registries did have some discrepancies. The abstractors in the study often were required to assign codes based on a strict interpretation of SSS1977 that was inconsistent with their own experience. Finally, few central registries provided extensive field training in the coding of SSS1977.

The NAACCR specifications for the assignment of SSS1977 result in a narrower time period than that which applies for SSS2000. The timing rules specified in SSS2000 now apply for all standard staging systems. In these data, there were regional lymph nodes and additional lung nodules identified after the 2-month staging period. Several abstractors commented on the difficulty of establishing timing, and there may have been additional cases affected by timing.

The changes that did occur had little effect on the classification of cases to one of the localized-regional-distant-unknown stage groups for either breast or lung cancer records. The assignment of a different stage category was greater for SSS2000 lung cancer records than breast cancer records, and it was the greatest when comparing original stage category codes with the SSS2000. However for reasons stated above, this was not unexpected. Further, the difference was largely the result of not coding cases with malignant pleural effusion to a distant stage (code 7) in SSS1977 for this study, although many registries do so.

Based on the results outlined in this report, central registries can use both SSS1977 and SSS2000 to track longitudinal stage trends in their breast cancer and lung cancer cases. The data would suggest that data can be pooled that span the years before and after implementing SSS2000.

There are a few steps central registries can take to become more familiar with the quality of their own Summary Stage data. First, registries can compute the percentage distribution by site for major sites for each of several years to roughly determine the variability that currently exists. Second, registries can review the accuracy of SSS2000 for selected sites against abstracted text to determine whether any registrars are continuing to assign SSS1977 stage values where SSS2000 is different. Finally, registries can consider reviewing SSS2000 codes in future reabstracting studies to determine whether registrars who submit data are noting the necessary factors involved in site-specific stage assignment.

REFERENCES

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Young JL Jr, SD Roffers, LAG Reis, AG Fritz, and AA Hurlbut, eds. *SEER Summary Staging Manual – 2000 Codes and Coding Instructions (SSS2000*). National Cancer Institute, NIH Pub. No. 01-4969, Bethesda MD, 2001.

APPENDIX A

CHANGES IN STAGE CODE ASSIGNMENT BY ANATOMIC SITE FROM SSS1977 TO SSS2000

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C00.0-C00.6 C00.8-C00.9	lip		internal jugular, NOS	Distant	Regional, LN
C00.3, C00.6	upper lip/ commissure	nose		Regional	Distant
C01.9, C02.4	base of tongue/ lingual tonsil	soft palate, inferior surface/NOS		Distant	Regional, Ext
C02.0-C02.3, C02.8-C02.9	anterior 2/3 tongue, tip, border, & tongue, NOS	lateral pharyngeal wall		Distant	Regional, Ext
		soft palate, inferior surface		Distant	Regional, Ext
		tonsils		Distant	Regional, Ext
		mandible		Regional	Distant
C05.1-C05.2	soft palate, uvula	nasal cavity		Regional	Distant
C06.0-C06.1	cheek (buccal) mucosa, vestibule	musculature (buccinator)		Regional	Localized
		skin of cheek		Regional	Distant
C07.9	parotid gland		cervical NOS	Distant	Regional, LN
		facial (7th) nerve		Regional	Distant
C07.9, C08.1-C08.2, C08.8-C08.9	parotid gland & other major salivary glands	base of skull		Regional	Distant
		skull, NOS		Regional	Distant
		spinal accessory nerve		Regional	Distant
C09.0-C09.1, C09.8-C09.9. C10.0-C10.4, C10.8-C10.9	tonsil, oropharynx		submandibular (submaxillary)	Distant	Regional, LN
			submental	Distant	Regional, LN
C11.0-C11.3, C11.8-C11.9	nasopharynx	hard palate		Distant	Regional, Ext
		paranasal sinus		Distant	Regional, Ext
			submandibular (submaxillary)	Distant	Regional, LN
			submental	Distant	Regional, LN

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C12.9, C13.0-C13.2, C13.8-C13.9	pyriform sinus, hypopharynx, laryngopharynx	carotid artery		Distant	Regional, Ext
		cricoid cartilage		Distant	Regional, Ext
		thyroid cartlage		Distant	Regional, Ext
		thyroid gland		Distant	Regional, Ext
			submandibular (submaxillary)	Distant	Regional, LN
			submental	Distant	Regional, LN
			parapharyngeal	Distant	Regional, LN
			paratracheal	Distant	Regional, LN
			recurrent pharyngeal nerve chain	Distant	Regional, LN
			prelaryngeal	Distant	Regional, LN
			Delphian node	Distant	Regional, LN
C15.0	esophagus, cervical		scalene (inferior deep cervical)	Distant	Regional, LN
			supraclavicular (transverse cervical)	Distant	Regional, LN
C15.1, C15.4	esophagus, thoracic/middle		pericardium	Regional	Distant
C16.0-C16.6, C16.8-C16.9	stomach	intraluminal spread (only) to esophagus or duodenum		Regional	Localized
		linitis plastica (diffuse involvement of the entire stomach wall)		Regional	Localized
			celiac	Distant	Regional, LN
			hepatic	Distant	Regional, LN
C17.0-C17.3, C17.8-C17.9	small intestine	mesothelium		Localized	Regional, Ext
		serosa		Localized	Regional, Ext
		tunica serosa		Localized	Regional, Ext
		visceral peritoneum		Localized	Regional, Ext
		lymph nodes	superior mesenteric	Distant	Regional, LN
C19.9	rectosigmoid junction		internal iliac (hypogastric), NOS	Regional	Distant
C21.0	anus		internal iliac (hypogastric), NOS	Distant	Regional, LN
			obturator		
C21.1	anal canal		superficial inguinal (femoral)	Distant	Regional, LN

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C22.0-C22.1	liver & intrahepatic bile ducts	multiple nodules/ tumors in more than one lobe or on surface of parenchyma		Distant	Regional, Ext
		satellite nodules, NOS		Distant	Regional, Ext
			cardiac	Regional	Distant
			coronary artery	Regional	Distant
			posterior mediastinal	Regional	Distant
			renal artery	Regional	Distant
			retroperitoneal, NOS	Regional	Distant
		pleura		Regional	Distant
C23.9, C24.8-C24.9	gallbladder, other biliary and biliary, NOS	invasion of/through serosa		Localized	Regional, Ext
			pericholedochal (common bile duct)	Distant	Regional, LN
			periduodenal	Distant	Regional, LN
			peripancreatic (near head of pancreas only)	Distant	Regional, LN
			porta hepitus (portal) (hilar) [in hilus of liver]	Distant	Regional, LN
		cystic artery/vein		Regional	Distant
		hepatic artery		Regional	Distant
		portal vein		Regional	Distant
C24.0	extrahepatic bile duct	other parts of colon		Distant	Regional, Ext
		greater omentum		Distant	Regional, Ext
		proximal stomach		Distant	Regional, Ext
C24.1	ampulla of vater	proximal stomach		Distant	Regional, Ext
			celiac	Distant	Regional, LN
			infrapyloric (subpyloric)	Distant	Regional, LN
			lateral aortic (lumbar)	Distant	Regional, LN
			proximal mesenteric	Distant	Regional, LN
			retroperitoneal	Distant	Regional, LN
			superior mesenteric	Distant	Regional, LN
C25.0-C25.4	pancreas: head, body and tail	gall bladder		Regional	Distant
		kidney		Regional	Distant
		liver including porta hepatis		Regional	Distant
		mesenteric fat		Regional	Distant
		mesentery		Regional	Distant
		mesocolon		Regional	Distant
		peritonum		Regional	Distant
C25.0	head of pancreas	body of stomach		Distant	Regional, Ext

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C25.1-C25.2	body and/or tail of pancreas	adrenal (suprarenal) gland		Regional	Distant
		ileum		Regional	Distant
		jejunum		Regional	Distant
C32.0	larynx, glottis		submandibular (submaxillary)	Distant	Regional, LN
			submental	Distant	Regional, LN
			retropharyngeal	Distant	Regional, LN
		cricoid cartilage		Regional	Distant
		thyroid cartilage		Regional	Distant
C32.1	larynx, supraglottis		submandibular (submaxillary)	Distant	Regional, LN
			submental	Distant	Regional, LN
			retropharyngeal	Distant	Regional, LN
C32.2	larynx, subglottis		middle deep cervical internal jugular	Distant	Regional, LN
			submandibular (submaxillary)	Distant	Regional, LN
			submental	Distant	Regional, LN
			retropharyngeal	Distant	Regional, LN
		cricoid cartilage		Regional	Distant
		thyroid cartilage		Regional	Distant
C32.3, C32.8-C32.9	larynx, overlapping lesion or NOS (including cartilage)	cricoid cartilage		Regional	Distant
		thyroid cartilage		Regional	Distant
C34.0-C34.3, C34.8-C34.9	bronchus & lung	aorta		Distant	Regional, Ext
		brachial plexus from superior sulcus		Distant	Regional, Ext
		chest (thoracic) wall		Distant	Regional, Ext
		diaphragm		Distant	Regional, Ext
		pancoast tumor (superior sulcus syndrome)		Distant	Regional, Ext
		parietal (mediastinal) pleura		Distant	Regional, Ext
		multiple masses/separate tumor nodule(s) in the SAME lobe		Localized	Regional, Ext
		tumor of main stem bronchus <2.0 cm from carina		Localized	Regional, Ext
		separate tumor nodule(s) in different lobe		Localized	Distant

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C44.0, C44.2-C44.9* (see note at end)	skin except eyelid & excluding melanoma, Kaposi sarcoma, mycocis fungoides, sezary disease, and other lymphomas	underlying cartilage, bone, skeletal muscle		Distant	Regional, Ext
C44.0 * (see note at end)	skin of lip excluding melanoma, Kaposi sarcoma, mycocis fungoides, sezary disease, and other lymphomas		facial, NOS	Distant	Regional, LN
			buccinator (buccal)	Distant	Regional, LN
			nasolabial	Distant	Regional, LN
			submental	Distant	Regional, LN
			parotid, NOS	Distant	Regional, LN
			infra-auricular	Distant	Regional, LN
			preauricular	Distant	Regional, LN
C44.3 * (see note at end)	skin of face, other excluding melanoma, Kaposi sarcoma, mycocis fungoides, sezary disease, and other lymphomas		submental	Distant	Regional, LN
C44.0 * (see note at end)	skin of neck (not scalp, which has same topology code) excluding melanoma, Kaposi sarcoma, mycocis fungoides, sezary disease, and other lymphomas		submental	Distant	Regional, LN
C44.1 * (see note at end)	skin of eyelid excluding melanoma, Kaposi sarcoma, mycocis fungoides, sezary disease, and other lymphomas	underlying cartilage, bone, skeletal muscle		Distant	Regional, Ext
			submental	Distant	Regional, LN
C44.0-C44.9, C51.0-C51.2, C51.8-C51.9, C60.0-C60.1, C60.8-C60.9, C63.2, and M-8720-8790	melanoma of skin, vulva, penis and scrotum	subcutaneous tissue invaded (through entire dermis)		Localized	Regional, Ext

