The 2005 Summary of Quality Assessments of CINA Deluxe

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1. Introduction

The North American Association of Central Cancer Registries, Inc. (NAACCR) is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America. Data used for cancer incidence statistics are reviewed annually and certified when they meet NAACCR standards for high quality incidence data. However, as uses of the data submitted to NAACCR expand beyond calculation of incidence statistics and data files are made available to researchers for analytic and surveillance research, the need to expand data evaluation has become apparent. Thus all researchers granted access to use the NAACCR analytic files, referred to as CINA Deluxe, are asked to provide a report of their review of the quality of the file as it pertains to their proposed project. In addition, staff conduct *ad hoc* assessments of CINA Deluxe regarding data elements that have suspected or potential data quality concerns that could affect information of interest to the membership.

This report includes summaries from two quality assessment reviews of the Cancer in North America (CINA) Deluxe dataset. First, the data quality criteria, for incidence statistics only, in section 2 evaluates the use of override flags and potential data quality issues for selected cancers, and other selected edit inconsistencies that have been raised by members as potential problems.

Second, researchers are asked to assess the data items they use in their analysis for quality and completeness and to describe the impact of this assessment on their research analysis using the NAACCR data set, CINA Deluxe. Section 3 summarizes these results and this report includes the analysis of pancreatic cancer, by the Louisiana Tumor Registry completed during the past 12 months.

2. Quality Assessment of the CINA Analytic File, 1995-2002

2.1. Background

Data submitted by central cancer registries in response to the NAACCR Call for Data are included in the CINA file. IMS, under NAACCR contract, receives, processes, stores, and analyzes the data submitted by the central cancer registries. Data from 42 central cancer registries (36 states, 5 metropolitan areas, and the District of Columbia) met the NAACCR criteria for inclusion in the NAACCR U.S. Combined cancer statistics.[1] Data from each year of the five year period had to pass rigorous criteria for completeness of reporting, non-duplication of records, internal consistency among data items, and low percentage of death-certificate-only cases and cases with missing/unknown race, age, or county.[1] Although the criterion for inclusion in the NAACCR U. S. Combined incidence statistics is rigorous, it does not assess all data quality issues that may be important in research applications. Thus, all 65 central cancer registries that responded to the NAACCR Call for Data for 1995-2002 were included in this review.

2.2. Method

Data were reviewed from the submission, 1995-2002. This review was completed to analyze potential data quality issues within selected cancers (Quality Checks 1-3) and to review the use of override flags (Quality Checks 4-6) as described below:

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[1] Ellison JH, Wu XC, Howe HL, McLaughlin CC, Lake A, Firth R, Sullivan SK, Roney D, Cormier M, Leonfellner S, Kosary C, (eds). *Cancer in North America, 1998-2002. Volume One: Incidence.* Springfield, IL: North American Association of Central Cancer Registries, Inc. April 2005.

1) Examine grade in ICD-O-3 histology for Anaplastic Carcinoma, NOS (8021)
   Issue: Anaplastic carcinoma grade should be coded to 4 undifferentiated.
2) Review Type of Reporting Source and Diagnostic Confirmation for death certificate only (DCO) and autopsy only cases
   Issue: The Type of Report Src (DC/AO), DiagConf (SEERIF05) edit in EDITS produces a warning if type of report source = 6 and diagnostic confirmation is other than 1 or 6; and, if type of report source =7 and diagnostic confirmation is other than 9.
3) Review Acute Lymphoblastic Leukemia (ALL) ICD-O-2 histology (9821 and 9828) conversion to ICD-O-3 histology (9835 - 9837) with diagnosis years 1995-2000
   Issue: Cases of ALL ICD-O-2 histology converted to ICD-O-3 histology should be equivalent.
4) Review primary site Liver (C220), ICD-O-3 histology Hepatocellular Carcinoma (8170-8180) with override Site/Type Reviewed (1)
   Issue: The above-mentioned site and histology combination should not have an override site/type reviewed flag.
5) Examine primary site Skin (C440 – C449), ICD-O-3 histology Melanoma (8720) with override Site/Type Reviewed (1)
   Issue: The above-mentioned site and histology combination should not have an override site/type reviewed flag.
6) Examine primary site Cervix Uteri (C530 – C539), ICD-O-3 histology Squamous Cell Carcinoma (8070) with override Site/Type Reviewed (1)
   Issue: The above-mentioned site and histology combination should not have an override site/type reviewed flag.