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C44.0 and M-8720-8790	melanoma of lip		facial, NOS	Distant	Regional, LN
			buccinator (buccal)	Distant	Regional, LN
			nasolabial	Distant	Regional, LN
			submental	Distant	Regional, LN
			parotid, NOS	Distant	Regional, LN
			infra-auricular	Distant	Regional, LN
			preauricular	Distant	Regional, LN
C44.1, C44.3, C44.4 and M-8720-8790	melanoma of eyelid/canthus, face other, neck (but not scalp which has the same site code)		submental	Distant	Regional, LN
C50.0-C50.6, C50.8-C50.9	breast	adherence, attachment, fixation, induration, and thickening (skin changes)		Localized (because they were ignored in the definition)	Regional, Ext
		ipsilateral lymph nodes:	infraclavicular (subclavicular)	Distant	Regional, LN
C51.0-C51.2, C51.8-C51.9* (see note at end)	vulva including skin of vulva except melanoma, Kaposi sarcoma, mycosis fungoides, Sezary disease, and other lymphomas	bladder, NOS excluding mucosa		Distant	Regional, Ext
		bladder wall		Distant	Regional, Ext
		rectal wall, NOS		Distant	Regional, Ext
		rectum, NOS excluding mucosa		Distant	Regional, Ext
			external iliac	Regional	Distant
C52.9	vagina	bladder, NOS excluding mucosa		Distant	Regional, Ext
		bladder wall		Distant	Regional, Ext
		rectal wall, NOS		Distant	Regional, Ext
		rectum, NOS excluding mucosa		Distant	Regional, Ext
		pelvic wall (frozen pelvis)		Distant	Regional, Ext
C52.9	vagina, lower third (no distinct site code)		inguinal, NOS	Distant	Regional, LN
			superficial inguinal (femoral)		

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C52.9	vagina, upper two-thirds (no distinct site code)		pelvic, NOS	Distant	Regional, LN
C53.0-C53.1, C53.8-C53.9	cervix uteri	ureter, intra- & extramural (extension)		Distant	Regional, Ext
		vulva (extension)		Distant	Regional, Ext
		fallopian tube(s) (extension)		Distant	Regional, Ext
		ovary(ies) (extension)		Distant	Regional, Ext
		urethra (extension)		Distant	Regional, Ext
		frozen pelvis		Distant	Regional, Ext
C54.0-C54.3, C54.8-C54.9, C55.9	uterus	ureter (extension)		Distant	Regional, Ext
		vulva (extension)		Distant	Regional, Ext
		bladder, NOS excluding mucosa (metastasis)		Distant	Regional, Ext
		bladder wall (metastasis)		Distant	Regional, Ext
		rectal wall, NOS (metastasis)		Distant	Regional, Ext
		rectum, NOS excluding mucosa (metastasis)		Distant	Regional, Ext
		pelvic wall (metastasis)		Distant	Regional, Ext
		frozen pelvis		Distant	Regional, Ext
		vagina (extension or metastasis)		Distant	Regional, Ext
			superficial inguinal (femoral)	Regional	Distant

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C56.9	ovary	tumor limited to ovary(ies), capsule(s) ruptured		Localized	Regional, Ext
		implants on ovary(ies)		Distant	Regional, Ext
		tumor on ovarian surface		Distant	Regional, Ext
		implants on adnexa (includes contralateral)		Distant	Regional, Ext
		implants on contralateral broad ligament		Distant	Regional, Ext
		implants on fallopian tube(s) (includes contralateral)		Distant	Regional, Ext
		implants on contralateral mesovarium		Distant	Regional, Ext
		extension or implants on uterus		Distant	Regional, Ext
		bladder, bladder serosa		Distant	Regional, Ext
		cul de sac (rectouterine pouch)		Distant	Regional, Ext
		parametrium		Distant	Regional, Ext
		rectosigmoid		Distant	Regional, Ext
		rectum		Distant	Regional, Ext
		sigmoid colon		Distant	Regional, Ext
		sigmoid mesentery		Distant	Regional, Ext
		ureter (pelvic portion)		Distant	Regional, Ext
		uterine serosa		Distant	Regional, Ext
			inguinal	Distant	Regional, LN
			lateral sacral (laterosacral)	Distant	Regional, LN
C57.0	fallopian tube		inguinal	Distant	Regional, LN
			lateral sacral (laterosacral)	Distant	Regional, LN

Primary Site or Subsite		Involvement		Summary Stage	
Codes	Description	Tissue	Nodes	1977	2000
C61.9	prostate gland	levator muscles		Distant	Regional, Ext
		skeletal muscle, NOS		Distant	Regional, Ext
		ureter(s)		Distant	Regional, Ext
		no extracapsular extension, but margins involved		Localized	Regional, Ext
			common iliac	Regional	Distant
C62.0-C62.1, C62.9	testis		pericaval, NOS	Distant	Regional, LN
C64.9	kidney parenchyma	psoas muscle		Distant	Regional, Ext
			paracaval	Distant	Regional, LN
66.9 (left laterality)	left ureter	descending colon		Regional	Distant
66.9 (right laterality)	right ureter	ascending colon		Regional	Distant
C67.0-C67.9	bladder	prostatic urethra		Distant	Regional, Ext
			common iliac	Regional	Distant
C67.0-C67.9 (male)	bladder in males	pubic bone		Regional	Distant
		rectum		Regional	Distant
C70.0, C71.0-C71.9	brain	Regional (change in code only)		code 2	code 5
C73.9	thyroid gland		Delphian node	Distant	Regional, LN
			mediastinal, NOS	Distant	Regional, LN
			supraclavicular (transverse cervical)	Distant	Regional, LN

* Note: Histologies excluded from certain site groups are M-8720-8790, 9140, 9700, 9701, M-9590-9591, 9596, 9650-9655, 9659, 9661-9665, 9667, 9670-9671, 9673, 9675, 9678-9680, 9684, 9687, 9689-9691, 9695, 9698-9702, 9705, 9708-9709, 9714, 9716-9719, 9727-9729; they are in other groups.

APPENDIX B

SEER SUMMARY STAGE COMPARABILITY PROJECT: DATA PREPARATION

Files

1 Study –Key-SSS (unique case identifier) and Primary Site for all eligible cases to be used in random case selection
2 "Reference File" for *internal registry use only*, a file that will facilitate re-linking the information above to the registry data in order to extract the next two types of files
3 Confidential case identification information for Abstract Plus input (randomly selected cases only)
4 Specified registry information for the case with personal identifiers removed and the Study—Key-SSS included for use in analysis (randomly selected cases only)
5 Extraction file produced by Abstract Plus after abstracting is completed (likewise with personal identifiers removed and the Study—Key-SSS included).

I. Eligible cases are those that meet all of the following criteria:

A. Year of diagnosis = 2000
B. Primary Sites (ICD-O-2/3): C34.0, C34.1, C34.2, C34.3, C34.8, C34.9, C50.0, C50.1, C50.2, C50.3, C50.4, C50.5, C50.6, C50.8, C50.9
    1. For Breast (C50.x), Sex = 2 (female)
C. Histologies (ICD-O-2): 8010 - 8580
D. Behavior (ICD-O-2) = 3
E. Reported by a *hospital located within your state that provided some form of first course treatment for this cancer*
    1. Class of Case for the respective hospital = 1 or 2 -- OR --
    2. Date of any first course treatment is within the admission-discharge date range for the hospital -- OR --
    3. Any other method that you use when you need to identify these cases in your data.
F. Unduplicated: If a qualifying report for an eligible case was made by more than one in-state hospital, select the report from the hospital with *lower* hospital identification number as used within your registry (for example, if hospitals 1023 and 1254 both provided some form of first course treatment for the patient, select hospital 1023)

II Study—Key-SSS

A. To assure smooth identification of cases for record-linkage and for communication between the analyst and the central registries a unique case identifier will be used.
B. The Study—Key-SSS will consist of two portions, the two-character state postal code for the registry state and a number which is assigned by the registry.
C. For all qualifying cases (as identifying above), using any sequence you want, assign sequential numbers to all eligible cases without respect to primary site. This act obliterates any potentially identifying meaning that secondary parties (such as the analyst) can impute to record number.
D. Generate the Study—Key-SSS by concatenating your 2-character state code (NJ, MN, or WI) with the number just assigned, so that the numeric portion is right-justified and zero-filled for a total of 9 places. For example: NJ0004536, MN0053773, WI0000021.

NOTE: Because you will use the Study—Key-SSS to pull information from the registry database for the next step, you will need to need to retain some form of electronic record of what you just did ("Reference File"). Step III will require you to generate records with the personal information, the hospital whose record you picked, and your registry's consolidated information for the case. You will want to keep the Study—Key-SSS, the hospital identifier for the record selected and case identification (which may be the registry's tumor identification number or some combination of personal identifiers, site and histology, laterality, diagnosis date, etc.).

Submit* a single file consisting of the following:

Columns 1-9	Study—Key-SSS (as described above)
Columns 10-13	Primary Site ('C' followed by 3 digits with period dropped, e.g., C509)

NOTE: The study analyst will return to you a similarly formatted file consisting of randomly selected identifiers for 200 female breast and 200 lung cases. The remainder of the study will be limited to these cases. Please retain your reference file so you can identify the case if questions arise during the analysis.

Files generated from randomly selected cases. Two files will be generated in NAACCR 9 layout form, with the Study—Key-SSS added in columns 1053-1061, and will consist solely of the records selected randomly by the study analyst from the file of Study—Key-SSSs and Primary Sites described above. The two files are the input file for Abstract Plus and the Analysis File. It may be most efficient to generate a single NAACCR 9 file consisting of all records needed in either file as a first step. Lung and female breast cases should be in the same file.

A. Field content should be your registry's consolidated information for the randomly selected cases with the exceptions that follow.
B. The reporting hospital should be the one selected in Step I. Minnesota, please convert your state hospital numbers to the ACOS codes used in the Abstract Plus software for this project. Wisconsin and New Jersey will use their state hospital numbers for this purpose.
C. If your state generates consolidated text fields, they are preferred. If consolidated text fields are not maintained, please use the text fields submitted with the selected hospital report.
D. Check the integrity of the resulting file by running one or more EDITS metafiles, generating frequency counts of key items, or using other procedures to confirm that your registry data have transferred as you expected.

III Input file for Abstract Plus

See the layout for this file for items required to be input. You may use a standard NAACCR 9 transmission file (Record Type A, 5966 character record) with complete information plus the Study—Key-SSS in columns 1053-1061 and no further alteration for the least stressful application if you have a routine NAACCR extraction procedure available. Text information and a few codes that will be re-entered in the field will be stripped by Abstract Plus as the data are read in (so that you can enter fresh information in the field).

IV Analysis File

See the layout for this file for items required to be submitted for this project. Additional items generated by NAACCR 9 Record Type A extraction procedures may be included (plus the Study—Key-SSS in columns 1053-1061, but please remember to remove your confidential information.

A. Please blank out confidential fields such as patient name and address, hospital identifiers, or death certificate numbers.
B. If you purge identifying information in text fields before submission, please be careful to maintain the meaning of the text. For example, substitute "patient" for the patient's name and apply other standard nouns as appropriate. In addition, perform this type of activity in a way that preserves the column layout of the tape following the altered text.
C. Submit* the file in ASCII format when you have successfully loaded the companion file into Abstract Plus, but before field abstracting has begun.

V Submit* the file extracted from Abstract Plus after all cases are abstracted. **Use the "Export All" option when you extract the file.**

This file will consist of the Study—Key-SSS and the codes and text abstracted in the field only. It will be linked by the study analyst to the analysis file.

* Submit =

Submit files according to the specified layout to:

Jerri Linn Phillips
1550 Eddy Street, Apt. 401
San Francisco CA 94115
(415) 771-0914
oncowonk@mindspring.com

All data submissions should be in ASCII form with a carriage return, line feed at the end of each line, and zipped. Do not use any other form of encryption; submission files will not contain identifying information. Submission may be by diskette or CD (IBM formatted) or electronic (e-mail attachment, Web download, or ftp). Let me know by e-mail or telephone what you are sending and the method you are using.

Please call or e-mail Jerri Linn if you have any questions about data preparation.

APPENDIX C

STUDY DATA ITEMS – NAME AND NAACCR NUMBER

To be Abstracted	To be Provided by the Registry
	A unique identifier assigned by central registry that the registry can link to identification items – 6 Characters (not a NAACCR data item)
For identification by abstractors, not to be submitted to study project following abstracting	
	Hospital Number
	Medical Record Number
	Last Name [2230]
	First Name [2240]
	Middle Name [2250]
	Birth Date [240]
To confirm the case was eligible for the study	
Primary Site [400]	Primary Site [400]
Laterality [410]	Laterality [410]
Histology (92-00) ICD-O-2 [420]	Histology (92-00) ICD-O-2 [420]
Behavior (92-00) ICD-O-2 [430]	Behavior (92-00) ICD-O-2 [430]
Date of Diagnosis [390]	Date of Diagnosis [390]
Class of Case [610]	Class of Case (this hospital) [610]
Additional items for analysis	
SEER Summary Stage 2000 [759]	SEER Summary Stage 1977 [760]
SEER Summary Stage 1977 [760]	Text—DX Proc—PE [2520]
RX Date – Surgery [1200]	Text—DX Proc—X-ray/scan [2530]
Text—Staging [2600]	Text—DX Proc—Scopes [2540]
Text—DX Proc—PE [2520]	Text—DX Proc—Lab Tests [2550]
Text—DX Proc—X-ray/scan [2530]	Text—DX Proc—Op [2560]
Text—DX Proc—Scopes [2540]	Text—DX Proc—Path [2570]
Text—DX Proc—Lab Tests [2550]	Text—Staging [2600]
Text—DX Proc—Op [2560]	RX Text—Surgery [2610]
Text—DX Proc—Path [2570]	RX Text—Radiation (Beam) [2620]
Text—Staging [2600]	RX Text—Radiation Other [2630]
RX Text—Surgery [2610]	RX Text—Chemo [2640]
RX Text—Radiation (Beam) [2620]	RX Text—Hormone [2650]
RX Text—Radiation Other [2630]	Age at Diagnosis [230]
RX Text—Chemo [2640]	Sex [220]
RX Text—Hormone [2650]	Race1 [160]
	Spanish/Hispanic Origin [190]
	Addr at DX—State [80]
V.2002.07.11	

APPENDIX D

TRAINING AGENDA

Abstractor Training - Summary Stage Study Comparability Project
Agenda and Meeting Specifications
October 23, 2002

States – please provide an LCD projector and a room where multiple electronic devices can be plugged in simultaneously (except trainers will provide the space in MN – still need to confirm availability of an LCD projector there).

Attendees should bring the laptop computer they intend to use for abstracting. NOTE: if the computer already has a version of Abstract Plus installed, it will need to be uninstalled before the project version can be installed.

Laptop computer specifications:
Processor: Pentium (or Pentium equivalent)
RAM: 32 MB (minimum) 64 MB (recommended)
Hard drive free space: 60 MB
Mouse
CD ROM Drive (needed to install abstracting software)

Handouts will be provided at the training.

Agenda (4 – 6 hours)
Study Background and Scope – Jerri Linn
Flow – Time Line - Ken
Data Item Tables – Ken
Data Preparation – Jerri Linn
Abstracting/coding in the field – Jerri Linn
- SEER Summary Stage 1977 and SEER Summary Stage 2000
- Text fields
- Other descriptors
- What to do if the record does not support the case described

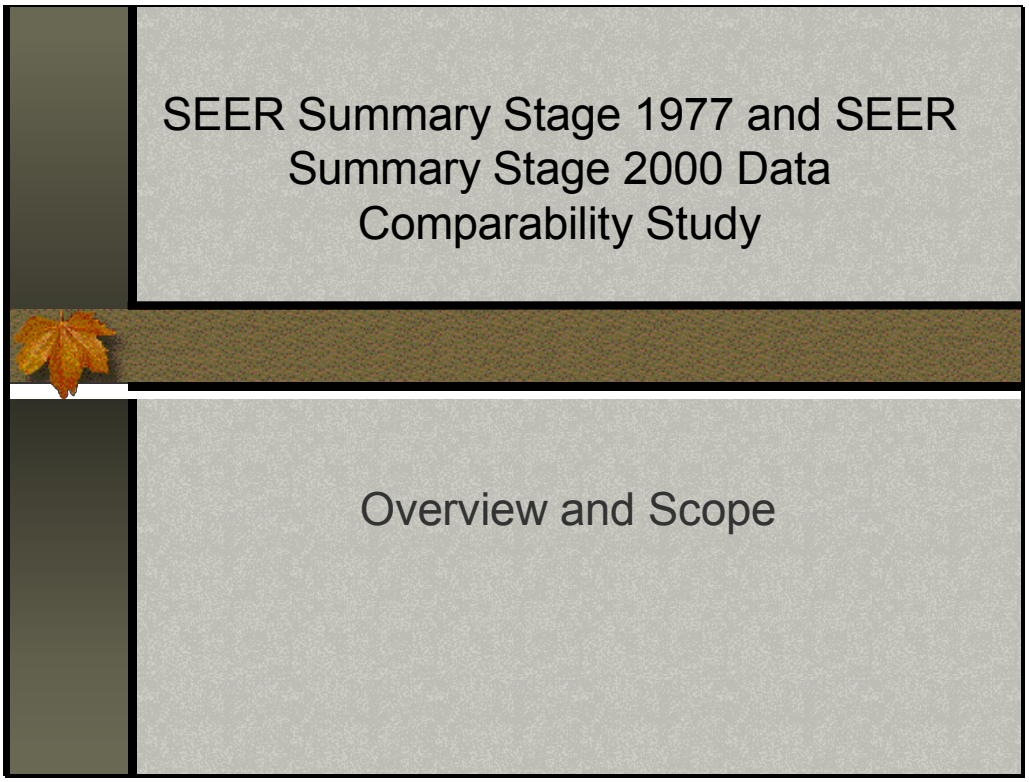
Installation and Use of the Abstract Plus Software – Ken
Project Edit Set – Jerri Linn
Electronic Abstracting Exercises – Jerri Linn

Attendees:
NJ: 3 – 4
MN: 1 – 2
WI: 2 – 3
Total: 6 – 9

Handouts:
Background and Scope of Project
Flow
Data Item Tables
Data Preparation
Abstracting Guidelines
Contact Information & FTP Specifications

APPENDIX E

OVERVIEW AND SCOPE



History

- **SEER Summary Stage 1977**
  - Unidimensional measure computed from SEER Extent of Disease (EOD) items as they were defined at the time
- **Changes prior to release of SSS 2000**
  - Some EOD component definitions changed
  - Adoption of ICD-O-2 then ICD-O-3
  - EOD timing rules modified
  - Increased direct coding of Summary Stage 1977 without use of EOD components, most recently by NPCR registries

History

- Changes introduced by SEER Summary Stage 2000
  - Site-specific definitions for every site: no more non-specific staging schema
  - More detailed coding instructions
  - Stage reassignment of some anatomic areas
  - Timing explicit in coding instructions, different from those for SSS 1977

The Question We Seek to Answer

- **Is there a stage shift from the SSS 1977 stage assignment to the SSS 2000 assignment that can affect data interpretation for the types of analysis most typically performed by central registries?**

Considerations

- By far, the most common uses of Summary Stage by central registries are:
  - To compare multiple populations in a single time period
    - As long as everyone is using same coding rules, the change does not affect these comparisons
  - To track changes in stage distribution
    - For sites subject to cancer control efforts
      - Effectiveness of screening
      - Predict mortality or long-term morbidity
    - Using percent distributions for each time period

Considerations

- Nearly every site is affected:
  - Principal effect is on *training*
  - Not possible to evaluate data effects of changes for every site
- Most site-specific stage changes do not involve a large number or a large proportion of cases
- Only some of the cases in changed stages will be reassigned

How Many Cases Were Subject to Potential Changes?

- % of cases in site-specific *stages* that changed (invasive, unknown = not changed)
  - F Breast: 52% (local – 48%, distant – 4%)
  - Lung: 66% (local – 20%, distant – 46%)

How Many Cases Were Subject to Change … By Specific Changes?