2.3. Results

In this report, central cancer registries that met the NAACCR quality criteria for inclusion in the NAACCR combined cancer statistics will be referred to as registries that met the NAACCR criteria and central cancer registries that did not meet the NAACCR criteria for inclusion in the NAACCR combined cancer statistics will be referred to as registries that did not meet the NAACCR criteria.

2.3.1. Quality Check 1

Criteria selected: ICD-O-3 histology for Anaplastic Carcinoma, NOS (8021)

Out of a total of 6,113 anaplastic carcinoma cases only 3 were coded to an unknown grade (.05 percent). All 3 are from one registry and this registry meets the NAACCR criteria. The edit, Morphology--Type/Behavior ICD-O-3 (SEER MORPH), is included in the NAACCR Call for Data metafile and should also be used by central registries to identify cases that are coded to a grade other than the implied statement of grade in the ICD-O-3 term.

2.3.2. Quality Check 2

Criteria selected: Type of Reporting Source and Diagnostic Confirmation for death certificate only (DCO) and autopsy only

Out of a total of 202,512 death certificate only (DCO) cases, four were coded to a diagnostic confirmation other than Unknown. Two were coded to Microscopically Confirmed and 2 were coded to Positive Histology. Two were from registries that did not meet NAACCR criteria (.001 percent of the cases that did not meet NAACCR criteria) and 2 were from registries that met NAACCR criteria (.005 percent of the cases that met NAACCR criteria).

All of the DCO subsequent primaries (4,289 cases) were DCOs.

All autopsy only cases had the diagnostic confirmation coded correctly.

Table 1. Death Certificate Only Cases
With Diagnostic Confirmation other than Unknown
CINA Analytic File, 1995-2002

	Meet NAACCR Criteria					
	Yes		No		Total	
Diagnostic Confirmation	**n**	**%**	**n**	**%**	**n**	**%**
Unknown	158,959	100	43,549	100	202,508	100
All other	2	.001	2	.005	4	.002
Total	158,961	100	43,551	100	202,512	100
	Fisher exact test = 0.2043; 1df, p = N.S.					

*Shaded cells indicate quality issues.

2.3.3. Quality Check 3

Criteria selected: Acute Lymphoblastic Leukemia ICD-O-2 histology (9821 and 9828) conversion to ICD-O-3 histology (9835 - 9837) with diagnosis years 1995-2000

A total of 25,039 acute lymphoblastic leukemia cases with diagnosis years 1995-2000 were coded to 9821 and 9828 using ICD-O-2 and a total of 25,046 were converted to ICD-O-3 codes 9835-9837. Registries that met NAACCR criteria have 7 more acute lymphoblastic leukemia cases in the ICD-O-3 conversion codes 9835-9837 (5 of these are from one registry) and these numbers should be the same.

2.3.4. Quality Check 4

Criteria selected: Primary site Liver (C220), ICD-O-3 histology Hepatocellular Carcinoma (8170-8180) with override Site/Type Reviewed (1)

A total of 73,391 hepatocellular carcinomas of the liver are on the CINA file with 2,088 site/type overrides flagged as reviewed. Registries that met NAACCR criteria submitted 60,532 with 0.4 percent flagged (251 of the cases that met NAACCR criteria) and registries that did not meet NAACCR criteria submitted 12,859 with 14.3 percent flagged (1,837 of the cases that did not meet NAACCR criteria). One registry submitted 1,810 of the 1,837 flagged that did not meet NAACCR criteria

Table 2. Hepatocellular Carcinoma of Liver
Site/Type Override Flag
CINA Analytic File, 1995-2002

	Meet NAACCR Criteria				Total	
	Yes		No			
Override	**n**	**%**	**n**	**%**	**n**	**%**
Flagged as reviewed	251	0.4	1,837	14.3	2,088	2.8
Not flagged as reviewed	60,281	99.6	11,022	85.7	71,303	97.2
Total	60,532	100	12,859	100	73,391	100
	χ^2 test = 7382.71; 1df, p < .0001					

*Shaded cells indicate quality issues.

2.3.5. Quality Check 5

Criteria selected: Primary site Skin (C440 – C449), ICD-O-3 histology Melanoma (8720) with override Site/Type Reviewed (1)

A total of 186,850 melanoma of the skin are on the CINA file with 4,652 site/type overrides flagged as reviewed. Registries that met NAACCR criteria submitted 152,996 with 0.3 percent flagged (508 of the cases that met NAACCR criteria) and registries that did not meet NAACCR criteria submitted 33,854 with 12.2 percent flagged (4,124 of the cases that did not meet NAACCR criteria). One registry submitted 3,947 of the 4,124 flagged that did not meet NAACCR criteria.