- F Breast – Distant in SSS 1977
  - Infraclavicular nodes (subclavicular) were distant in SSS 1977 and are regional in SSS 2000
  - Distant according to SSS 1977 *and* SSS 2000:
    - Nodes: cervical NOS, contralateral/bilateral axillary, contralateral/bilateral mammary, supraclavicular, other distant nodes
    - Extension: skin over axilla, contralateral breast, sternum, upper abdomen
    - Metastasis: adrenal gland, bone other than adjacent rib, contralateral breast (if metastasis), lung, ovary, satellite skin nodules other than over primary breast

How Many Cases Were Subject to Change … By Specific Changes?

- F Breast – Local in SSS 1977
  - Note reads: "Consider adherence, attachment, fixation, induration, and thickening as clinical evidence of extension to skin or subcutaneous tissue; code regional by direct extension. These terms would have been ignored in the 1977 Summary Staging Guide and cases would have been considered localized in the absence of further disease."

How Many Cases Were Subject to Change … By Specific Changes?

- Lung
  - Distant in SSS 1977, Regional in SSS 2000
    - brachial plexus from superior sulcus
    - chest (thoracic) wall
    - Diaphragm
    - Pancoast tumor (superior sulcus syndrome)
    - parietal (mediastinal) pleura

How Many Cases Were Subject to Change … By Specific Changes?

- Lung
  - Localized in SSS 1977, Regional in SSS 2000
    - multiple masses/separate tumor nodule(s) in the SAME lobe
    - tumor of main stem bronchus <2.0 cm from carina
    - separate tumor nodule(s) in different lobe

How Accurate are SSS 1977 Codes Currently On File in Central Registries?

- Historic problems with reabstracting validity for staging variables
  - Summary Stage (NPCR): ~ 11% error rate
  - Also EOD and AJCC staging
- Inconsistency among central registries in training and monitoring Summary Stage practices
  - % Lung SSS 1977 Unknown for 4 committee registries: 11%, 25%, 34%, 43%
- Documented weaknesses in training for SSS 2000
  - NC: reviewed text for 40 recent ovary, prostate, lung cases; codes not consistent with SSS 2000 manual

What We Plan to Do: Analysis

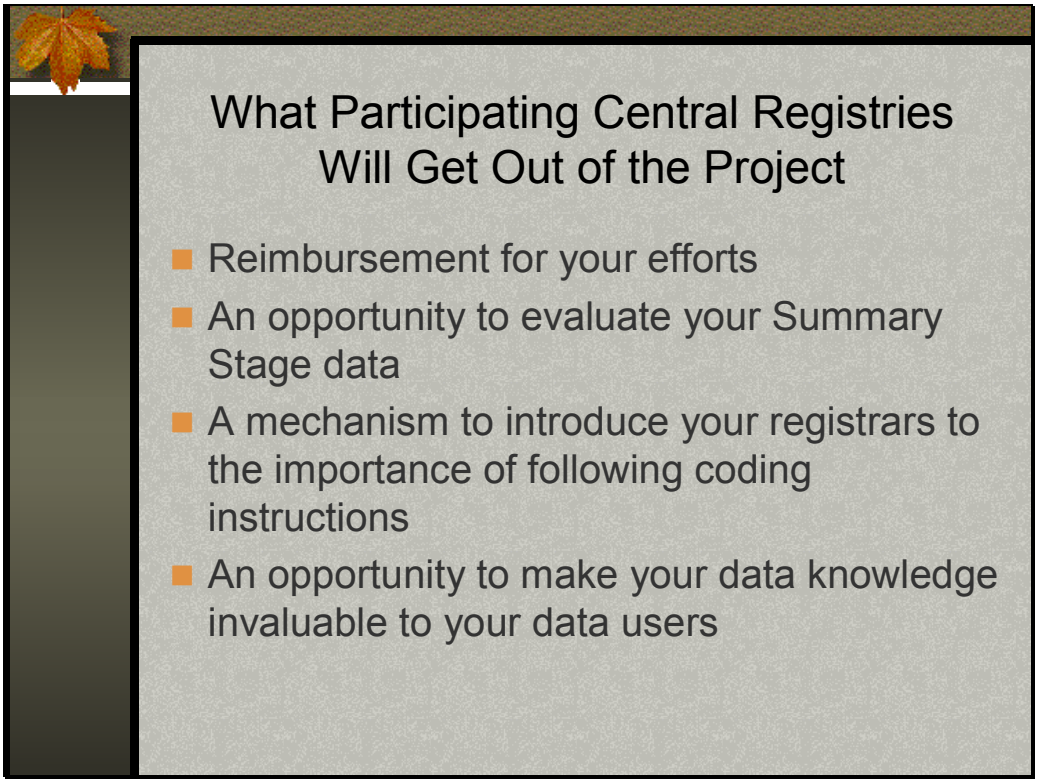
- Compare reabstracted SSS 1977 stage with reabstracted SSS 2000 stage for same cases
- To set framework for analysis:
  - Use central registry descriptive data to compare the sample to the general population of cancer patients
  - Compare reabstracted SSS 1977 with registry records of SSS 1977

Approach

- **3 central registries**
- **Sample**
  - invasive
  - FEMALE BREAST and LUNG carcinoma cases
  - diagnosis year 2000
  - In-state hospital report source
  - class of case 1 and 2 (first course treatment at hospital)
- **Abstract SSS 1977 and SSS 2000 in hospitals**
- **Supplement with non-identifying descriptive data from registry**

What We Plan to Do: Actions

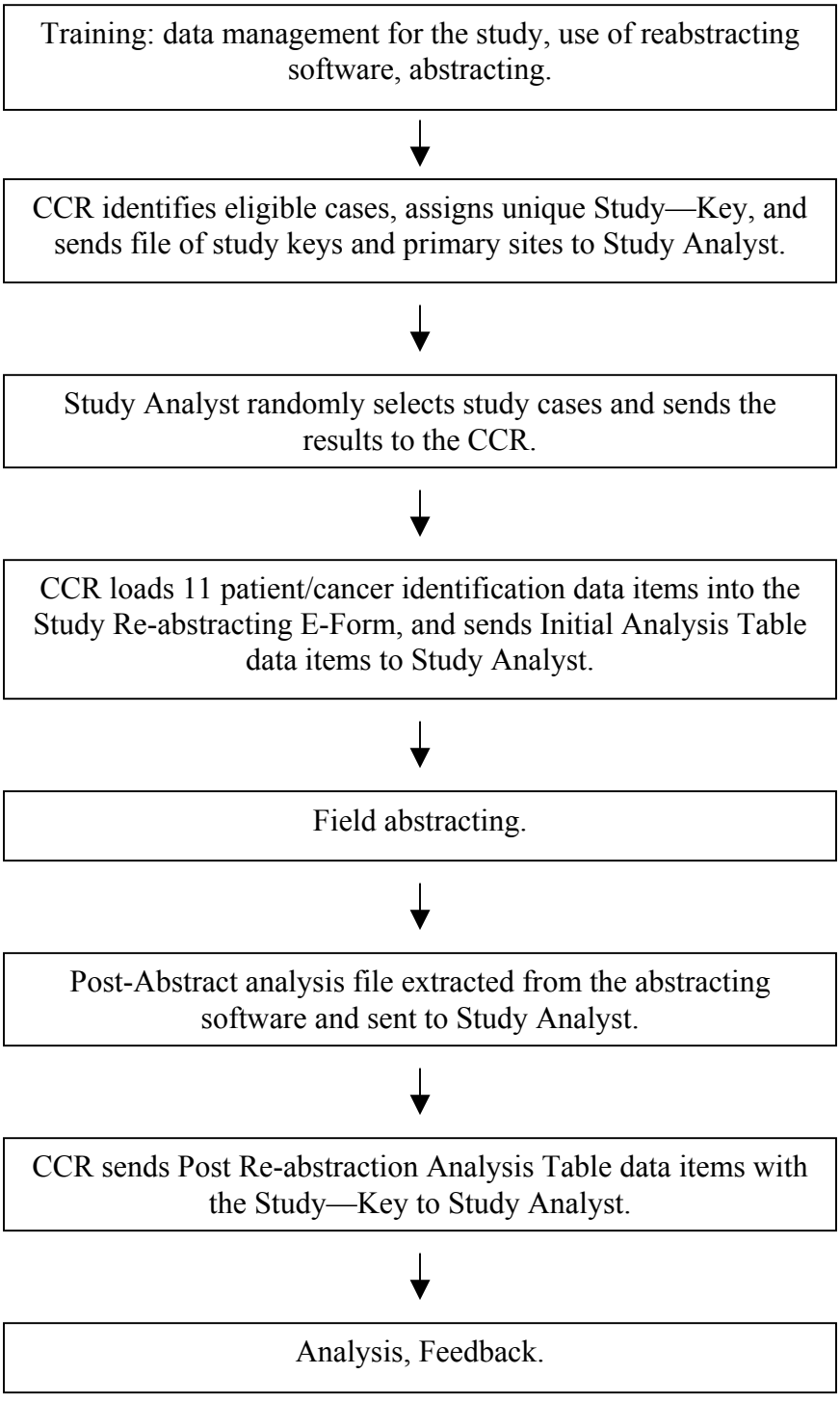
- Provide guidelines for registry interpretation of SSS time trends
- Provide information central registries can use to communicate effects of code change to data users
- Possibly generate suggestions for the collection and use of SSS information, including the use of text fields
- Provide prototype for looking at changes in other data systems that affect long-term registry use


What Participating Central Registries Will Get Out of the Project
Reimbursement for your efforts
An opportunity to evaluate your Summary Stage data
A mechanism to introduce your registrars to the importance of following coding instructions
An opportunity to make your data knowledge invaluable to your data users

APPENDIX F

DATA FLOW

Summary Stage Study – Data Flow
October 3, 2002



APPENDIX G

DATA ITEMS

Initial Analysis Table							September 30, 2002
ID	**Data Item Name**	**NAACCR Data Item #**	**Create/ NAACCR**	**Column #**	**Length**	**Source**	**Enter/Read-Only**
1	Study--Key-SSS	N/A	Create	1053-1061	9	CCR	Read-Only
2	Primary Site [400]	400	NAACCR	227-230	4	CCR	Read-Only
3	Laterality [410]	410	NAACCR	295-295	1	CCR	Read-Only
4	Histology (92-00) ICD-O-2 [420]	420	NAACCR	232-235	4	CCR	Read-Only
5	Behavior (92-00) ICD-O-2 [430]	430	NAACCR	236-236	1	CCR	Read-Only
6	Date of Diagnosis [390]	390	NAACCR	219-226	8	CCR	Read-Only
7	SEER Summary Stage 1977 [760]	760	NAACCR	388-388	1	CCR	Read-Only
8	Age at Diagnosis [230]	230	NAACCR	119-121	3	CCR	Read-Only
9	Sex [220]	220	NAACCR	118-118	1	CCR	Read-Only
10	Race1 [160]	160	NAACCR	103-104	2	CCR	Read-Only
11	Spanish/Hispanic Origin [190]	190	NAACCR	115-115	1	CCR	Read-Only
12	Addr at DXCState [80]	80	NAACCR	72-73	2	CCR	Read-Only
13	TextCDX ProcCPE [2520]	2520	NAACCR	1917-2116	200	CCR	Read-Only
14	TextCDX ProcCX-ray/scan [2530]	2530	NAACCR	2117-2366	250	CCR	Read-Only
15	TextCDX ProcCScopes [2540]	2540	NAACCR	2367-2616	250	CCR	Read-Only
16	TextCDX ProcCLab Tests [2550]	2550	NAACCR	2617-2866	250	CCR	Read-Only
17	TextCDX ProcCOp [2560]	2560	NAACCR	2867-3116	250	CCR	Read-Only
18	TextCDX ProcCPath [2570]	2570	NAACCR	3117-3366	250	CCR	Read-Only
19	TextCStaging [2600]	2600	NAACCR	3447-3746	300	CCR	Read-Only
20	RX TextCSurgery [2610]	2610	NAACCR	4475-4624	150	CCR	Read-Only
21	RX TextCRadiation (Beam) [2620]	2620	NAACCR	2624-4774	150	CCR	Read-Only
22	RX TextCRadiation Other [2630]	2630	NAACCR	4775-4924	150	CCR	Read-Only
23	RX TextCChemo [2640]	2640	NAACCR	4925-5124	200	CCR	Read-Only
24	RX TextCHormone [2650]	2650	NAACCR	5125-5324	200	CCR	Read-Only

APPENDIX H

ABSTRACTING/CODING IN THE FIELD

I Cancer Identification

A. Code primary site, histology and behavior according to ICD-O-2; pick lists are available within Abstract Plus, and only valid codes will be accepted by the program.
B. Both breast and lung cancers require laterality coding; pick list is in Abstract Plus, and only valid codes will be accepted by the program.
C. Date of diagnosis: MMDDCCYY, date of initial diagnosis by a recognized medical practitioner for the respective cancer.

The purpose of abstracting these items in the field is not to check their re-abstracting reliability but to help ascertain that the case being abstracted is the same as the one selected. Code from the patient record even if it is not identical to the registry's consolidated codes. If there is a discrepancy that will not affect the coding of SEER Summary Stage 1977 or SEER Summary Stage 2000, there is no need to provide an explanation in the text.

D. Discrepancies that do not affect case eligibility but have an effect on the assignment of SEER Summary Stage 1977 or SEER Summary Stage 2000; for example, some differences in date of diagnosis, subsite or laterality.
    1. Review the record to be certain that there are not two separate primaries involved.
    2. Code the cancer information according to what is in the patient record.
    3. Use the text fields to explain the discrepancy. For example, the day and month of the date of diagnosis were reversed, the tumor was the only one found and the laterality codes are inconsistent.
    4. Code SEER Summary Stage 1977 and SEER Summary Stage 2000 based on your coding of the cancer identification, not based on the description in the imported registry file.

E. Discrepancies that affect eligibility of the case for inclusion in the study; for example, a breast cancer patient who was really male (or hermaphrodite or transsexual), a large cell lymphoma histology that was recorded as large cell carcinoma, a metastatic lung lesion rather than a lung primary, a year of diagnosis that should have been recorded as 1999.
    1. Review the record to be certain that there are not two separate primaries involved.
    2. Code the cancer information according to what is in the patient record (Use ICD-O-2 for this purpose, even if year of diagnosis is more recent than 2000).
    3. Use the text fields to describe the discrepancy, explain why the patient record does not support the registry's consolidated codes, and to support your choice of codes.
    4. Code SEER Summary Stage 1977 and SEER Summary Stage 2000 both as "9". EXCEPTION: in the name of planning ahead, if you find a case identified as a lung primary that was actually a metastatic breast tumor for a cancer that would have been eligible for the study, assign the appropriate Summary Stage codes.

Please keep a separate account of the cases for which cancer identification discrepancies either make the case ineligible for the study or affect Summary Stage codes, and provide it to the study analyst at the same time your extracted file is submitted.

II SEER Summary Stage Coding

A. Code SEER Summary Stage 1977 according to the *Summary Staging Guide*, SEER Program, 1977. Use *only* the instructions provided there; do not rely on your familiarity with EOD or AJCC, or other practices not in the Guide.

1. Timing: For both breast and lung, SEER Summary Stage 1977 is limited to information available within 2 months of the date of diagnosis.
2. Note that primaries of the *carina* of the lung (a *portion* of the main bronchus not identifiable through the ICD-O-2 site code) are not coded according to the Bronchus and Lung instructions in SEER Summary Stage 1977, but according to the non-site-specific staging scheme.

B. Code SEER Summary Stage 2000 according to the *SEER Summary Staging Manual – 2000 Codes and Coding Instructions*, SEER, 2001. Use *only* the instructions provided there; do not rely on your familiarity with EOD or AJCC, or other practices not in the Manual.

1. Timing: Summary stage should include all information available through completion of surgery(ies) in the first course of treatment or within four months of diagnosis in the absence of disease progression, whichever is longer.

C. Use the text fields to record all information relevant to the assignment of Summary Stage codes, paying particular attention to the factors that affect your decision to code them similarly or differently. Remember to indicate timing and involved tissue.

III RX Date—Surgery

MMDDCCYY on which any surgical treatment was performed. If no surgical treatment was performed, code 00000000. Identify the type(s) of surgery in the text fields.

IV Edits of Abstracted Codes

Because Abstract Plus will not permit storage of certain invalid fields, the standard edits that are of most interest check that Diagnosis and RX Summ—Surgery dates are valid according to NAACCR standards, that histology ICD-O-2 and behavior ICD-O-2 are present for cases diagnosed before 2001, that laterality codes are consistent with primary site, and that site and morphology type are consistent. The latter does not have an associated override flag in this application; if a case is rejected and the record confirms you have coded it correctly, use the text fields to support your coding (it will continue to give you error messages when you run that edit). Both Summary Stage 1977 and Summary Stage 2000 are required to be non-blank for this project.

APPENDIX I

ABSTRACT PLUS CONTACT AND FTP SPECIFICATIONS

Abstract Plus – Technical Questions

Contact: Joe Rogers
770-488-4701
jrogers@cdc.gov

FTP Specifications

Web Site: sftp.cdc.gov
Username: nccdnc
Password: cndsc1998

To download the SEER Summary Stage (SSS) version of Abstract Plus for NAACCR V9c on the CDC FTP server, you can use a conventional FTP program or Internet Explorer (IE). If you are using the latest version of IE, you can retrieve the SSS installation by clicking on this link ftp://nccdnc:cndsc1998@sftp.cdc.gov/. The install file name is: ap11240i_9c_SSS.exe. In order to use IE, you should have "Enable folder view of FTP sites" checked as an option. You can find this option by opening your browser and selecting the Tools Menu>Internet Options…> Advanced Tab. With this installation of Abstract Plus, you will need to uninstall any previous version of Abstract Plus.

APPENDIX J

ABSTRACT PLUS PRESENTATION AGENDA

Abstractor Training - Summary Stage Study Comparability Project
Abstract Plus Presentation Agenda
October 23, 2002

Installation and Use of the Abstract Plus Software
Abstract Plus History & Purpose
Load E-Abstracting Tool onto Laptops
FTP Version – November 22, 2002
- Web Address
- UserID and Password

Systems Administration
- Enter User ID
- Administrator Password
- AbsPlus\MDBS Directory (password)
- Encryption Example

Menu Overview
- File
- Edit
- Options
- Utilities
- Reports
- Help

Load Data (Import)
Searching for Cases by name by hospital
Abstracting Overview with Edits
Backup Procedure
Export

APPENDIX K

ABSTRACT PLUS INSTRUCTIONS FOR EXPORTING AND EXTRACTING

Summary Stage Study – Abstract Plus Software
Instructions for Exporting and Extracting
December 6, 2002

Summary: This process involves two steps. The Export function takes place within Abstract Plus. The Extraction function takes place in MS Windows Explorer and extracts the non-confidential data items to be included in the analysis. The extraction file will be sent to the Study Analysis, Jerri Linn Phillips. These procedures should be run after all identified cases (source records) have been re-abstracted.

Instructions for Exporting (In Abstract Plus):
In the Menu: Click - Options
Click - Export Abstracts in NAACCR Format
The Export Abstracts in NAACCR Format window opens:
Click - Export All Abstracts in Database box
Click – Select
Click – Export
The Save NAACCR File As Windows window opens:
Enter a name for the Export File in the Filename box
Save
The Report of Export File for Transmit window opens:
Print or Save or both
Close
Return to the Export Abstracts in NAACCR Format window:
Close

Instructions for Extracting (In Windows Explorer):
Find C:\AbsPlus\export sub-directory (the drive could be D: or …)
Double click: ExtractFields.exe
A Login window opens:
Click – Open (don't enter anything in the User ID and password boxes.)
The Data Extraction Tool window opens:
Click – Browse
Find and highlight the Export File
Open
The Data Extraction Tool window opens:
Click – Extract
Enter a name for the Extraction File in the Filename box
Click – Save
Extraction complete window opens (on top of the Data Extract Tool window):
Click – OK
The Data Extraction Tool window:
Click – Close

[Verify the Extraction file and send to Jerri Linn.]

APPENDIX L

EDIT LOGIC REPORT FOR METAFILE SSSPROJ.EMF

****

Edit Logic Report for Metafile
SSSPROJ.EMF 10/20/02 16:04:36

****

Ordered By:
Edit Name

Filtered by:
Edit Set = "SSS Project"

Edit Logic Report for Metafile SSSPROJ.EMF 10/20/02 16:04:36

EDIT NAME:
Behavior ICDO2, Date of Diagnosis (SSS)

AGENCY: **DATE LAST MODIFIED:**
SSS 10/20/02

EDIT SETS:
SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Date of Diagnosis (SSS)	9390	Date of Diagnosis (SSS)	9390
Beh (92-00) ICD-O-2 (SSS)	9430	Beh (92-00) ICD-O-2 (SSS)	9430

TABLES:

ERROR MESSAGES:
MESSAGE NUMBER: 1112
If year of %F1 < 2001, then %F2 cannot be blank.
If year of Date of Diagnosis (SSS) < 2001, then Beh (92-00) ICD-O-2 (SSS) cannot be blank.