Table 3. Melanoma of Skin
Site/Type Override Flag
CINA Analytic File, 1995-2002

	Meet NAACCR Criteria				Total	
	Yes		No			
Override	**n**	**%**	**n**	**%**	**n**	**%**
Flagged as reviewed	508	0.3	4,124	12.2	4,652	2.5
Not flagged as reviewed	152,488	99.7	29,730	87.8	182,198	97.5
Total	152,996	100	33,854	100	186,850	100
	χ^2 test = 16100.42; 1df, p < .0001					

*Shaded cells indicate quality issues.

2.3.6. Quality Check 6

Criteria selected: Primary site Cervix Uteri (C530 – C539), ICD-O-3 histology Squamous Cell Carcinoma (8070) with override Site/Type Reviewed (1)

A total of 58,459 squamous cell carcinoma of the cervix uteri are on the CINA file with 1,518 site/type overrides flagged as reviewed. Registries that met NAACCR criteria submitted 45,647 with 0.5 percent flagged (231 of the cases that met NAACCR criteria) and registries that did not meet NAACCR criteria submitted 12,812 with 10 percent flagged (1,287 of the cases that did not meet NAACCR criteria). One registry, the same registry as in Quality Check 5, submitted 1,257 of the 1,287 flagged that did not meet NAACCR criteria.

Table 4. Squamous Cell Carcinoma of Cervix Uteri
Site/Type Override Flag
CINA Analytic File, 1995-2002

	Meet NAACCR Criteria				Total	
	Yes		No			
Override	**n**	**%**	**n**	**%**	**n**	**%**
Flagged as reviewed	231	0.5	1,287	10	1,518	2.6
Not flagged as reviewed	45,416	99.5	11,525	90	56,941	97.4
Total	45,647	100	12,812	100	58,459	100
	χ^2 test = 3599.22; 1df, p < .0001					

*Shaded cells indicate quality issues.

2.4. Conclusion

Overall, 19 central cancer registries did not have findings in any of the quality checks and 46 central cancer registries had a finding in one or more of the data quality checks. Seventeen registries had findings in only one quality check, 26 registries had findings in two to three quality checks, and 3 registries had findings in four or more of the six quality checks. These data quality checks reveal the need for internal quality checks other than the NAACCR Call for Data metafile, for use in incidence statistics like CINA and Registry Certification.

Quality check 1 identified the continued need to include the edit, Morphology—Type/Behavior ICD-O-3 (SEER MORPH), in the NAACCR Call for Data metafile to identify cases that are coded to a grade other than the implied statement of grade in the ICD-O-3 terms.

Quality check 2 identified the continued need to include the edit, Type of Report Srce (DC/AO), Diag Conf (SEER IF05), in the NAACCR Call for Data metafile. This edit verifies that if the type of reporting source is coded to '7 - death certificate only' then the diagnostic confirmation must be coded to '9 - unknown whether or not microscopically confirmed'. All of the DCO subsequent primaries were DCOs, however, there were 92 DCO subsequent primaries with a sequence of 4 or higher. DCO subsequent primaries should be reviewed to verify they are not metastatic disease from a previous primary malignancy. All of the type of reporting source '6 – autopsy only' cases are correctly coded to diagnostic confirmation '9 – unknown whether or not microscopically confirmed'.

Quality check 3 verifies that the ICD-O-2 histologies 9821 and 9828 for diagnosis years 1995-2000 were converted to ICD-O-3 histologies 9835-9837. The ICD-O-3 histologies have seven (5 of these were from one registry) more cases than the ICD-O-2 histologies. Data conversions should be reviewed to verify the data are converted accurately.

Quality checks 4-6 identified an overuse of override flags. Data in this review have been flagged when the data are valid. Even though overuse of override flags on valid data does not affect data analysis, the overall misuse of override flags on all data may affect data analysis. If override flags are not utilized correctly it is likely that some of the flagged data are invalid and have not been reviewed or verified. Therefore, even though the data are flagged the information could be incorrect and affect the quality of the central registry data. Data submitted by reporting facilities that use the override flags should be reviewed to ensure the flags are used properly.