DESCRIPTION:

If year of Date of Diagnosis (SSS) is less than 2001, then Beh (92-00) ICD-O-2 (SSS) cannot be blank.

ERROR CORRECTION HELP:

EDIT LOGIC:

```
If ( DATE_YEAR(#S"Date of Diagnosis (SSS)") < 2001)
        If ( EMPTY (#S"Beh (92-00) ICD-O-2 (SSS)"))
                return FAIL;

return PASS;
```

EDIT NAME:
Date of Diagnosis (SSS)

AGENCY: SSS
DATE LAST MODIFIED: 10/20/02

EDIT SETS:
SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Date of Diagnosis (SSS)	9390	Date of Diagnosis (SSS)	9390

TABLES:

ERROR MESSAGES:
MESSAGE NUMBER: 1003
%F1 (%V1) is an invalid date
Date of Diagnosis (SSS) ((value of Date of Diagnosis (SSS))) is an invalid date

DESCRIPTION:

The edit does the following--with respect to the Reabstracted Date of Diagnosis:

1. This edit first checks that the date is a valid date using the following generic date checking criteria:

    a) All parts of a date must be must be zero-filled; blanks and non-digits are not allowed.

    b) Allowable values for month, day, and year are verified. Checks are performed first for error conditions, then missing conditions, then unknown conditions; within this order, first year is checked, then month, then day. Checking is halted when the first non-valid condition is reached.

    ERROR conditions:
    YEAR--lowest allowed value is current (system) year - 150; highest allowed year is current (system) year + 5.

MONTH--allowed values are 0-12 and 99.
DAY--allowed values are 0-31 and 99. Upper bounds for known values are checked for each individual month, and a value of 29 for February is allowed only in leap years or for unknown or missing years (9999 or 0000).

MISSING conditions: missing values (0) are not allowed for year, month, or day.

UNKNOWN conditions: unknown values are allowed for year, month, and day, but see individual date edit descriptions for checks of validity between unknown components of year.

2. Checks specific to Date of Diagnosis are then performed:

   a) If the year is unknown (9999), month and day must be unknown (99 and 99, respectively).

   b) If the month is unknown (99), the day must be unknown (99).

   c) Year of diagnosis must be less than or equal to the current year.

   d) If the year of diagnosis is equal to the current year and month is known, the month must be less than or equal to the current month.

   e) If the diagnosis year and month are equal to the current year and month and the day is known, the day must be less than or equal to the current day.

ERROR CORRECTION HELP:

EDIT LOGIC:

```
int ret_val, hi_year, hi_month, hi_day, year, month, day;

/* Detect non-numerics and goofy values. */

ret_val = VALID_DATE(#S"Date of Diagnosis (SSS)");

if (ret_val == DT_ERROR )
{error_text ("Date of Diagnosis Error: %DC"); return FAIL;}

if (ret_val == DT_MISSING )
{error_text ("Date of Diagnosis Error: %DC"); return FAIL;}

hi_year =DATE_YEAR(DT_TODAY);
hi_month =DATE_MONTH(DT_TODAY);
hi_day =DATE_DAY(DT_TODAY);
```

```
month = DATE_MONTH(#S"Date of Diagnosis (SSS)" );
day = DATE_DAY(#S"Date of Diagnosis (SSS)" );
year = DATE_YEAR(#S"Date of Diagnosis (SSS)");

if ( year == 9999 AND month == 99 and day == 99 )
return PASS;

if ( year == 9999 AND month != 99 )
return FAIL;

if ( month == 99 AND day != 99 )
return FAIL;

if ( year > hi_year )
return FAIL;

if ( year == hi_year and month != 99 and month > hi_month )
return FAIL;

if ( year == hi_year and month == hi_month and day != 99 and day > hi_day )
return FAIL;

return PASS;
```

EDIT NAME:

Histology ICDO2, Date of Diagnosis (SSS)

AGENCY: **DATE LAST MODIFIED**:

SSS 10/20/02

EDIT SETS:

SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Date of Diagnosis (SSS)	9390	Date of Diagnosis (SSS)	9390
Hist(92-00) ICD-O-2 (SSS)	9420	Hist(92-00) ICD-O-2 (SSS)	9420

TABLES:

ERROR MESSAGES:

MESSAGE NUMBER: 1112

If year of %F1 < 2001, then %F2 cannot be blank

If year of Date of Diagnosis (SSS) < 2001, then Hist(92-00) ICD-O-2 (SSS) cannot be blank

DESCRIPTION:

If year of Date of Diagnosis (SSS) is less than 2001, then Hist (92-00) ICD-O-2(SSS) cannot be blank.

ERROR CORRECTION HELP:

EDIT LOGIC:

```
If ( DATE_YEAR(#S"Date of Diagnosis (SSS)") < 2001)
If ( EMPTY (#S"Hist(92-00) ICD-O-2 (SSS)"))
return FAIL;

return PASS;
```

EDIT NAME:
Laterality (SSS)

AGENCY:	**DATE LAST MODIFIED:**
SSS	10/20/02

EDIT SETS:
SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Laterality (SSS)	9410	Laterality (SSS)	9410

TABLES:

ERROR MESSAGES:
MESSAGE NUMBER: 272
Laterality not valid

DESCRIPTION:

Must be a valid Laterality code (0...4,9).

ERROR CORRECTION HELP:

EDIT LOGIC:

```
return INLIST(#S"Laterality (SSS)","0,1,2,3,4,9");
```

EDIT NAME:
Laterality, Primary Site (SSS)

AGENCY: SSS

DATE LAST MODIFIED: 10/20/02

EDIT SETS:

SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Primary Site	400	SITE	400
Laterality (SSS)	9410	Laterality (SSS)	9410

TABLES:

ERROR MESSAGES:

MESSAGE NUMBER: 1006
Laterality must be provided for specified paired organs/sites

DESCRIPTION:

This edit is skipped if any of the single field edits for Laterality Primary Site have failed.

The following paired organ sites must have a code other than zero for Laterality:

C079	Parotid gland
C080	Submandibular gland
C081	Sublingual gland
C090	Tonsillar fossa
C091	Tonsillar pillar
CO98-C099	Tonsil, NOS
C301	Middle ear
C310	Maxillary sinus
C312	Frontal sinus
C341-C349	Lung
C384	Pleura
C400	Long bones of upper limb, scapula and associated joints
C401	Short bones of upper limb and associated joints
C402	Long bones of lower limb and associated joints
C403	Short bones of lower limb and associated joint
C441	Skin of eyelid
C442	Skin of external ear
C443	Skin of other and unspecified parts of face (midline code`9')
C445	Skin of trunk (midline code `9')
C446	Skin of upper limb and shoulder
C447	Skin of lower limb and hip
C471	Peripheral nerves and autonomic nervous system of upper limb and shoulder

C472	Peripheral nerves and autonomic nervous system of lower limb and hip
C491	Connective, subcutaneous, and other soft tissues of upper limb and shoulder
C492	Connective, subcutaneous, and other soft tissues of lower limb and hip
C500-C509	Breast

EDIT NAME:

Laterality, Primary Site (SSS)

C569	Ovary
C570	Fallopian tube
C620-C629	Testis
C630	Epididymis
C631	Spermatic cord
C649	Kidney, NOS
C659	Renal pelvis
C669	Ureter
C690-C699	Eye
C740-C749	Adrenal gland
C754	Carotid body

ERROR CORRECTION HELP:

EDIT LOGIC:

```
if ( USR4( 270, 272, 0, 0, 0 ) )
return PASS;

if ( INLIST(#S"Laterality (SSS)","0") )

if ( ( INLIST( #S"Primary Site", "079,080,081,090,091,098,099,301,310,312",
"Cddd",2,3) OR

INLIST( #S"Primary Site", "341-349,384,400-403,441-443,445-447,471",
"Cddd",2,3) OR

INLIST( #S"Primary Site", "472,491,492,500-509,569,570,620-629,630",
"Cddd",2,3) OR

INLIST(  #S"Primary Site", "631,649,659,669,690-699,740-749,754",
“Cddd",2,3)  ) )
return FAIL;

return PASS;
```

EDIT NAME:

Primary Site (SSS)

AGENCY: **DATE LAST MODIFIED:**
SSS 10/20/02

EDIT SETS:
SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Primary Site (SSS)	9400	Primary Site (SSS)	9400

TABLES:
SITE_TBL.DBF.SITECODE

ERROR MESSAGES:
MESSAGE NUMBER: 270
Primary Site not valid

DESCRIPTION:

Must be one of the topography codes defined by the International Classification of Diseases for Oncology, Second Edition or Third Edition. (The decimal point is dropped and the `C' is required.)

ERROR CORRECTION HELP:

EDIT LOGIC:
return LOOKUP(#S"Primary Site (SSS)","SITE_TBL.DBF.SITECODE");

EDIT NAME:
Primary Site, Morphology-Type Check (SSS)

AGENCY: **DATE LAST MODIFIED:**
SSS 10/20/02

EDIT SETS:
SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
Hist(92-00) ICD-O-2 (SSS)	9420	Hist(92-00) ICD-O-2 (SSS)	9420
Primary Site (SSS)	9400	Primary Site (SSS)	9400

TABLES:
IF25BITA.BIN
IF25BITB.BIN
IF25REF.BIN

ERROR MESSAGES:

MESSAGE NUMBER: 355
Site & Morphology conflict - ICDO2
MESSAGE NUMBER: 380
Catastrophic Error in IF25 - ICDO2

DESCRIPTION:

This edit is skipped if any of the single field edits for Primary Site or Histology (92-00) ICD-O-2 (SSS0 have failed or if Histology (92-00) ICD-O-2 (SSS) is empty.

Over-ride Site/Type is ignored by the edit -- contradictory cases should be documented in text and reported to Study Analyst.

If Primary Site is not in the range C000-C999, or if Histology (92-00) ICD-O-2 is not in the range 8000-9999, the message "Catastrophic error in IF25" is returned and no further editing is done.

The SEER Site/Histology Validation List (Appendix A) designates all four-digit histologies (specified as in situ or malignant in ICD-O) that do not require review for each site. Any site/histology combination not in the Site/Histology Validation List will be accepted only if the case has been reviewed, accepted as coded, and Over-ride--Site/Type = 1. All other combinations will generate the message "Incompatible site and morphology". Since basal and squamous cell carcinomas of non-genital skin sites are not reportable to SEER, these site/histology combinations do not appear on the validation list.

Within the edit logic, the SEER Site/Histology Validation List is represented by three binary tables.

The Site/Histology Validation List contains those histologies commonly found in the specified primary site. Histologies that occur only rarely or never may not be included. Review of these rare combinations often results in changes to the primary site and/or morphology, rather than a decision that the combination is correct. The over-ride flag should not be set to 1 if the primary site or histologic type are changed to a combination that will pass the edit. However, if upon review the site/type combination is found to be accurate and in conformance with coding rules, it may be left as coded and the Over-ride--Site/Type flag coded to 1.

ERROR CORRECTION HELP:

This edit forces review of atypical site-type combinations. Combinations not requiring review are presented, by primary site, in the printed "SEER Site/Histology Validation List". This edit does not imply that there are errors but rather that the combination of site and histology are so unusual that they should be checked to ensure that they correctly reflect what is in the medical record. Resolution of discrepancies may require inspection of the abstracted text, either

online or as recorded on a paper abstract. Review of the original medical record may be necessary.

Review of these cases requires investigating whether a) the combination is biologically implausible, or b) there are cancer registry coding conventions that would dictate different codes for the diagnosis. The following resources can be checked:

Current oncology and pathology textbooks
Current medical journal articles, e.g., via MEDLINE
Pathologist advisors to the registry

If upon review it is decided that the case is appropriately coded, set the Over-ride--Site/Type flag to 1 so that the case will not be flagged for review when the edit is run again.

EDIT LOGIC:

```
int siteval, histval, ref, result;

if ( EMPTY (#S"Hist(92-00) ICD-O-2 (SSS)"))
return PASS;

if ( USR4( 270, 301, 0, 0, 0 ) )
return PASS;

if ( NOT INLIST( #S"Primary Site (SSS)", "000-999", "Cddd", 2, 3 ) OR

NOT INLIST( #S"Hist(92-00) ICD-O-2 (SSS)", "8000-9999", "dddd" ) )
return ERROR_MSG( 380 );

result = 0;

siteval = VAL( RIGHT( #S"Primary Site (SSS)", 3 ) ) + 1;
histval = VAL( #S"Hist(92-00) ICD-O-2 (SSS)" ) - 7999;

ref = BINLOOKUP("IF25REF.BIN", siteval );

if ( ref != 0 )

if ( ref > 127 )   /* ref is negative */

ref = 256 - ref;
result = !BINLOOKUP( "IF25BITB.BIN", ref, histval );

else   /* ref is positive */
result = !BINLOOKUP( "IF25BITA.BIN", ref, histval );
```

return result;

EDIT NAME:
RX Date--Surgery (SSS)

AGENCY: **DATE LAST MODIFIED:**
SSS 10/20/02

EDIT SETS:
SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
RX Date--Surgery (SSS)	991200	RX Date--Surgery (SSS)	991200

TABLES:

ERROR MESSAGES:
MESSAGE NUMBER: 1003
%F1 (%V1) is an invalid date
RX Date--Surgery (SSS) ((value of RX Date--Surgery (SSS))) is an invalid date

DESCRIPTION:

This edit does the following with respect to the reabstracted RX Date-Surgery:

1. This edit first checks that the date is a valid date using the following generic date checking criteria:

   a) All parts of a date must be must be zero-filled; blanks and non-digits are not allowed.

   b) Allowable values for month, day, and year are verified. Checks are performed first for error conditions, then unknown conditions; within this order, first year is checked, then month, then day. Checking is halted when the first non-valid condition is reached.

      ERROR conditions:
      YEAR--lowest allowed value is current (system) year - 150; highest allowed year is current (system) year + 5.
      MONTH--allowed values are 0-12 and 99.
      DAY--allowed values are 0-31 and 99. Upper bounds for known values are checked for each individual month, and a value of 29 for February is allowed only in leap years or for unknown or missing years (9999 or 0000).

UNKNOWN conditions: unknown values are allowed for year, month, and day, but see individual date edit descriptions for checks of validity between unknown components of year.

2. Checks specific to RX Date--Surgery are then performed:

   a) If the year is 0000, month and day must also equal 00. (A date of all zeroes means there was no cancer-directed surgery.) A partial date of zeroes will fail as a MISSING condition.

   b) If the year is unknown (9999), month and day must be unknown (99 and 99, respectively).

   c) If the month is unknown (99), the day must be unknown (99).

   d) Year of must be less than or equal to the current year.

   e) If the year is equal to the current year and month is known, the month must be less than or equal to the current month.

   f) If the year and month are equal to the current month and the day is known, the day must be less than or equal to the current day.

ERROR CORRECTION HELP:

EDIT LOGIC:

```
int retval, hi_year, hi_month, hi_day, year, month, day;

/* Detect non-numerics and goofy values. */

retval = VALID_DATE(#S"RX Date--Surgery (SSS)" );

if ( retval == DT_ERROR )

error_text ("RX Date--CA Dir Surg Error: %DC");
return FAIL;

hi_year =DATE_YEAR(DT_TODAY);
hi_month =DATE_MONTH(DT_TODAY);
hi_day =DATE_DAY(DT_TODAY);

month = DATE_MONTH(#S"RX Date--Surgery (SSS)" );
day = DATE_DAY(#S"RX Date--Surgery (SSS)" );
year = DATE_YEAR(#S"RX Date--Surgery (SSS)");
```

```
if ( year == 0000 AND month == 00 and day == 00 )
return PASS;

if ( retval == DT_MISSING )
error_text ("RX Date--Surgery: %DC");
return FAIL;

if ( year == 9999 AND month == 99 and day == 99 )
return PASS;

if ( year == 9999 AND month != 99 )
return FAIL;

if ( month == 99 AND day != 99 )
return FAIL;

if ( year > hi_year )
return FAIL;

if ( year == hi_year and month != 99 and month > hi_month )
return FAIL;

if ( year == hi_year and month == hi_month and day != 99 and day > hi_day )
return FAIL;

return PASS;
```

EDIT NAME:

Summary Stage 1977 (SSS)

AGENCY:	**DATE LAST MODIFIED:**
SSS	10/20/02

EDIT SETS:

SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
SEER Summ Stage 1977(SSS)	9760	SEER Summ Stage 1977(SSS)	9760

TABLES:

ERROR MESSAGES:

MESSAGE NUMBER: 1008
%V1 is not a valid value for %F1

(value of SEER Summ Stage 1977(SSS)) is not a valid value for SEER Summ Stage 1977(SSS)

DESCRIPTION:

This edit does not permit reabstracted SSS 1977 to be blank. Use 9 if you have an aberrant case (for example, behavior of 0) and clarify in text.

Must be a valid SEER Summary Stage 1977 code (0-5, 7, 9).

ERROR CORRECTION HELP:

EDIT LOGIC:

return INLIST(#S"SEER Summ Stage 1977(SSS)","0-5,7,9");

EDIT NAME:

Summary Stage 2000 (SSS)

AGENCY: **DATE LAST MODIFIED:**

SSS 10/20/02

EDIT SETS:

SSS Project

FIELDS:

Std Name	Std Num	Local Name	Loc Num
SEER Summary Stage 2000	759	SEER Summary Stage 2000	759

TABLES:

ERROR MESSAGES:

MESSAGE NUMBER: 1008
%V1 is not a valid value for %F1
(value of SEER Summary Stage 2000) is not a valid value for SEER Summary Stage 2000

DESCRIPTION:

This edit does not allow the reabstracted SSS 2000 to be blank. Use 9 for aberrant cases (for example, benign cases), and document in the text.

Must be a valid SEER Summary Stage 2000 code (0-5, 7, 9).

ERROR CORRECTION HELP:

EDIT LOGIC:

```
if ( EMPTY (#S"SEER Summary Stage 2000"))
return PASS;

return INLIST(#S"SEER Summary Stage 2000","0-5,7,9");
```

APPENDIX M

STAGING SCENARIOS

BREAST CASE # 1

Physical Examination

Right Breast: 5 x 3 cm mass noted on physical exam by family physician. No pain or tenderness; no nipple discharge. Skin thickened adjacent to areolar area; slight nipple retraction.
Left Breast: No masses palpated.
No enlarged *lymph nodes*.

Imaging

4-12-2000 Chest x-ray: within normal limits.
4-13-2000 Bone scan: no evidence of skeletal disease
4-14-2000 Thoracic and lumbar spine: negative for metastasis

Laboratory

4-14-2000 SMA 12: within normal limits
4-15-2000 Estrogen receptor assay: positive for estrogen receptors

Surgical Observations

3-13-2000 Needle aspiration of right breast
4-15-2000 Biopsy and right modified radical mastectomy

Pathologic Report

3-13-2000 Grade IV adenocarcinoma of right breast
4-15-2000 Infiltrating ductal carcinoma of right breast with vascular and lymphatic invasion; no evidence of tumor in 32 regional node. Tumor is attached to fat; tumor size is 7.0 x 4.0 x 4.0 cm; lesion is located at 12:00; differentiation is grade ii.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

BREAST CASE # 2

Physical Examination

Left Breast: Lump in LOQ present for 3 months. Firm, hard, with chronic intermittent pain. No skin lesions; no nipple discharge or retraction. Mass is freely moveable; 2 cm in size.
Right Breast: Within normal limits.
No organomegaly; no palpable lymph nodes.

Imaging

1-22-2000 Bilateral mammogram: left breast mass; right breast normal.
1-29-2000 Chest x-ray: normal.
1-30-2000 Liver/spleen scan: normal

Laboratory

1-22-2000 SMA 20: within normal limits

Surgical Observations

1-29-2000 Carcinoma of left breast; size: 1.5 x 1.5 cm.
2-6-2000 Left modified mastectomy.

Pathology Report

1-29-2000 Carcinoma of left breast; size: 1.5 x 1.5 cm
2-6-2000 Fibrocystic disease of left breast; no residual tumor. No pathologic disease in 17 axillary lymph nodes.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

BREAST CASE # 3

Physical Examination

Right Breast: 4 x 3 cm firm, irregular mass at 1:00 position. No skin changes; no dimpling, no nipple discharge. Freely moveable mass.
Left Breast: No masses palpated.
Palpable lymph nodes in right axilla.

Imaging

1-22-2000 Mammogram: suspected lesion in right breast. Faint calcification at mirror image in left breast.
10-22-2000 Chest x-ray: within normal limits.

Laboratory

10-22-2000 SMA 12: fasting blood sugar elevated.
10-29-2000 Estrogen/progesterone receptors: ER mildly positive; PR negative.

Surgical Observations

10-22-2000 Right breast biopsy and right modified radical mastectomy.