A comparison review of the registries that met NAACCR criteria with the registries that did not meet NAACCR criteria was completed. In quality checks 4-6, registries that did not meet NAACCR criteria had a higher percentage of cases with issues than registries that met NAACCR criteria, even though the count and percentages were small. The override flag differences between registries that met or did not meet NAACCR criteria were statistically significant for quality checks 4-6.

Central cancer registries with any findings from this review will receive a report specific to their registry accompanying this summary report. Central cancer registries without issues in the above processes will receive only this summary report.

3. Descriptive Epidemiology of Pancreatic Cancer in the United States, 1996-2000. Catherine Correa, L Joseph Su, Elizabeth Fontham, Vivien Chen

This report is reproduced in part from the Louisiana Tumor Registry quality assurance report, Descriptive Epidemiology of Pancreatic Cancer in the United States.[2]

In the United States, 32 central cancer registries granted consent for use of their data in this analysis. Most articles detailing pancreatic cancer report only the subsite categories head, body, and tail. However, the current usage as reflected by the most authoritative manuals on cancer topography and morphology (International Classification of Diseases for Oncology manuals) list not only the head, body, and tail as pancreatic subsites, but also the pancreatic duct, the islets of Langerhans, neck and other, overlapping lesions, and pancreas, NOS. Even the current stage guides detail how to stage for all 8 pancreatic subsites, not just to head, body, and tail.

There are no authoritative guidelines for coding to the pancreatic duct, the islets of Langerhans, and neck and other. The final report shows that 648 pancreatic cancer cases were coded to the pancreatic duct. This was less than 1 percent of the total number of microscopically confirmed cases, although more than 80 percent of pancreatic cancers were considered ductal adenocarcinomas. Similarly, 107 islet cells of islet cell subtypes were coded as originating in the islets of Langerhans. The remaining 916 islet cells and islet cell subtypes were coded to the other 7 pancreatic subtypes; 112 non-islet cells were also coded to the islet of Langerhans.

Dr. Leslie Sobin of the AFIP suggested that the subsite, islets of Langerhans, was a vestige from the past when ICD did not have any histology codes and site codes were used to cover things like lymphomas. The only way to separate carcinomas from islet cell tumors was to use the topography. Now that there are morphology codes corresponding to "islet cells", the site code "islets of Langerhans" is redundant. Although, Dr. Sobin did not have time to address the subsites, pancreatic duct and neck and other, the appropriateness of the current usage of these topography sites needs to be addressed.

[2] Howe HL, Hinds RA (editors). *NAACCR Annotated Bibliography of Research and Publications: Multi-registry Cancer Incidence and Mortality Studies in the United States and Canada*. Springfield (IL): North American Association of Central Cancer Registries, December 2005, p. 48.

Table 5. Pancreatic cancer frequencies and percent distribution by subsite and histologic subtype