Pathology Report

10-22-2000 Intraductal carcinoma of breast with extensive retrograde lobular extension and stromal invasion. No tumor present in 3 lymph nodes at apex of right axilla. Extensive intraductal comedocarcinoma and retrograde lobular extension. Metastatic adenocarcinoma to 4/14 axillary lymph nodes, 1/3 infraclavicular nodes, and 0/15 intramammary nodes. No definite perineural or blood vascular invasion is seen, although foci of lymphatics are identified. Tumor size: 4.1 x 3.5 x 3.0 cm.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

BREAST CASE # 4

Physical Examination

Right Breast: 4 x 5 x 3 cm hard mass at 6:00. Normal nipple without discharge. Lesion not attached to fascia or muscle.
Left Breast: normal.
No enlarged lymph nodes or abdominal masses palpated.

Imaging

4-21-2000 Chest x-ray: normal.
4-22-2000 Bone scan: abnormality in left knee.
4-22-2000 Liver/spleen scan: normal.

Laboratory

4-20-2000 SMA 20: within normal limits

Surgical Observation

4-21-2000 Aspiration biopsy.
4-22-2000 Right radical mastectomy: lesion located in lower quadrant

Pathology Report

4-21-2000 Right breast: cells compatible with adenocarcinoma
4-22-2000 5.5 cm area of intraductal carcinoma with 3 cm central area of invasive carcinoma in right breast. Negative nipple. 1 of 5 axillary lymph nodes positive at level I; 10 negative lymph nodes at levels II and III.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

BREAST CASE # 5

Physical Examination

Right Breast: No discrete masses, no discharge noted.
Left Breast: Palpable mass at about the 6:00 area. No nipple retraction noted; no discharge.
Remainder of the physical examination was negative.

Imaging

7-2000 Mammogram: abnormal mass at 6:00 in left breast; right breast normal.

Laboratory

10-24-2000 SMA 20: Within normal limits.

Surgical Observations

10-3-2000 Excisional biopsy
10-24-2000 Modified radical mastectomy, left.

Pathology Report

10-3-2000 Ductal carcinoma *in situ* (DCIS), apocrine type with extensive necrosis with one focus showing microinvasion (measuring less than 1 mm in diameter). The morphology of the DCIS is classified as high-grade.

10-24-2000 Breast left, modified radical mastectomy: extremely rare duct involved by micropapillary duct carcinoma in situ, no residual invasive carcinoma seen.
Margins negative.
Lymph nodes: metastatic ductal carcinoma involving one of twenty-four (1/24) of which showed "micrometastasis" not greater than 2.0 mm.
ER/PR Assays are both negative
Her2 Hercep test is 0/negative

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from *AJCC TNM 6th Training Materials*, May 2002

LUNG CASE # 1

Physical Examination

Neck: supple, no palpable nodes.
Abdomen: liver down a finger breadth
Rectal: prostate enlarged 2+ without nodules, smooth

Imaging

12-2-2000 Chest: soft spherical tissue density mass occupying the anterior segment of RUL medially and in the subpleural location. Mass measures 5.0 x 3.0 cm. There is an associated hilar mass. Represents most likely a primary bronchogenic carcinoma with nodal metastasis to hilum and right paratracheal area. Left is essentially WNL.
2-14-2001 Brain scan normal.

Laboratory

2-14-2001 Alkaline phosphatase: 55 (30-95)

Surgical Observation

2-15-2001 Right scalene node biopsy: no observations recorded.
2-15-2001 Needle biopsy lung: no observations recorded.

Pathology

2-15-2001 Right scalene node biopsy: 5 small nodes metastatic squamous cell carcinoma; probable lung primary.
2-15-2002 Needle biopsy lung: squamous cell carcinoma. No other details.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

LUNG CASE # 2

History

Symptoms began approximately 6 months prior to admission. Minimal sputum productive cough; night sweats; 5-10 pound weight loss. 1 ½ pack per day cigarette smoker x 30 years.

Physical Examination

No lymphadenopathy or organomegaly.

Laboratory

12-4-2000 CBC and diff and SMA 12: within normal limits

Imaging

12-4-2000 Chest x-ray: solitary 3 cm nodule in right upper lobe
12-4-2000 Bone, brain and liver scans: within normal limits

Surgical Observations

12-5-2000 Bronchoscopy with biopsy
12-6-2000 Right upper lobectomy: Right upper lobe, 2 tumors, 2.5 cm and 1.0 cm in diameter. No gross hilar or mediastinal nodes noted.

Pathology

12-5-2000 Bronchial secretions positive for malignant cells.
12-5-2000 Undifferentiated large cell carcinoma, transbronchial biopsy.
12-6-2000 Two tumors from right upper lobe, 4.0 and 0.7 cm, both showing poorly differentiated adenocarcinoma, 0/12 hilar lymph nodes positive.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

LUNG CASE # 3

History

Patient complained of being tired, loss of appetite with no weight loss. Sharp chest pain first noted three months prior to admission. Heavy smoker x 30 years. Coal miner.

Physical Examination

No lymphadenopathy or masses palpable.

Laboratory

7-5-2000 Laboratory values within normal limits.

Imaging

7-5-2000 Chest x-ray: mediastinal mass with no clearly demonstrated mass in either lung. There is a slight haziness in the left hilum area that is inconclusive for the evaluation: suggest tomogram or CT scan.
7-5-2000 Bone, brain and liver scans: within normal limits.

Surgical Observations

7-6-2000 Left thoracotomy and biopsy of mediastinal lymph nodes: Left upper lobe retracted and large mass palpated beneath aortic arch; other masses noted in mediastinum; pea-sized tumor noted in left upper lobe.

Pathology

7-6-2000 Metastatic squamous cell carcinoma of one para-aortic lymph node and ten mediastinal lymph nodes.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

LUNG CASE # 4

History

Tremors of right leg and arm; loss of memory; difficulty breathing.

Physical Examination

No lymphadenopathy; wheezing on deep inspiration of both lungs, more predominant on right.
No palpable masses.
Neurological examination: Motor reflexes on right decreased: positive Babinski's and Hoffman's sign.

Laboratory

4-19-2000 Markedly elevated WBC; below normal RBC, HGB, and HCT. Elevated CPK and alkaline phosphatase.

Imaging

4-19-2000 Chest x-ray: Complete actelectasis, obstructive pneumonitis and pleural effusion of right lung compatible with diagnosis of malignant neoplasm.
4-20-2000 Brain CT scan: Discrete masses in left parietal and occipital lobes consistent with clinically described carcinoma of lung.

Surgical Observations

No surgery.

Pathology

4-19-2000 Sputum positive for malignant cells.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from: *Workbook for Staging of Cancer*. Fritz A, Hultstrom D, McKee R, eds. National Cancer Registrars Association, 1994.

LUNG CASE # 5

History

Benign brain tumor in 1989, myocardial infarction in 1995, chronic emphysema and CHF as a result of 50+ years of smoking.

Physical Examination

2-3-2000 Patient admitted with CHF, chronic cough without hemoptysis.

Imaging

1-2000 Chest x-ray: peripheral nodular mass-like infiltrate, right upper lobe measuring 3.0 cm; questionable second lesion in left mid-lung; overall appearance worrisome for neoplasm of lung. Hilar appears normal.

1-2000 CT scan: cavitary, large, ill-defined mass in RUL; LUL has a hazy ill-defined opacity.

2-4-2000 MRI of chest: 3.5 cm mass in RUL; probable primary carcinoma of the lung with evidence consistent with metastatic disease in LUL.

Surgical Observation

2-5-2000 Bronchoscopy with biopsy recommended by managing physician but declined by family. No further diagnostic or staging work-up, no treatment.

SEER Summary Stage 1977 _____
SEER Summary Stage 2000 _____
Text:

Adapted from *FORDS Training Materials*, 2002.

APPENDIX N

PARTICIPANT OBSERVATIONS

Participating central registries were invited to contribute summaries of their experiences with the project and observations from the field. This report from the MCSS characterizes informal observations from all three registries.

1. The Project

The major tasks in conducting the reabstracting study included: preparation of submission of the study to the Minnesota Department of Health Institutional Review Board; preparation and submission of the original data file to the NAACCR study coordinator for the selection of study cases; creation of study file and installation of abstracting software and study cases on the laptop computer; scheduling visits to study facilities and ordering charts; facility visits and data abstracting; data review and preparation of study data for submission. The MDH Institutional Review Board determined that the study was exempt from its review, though two facilities did require that the study be reviewed by their own IRBs. The major challenge lay in scheduling visits into an efficient travel pattern around the state, coordinating the summary stage project with another data review project undertaken by the Minnesota Cancer Surveillance System at many of the same facilities, and accomplishing the travel during the winter. Records for review were obtained by outstate MCSS staff from two facilities in very outlying corners of the state. The study abstracting was finished before HIPAA regulations went into effect, but two facilities required that the abstractor sign forms that would be placed into the patient records, and a third facility preselected admission records for review that their staff determined were directly related to the cancer diagnosis. Computerization of records presented the major challenge in acquiring records for review, as many facilities are now in the process of developing their electronic records, records for the study year may have been partially online and partially maintained in paper form, and paper charts may have been sent offsite for microfilming. Abstracting at a number of facilities required staff introductions to operating within their computer systems. The Abstract Plus software for gathering the data is straightforward to use, but its limited text space, particularly in the field for recording x-ray and scan information, required very dense abbreviating in many cases. Amount of time spent on each case was mostly determined by the form of the chart, with computer records generally taking longer to abstract than paper records. Time spent on the project averaged over the cases, including travel and review, was about 24 minutes per case. The abstracting was accomplished over a three-month time period, and overall was an interesting and enjoyable experience, and staff at the facilities visited were helpful.

2. Field Impressions

Field impressions of coding variations between the 1977 and 2000 summary stage schemes were that lung cancer stage was affected much more than breast cancer stage, that timing differences did impact some cases, and that coding clarifications made for the purposes of the study may not have coincided with coding practice in the field. Two coding issues that required special

directions for the study were how to address pleural effusions in assigning stage for lung cancer within the 1977 scheme, and how to address isolated tumor cells found in axillary nodes in assigning stage for breast cancer in both 1977 and 2000 schemes. The 1977 scheme does not specifically mention pleural effusion, and SEER issued a statement on isolated tumor cells after study abstracting was completed. The definition of the time for accumulation of staging information requires interpretation to determine whether a case fits in the "absence of disease progression" criterion. Lung cancer remains more difficult to code due to the greater number of variables that determine stage assignment and necessary reliance on radiographic and other clinical observations in many cases where surgery is not performed.