Microscopically Confirmed Cases Only

Histologic Subtypes	Head		Body		Tail		Pancreatic Duct		Islets of Langerhans		Neck & Other		Overlapping Lesions		Pancreas, NOS		Total	
	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%
Ductal adenocarcinoma	2,635	65.2%	323	8.0%	335	8.3%	86	2.1%	0	0.0%	18	0.5%	245	6.1%	399	9.9%	4,041	100%
"Mucinous adenocarcinomas"	2,120	47.1%	416	9.2%	590	13.1%	32	0.7%	0	0.0%	22	0.5%	302	6.7%	1,024	22.7%	4,506	100%
Signet ring cell carcinoma	240	50.0%	28	5.8%	51	10.6%	2	0.4%	0	0.0%	0	0.0%	33	6.9%	126	26.3%	480	100%
Adenosquamous carcinoma	199	46.4%	48	11.2%	61	14.2%	0	0.0%	0	0.0%	4	0.9%	41	9.6%	76	17.7%	429	100%
"Undifferentiated (anaplastic) carcinomas"	130	40.8%	32	10.0%	45	14.1%	1	0.3%	0	0.0%	3	0.9%	27	8.5%	81	25.4%	319	100%
"Carcinoma, giant cells"	37	42.1%	4	4.6%	12	13.6%	0	0.0%	0	0.0%	0	0.0%	8	9.1%	27	30.7%	88	100%
"Serous cystadenocarcinomas"	3	37.5%	1	12.5%	1	12.5%	0	0.0%	0	0.0%	0	0.0%	1	12.5%	2	25.0%	8	100%
"Mucinous cystadenocarcinomas"	123	28.8%	36	8.4%	151	35.4%	5	1.2%	0	0.0%	4	0.9%	51	11.9%	57	13.4%	427	100%
Intraductal papillary adenocarcinoma	30	62.5%	2	4.2%	3	6.3%	5	10.4%	0	0.0%	1	2.1%	2	4.2%	5	10.4%	48	100%
Other papillary and cystic adenocarcinomas	183	50.6%	29	8.0%	41	11.3%	10	2.8%	0	0.0%	1	0.3%	23	6.4%	75	20.7%	362	100%
Acinar cell carcinoma	75	32.9%	19	8.3%	56	24.6%	1	0.4%	0	0.0%	1	0.4%	18	7.9%	58	25.4%	228	100%
Solid-pseudopapillary	3	33.3%	0	0.0%	4	44.4%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	2	22.2%	9	100%
"Squamous cell carcinomas"	109	44.7%	23	9.4%	35	14.3%	6	2.5%	1	0.4%	3	1.2%	18	7.4%	49	20.1%	244	100%
Adenocarcinoma, NOS	28,716	53.0%	4,760	8.8%	5,456	10.1%	448	0.8%	15	0.0%	292	0.5%	3,475	6.4%	11,041	20.4%	54,203	100%
Other Adenocarcinomas	122	52.4%	16	6.9%	16	6.9%	7	3.0%	0	0.0%	2	0.9%	23	9.9%	47	20.2%	233	100%
Carcinoma, NOS	2,382	41.8%	359	6.3%	527	9.3%	31	0.5%	8	0.1%	23	0.4%	236	4.1%	2,133	37.4%	5,699	100%
Other Carcinomas	168	42.5%	36	9.1%	60	15.2%	2	0.5%	0	0.0%	0	0.0%	29	7.3%	100	25.3%	395	100%
Pancreatoblastoma	7	33.3%	2	9.5%	2	9.5%	0	0.0%	0	0.0%	0	0.0%	1	4.8%	9	42.9%	21	100%
Mixed exocrine and endocrine	1	16.7%	0	0.0%	3	50.0%	0	0.0%	1	16.7%	0	0.0%	0	0.0%	1	16.7%	6	100%
Islet cell	255	29.3%	53	6.1%	214	24.6%	2	0.2%	83	9.6%	9	1.0%	68	7.8%	185	21.3%	869	100%
Insulinoma	5	13.2%	1	2.6%	12	31.6%	0	0.0%	7	18.4%	0	0.0%	2	5.3%	11	29.0%	38	100%
Glucagonoma	7	25.9%	0	0.0%	8	29.6%	0	0.0%	8	29.6%	0	0.0%	0	0.0%	4	14.8%	27	100%
Gastrinoma	29	45.3%	4	6.3%	5	7.8%	0	0.0%	6	9.4%	2	3.1%	3	4.7%	15	23.4%	64	100%
VIPoma	7	28.0%	0	0.0%	8	32.0%	0	0.0%	3	12.0%	0	0.0%	2	8.0%	5	20.0%	25	100%
"Carcinoids"	62	37.4%	9	5.4%	34	20.5%	1	0.6%	6	3.6%	3	1.8%	6	3.6%	45	27.1%	166	100%
"Small cell carcinomas"	121	51.7%	14	6.0%	27	11.5%	2	0.9%	0	0.0%	0	0.0%	7	3.0%	63	26.9%	234	100%
Neuroendocrine and "other neuroendocrine"	467	36.8%	90	7.1%	275	21.7%	1	0.1%	71	5.6%	9	0.7%	79	6.2%	277	21.8%	1,269	100%
"Non-epithelial cancers"	52	36.1%	15	10.4%	27	18.8%	1	0.7%	1	0.7%	1	0.7%	12	8.3%	35	24.3%	144	100%
"Neoplasms, NOS"	597	38.4%	60	3.9%	114	7.3%	5	0.3%	9	0.6%	7	0.5%	52	3.3%	712	45.8%	1,556	100%

Source: NAACCR Research File, 1995-2000

(1995-2000) Arizona, California, Colorado, Connecticut, Atlanta, Hawaii, Idaho, Illinois, Iowa, Kentucky, Louisiana, Michigan, Minnesota, Nebraska, New Jersey, Pennsylvania, Rhode Island, Utah,

Washington, West Virginia, (1996-2000) Washington DC, Florida, Montana, Oregon, Wisconsin, Wyoming, (1995-1998) Maine 1995-1998, (1998-2000) Missouri, New Hampshire, (1997-2000) North Dakota, South Carolina, (1996-1999) Texas